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Looking East and West on advance decision-making in pregnancy: the pregnant advance directive holder in Irish, English and New York state law

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**Looking East and West on Advance Decision-Making in Pregnancy:
The Pregnant Advance Directive Holder in Irish, English and New York State Law**

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Abstract

In Western society, the point in a woman's life when she routinely ceases having control over her person in a treatment context – if such a point in time arises – is pregnancy. The Assisted Decision-Making (Capacity) Act 2015 typifies this, providing that advance directives intended to apply in pregnancy be referred for High Court adjudication. The singling out of pregnant women for special treatment where their bodily integrity and self-determination are concerned did not suddenly start with this Act. Instead, impingement on the interests of pregnant women has existed in many domestic legal frameworks for decades. This research discusses the development of such laws and the underpinning moral issues to explain why the Irish legislature drafted the Act in this manner. In doing so, it highlights the many and varied issues – ethical and legal – with the position adopted. Perhaps obvious, but it is only by describing the law applicable to non-pregnant individuals that the extent of these 'pregnancy exceptions' are fully articulated.

Aiding this exposition, is a discussion of the law in other jurisdictions, namely England and Wales and New York State (and the greater United States). The Irish legislature was undoubtedly guided by the now-repealed 8th Amendment to the Irish Constitution, which protected the right to life of the unborn, however, there is a wealth of international law demonstrating that in pregnancy, exceptions have always been made to the usual rules governing medical treatment. These exceptions can be explicit in laws prohibiting life-sustaining treatment from being withdrawn from pregnant women, despite their wishes. Or, they can be more subtle in laws that allow, however inadvertently, for consent to treatment to be coerced.

Spanning seven chapters, this thesis comprehensively discusses informed consent, end-of-life decision-making, advance directives and critically, how the law operates in these areas when the individual is pregnant.

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Table of Cases

England and Wales

AA Re, [2012] EWHC 4378

Re A (A Minor) [1993] 1 Med. L. Rev. 98

A (Children) (Conjoined Twins: Surgical Separation), Re [2000] EWCA Civ 254

A (Medical Treatment: Male Sterilisation), Re [2000] 1 FLR 549

A Hospital NHS Trust v K [2012] EWHC 2922 (COP)

A Local Authority v E [2012] All ER (D) 96

A NHS Trust v DE [2013] EWHC 2562 (Fam)

A Primary Care Trust v CW [2010] EWHC 3448

Abertawe Bro Morgannwg University Local Health Board v RY [2017] EWCOP 2

Aintree University Hospital Foundation Trust v James [2014] 1 All ER 573

Airedale NHS Trust v Bland [1993] 1 All ER 821

Re AK (Medical Treatment: Consent) (2001) 58 BMLR 151

Al Hamwi v Johnston and another [2005] All ER (D) 278

An NHS Trust v X [2005] EWCA Civ 1145

B (Adult: Refusal of Medical Treatment), Re [2002] 2 All ER 449

B v A Local Authority [2020] Fam 105

Barnsley Hospital NHS Foundation Trust v MSP [2020] EWCOP 26

Bolam v Friern Hospital Management Committee [1957] 1 WLR 582

Bolitho v City and Hackney Health Authority [1997] 4 All ER 771

Bolton Hospitals NHS Trust v O [2003] 1 FLR 824

Briggs v Briggs [2016] EWCOP 53

C (Adult: Refusal of Treatment), Re [1994] 1 WLR 29

Cambridge University Hospitals NHS Foundation Trust v BF [2016] EWCOP 26

Chatterton v Gerson [1981] QB 432

Chester v Afshar [2005] 1 AC 134

Collins v Wilcock [1984] 3 All ER 374

D (Withdrawal of Treatment), Re [2012] EWCOP 885

E (A Minor)(Wardship: Medical Treatment), Re [1993] 1 FLR 386

F v West Berkshire Health Authority [1989] All ER 545

F (Mental Patient: Sterilisation), Re [1990] 2 AC 1

Freeman v Home Office [1984] 1 All ER 1036

Gillick v West Norfolk and Wisbech Area Health Authority and another [1985] 3 All ER 402

Gold v Haringey Health Authority [1988] QB 481

HE v A Hospital NHS Trust [2003] EWHC 1017 (Fam)

Heart of England NHS Foundation Trust v JB [2014] EWHC (COP)

Hills v Potter [1984] 1 WLR 641

ITW v Z and M [2009] EWHC 2525 (Fam)

King's College Hospital NHS Foundation Trust v C [2015] EWCOP 80

L (Patient: non-consensual treatment), Re [1997] 2 FLR 837

LBL v RYJ [2011] FLR 1279

Local Authority X v MM [2007] EWHC 2003 (Fam)

M v N and ors [2015] EWCOP 9

M (Adult Patient)(Minimally Conscious State: Withdrawal of Treatment), Re [2012] 1 All ER 1313

M (Statutory Will), Re [2009] EWHC 2525 (Fam)

M (Withdrawal of Treatment: Need for Proceedings), Re [2017] EWCOP 19

MB (Medical Treatment), Re [1997] 2 FLR 426

Montgomery v Lanarkshire Health Board [2016] 1 LRC 350

NHS Cumbria CCG v Rushton [2018] EWCOP 41

NHS Trust 1 v G: Practice Note (2014) 142 BMLR 209

NHS Trust A v M, NHS Trust B v H [2001] Fam 348

NHS Trust v L [2012] EWHC 2741 (COP)

NHS Trust v L and Ors [2012] EWHC 4313 (Fam)

Norfolk and Norwich Healthcare (NHS) Trust v W [1996] 2 FLR 613

Nottinghamshire Healthcare NHS Trust v RC [2014] EWCOP 1136

Nottinghamshire Healthcare NHS Trust v RC [2014] EWCOP 1317

Paton v British Pregnancy Advisory Service Trustees [1979] QB 276.

Pearce v United Bristol Healthcare NHS Trust [1998] 48 BMLR 118

R (Burke) v The General Medical Council and Others [2004] EWHC 1879

Rochdale NHS v C [1997] 1 FCR 274

Royal Free NHS Foundation Trust v AB [2014] EWCOP 50

S (Adult: Refusal of Treatment) Re, [1992] 4 All ER 671

Sheffield Teaching Hospitals NHS Foundation Trust v TH [2014] EWCOP 4

Sidaway v Board of Governors of Bethlem Royal Hospital [1985] 1 All ER 643

Slater v Baker and Stapleton 2 Wils KB, 95 ER 850 (1767)

St George's Healthcare NHS Trust v P [2015] EWCOP 42

St. George's Healthcare NHS Trust v S, R v Collins and others, ex parte S [1999] Fam 26

T (Adult: Refusal of Treatment), Re [1993] Fam 95

University Hospitals NHS Trust v CA [2016] EWCOP 51

Wilson v Pringle [1986] 3 WLR 1

Wyatt v Curtis [2003] EWCA Civ 1779

X Primary Care Trust v XB [2012] EWHC 1390 (Fam)

Y (Mental Patient: Bone Marrow Donation), Re [1996] 2 FLR 787

Ireland

A Ward of Court (withholding medical treatment), Re (No. 2) [1996] 2 IR 79

AB v CD [2016] IEHC 541

Attorney General (SPUC) v Open Door Counselling Limited and the Wellwoman Centre Ltd
[1988] 1 IR 593

Bolton v Blackrock Clinic & Others (SC, 23 January 1997)

Buckley v O'Herlihy & the National Maternity Hospital [2010] IEHC 51

Daniels v Heskin [1954] IR 73

Dunne v National Maternity Hospital [1989] IR 91

Farrell v Varian (1995) MLJI 29

K, Re (HC, 22 September 2006)

Fitzpatrick v FK [2009] 2 IR 7

Fitzpatrick v White [2008] 3 IR 551

Fleming v Ireland [2013] 131 BMLR 30

Geoghegan v Harris [2000] 3 IR 536

Governor of X Prison v PMcD [2016] 1 ILRM 116

Health Service Executive v B [2017] 1 ILRM 54

Health Service Executive v JM [2017] IEHC 399

Health Service Executive v KW [2015] IEHC 215

Health Service Executive v R (A person of unsound mind not so found represented by his Solicitor) and ors [2016] IEHC 445

Healy v Buckley [2010] IEHC 191

JM v The Board of Management of Saint Vincent's Hospital [2003] 1 IR 321

McGee v Attorney General [1974] IR 284

Morrissey v Health Service Executive [2020] IESC 6

Nolan v Carrick [2013] IEHC 523

Norris v Attorney General [1984] IR 36

North Western Health Board v HW and CW [2001] 3 IR 622

O'Donovan v Cork County Council [1967] IR 173

PP v Health Service Executive [2015] 1 ILRM 324

Pyne & Anor v Western Health Board & Anor [2005] IEHC 415

Ryan v Attorney General [1965] IR 294

Shuit v Mylotte [2006] IEHC 89

Simpson v The Governor of Mountjoy Prison [2019] IESC 81

SR (A Ward of Court), Re [2012] 1 IR 305

Walsh v Family Planning Services [1992] 1 IR 496

Warnock v National Maternity Hospital [2010] IEHC 25

Wolfe v St. James's Hospital [2002] IESC 10

United States

AC, Re 573 A 2d 1235 (DC 1990)

Albala v City of New York 54 NY 2d 269 (1981)

Ankrom v Alabama 152 So 3d 373 (Ala 2013)

Baby Boy Doe, Re 632 NE 2d 326 (Ill 1994)

Barber v Superior Court 147 Cal App 3d 1006 (1983)

Breithaupt v Abram 352 US 432 (1957)

Burton v Florida 49 So 3d 263 (Fla 2010)

Canterbury v Spence 464 F 2d 772 (DC 1972)

Cantwell v Connecticut 310 US 296 (1940)

Conroy, Re 98 NJ 321 (1985)

Conservatorship of Drabick 200 Cal App 3d 185 (1988)

Couture v Couture 549 NE 2d 571 (Ohio 1989)

Crouse-Irving Memorial Hospital v Paddock 127 Misc 2d 101 (NY

1985) *Cruzan v Harmon* 760 SW 2d 408 (Mo 1988)

Cruzan v Director, Missouri Department of Health 497 US 270 (1990)

Darrah v Kite 32 AD 2d 208 (NY 1969)

DiNino v Gorton 684 P 2d 1297 (Wash 1984)

Di Rosse v Wein 24 AD 2d 510 (NY 1965)

Doe, Re 53 Misc 3d 829 (NY 2016)

Dray v Staten Island University Hospital No. 500510/14 (Sup Ct, Kings County 2015)

Dray v Staten Island University Hospital 160 AD 3d 614 (NY 2018).

Dries v Gregor 72 AD 2d 231 (NY 1980)

Dubreil, Re 629 So 2d 819 (Fla 1993)

Dyckes v Stabile 153 AD 3d 783 (NY 2017)

Eisenstadt v Baird 405 US 438 (1972)

Estate of Cruzan Estate No. CV384-9P (Cir Ct, Jasper County, 1988)

Estate of Longeway, Re 133 Ill 2d 33 (1989)

Feinberg v Feit 23 AD 3d 517 (2005)

Ferguson v City of Charleston 532 US 67 (2001)

Fetus Brown, Re 689 NE 2d 397 (Ill 1997)

Fogal v Genesee Hospital 41 AD 2d 468 (NY 1973)

Fosmire v Nicoleau 144 AD 2d 8 (NY 1989)

Fosmire v Nicoleau 75 NY 2d 218 (1990)

Gabrynowicz v Heitkamp 904 F Supp 1061 (ND 1995)

Grace Plaza v Elbaum 82 NY 2d 10 (1993)

Griswold v Connecticut 381 US 479 (1965)

Harvey U, Re 116 AD 2d 351 (NY 1986)

Hicks v Alabama 153 So 3d 53 (Ala 2014)

Hughson v St. Francis Hospital 92 AD 2d 131 (NY 1983)

Jacobson v Massachusetts 197 US 11 (1905)

Jamaica Hospital, Re 128 Misc 2d 1006 (NY 1985)

Jefferson v Griffin Spalding County Hospital Authority 247 Ga 86 (1981)

Jobes, Re 529 A 2d 434 (NJ 1987)

Johnson v Florida 602 So 2d 1288 (Fla 1992)

Karlsons v Guerinot 57 AD 2d 73 (NY 1977)

Klein Re, 145 AD 2d 145 (NY 1989)

Kovacic v Griffin 170 AD 3d 1143 (NY 2019)

Largey v Rothman 110 NJ 204 (1988)

Laurie v Senecal 666 A 2d 806 (RI 1995)

Lawrence, Re 79 NE 2d 32 (Ind 1991)

Lynn G v Hugo 96 NY 2d 306 (2001)

Marietta, Re 125 AD 3d 581 (NY 2015)

Mausner v William E 264 AD 2d 485 (NY 1999)

McConnell v Beverly Enterprises-Connecticut, Inc. 553 A 2d 596 (Conn 1989)

McConnell, Re 147 AD 2d 881 (NY 1989)

McFall v Shimp 10 Pa D & C 3d 90 (1978)

Means v United States Conference of Catholic Bishops 836 F 3d 643 (6th Cir 2016)

Mercy Hospital v Jackson 306 Md 556 (1986)

Mohr v Williams 104 NW 12 (Minn 1905)

Murriello v Crapotta 51 AD 2d 381 (NY 1976)

Nisenholtz v Mount Sinai Hospital 126 Misc 2d 658 (Sup Ct, NY County 1984)

Obergefell v Hodges 576 US 644 (2015)

Paris M v Creedmoor Psychiatric Center 30 AD 3d 425 (NY 2006)

Pemberton v Tallahassee Memorial Regional Medical Center 66 F Supp 2d 1247 (Fla 1999)

Peter, Re 529 A 2d 419 (NJ 1987)

People v Jorgensen 26 NY 3d 85 (2015)

People v Eulo, 63 NY 2d 341 (1984)

Planned Parenthood v Casey 505 US 833 (1992)

Pratt v Davis 224 Ill 300 (1906)

Quinlan, Re 70 NJ 10 (1976)

Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson 42 NJ 421 (1964)

Retkwa v Orentreich 154 Misc 2d 164 (Sup Ct, NY County 1992)

Rivers v Katz 67 NY 2d 485 (1986)

Roe v Wade 410 US 113 (1973)

Rolater v Strain 39 Okla 572 (1913)

S v Kingsboro Psychiatric Center 149 AD 2d 424 (NY 1989)

Santos v Goldstein 16 AD 2d 755 (NY 1962)

Satz v Perlmutter 362 So 2d 160 (Fla 1978)

Schloendorff v New York Hospital 211 NY 125 (1914)

Singletary v Costello 665 So 2d 1099 (Fla 1996)

State v Pemberton No. 96-759 (Cir Ct, Leon County 1996)

Storar, Re 52 NY 2d 363 (1981)

Superintendent of Belchertown State School v Saikewicz 373 Mass 728 (1977)

Union Pacific Railway Company v Botsford 141 US 250 (1891)

United States v Windsor 570 US 744 (2013)

Van Holden v Chapman 450 NYS 2d 623 (1982)

Viera v Khasdan NY Slip Op 03717 (NY App 2020)

Washington v Harper 494 US 210 (1990)

Washington v Glucksberg 521 US 702 (1997)

Webster v Reproductive Health Services 492 US 490 (1989)

Westchester County Medical Center [O'Connor], Re 72 NY 2d 517 (1988)

William S, Re 31 AD 3d 567 (NY 2006)

Williams v Cordice 418 NYS 2d 995 (1979)

Wyoming Valley Health Care Systems, Inc. & Baby Doe v Jane Doe & John Doe No. 3-E-2004
(Pa Ct Com Pl 2004)

Zant v Prevatte 286 SE 2d 715 (Ga 1982)

Zelesnik v Jewish Chronic Disease Hospital 47 AD 2d 199 (NY 1975)

European

Denmark, Norway, Sweden and the Netherlands v Greece [1969] 12 YB 1

East African Asians v United Kingdom [1973] EHRR 76

Pretty v United Kingdom [2002] 35 EHRR 1

X v Austria [1980] 18 DR 154

Table of Legislation

International

European Convention on Human Rights; Article 2; Article 3; Article 8; Article 9; Article 12

United Nations Convention on the Elimination of All Forms of Discrimination against Women of 18 December 1979

United Nations Convention on the Rights of Persons with Disabilities; Article 12

England and Wales

Court of Protection Rules 2007; Practice Direction 9E

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Mental Health Act 1983; Section 63; Section 145(4)

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Assisted Decision-Making (Capacity) Act 2015

- Section 1(3)
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- Section 8(2); s 8(3); s 8(4); s 8(5); s 8(6)(a); s 8(6)(b); s 8(6)(c); s 8(6)(d); s 8(7)(a); s 8(7)(b); s 8(7)(c); s 8(7)(d); s 8(8); s 8(9)
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- § 2503
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- § 2504 section 1; s 3
- § 2805-d section 1; s2; s 4(a); s 4(d); s 4(b); s 4(c)
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- § 2994-a section 5
- § 2994-c section 1; s 2; s 3; s 3(d); s 6; s7
- § 2994-d section 1(c); s 1(d); s 4; s 4(ii); s 5(a)(i); s 5(a)(ii); s 5(b)
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Surrogate's Court Procedure Act; § 1750-b section 2(a)

Other US

Alabama Code; § 22-8A-4; § 26-15-3.2

Alaska Statutes; § 13.52.055a

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California Health & Safety Code; § 7188

California Health Care Decisions Law; § 4650(b); § 4701

Colorado Revised Statutes; § 15-18-104

Delaware Code; Title 16 § 2503 section(5)(j)

Georgia Code; § 31-32-9

Illinois Compiled Statutes; 755 ILCS 35/ ('Illinois Living Will Act') section 2(d)

Iowa Code; § 144A.6 section 2

Minnesota Statutes; § 145C.05(2)(a); § 145C.10(g)

Missouri Revised Statutes; § 459.010 section 3; § 459.025

New Jersey Revised Statutes; § 26:2H-56 section 4

North Dakota Century Code; § 23-06.5-09 section 5

Pennsylvania Consolidated Statutes; Title 20 § 5429(a)

Rhode Island; § 23-4.11 section 6(c)

South Dakota Codified Laws; § 34-12D-10

Texas Health and Safety Code; § 166.049; § 166.098

Vermont Statutes; Title 18 § 9702(a)(8).

Washington Revised Code; § 70.122.030 section (1)(d)

Wisconsin Statute; § 48.193; § 154.01; §154.07 section (2)(2)

Other Jurisdictions

Patients' Rights Law 1996, Laws of State of Israel

Chapter 1

Introduction

The word ‘pregnant’ comes from the Latin words *prae* and *gnasci*, which literally translate to ‘before’ and ‘be born’. From the outset, the origins of the term ‘pregnant’ relate entirely to the foetus. It is the entity that is before birth. The woman appears to be in a kind of facilitatory role regarding this entity before it is born, without even being referenced by the word itself. Perhaps that is unsurprising to an extent; ‘pregnant’ is an adjective, the purpose of which is to describe the woman. Naturally, the origins of ‘pregnancy’ are the same, entirely relating to the foetus and never encompassing the person experiencing the state. This research is certainly not suggesting replacing the word ‘pregnant’ with another word more reflective of the nature and social context of pregnancy; however, perhaps the origins of the term – the exclusive focus on the entity before birth and not the woman – illuminate a starting point for the legal and ethical issues that relate to the state of ‘being pregnant’. One such area of intense complexity is that of the medical treatment of pregnant women and closely related to that is the refusal of recommended intervention in pregnancy, whether contemporaneously or in advance. It is this often-unresolved legal tension, particularly in relation to advance refusals, that inspired this research. As with many matters of medical law and ethics, there is little agreement on the position of advance directives in pregnancy, nor what that position ought to be. Arguably, this legal uncertainty is exemplified by the approach that has been taken by the Irish legislature in the Assisted Decision-Making (Capacity) Act 2015 in which specific provisions pertaining to the effect of advance directives in pregnancy have been included.¹

On the one hand, many jurisdictions make strong statements regarding the right of a competent adult to refuse medical treatment, contemporaneously and in advance. These protections are afforded in legislation, developed through common law precedent or interpretations of constitutional law; indeed, sometimes a mix of some, or all three. Yet, pregnancy often appears to create an exception, whether explicitly in that it is specified in legislation or interpreted by the courts in light of related legislation or jurisprudence, or whether more subtly or secretly in hospital policies or in the decisions of medical professionals involved in the care of pregnant women in practice. The various forms that this ‘exception’ takes will be considered extensively

¹ Assisted Decision-Making (Capacity) Act 2015, s 85(6).

by this research; naturally, compelled interventions are the most obvious example of such exceptions in the law, but other, less obvious manifestations of this exception will also be considered, such as the questions of capacity that arise for women in labour. From the medical side, reports of the coercion of pregnant women where threats of arrest for a related or unrelated issue, or a complaint to child protective services, is leveraged in order to get consent to the recommended treatment are the most obvious examples. There are other, less obvious examples of the ‘pregnancy exception’ in healthcare, such as the tendency to treat pregnant women differently to their non-pregnant counterparts in terms of how the risks of particular interventions and treatments are conveyed and understood. For example, Anne Lyerly *et al* assert that there is an insidious and damaging dichotomy in the treatment of pregnant women:

When treating pregnant women’s nonobstetrical medical needs (...) there is a tendency to notice the risks of intervening without adequately noting the risks of failing to intervene. In contrast, when we turn from management of pregnancy to management of birth, we note a tendency to intervene without due regard for the burdens to both fetus and woman that such interventions may bring. If risk perception is often distorted, the nature of the distortion changes markedly depending on the circumstance of a pregnant woman’s health needs.²

The latter point is certainly borne out by the cases considered as part of Chapter 6. The former is arguably borne out by the anecdotal evidence coming not only from United States, where Dr Lyerly is based, but also Ireland.³ This idea of different treatment in pregnancy is one that will arise throughout this research, as it is argued that it is not just the explicit examples of different treatment but also the less obvious examples that are key to fully explaining the overall value of this work.

Several research questions have been generated by this thesis; they can, however, be distilled down into two interrelated questions. The first core question is whether, from a legal perspective, an otherwise valid advance directive will likely be disregarded or overridden in Ireland if the

² Anne Lyerly and others, ‘Risk and the Pregnant Body’ (2009) 39 *The Hastings Center Report* 34, 35.

³ Kate Campbell, ‘I needed surgery but because I was pregnant, I was left to rot’ *Irish Times* (Dublin, 19 May 2018) <<https://www.irishtimes.com/life-and-style/health-family/i-needed-surgery-but-because-i-was-pregnant-i-was-left-to-rot-1.3500349>> accessed 28 August 2020. There are also anecdotal accounts of women, including Irish patients, using phrasing like ‘I was informed that I would be’ induced or given a Caesarean section or ‘I was told I was being booked in’ for induction / Caesarean and not that either was being presented as an option to the woman. In other words, there appeared to be no discussion of the alternatives and in the case of induction, there was sometimes no discussion of why this was being recommended. See also Irish Maternity Support Network ‘Report of the Irish Maternity Support Network to the UN Special Rapporteur on Women on Mistreatment and Violence against Women during Reproductive Health Care with a Focus on Childbirth’ (17 May 2019) available in Annex 1. For the United Kingdom, see Birthrights and Birth Companions, ‘Holding It All Together: Understanding How Far the Human Rights of Women Facing Disadvantage are Respected during Pregnancy, Birth and Postnatal Care’ (2019) <<https://www.birthrights.org.uk/wp-content/uploads/2019/09/Holding-it-all-together-Full-report-FINAL-Action-Plan.pdf>> accessed 16 October 2020, 26-40.

patient is pregnant when the decision ought to be given effect. Plainly, the second question is given that pregnancy may well invalidate an advance directive, should this be the case legally and ethically? Overall then, the core question is: what is the legal position of the pregnant advance directive holder in Ireland and what ought it to be?

In order to answer this core question and the multitude of ancillary questions, this thesis takes a formulaic approach to the core issue of advance directives in pregnancy. It discusses the legal and ethical concepts underpinning advance directives, such as informed consent and end-of-life decision-making, first, articulating how these laws developed and critically, how they apply to non-pregnant people. Thus, the discussion in each chapter builds on the previous one(s), culminating in an exploration of not only the pregnancy exceptions found in many advance directive statutes from the US and in Ireland, but also compelled intervention in pregnancy. It is in that chapter that this thesis will have all of the salient information, as provided by the previous chapters, to answer the core research question, namely the validity of an advance directive in pregnancy in Ireland and the appropriateness of that legal position.

In order to answer this question, particularly the second part, it was considered insufficient to examine the law in Ireland as though it were in a vacuum and independent of outside influences. Rather, it was deemed necessary to consider the approaches of other common law jurisdictions to the issue of advance refusals in pregnancy to support this research in its aim. Thus, this research will also look at aspects of the law in England and Wales and the US, particularly New York State. Furthermore, it was viewed as necessary to conduct ethical analysis in each chapter; considering the law as though it operates in ignorance of morals and ethics would do a disservice to a very complex question and fail to appreciate why individuals, lawmakers, physicians and judges find it so challenging to make these decisions.

As this research progresses, one matter is worth highlighting briefly – that of the relationship between religion and the issue of refusal of medical intervention in pregnancy, whether in advance or contemporaneously. The relationship between the law and religion can be described as one of peaceful co-existence, until it is not. Perhaps emphasised by this quote from the judgment in *Re Quinlan* wherein the relationship between religion, law and medicine is discussed:

The civil law is not expected to assert a belief in eternal life; nor (...) is it expected to ignore the right of the individual to profess it, and to form and pursue his conscience in accord with that belief. Medical science is not (...) expected to prevent [death] when it is inevitable and all hope of a return to an even partial exercise of human life is irreparably lost. Religion is not expected to define biological death; nor (...) is it expected to relinquish its responsibility to assist man in the formation and pursuit of a correct conscience as to the acceptance of natural death (...)⁴

First, religion will feature heavily in the context of the decision of the woman to refuse medical treatment; often her own religious convictions prevent her from accepting a particular form of intervention. This theme will emerge most obviously in Chapter 6, which considers compelled intervention in pregnancy. Second, religion – or more accurately, religious lobbying – has affected the decisions of legislators in the United States vis-à-vis advance directive legislation and specifically where there are severe restrictions or complete nullification of advance directives in pregnancy.⁵ This facet of legislative decision-making is worth bearing in mind as this research progresses, as is the obvious tension created by it. On the one hand, the right to practice one's religion receives significant support within the United States; on the other hand, it does not receive quite the same support where it may result in foetal injury.

Finally, the issue of hospital patronage is worth examining briefly before progressing further with this research, considering the jurisdictions that will be discussed in the coming chapters. Ireland has a long-standing tradition of Catholic Church-founded and controlled hospitals and to this day, many hospitals in Ireland are still under the patronage of the Catholic Church, though, strictly speaking, none of these are maternity hospitals.⁶ With that said, concern was expressed in 2016 when the intention to transfer the National Maternity Hospital to the campus at St Vincent's hospital – owned by the Religious Sisters of Charity – was announced and such concern persists.⁷ In particular, Dr Peter Boylan, former Master of the NMH expressed concern in May 2020 that it would be 'hard to see how such a report [obliged by St Vincent's Holdings CLG becoming a public juridic person] could include the numbers of elective sterilisations,

⁴ *Re Quinlan* 70 NJ 10 (1976); 32-33.

⁵ See James M Hoefler and Brian E Kamoie, *Deathright: Culture, Medicine, Politics, and the Right to Die* (Westview Press 1994) 202-5 regarding the influence of the Catholic lobby on pregnancy exclusions in advance directive legislation.

⁶ For completeness, it is worth noting that the National Maternity Hospital (Holles Street) is owned by a private trust whose chair is the Archbishop of Dublin. This is distinguishable from the hospitals owed by the Catholic Church, however, as the Catholic Church appears to have no influence on hospital policy through this relationship, nor does it appear that it wishes to. It has been reported that the current Archbishop of Dublin, Dr Diarmuid Martin, has spoken with previous Ministers for Health regarding changing the organisational structure, so that the Archbishop of Dublin is not automatically appointed as chair. Cliodhna Russell, 'Religion and health care: What role does the Catholic Church play in Irish hospitals?' *The Journal* 30 April 2017 <<https://www.thejournal.ie/religion-health-care-catholic-church-3360849-Apr2017/>> accessed 9 July 2020.

abortions and artificial fertilisation procedures carried out in the hospital in the year, and continue to be approved by the Vatican'.⁸ While it is not certain that St Vincent's Holdings CLG will become a public juridic person, Dr Boylan cites other Catholic orders, internationally and in Ireland, which have done so for their health organisations. Furthermore, this current lack of ownership of maternity hospitals by the Catholic Church does not mean that it has had no influence on matters with a reproductive health dynamic in the hospitals that it does own, or that influence is not exerted through individual physicians.⁹

A similar dynamic exists in the US, where the Catholic Church is the largest provider of non-profit healthcare in the nation.¹⁰ It perhaps goes without saying that these are vastly different situations to that in the UK. While it is not being suggested that this alone explains the jurisdictional differences in the treatment of pregnant women refusing intervention in hospitals, it is argued that it may go some way towards explaining it, particularly if there are penalties for a physician who fails to uphold the religious ethos of a hospital.¹¹ A recent study carried out by the National Bureau of Economic Research in the US highlights the effect that religious ethos can have on the provision of services.¹² It demonstrated that where mergers have taken place between a secular and Catholic hospital or group, there was a reduction of 31% in tubal ligations, with no corresponding decrease in other related procedures such as Caesarean sections.¹³ Furthermore, women have been denied particular care because it contravenes the ethos of the

⁷ See for example, Claire Hogan, 'Catholic Church's Influence over Irish Hospital Medicine Persists' *Irish Times* (Dublin, 28 April 2016) <<https://www.irishtimes.com/opinion/catholic-church-s-influence-over-irish-hospital-medicine-persists-1.2626856>> accessed 9 July 2020.

⁸ Dr Peter Boylan, 'National Maternity Hospital Concerns' (Letters to the Editor) *Irish Times* (Dublin, 22 May 2020) <<https://www.irishtimes.com/opinion/letters/national-maternity-hospital-concerns-1.4259557>> accessed 24 July 2020. This letter was written in reply to one from Prof Shane Higgin and others 'The National Maternity Hospital Project' (Letters to the Editor) *Irish Times* (Dublin, 21 May 2020) <<https://www.irishtimes.com/opinion/letters/the-national-maternity-hospital-project-1.4258455>> accessed 24 July 2020.

⁹ For example, in 1983, a woman named Sheila Hodges was refused the continuation of her cancer treatment in Our Lady of Lourdes Hospital in Drogheda because she became pregnant. A termination of pregnancy, an early delivery of the baby and a Caesarean section were also all refused by the hospital. She and her premature daughter subsequently died; Kitty Holland, 'Reasons For Women Not To Be Cheerful' *Irish Times* (Dublin, 29 December 2012) <<https://www.irishtimes.com/news/reasons-for-women-not-to-be-cheerful-1.5496>> accessed 14 September 2020. In 2005, the ethics committee of the Mater Hospital in Dublin deferred approval of the clinical trial of a potential lung cancer drug because the trial required participants to use contraception; 'Clinical trial of cancer drug deferred' *Irish Times* (Dublin, 3 October 2005) <<https://www.irishtimes.com/news/clinical-trial-of-cancer-drug-deferred-1.500245>> accessed on 24 July 2020. In 2010, a complaint was lodged with the Medical Council regarding a physician in Galway who refused to provide the infertility treatment NaPro Technology to an unmarried couple on the basis that he believed only married people should have children. Noel Baker, 'Clinic Insists Couples Must be Married to Get Fertility Treatment' *Irish Examiner* (Cork, 15 April 2010) <<https://www.irissexaminer.com/news/arid-20117246.html>> accessed 10 September 2020.

¹⁰ Rebecca J Cook and Bernard M Dickens, 'Reproductive Health and the Law' in Pamela R Ferguson and Graeme T Laurie (eds) *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean* (2015 Ashgate) 13. See also the website of the Catholic Health Association of the United States <<https://www.chausa.org/about/about>> accessed 24 July 2020.

¹¹ Elizabeth Sepper recounts a story of a psychiatrist who lost his admitting privileges after the clinic where he worked merged with a Catholic hospital because he refused to agree to the Ethical and Religious Directives for Catholic Health Care Services (ERD) on the ground that they interfered with the rights of his patients: Elizabeth Sepper, 'Taking Conscience Seriously' (2012) 98 Va L Rev 1501, 1524. She also discusses the potential for the termination of the employment contracts of physicians who violate religiously motivated hospital policies [1526].

¹² Elaine L Hill and others, 'Reproductive Health Care in Catholic-Owned Hospitals' (2017) National Bureau of Economic Research Research Paper 23768 <<https://www.nber.org/papers/w23768.pdf>> accessed 9 September 2020.

¹³ *ibid.*

hospitals.¹⁴ Religion, therefore, can be said to go to the core of why treatment in pregnancy can be a contentious issue for healthcare providers and as Rebecca Cook and Bernard Dickens argue, ‘raises issues of service providers’ conscience’, which often carries legislative protection, not only where abortion is concerned.¹⁵

Jurisdictions

As discussed, this research explores how advance refusals in pregnancy are treated in England and Wales and New York – and the greater United States – in addition to considering the issue in light of Irish law and traditions. These jurisdictions form a very important part of this thesis. At various points in time, their approach serves as a lesson to Ireland either because they have achieved best practice and we ought to follow this approach or because they have made a legislative error – or no choice at all – and we ought to avoid such a course of action. There are marked differences in how these jurisdictions approach many of the broader legal issues, which form the ‘building blocks’ of the issue of advance refusals in pregnancy. The appeal of England and Wales as a jurisdiction is clear; first, both England and Wales and Ireland share a virtually identical legal system. As two jurisdictions with legal traditions grounded in the common law, the critical importance of precedent is shared and will be evidenced by many of the cases discussed throughout this research. Second, as Ireland’s nearest neighbour, English jurisprudence often serves as persuasive authority in the Irish Courts and its legislation as a source of inspiration to the Irish legislature. In fact, it is quite challenging to consider Irish law without concurrently considering English law because so many Irish judgments contain references to jurisprudence from England and Wales, certainly within medical law. Furthermore, though not identical, our courts systems are very similar, which means that equivalences and distinctions can be drawn with ease; in other words, courts of similar standing consider similar matters in

¹⁴ For example, Tamesha Means was discharged from a Michigan hospital run by Mercy Health Partners twice while suffering from preterm premature rupture of membrane, which usually results in a stillbirth or the death of the baby soon after birth. Despite the gravity of her condition and the considerable risk to her health, Ms Means was discharged with pain medication and was neither informed of the risk to her health of infection nor that the foetus was unlikely to survive. Critically, she was not given the option of artificially completing the miscarriage or terminating the pregnancy. She returned to the hospital the next day with a fever, excruciating pain and bleeding, at which point she was still not given any additional treatment or options, even though a serious bacterial infection was suspected. She was again discharged when her fever abated. She returned for a third time with contractions and while preparations were being made to discharge her again, she delivered the baby, which died shortly afterwards. Ms Means was suffering from two acute bacterial infections when she gave birth; *Means v United States Conference of Catholic Bishops* 836 F 3d 643 (6th Cir 2016). See also Lori Freedman and others, ‘When There’s a Heartbeat: Miscarriage Management in Catholic-owned Hospitals’ (2008) 98 Am J Public Health 1774. For a broader discussion of the impact of Catholic ownership of hospitals on the provision of healthcare - for example, in matters such as informed consent to treatment and the advice provided to HIV-positive patients and rape victims regarding contraceptives – see Elizabeth Sepper, ‘Taking Conscience Seriously’ (2012) 98 Va L Rev 1501, 1520-1523.

¹⁵ Rebecca J Cook and Bernard M Dickens, ‘Reproductive Health and the Law’ in Pamela R Ferguson and Graeme T Laurie (eds) *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean* (2015 Ashgate) 18. See Public Health Law § 2994-n (2) for conscientious objections in New York.

both jurisdictions. Finally, and arguably most important for the purposes of this research, England and Wales has a rich body of jurisprudence pertaining to medical treatment in pregnancy. Despite not being restricted by a constitutional protection of the unborn or some other similar constraint, the courts in England and Wales have struggled with allowing a pregnant woman to refuse medical treatment that would likely harm her foetus. This jurisprudence will provide immeasurable value when core questions are being answered in Chapter 6.

The appeal of New York is perhaps not as apparent from the outset, however, as a jurisdiction, it presents a fascinating picture. On the one hand, it would be legitimate to hold the belief that New York is a liberal ‘safe haven’, a jurisdiction wherein the rights of the individual, particularly the pregnant woman, would be paramount. After all, New York has had legal abortion up to the 24th week of pregnancy since 1970, before the US Supreme Court judgment in *Roe v Wade*.¹⁶ It is the home of one of the earliest informed consent cases in the United States, *Schloendorff v New York Hospital*.¹⁷ On the other hand, when the jurisprudence from New York is explored, a curious dichotomy can be found in relation to non-consensual medical treatment and informed consent. This dichotomy will become more apparent with each chapter. From a legal standpoint, its appeal as a jurisdiction rests on several factors; first, as was the case for England and Wales, it is a common law system. In the course of considering the case law, however, it will become clear that the effect of precedent may not be quite as strong as would be expected. Second and on a related note, the courts structure is quite different. Complex medico-legal matters are not heard in the High Court, Court of Protection or equivalent, as they are in England and Wales and Ireland, but instead in county courts, referred to as ‘Supreme Courts’. While this may be a feature of the sheer size of New York, it means that only those cases that are appealed more than once will reach its highest court – the Court of Appeals of the State of New York. Otherwise, the matter is heard in courts that also hear quite run-of-the-mill civil matters such as divorce, separation and annulment proceedings. With all due respect to the profession of judge, it is questionable if judges in courts of this level have sufficient experience to deal with such complex matters, certainly compared with their counterparts in Ireland and England and Wales. As will

¹⁶ 410 US 113 (1973).

¹⁷ 211 NY 125 (1914).

also become apparent, this results in a confusing legal situation for many issues and leaves open the distinct possibility of multiple parallel lines of authority in New York.

The next appeal of New York rests on the fact that it has recently overhauled its healthcare decision-making legislation, yet advance directives were not included in the new legislation; the new Act will be discussed at length as this research progresses.¹⁸ Third, as part of the United States, New York has a written constitution, which adds an additional dynamic to cases considering the refusal of medical treatment, just like it does in Ireland. Finally, there is a shared religious dynamic between New York and Ireland; while Ireland undoubtedly has less religious diversity than New York, it is still the case that both have quite a strong Roman Catholic presence, both amongst the population and within lobbying efforts. By assessing the legal position in Ireland with reference to the legal position in England and Wales and New York, it is felt that a more complete picture of the strengths and weaknesses of Irish law can be identified.

Ethical Analysis

With matters such as medical decision-making, it is almost impossible to ignore the role of ethics. Complex issues of this nature are often this challenging and uncertain because of the inseparable ethical dimension. In short, not everyone views right and wrong in the same way, nor do they view the same actions to be duties, rights or responsibilities. To consider this area of law without understanding the ethical challenges and justification for its very existence would be to fail to fully analyse the topic. The relationship between the law and moral theory, although long established, is also complex. In general, we expect that laws will reflect what society perceives to be ‘good’ or ‘bad’ behaviours. We expect the law to discourage or completely prohibit the bad and mandate or incentivise the good. Issues within the healthcare context are often quite divisive from a moral perspective, meaning that sometimes there may be no ‘right answers’, just ones that have better justification than the alternatives. Issues surrounding medical treatment such as abortion, assisted suicide, surrogacy and preimplantation genetic diagnosis have all garnered fierce ethical debate and disagreement. This should not mean that ethical issues in healthcare should not be considered; on the contrary, it is precisely why they should be. As Julian Savulescu *et al* argue in the next extract:

¹⁸ The ‘new Act’ refers to the Family Health Care Decisions Act, which was introduced in 2010.

The most profound questions that health professionals face are not scientific or technical, but ethical (...) Life can be prolonged at enormous cost, sometimes far beyond the point that the individual appears to be gaining a net benefit (...) Science can tell us how to achieve something, but it cannot tell us whether we should achieve that end—whether it is good. For that, we need ethics (...) Where there are no options, there are no ethical questions. However, once there are options, there arise pressing questions about whether to pursue them (...) We require values and principles to decide how to use medicine and science.¹⁹

As Nils Hoppe and Jose Miola argue, it is not the job of the law ‘to enshrine all moral obligations we might care to think of’, rather it will ‘merely try to encompass those moral obligations that are considered most weighty, although this assessment can clearly be contentious’.²⁰ In a way, this research attempts the same, namely consideration of the ‘most weighty’ moral issues in the context of advance decisions in pregnancy.

The primary research question is not one single ethical issue, but instead multiple ethical questions, which build upon one another. Not only must the ethics of the right to refuse medical treatment be considered, but also the morality of refusing life-saving treatment. Do the ethical implications and considerations change when the refusal results in death? Ought they to? Is it right for an agent to act in a way that is likely to end her life? Should a distinction be made between those who are terminally ill and those who are otherwise healthy? Should those with dependents be held to a different standard to those who have minimal responsibility for others? What if the refusal is made in advance rather than contemporaneously; do new ethical concerns arise that are not present in the case of contemporaneous refusal? If so, how should they be resolved? What of pregnancy? Does that make unethical what would be ethical for a non-pregnant person? Is it immoral for a physician to treat a pregnant woman differently to a non-pregnant patient, or is it immoral for him²¹ to treat her the same? To confine this research to just the legal questions would be to miss the rich and complex discourse that exists outside of the law and to miss the inconsistent ways in which ethics and morals are discussed in jurisprudence.

¹⁹ Julian Savulescu and others, ‘Philosophical Medical Ethics: More Necessary Than Ever’ (2018) 44 J Med Ethics 434.

²⁰ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 2.

²¹ For convenience and the avoidance of confusion, male pronouns (he/him/his) will be used to describe the physician and female pronouns (she/her) will be used to describe the patient save where the facts of a case or quote dictate otherwise. Furthermore, rather than using gender neutral terms, this research will make reference to ‘the pregnant woman’ or the ‘woman’. This is, in no way, an attempt to exclude transgender individuals who may be affected by the issue of advance directives in pregnancy, rather it is a reflection of common parlance on the topic and the fact that no cases concerning members of the transgender community have arisen during the course of this research.

When this thesis speaks about rights, in general it is speaking about legal rights. Talk of rights in an ethical context, where there is no legal right, is a tricky business leading to blurring and confusion. While this research uses terms like self-determination and bodily integrity, these two are vulnerable to being *banded about*. Thus, if they are to have the desired meaning and significance and carry weight in the arguments advanced, it is essential to define what they mean. Rosamund Scott explains an interest in self-determination as ‘concerning a person’s interest in reflectively making significant personal choices’, while interest in bodily integrity can be understood as ‘being able to decide what happens to one’s own body’, which she argues is important because ‘one’s own body is a central part of oneself and so of one’s sense of self’.²² Indeed, as Judith Jarvis Thomson argues; ‘if a human being has any just, prior claim to anything at all, he has a just, prior claim to his own body’.²³

How the ‘just claim’ that a pregnant woman has to her own body co-exists with, or is subordinated to, any just claims of the foetus is clearly worthy of discussion. Furthermore, this is not to say that rights in respect of the interests in bodily integrity and self-determination have not been found by the courts, indeed the opposite is true. It is just to say that in the ethical context, particularly where pregnancy is concerned, speaking of interests gives greater clarity to the overall debate.

The Assisted Decision-Making (Capacity) Act 2015

Before outlining the structure of this thesis, it is necessary to give a brief introduction to the Assisted Decision-Making (Capacity) Act 2015 (‘ADM(C)A’), the relevant parts of which will be discussed in more detail throughout the chapters in this thesis. Though signed in 2015, this Act will not be commenced until 2022. Consequently, this necessitated a choice to be made between dedicating significant time to discussing the current system for dealing with incompetent individuals – wardship – or confining the discussion to the Act with the understanding that it has not yet been commenced. This research will focus on the Act, rather than the wardship system as it is thought that discussing wardship in any great detail would lead to quick obsolescence of a significant part of the research and it lacking real relevance within a short space of time. As will become apparent as this research progresses, that is not to suggest

²² Rosamund Scott, *Rights, Duties and the Body: Legal and Philosophical Reflections on Refusing Medical Treatment during Pregnancy* (Hart 2002) 61.

that the historical development of the various issues – informed consent, end-of-life treatment and so forth – will not be discussed. Rather, the jurisprudence relating to each of these issues will be considered in detail. It is only the framework within which they will be considered that is different.

The 2015 Act is an ambitious piece of legislation, arguably combining the strengths of the Mental Capacity Act 2005 from England and Wales and new provisions, in order for Ireland to meet many, but not all, of its obligations under the United Nations Convention on the Rights of Persons with Disabilities. It provides for advance refusal of treatment through an advance directive, but also provides for the individual to appoint a Designated Healthcare Representative to make healthcare decisions on her behalf.²⁴ Although the history of the Act and specific sections of relevance will be discussed in detail during the course of the research, for now, it is worth giving a brief overview of the guiding principles. The Act advocates for intervention only when essential; it requires that intervention be confined to situations where ‘it is necessary to do so having regard to the individual circumstances of the (...) person’.²⁵ Capacity must be construed functionally according to section 3; it must be presumed and an individual shall not be considered incompetent to make the relevant decision merely because she has or will likely make an unwise decision and ‘unless all practicable steps have been taken, without success, to help (...) her’ make the decision.²⁶ Any intervention must be ‘proportionate’ and:²⁷

- (i) be made in a way that minimises the ‘restriction of the relevant person’s rights’ and her ‘freedom of action’;²⁸
- (ii) be made with due regard for the ‘dignity, bodily integrity, privacy, autonomy’ of the individual and be as limited in duration as possible.²⁹

Insofar as is practicable, the person intervening must firstly encourage, facilitate and improve the participation of the individual in the intervention.³⁰ Second, effect must be given ‘to the past and

²³ Judith Jarvis Thomson, ‘A Defense of Abortion’ in D Kelly Weisberg *Applications Of Feminist Legal Theory* (Temple University Press 1996) 975. First published: Judith Jarvis Thomson, ‘A Defense of Abortion’ (1971) 1 *Phil & Pub Aff.* 47.

²⁴ This research is concerned with advance refusals of medical treatment through an advance healthcare directive; accordingly, no further analysis will be given to the designated healthcare representative framework.

²⁵ Assisted Decision-Making (Capacity) Act 2015, s 8(5).

²⁶ *ibid* s 8(2), 8(4) and 8(3) respectively.

²⁷ *ibid* s 8(6)(c).

²⁸ *ibid* s 8(6)(a).

²⁹ *ibid* s 8(6)(b)(d).

³⁰ *ibid* s 8(7)(a).

present will and preferences’ of the individual, if ascertainable.³¹ Third, the intervener must ‘take into account the beliefs and values of the relevant person (...) and any other factors which the relevant person would be likely to consider if he or she were able to do so’, if ascertainable.³² Fourth, unless inappropriate or impracticable, the intervener should consider the views of ‘any person named by the relevant person as a person to be consulted’ and ‘any decision-making assistant, co-decision-maker, decision-making representative or attorney for the relevant person’.³³ The intervener may consider the views of those caring for the relevant person, those with a bona fide interest in her welfare or healthcare professionals.³⁴ Finally, regard must be had to the likelihood of the individual recovering decision-making capacity and ‘the urgency of making the intervention prior to such recovery’.³⁵

Clearly, the legislature has made great strides towards protecting individual autonomy and the interests of every individual in self-determination, particularly those who are at risk of loss or fluctuating capacity due to an intellectual disability or degenerative condition. While the legislation is certainly not perfect, it bears many of the hallmarks of a framework, which tries to keep the individual at the centre. How these aspirations regarding the individual and her autonomy may be said to change in respect of pregnant women will become apparent as this research progresses.

The 8th Amendment

In 1983, Bunreacht na hÉireann was amended on foot of a constitutional referendum and Article 40.3.3 was inserted. This became known as ‘the 8th Amendment’ and the Article in question provided:

The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right.

In 2018, the 8th Amendment was repealed by constitutional referendum and the wording of Article 40.3.3 was changed to ‘[p]rovision may be made by law for the regulation of termination of pregnancy’. This brief explanation of the constitutional protection afforded to the ‘right to life

³¹ *ibid* s 8(7)(b).

³² *ibid* s 8(7)(c).

³³ *ibid* s 8(7)(d).

³⁴ *ibid* s 8(8).

³⁵ *ibid* s 8(9).

of the unborn' is important for two of reasons. First, this 'right to life' has had a constant presence in Irish jurisprudence, not only where matters directly related to abortion have been considered but critically where other issues are before the court, including healthcare in pregnancy. The importance of the 8th Amendment will be clear during the analysis conducted in Chapter 6. Second, and more importantly from the perspective of this research, the 8th Amendment had not been repealed when the ADM(C)A 2015 was drafted or signed into law. Thus, it had not been repealed when the section that is the primary focus of this research, section 85(6), was drafted.³⁶ Consequently, questions arise as to the legal basis for this section, which will be discussed in Chapter 6.

Original Contribution

The preceding paragraphs should give an indication as to the original contribution of this thesis to scholarship, however, a clear statement of that contribution will undoubtedly be helpful. Not only does this thesis consider advance directives in general in Ireland in light of the ADM(C)A 2015, which is an area that has not received significant analysis in and of itself, but also considers how an advance directive in pregnancy is likely to be treated under Irish law. Although there have been some academic contributions on the former,³⁷ the most important contribution to scholarship rests on the second. Perhaps owing to the recency of the legislation, heretofore, there have been no other academic works that have considered advance directives in pregnancy in Ireland from a legal and ethical perspective.

Thesis Structure

This research is divided into five core chapters, an introduction and a conclusion. Chapter 2 explores the meaning of ethics and morals and slowly builds to considering the relationship between medical ethics and law. In this way, this chapter underpins the ethical analysis in the

³⁶ Section 85(6) states: (a) Where a directive-maker lacks capacity and is pregnant, but her advance healthcare directive does not specifically state whether (...) she intended a specific refusal of treatment set out in the directive to apply if she were pregnant, and it is considered by the healthcare professional concerned that complying with the refusal of treatment would have a deleterious effect on the unborn, there shall be a presumption that treatment shall be provided or continued. (b) Where a directive-maker lacks capacity and is pregnant and her advance healthcare directive sets out a specific refusal of treatment that is to apply even if she were pregnant, and it is considered by the healthcare professional concerned that the refusal of treatment would have a deleterious effect on the unborn, an application shall be made to the High Court to determine whether or not the refusal of treatment should apply. (c) In determining an application under paragraph (b), the High Court shall have regard to the following: (i) the potential impact of the refusal of treatment on the unborn; (ii) if the treatment that is refused were given to the directive-maker, the invasiveness and duration of the treatment and the risk of harm to the directive-maker; (iii) any other matter which the High Court considers relevant to the application.

³⁷ See, for example, Mary Donnelly, 'Developing a Legal Framework for Advance Healthcare Planning: Comparing England & Wales and Ireland' (2017) 24 *European Journal of Health Law* 67.

subsequent chapters. In the beginning, the reader is introduced to some normative ethical frameworks, which are used in the resolution of complex ethical dilemmas both in the context of medical decision-making and outside of it. It then progresses to looking at medical ethics, its history and its relevance, in addition to discussing the primary method of resolving complex dilemmas within medical ethics, namely the Four Principles or Principlism – Autonomy, Beneficence, Non-Maleficence and Justice. It concludes by exploring some of the key criticisms of Principlism, while also justifying its prominence for the duration of the thesis.

Chapter 3 focuses on informed consent to medical treatment. Not only does it consider the legal development of what is often termed ‘the doctrine of informed consent’, but also the ethical issues raised by it. The early part of Chapter 3 looks at the history of informed consent and discusses some major events – and the resulting societal shift – that preceded the doctrine. Scientific developments, in addition to scandals concerning members of the medical profession, are often thought to have been a precursor to the endorsement of the doctrine of informed consent by the courts. Using Principlism, the ethical justification for the duty to seek consent prior to intervening is explored. For informed consent to be given, the ‘giver’ must have capacity to make decisions of this nature and must do so voluntarily having received the information necessary to make the choice. Thus, the ethical analysis in this chapter looks at ethical considerations such as respect for autonomy and beneficence. The legal analysis of informed consent focuses primarily on two aspects; first, it focuses on the capacity to consent and how the law in Ireland, England and Wales and New York treats decision-making capacity. Second, it looks at how the law treats information disclosure and the duty placed on medical professionals in this regard. In addition to this more ‘generalist’ examination of informed consent, informed consent in pregnancy, or more accurately how pregnancy appears to shift and change the accepted norms of the law of informed consent, will also be considered.

Building on the previous discussions, Chapter 4 looks at the issue of end-of-life decision-making, exploring various end-of-life scenarios and detailing the legal development of the competent right to refuse life-sustaining treatment and its limitations. It also considers the legal position of patients with prolonged disorders of consciousness, who either left no instructions as to what treatment should not be administered or whose instructions, though left, were not legally binding. In looking at these complex legal situations, Chapter 4 also considers the underlying

ethical issues. The four principles³⁸ will be discussed in the context of life-sustaining treatment and the changing weight, scope, importance and applicability of the principles will become evident when competent and incompetent patients are discussed. Often, this research will contend that the best method of resolving the complexities associated with the refusal, withdrawal or withholding of life-sustaining treatment is by giving due respect to the autonomy of the individual and her interests in self-determination and bodily integrity. This chapter examines how the right to refuse life-sustaining treatment has been constructed by the law, not solely as a right derived from common law, but rather a combination of sources including common law, legislation and constitutional law.

In contrast to the approach in the previous chapter, the specific issues associated with pregnancy in end-of-life decision-making will not be discussed. These will be reserved for Chapter 6, wherein a complete discussion of compelled intervention in pregnancy will occur. This approach is deliberate, as arguably, it best highlights the glaring issues with medical treatment in pregnancy; first, that the life and health of the woman often becomes synonymous with the life and health of the foetus, often being treated as one. Her health often appears to garner no analysis or discussion in its own right in jurisprudence, almost as if to do so would be to admit that a particular course of action is being ordered in the interests of the foetus and not in the interests of the woman. Furthermore, to fully expose how differently pregnant women are treated, it is necessary to fully understand the response of the law to non-pregnant people who are making the same decisions.

Chapter 5 explores the concept of ‘advance directives’, sometimes referred to as ‘living wills’ or ‘advance decisions’. It details the history of their creation in law and the ethical justifications that underpin them. It also engages with the considerable criticism levelled at advance directives; amongst others that ‘the rewards of the campaign to promote living wills do not justify its costs [,] [n]or can any degree of tinkering ever make ... [it] an effective instrument of social policy’.³⁹ Like Chapter 4, there is no discussion of pregnancy and advance directives, as this discussion is also reserved for Chapter 6. Accordingly, Chapter 5 then discusses the jurisprudence on advance directives to demonstrate how the law treats those patients who are not pregnant.

³⁸ Autonomy, Beneficence, Non-Maleficence and Justice.

³⁹ Angela Fagerlin and Carl E Schneider, ‘Enough: The Failure of the Living Will’ (2004) 34 *Hastings Center Report* 30.

Finally, Chapter 6 brings together all of the legal and ethical analysis conducted in the previous chapters to look at the interrelated issues of compelled medical treatment in pregnancy and pregnancy exceptions in advance directive legislation. The Chapter examines the two issues – compelled treatment and pregnancy exclusions – together as a result of how the Irish legislation has been drafted. In order to theorise as to what criteria will be used by the Irish High Court in determining if an advance directive will be overridden in the interests of the foetus, it is necessary to establish the grounds on which the High Court has previously compelled treatment.⁴⁰ In order to assess if Ireland has taken the appropriate route with its legislation, Chapter 6 builds upon the analysis that has been conducted in the previous chapters vis-à-vis the rights of non-pregnant people.

Methodology

From the outset, it should be stated that this thesis primarily uses the doctrinal legal method, or black-letterism. The value of the doctrinal legal method cannot be underestimated; without establishing what the law is, how can one critique it or conclude that it is an effective instrument of social policy? How can one establish what effect the law has on groups within society, if one does not know the law? Some of the strength of black-letterism rests on it being a system that ‘emphasises coherence and unity’, or certainly one in which the researcher seeks coherence where that may be lacking.⁴¹ It is built upon ‘empirical and rational foundations’.⁴² As Shane Kilcommins argues: ‘It is loosely *empirical* in that lawyers work with the raw data of cases and other legal provisions. It is *rationalist* because it presupposes that the system is logical and internally coherent’.⁴³ In view of its features, strength and purpose, it is considered to be the most suitable primary methodology to underpin this research.

As Martin Dixon argues, however, ‘doctrinal scholarship in a vacuum loses much of its value’.⁴⁴ Thus, black-letterism serving as the primary method is not to say that the relationship between the law and wider society are excluded from analysis; indeed with matters such as healthcare, medical decision-making and pregnancy, it is impossible not to look at the wider implications

⁴⁰ Assisted Decision-Making (Capacity) Act 2015, s 85(6)(b)(c).

⁴¹ Shane Kilcommins, ‘Doctrinal Legal Method (Black-Letterism): assumptions, commitments and shortcomings’ in Laura Cahillane and Jennifer Schweppe (eds) *Legal Research Methods: Principles and Practicalities* (Clarus Press 2016) 9.

⁴² *ibid.*

⁴³ *ibid.*

that the law has on society or specific groups therein. Rather, it is to say that it would be misleading to refer to this piece as utilising socio-legal methodology. The same is true for comparisons with the law in other jurisdictions; as should be evident from the brief discussion earlier in this chapter, such comparisons are included in the course of this thesis. Equally misleading, however, would be to refer to this as comparative work, or one using comparative methodology. Instead, as one of the many methods of establishing the current position of Irish law and assessing if the approach taken by the Irish legislature is the most appropriate under the circumstances, this research utilises doctrinal methodology whilst comparing and contrasting different features of and themes present in other jurisdictions with Irish law.

While the doctrinal method has come in for its fair share of criticism, little time will be dedicated to defending it or its prevalence throughout this thesis; first, because this is a thesis about the legal position of a pregnant advance directive holder and not a thesis about legal methodology. Second, this adopts a similar approach to that taken by Martin Dixon towards research methodology in law – he argues ‘against the idea that one approach is to be preferred over another’⁴⁵ – that is, that there is no one right method in legal research, but there is one best suited to the research being undertaken, the question being answered and the researcher undertaking that task. With that said, a brief consideration of the perceived issues with the doctrinal method is useful, as Shane Kilcommins describes as follows:

On the face of it, the explanations [of doctrinal methodology] look thin, implicitly painting a picture of a method which is simplistic, thickly descriptive, and relatively unskilled, a join-the-dots, ‘taxonomic stock-taking’ exercise that could be undertaken by any adult with basic knowledge of the English language and some time on his or her hands. And yet, as lawyers, we know this is untrue.⁴⁶

Martin Dixon argues similarly:

A doctrinal approach (...) is initially the search for what the law *is*, not what it *should be*... So, when a (...) lawyer engaged in doctrinal research talks of critical analysis, they mean a dissection of the law *as is*, examining it for consistency and coherence, as well as a critical appreciation of the law in terms of policy-compatibility and future development. Furthermore, while it is true that ‘simply’ stating the law looks more like rule-identification rather than rule analysis, this often masks a much more complex task that is

⁴⁴ Martin Dixon, ‘A Doctrinal Approach to Property Law Scholarship: Who Cares and Why?’ (2014) 3 Prop L Rev 160. The version used by this research has been taken from the University of Cambridge Repository <<https://www.repository.cam.ac.uk/handle/1810/246249>> accessed 13 August 2020, thus the page numbering starts at 1. This page number for the above quote is 9.

⁴⁵ *ibid* 1.

⁴⁶ Shane Kilcommins, ‘Doctrinal Legal Method (Black-Letterism): assumptions, commitments and shortcomings’ in Laura Cahillane and Jennifer Schweppe (eds) *Legal Research Methods: Principles and Practicalities* (Clarus Press 2016) 2.

easily undervalued (...) In many cases, the most difficult research question of all is ‘what is the law?’ (...)’⁴⁷

That is certainly true of the first part of the primary research question in this thesis; what is the law in Ireland vis-à-vis a pregnant advance directive holder?⁴⁸

Conclusion

The question to be answered by this thesis is no small feat. ‘What is the law here?’ is a deceptively simple question and one that cannot be answered in a sentence or two. Rather, the answer rests on establishing a range of interrelated legal positions; what does the law say about the ability of a competent adult to refuse treatment? What about when refusal leads to death? How is decision-making incompetence established? What about competent pregnant women? When the courts have not decided a matter before, upon what grounds will they decide it and what is the persuasive precedent? How does the repeal of the 8th Amendment affect the previous precedent on medical treatment in pregnancy? Without understanding the development of the law in these areas, one misses something critical; thus, each chapter will give a detailed analysis of both the position of the law and how that came to be. Before engaging with the first of the legal issues – consent to medical treatment – this research begins with an introduction to medical ethics and a more detailed explanation of the role that will be played by ethical analysis in the course of this research.

⁴⁷ Martin Dixon, ‘A Doctrinal Approach to Property Law Scholarship: Who Cares and Why?’ (2014) 3 Prop L Rev 160 <<https://www.repository.cam.ac.uk/handle/1810/246249>> accessed 13 August 2020, 2-3.

⁴⁸ *ibid* 7; he goes on to argue that any assumption that it is a straightforward matter to determine what the law actually is mistaken. He clarifies: ‘I do not mean by this that it is unclear how the known law might be applied to novel fact situations. That is the stuff of everyday legal practice (...) Rather, it is the recognition that ‘the law’ itself might be unclear, as where an apparently simply statutory phrase has no determined meaning, or case law is inconsistent’.

Chapter 2

Introduction

As outlined previously, in order to understand the ethical considerations associated with the refusal of medical treatment in pregnancy, the role and development of medical ethics more generally must be understood. Therefore, this chapter delves into general ethical concepts and examines their relationship with medicine and the law, as ethical building blocks so to speak and explains and justifies the ethical framework that will be utilised from this chapter onwards – Principlism.¹ Thus, while each chapter identifies the ethical conflicts relevant to the specific legal issues being examined, the purpose of this chapter is to introduce modern medical ethics and specifically ‘the Four Principles’, as devised by Tom Beauchamp and James Childress.² In attempting to make medical ethics more practical, accessible and applicable to everyday medical dilemmas, Beauchamp and Childress devised these principles, namely (Respect for) Autonomy, Non-maleficence, Beneficence and Justice. Their aim was to aid medical professionals to identify and resolve the ethical issues arising in healthcare. The Principles have been described in positive terms as ‘a simple, accessible, and culturally neutral approach to thinking about ethical issues in health care’ by Ranaan Gillon.³ They have been criticised as ‘an approach which if followed by the bioethics community as a whole would (...) lead to sterility and uniformity of approach of a quite mindbogglingly boring kind’ by John Harris.⁴ Principlism, clearly, is not to everyone’s taste. Be that as it may, it is certainly a dominant approach within medical ethics and despite criticisms, which will be discussed in more detail later, it is favoured by this research as a method of looking at some of the complex ethical matters in healthcare.

It must be stated at the outset that this chapter cannot go further than an examination and synopsis of the key points of relevance within moral theory and medical ethics owing to its vastness as a subject and the confines of space. This may sometimes result in certain assumptions being made or premises being accepted without rigorous justification. It is hoped, however, that the more detailed and specific ethical arguments (as they apply to the legal concepts) in subsequent chapters will be sufficient in this regard. Principlism has featured

¹ First articulated in Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (1st edn, OUP 1979), now in its eight edition.

² Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (1st edn, OUP 1979); Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) in ‘Part II: Moral Principles’.

³ Ranaan Gillon, ‘Medical Ethics: Four Principles Plus Attention to Scope’ (1994) 309 *BMJ* 184.

⁴ John Harris, ‘In Praise of Unprincipled Ethics’ (2003) 29 *J Med Ethics* 303; It is worth noting that his critique is aimed at Principlism being used by bioethicists and does not necessarily critique its use by medical or legal professionals, or indeed amateur ethicists, as he accepts that ‘the four principles [may] constitute a useful “checklist” approach to bioethics for those new to the field, and possibly for ethics committees without substantial ethical expertise approaching new problems’.

heavily in medical ethics discourse over the last 40 years; after it is explained and its limitations explored in this chapter, it will then be used as the primary ethical framework to consider the issues arising throughout the rest of this research, while also leaving scope for the use of other ethical analysis where the need arises.

History of Bioethics and Medical Ethics

The word ‘ethics’, originally coming from the Ancient Greek word *ēthos* and later the Greek words (*hē*) *ēthikē* (*tekhnē*), meaning ‘(the science of) morals’; it has come to mean a set of moral principles relating to a specified group, field or form of conduct. Normative ethics, to which this research refers, is the practice of creating and evaluating moral standards in order to discern what is right and wrong. Thus, ethics can be considered to be a reflective process used to decide the appropriate action based on moral obligations in a given situation.⁵ ‘Bio’ comes from the Greek word *bios* meaning ‘(the course of) human life’.⁶ ‘Bioethics’ therefore means a set of moral principles pertaining to the course of life. In practical terms, it is understood to mean recognition and resolution of moral conflict arising from biological sciences and advances in medical technology, ‘a meeting ground for a number of disciplines, discourses and organisations concerned with ethical, legal and social questions raised by advances in medicine, science and biotechnology’.⁷

The term ‘bioethics’ is believed to date back to the 1920s, however, it appears that it did not come to prominence in the United States until the late 1960s and 1970s.⁸ Medical ethics, with ‘medical’ coming from the Latin *medicus* meaning ‘physician’, is generally understood in two ways; the first is as the code of behaviour to be adhered to by members of the medical community, which is perhaps the more traditional and paternalistic interpretation. It was a set of rules for doctors, designed by doctors.⁹ While they may have been scant in the early days, ethical guidelines are now substantial, issued by organisations such as the Irish Medical Council, the General Medical Council (GMC), the British Medical Association (BMA) and the American Medical Association (AMA). Be that as it may, it is submitted that this brand of ‘medical ethics’ is essentially still professionals writing guidelines for professionals. In that way, significant aspects of it operate in a similar fashion to the law, as quasi rules for physicians

⁵ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 3.

⁶ *Bios* was subsequently considered just to refer to ‘life’.

⁷ Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 1.

⁸ Ruth Chadwick and Duncan Wilson, ‘The Emergence and Development of Bioethics in the UK’ (2018) *Med L Rev* 183, 183-184; Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) viii.

⁹ See, for example, Onora O’Neill’s anecdote regarding an elderly doctor remarking ‘with mild nostalgia, that when he had studied medical ethics as a student, things had been easier: the curriculum had covered referrals, confidentiality – and billing’. Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 1.

to follow, with the potential for ‘punishment’ if the rules are not followed. It is submitted that while guidelines such as these are eminently useful in a legal context, it is not appropriate to view medical ethics as merely codes of professional ethics.

The second meaning of medical ethics, favoured by this research, is the identification and resolution of ethical conflicts arising in the context of medicine and healthcare. Put a little crudely, there is little use in considering the ‘rules’, without considering why they exist and any disagreement in relation to them. While some matters of medical ethics are almost entirely settled – such as the right of terminally ill patients to choose palliative treatment rather than invasive medical treatment – others, such as the very topic of this research, are not. Furthermore, it is submitted that the narrower rules or ‘system of behaviour’ definition is encompassed by this broader interpretation. As such, this research will refer to medical ethics – to a lesser extent, bioethics – when discussing conflicts arising from healthcare and medicine.¹⁰

One could contend that at least some of the impetus for the emergence of medical ethics as an area for consideration – as distinct from mere guidelines written by and for the use of medical professionals – came from two sources: first, advancements in science and healthcare and second, a lack of confidence in the tradition of self-regulation within the medical community. The former comprised of developments such as oral contraception, (live) organ transplantation and new or improved life-sustaining treatments.¹¹ The latter – in other words distrust of the medical profession – stemmed from several high-profile abuses by some physicians and researchers including the Tuskegee Syphilis Study and the Willowbrook State School Hepatitis Study, at least where the United States is concerned.¹² In both the United States and Europe, ‘confidence in the beneficence of medical science had (...) been dented by disturbing reports of invasive medical research on human subjects without their consent’ in Nazi Germany.¹³ In short, those outside the medical profession, such as philosophers, lawyers and sociologists felt that they had an important role to play in identifying issues in medicine and assisting physicians

¹⁰ It is worth noting that it is sometimes necessary to use the terms interchangeably, as this is the practice in some of the literature from the United States. Furthermore, while nursing ethics undoubtedly forms part of this overall field, this research will focus on the ethical issues arising between physicians and patient as it is argued that it is primarily within this relationship that the ethical issues surrounding refusals of treatment in pregnancy arise.

¹¹ Warren Reich, for example, identifies what he terms as ‘fertility control’ – encompassing issues such as contraception, sterilisation and abortion – as a major impetus in the development of bioethics; Warren Reich, ‘The Wider View: André Hellenger’s Passionate, Integrating Intellect and the Creation of Bioethics’ (1999) *Kennedy Inst Ethics J* 25, 37.

¹² These studies both involved human subject research and morally questionable practices from the medical professionals involved including negligent or deliberate exposure to disease and lack of informed consent. For a more comprehensive discussion of these events, see Chapter 3 where they are discussed in the context of the history of informed consent. See Henry Beecher, ‘Ethics and Clinical Research’ (1966) 274 *New Eng J Med* 1354 and Mary Donnelly, *Consent: Bridging the Gap between Doctor and Patient* (Cork University Press 2002) 8.

¹³ Kenneth Boyd, ‘Medical Ethics: Hippocratic and Democratic Ideals’ in Law’ in Sheila McClean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 30.

in dealing with them, in addition to challenging previously held values and beliefs. Kenneth Boyd, however, refers to this as the ‘short view’ of the emergence of medical ethics into the medical arena.¹⁴ He contends that the development of medical ethics in this way can actually be traced back to ‘the problematic success of the Hippocratic ideals in medicine and of democratic ideals in society’.¹⁵ Debating the merits of Boyd’s contention, however, will have to be left for another day.

As was discussed in the introduction, the 1970s saw bioethics coming to the fore in the United States. Independent bioethics institutes were formed, such as the Hastings Center, which had the goal of addressing ‘fundamental ethical and social issues in health care, science, and technology’.¹⁶ Universities, such as Georgetown, began establishing ‘centers’ for bioethics; the (now-titled) Kennedy Institute of Ethics was established in Georgetown in 1971, with the intention of dealing with ‘the most pressing ethical issues of our time’.¹⁷ Throughout the 1980s, other universities followed suit including Michigan State University, Stanford University and the University of Virginia.¹⁸ At the same time, bioethics organisations were being established at state level; in 1985, the New York State Task Force on Life and the Law was created to ‘examine legal and ethical issues arising from medical advances and to develop policy recommendations’ and this organisation still endures today, having produced reports on surrogacy, medical decision-making for the developmentally disabled and guidelines for determining brain death in the last decade. Ruth Chadwick and Duncan Wilson opine that the United Kingdom was initially sceptical towards the emergence of bioethics in the United States, however, it soon appeared to follow suit, tentatively in the 1970s and to a greater extent in the 1980s and 1990s.¹⁹ As had been the trend in the United States, universities in the United Kingdom began to establish ‘centres’ for medical ethics and independent bioethics organisations such as the Nuffield Council on Bioethics and the Scottish Council on Human Bioethics were founded in 1991 and 1997 respectively.²⁰ On an EU level, the European Group on Ethics in Science and New Technologies was formed in 1991; this independent body, more akin to a bioethical organisation than a purely medical ethics one, advises on all aspects of

¹⁴ *ibid* 29-31.

¹⁵ *ibid* 31.

¹⁶ <https://www.thehastingscenter.org/>

¹⁷ <https://kenedyinstitute.georgetown.edu/about/mission/>

¹⁸ Those universities established the Center for Ethics and Humanities in the Life Sciences, the Center for Biomedical Ethics and the Center for Biomedical Ethics and Humanities respectively

¹⁹ Ruth Chadwick and Duncan Wilson, ‘The Emergence and Development of Bioethics in the UK’ (2018) *Med L Rev* 183, 186; amongst other examples, they refer to the labelling of bioethics as ‘an American trend’ by *British Medical Journal* in 1978.

²⁰ The first of its kind in the United Kingdom, King’s College London formed the Centre for Medical Law and Ethics in 1978, with universities like the University of Manchester and the University of Keele following the lead and establishing the Centre for Social Ethics and Policy and Centre for Contemporary Ethical Studies respectively in the 1980s; <http://nuffieldbioethics.org/about/>; <http://www.schb.org.uk/about/>

Commission policies and legislation featuring an interaction between ethics and developments in science and technology.

Ireland was somewhat slower in this regard, with the Irish Council for Bioethics only being formed in 2002 and then disbanded in 2010 due to a cut in funding; its function was to consider the ethical issues raised by developments in science and medicine.²¹ During its existence, the Council reported on a range of important ethical issues including stem cell research. Arguably, this leaves Ireland in a somewhat precarious position regarding ethical dilemmas in healthcare, such as termination of pregnancy and surrogacy, as it is without a statutory body to consider these issues.²²

Normative Ethics

Broadly speaking, there are three competing approaches to normative ethical theory; teleological, deontological and virtue ethics.²³ Nils Hoppe and Jose Miola argue:

[T]he question of whether doing something is ‘right’ can be separated into considerations in relation to the action itself and of the type of person we should strive to be.²⁴

The former, they argue, encompasses teleological and deontological theories and the latter, virtue ethics. Teleology or teleological reasoning – in its most common form ‘consequentialism’ – is focused on the goal of the outcome. Consequentialism, found in the works of Jeremy Bentham and John Stuart Mill, broadly dictates that the rightness of the action can be found in its consequences. Deontology or deontological reasoning, popularised by the work of Immanuel Kant, is the belief that actions, in and of themselves, are either right or wrong, based on a system of rules or moral laws. Thus, deontology focuses on the act, as

²¹ It was established with key input by the Royal Irish Academy, though independent from it, as an independent, autonomous, non-statutory body charged with considering the ethical issues raised by developments in science and medicine. Barry Lyons, ‘The Irish Council for Bioethics: An Unaffordable Luxury?’ (2012) 21 *Camb Q Health Ethics* 375.

²² It is worth noting the following points however; the Irish Unit of the UNESCO Chair in Bioethics was established in 2016 and amongst its aims are to ‘collate state-of-the-art Irish research and coordinate research in topical bioethical issues’. <https://unesco.bioethicsireland.eu/home/aims-objectives/>. Furthermore, the National Advisory Committee on Bioethics (NACB) was established in 2012 with the task of advising the Minister for Health on the ethical and social implications of scientific developments in human medicine and healthcare. Perhaps a successor to the ICB, however, this committee has not met in recent years according to a Dáil debate in 2019; Dáil Deb 28 March 2019, [14560/19] <<https://www.oireachtas.ie/en/debates/question/2019-03-28/107/>> accessed 12 August 2020. The Royal Irish Academy has a Life and Medical Sciences Committee, an all-island multidisciplinary committee representing academia, industry, media, and other relevant stakeholders, which addresses issues of national and international through from lectures, expert statements, and so on. The Law Reform Commission considers ethical issues connected with proposals for law reform e.g. their legal and ethical analysis prior to the introduction of the Assisted Decision Making (Capacity) Act 2015, although this included participation from the Irish Council for Bioethics. Individual centres for ethics also exist in some Irish universities, such as the Institute of Ethics in Dublin City University and the Centre of Bioethical Research and Analysis at National University of Ireland Galway. Finally, multiple Research Ethics Committees (REC) exist within the Health Service Executive, however the function of these committees appears to be to regulate research involving human subjects, as opposed to providing guidance or adjudication on individual complex ethical dilemmas or ones which affect the nation more generally.

²³ For the purpose of this research, the traditional view of a competing or ‘rivalrous’ relationship between consequentialism and deontology (Kantianism) will be maintained, however, it is worth noting that some commentators, such as Derek Parfit reject this idea; Derek Parfit, *On What Matters: Volume One* (OUP 2011), in particular, Parts II and III.

²⁴ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 11.

distinct from its consequences, to establish its rightness. Virtue ethics, often credited to a significant degree to Aristotle, focuses on character of the actor, as distinct from either the act itself or its consequences.²⁵ Crudely put, according to virtue ethics, an action is permissible if it is the act of a virtuous person, or person of good moral character. Virtue ethics requires the person to acquire good habits of character – for example, Plato’s virtues of wisdom, courage, temperance and justice – and once she has done so, she will act in a manner consistent with those good habits. In the following section, both teleology and deontology will be considered in more detail; however, while virtue ethics undoubtedly has value and a place within medical ethics, it is felt that its primary idea – honourable desires or motives will lead to the morally right decision – can be seen as supplementing deontology and utilitarianism, rather than necessarily offering an alternative to it.²⁶

Utilitarianism

Perhaps the best-known formulation of consequentialist reasoning – utilitarianism – dictates that the right action will be the one that maximises ‘utility’. Therefore, whether an action is intuitively right or wrong is irrelevant; the morality of an action can only be judged on its outcome, which should be the maximisation of utility. One might naturally question what is meant by ‘utility’. Classic – or hedonistic – utilitarians such as Bentham considered utility to mean ‘pleasure’; he construed utility as ‘benefit, advantage, pleasure, good, or happiness’ or the prevention of ‘the happening of mischief, pain, evil, or unhappiness to the party whose interest is considered’.²⁷ Therefore, utilitarian theory, at that time, generally decreed that the morally permissible action was the one which produces the most happiness (pleasure), or the least suffering, for the most amount of people:

An action then may be said to conform to the principle of utility (...) when its tendency to increase the happiness of the community is greater than any tendency it has to lessen it.²⁸

²⁵ For modern formulations of virtue ethics, see Elizabeth Anscombe, ‘Modern Moral Philosophy’ (1958) 33 *Philosophy* 1; Alasdair MacIntyre, *After Virtue: A Study in Moral Theory* (3rd edn, University of Notre Dame Press 2007) and the works of Phillipa Foot.

²⁶ Commentators such as David Misselbrook argue that virtue ethics should be used as the system of moral analysis within medical ethics in a two-part paper in the *Journal of the Royal Society of Medicine*. See David Misselbrook, ‘Virtue Ethics – An Old Answer to a New Dilemma? Part 1. Problems with Contemporary Medical Ethics’ (2015) 108 *J R Soc Med* 53; David Misselbrook, ‘Virtue Ethics – An Old Answer to a New Dilemma? Part 2. The case for inclusive virtue ethics’ (2015) 108 *J R Soc Med* 89. For other proponents of virtue ethics within medical ethics, see P Gardiner, ‘A Virtue Ethics Approach to Moral Dilemmas in Medicine’ (2003) 29 *J Med Ethics* 297; David John Doukas, ‘Where is the virtue in professionalism?’ (2003) 12 *Camb Q Health Ethics* 147; David John Doukas, ‘Promoting Professionalism Through Virtue Ethics’ (2019) 19 *Am J Bioeth.* 37 (on the role of virtue ethics in matters such as committed wrongs upon patients by physicians, sexual misconduct, non-consensual procedures and drug abuse).

²⁷ Jeremy Bentham, *Introduction to the Principles of Morals and Legislation* (1789).

²⁸ *ibid.*

Classic utilitarian theory advanced, first with Mill:²⁹ though he was in agreement with Jeremy Bentham that that utility should be pursued, he spoke of ‘pleasure’ as ‘higher pleasures’ or those in line with one’s ‘higher faculties’.³⁰ The key point for Mill was a distinction between quantity and quality; no amount of the former could be calculated against the latter. Thus, utility was more akin to the idea of overall happiness or social utility.³¹ He also advanced the idea that not all pleasures are equal.³²

Many modern commentators separated utilitarianism from both the pursuit of pleasure or happiness, though not without acknowledging that contemporary accounts of utilitarianism could not exist without their predecessors and not without pointing out that their theories were a product of their time:

Though many details of the classical utilitarian position may be unacceptable to us today, we must not forget what the basic political and moral principles were they were fighting for (...) [T]hey fought for reason against mere tradition, dogmatism, and vested interests. In politics, they conceived the revolutionary idea of judging existing social institutions by an impartial rational test, that of social utility, and did not hesitate to announce it in clear and unmistakable terms if they felt that many of these institutions had definitely failed to pass this test. Likewise, in ethics, they proposed to subject all accepted moral rules to tests of rationality and social utility.³³

Contemporary utilitarians, such as John Finnis and John Harsanyi, then argued for a more refined theory of utilitarianism based on rational choices.³⁴ Still, the basis of utilitarianism can be understood as individuals should undertake the action that results in the maximum utility.

Instinctively, there are issues with adopting a consequences-driven approach to matters of moral conflict. First, the ability of individuals to predict the consequences of a particular action must vary; as a result, two strands within utilitarian theory emerged – the foreseeable consequence and actual consequence view. The former says that you must act in the way that *expects* to yield the most good or utility. The latter says you must act in the way that *does* yield the best consequences. As such, the same choice may be considered the right decision from the foreseeable consequence view and the wrong decision from the actual consequence view. In both the views, rescuing an individual from a burning building may initially be viewed as the

²⁹ John Stuart Mill, ‘Utilitarianism’ in James E White (ed) *Contemporary Moral Problems* (9th edn, Thomson 2009).

³⁰ *ibid* 39-40.

³¹ *ibid* 41: ‘[T]he happiness which forms the utilitarian standard of what is right in conduct, is not the agent’s own happiness, but that of all concerned. As between his own happiness and that of others, utilitarianism requires him to be as strictly impartial as a disinterested and benevolent spectator.’

³² *ibid* 39: ‘It is quite compatible with the principle of utility to recognize the fact, that some kinds of pleasure are more desirable and more valuable than others. It would be absurd that (...) the estimation of pleasures should be supposed to depend on quantity alone.’

³³ John Harsanyi, ‘Morality and the Theory of Rational Behavior’ (1977) 44 *Soc Res* 623, 624-625.

³⁴ *ibid*; John Finnis, *Fundamentals of Ethics* (Georgetown University Press 1983). See also the works of John Harris, Julian Savulescu and Peter Singer.

morally permissible action. If, however, that individual later went on to weaponize a deadly virus for profit or become a prolific serial killer, then the decision may be evaluated quite differently under the two views.

The second issue with classic utilitarian theory is that the time required to ponder and speculate as to the consequences arising from every single action would be significant. This concern is represented in a second division within utilitarian theory – *act-utilitarianism* and *rule-utilitarianism*.³⁵ Act utilitarians assess actions on a case by case basis; the right action will be ‘the one that, of all the actions open to the agent, has consequences that are better than, or at least no worse than, any other action open’.³⁶ Rule utilitarians apply the principle of utility to a particular rule and then follow that rule if it would lead to the best overall consequences. For them, ‘the right action is the one that is in accordance with the rule that, if generally followed, would have consequences that are better than, or at least no worse than, any other rule that might be generally followed in the relevant situation’.³⁷ Accordingly, with the same set of circumstances, act utilitarians and rule utilitarians may come to different decisions as to what the morally right action is. As Peter Singer explains:

Rule-utilitarians will not accept [a] (...) rule without being persuaded that it will have better consequences than any other rule. Act-utilitarians will need to be assured that it will have the best consequences to follow the rule in every instance in which it applies.³⁸

Even aside from the challenges in ascertaining exactly how one can be a *good utilitarian*, a greater issue exists with the theory. If the primary – sometimes sole – focus is the outcome, then the needs of the many can outweigh the needs of the few; arguably, this leaves the door open to sacrifice one (or the few) for the benefit of others, if the overall balance of benefits over burdens is positive. There may be legitimacy in jailing innocent people in order to quell violent riots or in diverting a runaway train to hit one person instead of the five that it is on course to hit.³⁹

Deontology

Coming from the Greek word *deon*, which means ‘that which is binding, duty’, deontological theory is a duty-based theory in that it dictates that the correctness of an action hinges on

³⁵ See Roy F Harrod, ‘Utilitarianism Revised’ (1936) 45 *Mind* 137; Richard Brandt, *Ethical Theory: The Problems of Normative and Critical Ethics* (Prentice-Hall 1959).

³⁶ Peter Singer, ‘Voluntary Euthanasia: A Utilitarian Perspective’ (2003) 17 *Bioethics* 526, 526-7.

³⁷ *ibid* 527.

³⁸ *ibid* 528.

³⁹ The so-called ‘Trolley Problem’ was popularised by Phillipa Foot. See Phillipa Foot, *Vices and Virtues: And Other Essays in Moral Philosophy* (Oxford 2002) 23 (first published as Phillipa Foot, ‘The Problem of Abortion and the Doctrine of Double Effect’ (1967) 5 *Oxford Rev* 5).

whether or not the action itself is right or wrong according to a set of rules. Thus, there are rational duties and behaviours that ought to guide actors and the rightness of the action ‘lies in the path taken rather than the destination sought’.⁴⁰ Perhaps the most well-known deontological theorist is German philosopher Kant, who devised the ‘Categorical Imperative’ during the 1700s. It is an unconditional rule, which dictates that we respect the humanity in ourselves and others and act in accordance with moral law: ‘I ought never to act in such a way that I couldn’t also will that the maxim on which I act should be a universal law.’⁴¹ In the first formulation, Kant asks of individuals that they act only in a way that they would and could will everyone else to act: ‘Act in such a way that you treat humanity, whether in your own person or in the person of any other, never merely as a means to an end, but always at the same time as an end.’⁴²

Kant’s universality has been equated with ‘reciprocity’;⁴³ that idea that you should not expect from others what you do not feel you have an obligation to do yourself. Or to put it another way, the idea that you should treat others as you would like to be treated.⁴⁴ In the second formulation, Kant instructs that human beings have intrinsic value and accordingly, that they must be treated with respect and not treated as a ‘thing’ or *only* a means to achieve an end. Critical to Kant’s theory was moral autonomy, or the ability to consider matters and give oneself a moral law possessed by rational agents. In his view, autonomy did not mean being free from the constraints of laws, but instead by being subject to laws that are of the making of the individual. Autonomy – though not necessarily Kantian Autonomy – as will be apparent later, is often a central consideration in the resolution of conflicts within healthcare decision-making.

W.D. Ross, a more modern deontological theorist devised seven *prima facie* duties; fidelity (keeping a promise), reparation (compensating another for harm), gratitude, justice (prevention of the distribution of pleasure which is not based on merit), beneficence (improving the conditions of others), self-improvement (in the context of virtue and intelligence) and non-maleficence.⁴⁵ These duties form the criteria that indicate if an act is morally right in the circumstances. A particular decision may involve any number of these duties and in some

⁴⁰ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 13.

⁴¹ Immanuel Kant, *Groundwork of the Metaphysics of Morals* (1785).

⁴² *ibid.*

⁴³ John Harsanyi, ‘Morality and the Theory of Rational Behavior’ (1977) 44 Soc Res 623, 624.

⁴⁴ *ibid.*

⁴⁵ WD Ross, *The Right and the Good* (1930) 21.

circumstances they may even conflict, however, some duties were more important than others, for example fidelity is more important than the duty to promote good according to Ross.

Both consequentialist and deontological theory are appealing to ethicists, wishing to argue over complex theories and specific scenarios, but their usefulness as a means of assisting in the resolution of challenging ethical issues in healthcare is less clear. The rules inherent in deontology may not adapt sufficiently well to handle complex situations. On the face of it, 'thou shalt not kill' seems clear, but how does it apply to a situation where a termination is requested? Leaving aside the law, does the deontologist never perform a termination? Or always, because the maxim is confined to the born? Does his response depend on how far the pregnancy has progressed? Does it depend on the impact of the pregnancy on the woman or the risk of that pregnancy causing death or grave harm? If we should, as Kant argued, never view the human body or a person as property, then can issues that concern the use of the human body or its parts, such as surrogacy or paid egg and sperm donation, be justified?⁴⁶ With utilitarianism, the good outcome can depend on what kind of utilitarian he is. As described previously, the action believed to be the right one by a rule utilitarian will not always be the same as the one believed to be right by an act utilitarian; both are considered to have acted morally, but both decisions cannot avoid harm. Perhaps, ethicists will read this and the following paragraph and argue that it is an overly simplistic account of both deontology and utilitarianism. Perhaps, they would be right. Generally, however, neither doctors nor patients are accomplished philosophers; their ability to engage in a complex utilitarian debate about the merits of the therapeutic exception to informed consent at the bedside is non-existent, or at the very least, severely limited. To paraphrase Emily Jackson: it's all very interesting, but how do these theories help one to make complex ethical decisions?⁴⁷

This should not be interpreted as implying that normative theories do not have a place in healthcare. Rather, if we look more closely, we can see examples of both deontological and utilitarian reasoning within common issues. Resource allocation and resource shortages, for example, often see the broad use of utilitarian reasoning. When allocating funding in healthcare, decision-makers generally attempt a broad utilitarian approach; funding is allocated in the way that is believed will positively affect the greatest number of people. Deontological

⁴⁶ 'Man cannot dispose over himself because he is not a thing; (...) a person cannot be a property and so cannot be a thing which can be owned, for it is impossible to be a person and a thing, the proprietor and the property. Accordingly a man is not at his own disposal. He is not entitled to sell a limb, not even one of his own teeth.' Immanuel Kant, *Lectures on Ethics* (Louis Infield tr, Harper & Row 1963).

⁴⁷ Emily Jackson, *Medical Law: Text, Cases and Materials* (4th edn, OUP 2016) 15; 'Moral philosophy can be a helpful way of framing medical dilemmas, but it will seldom provide clear answers for doctors faced with difficult choices. For example, a doctor might be told that: "A utilitarian would do X, and a Kantian would do Y", which might be interesting, but is not terribly helpful.'

reasoning can also be seen in a number of areas in healthcare; opponents of the practices of physician assisted suicide and euthanasia often use deontological arguments to articulate why the practice is morally wrong. The taking of the life of an innocent human is contrary to moral law or intrinsically wrong, therefore physician assisted suicide and euthanasia are morally wrong. While that may be true for some physicians, the existence of physician assisted suicide and euthanasia in some countries demonstrates that it is not a universal moral truth for all physicians that to ‘kill’ his patient is wrong.

Principlism

As outlined previously, the Four Principles are; (Respect for) Autonomy, Non-maleficence, Beneficence and Justice.⁴⁸ They should look quite familiar; as discussed, ‘autonomy’ featured quite heavily in the works of Kant and the other three principles were articulated by Ross in ‘The Right and the Good’, amongst other philosophers. What is therefore interesting to note about both beneficence and non-maleficence is that, despite being ‘rules’ given by a deontologist, they are considered to be consequentialist principles, as they ‘require us to take into account possible benefits and harms’, in other words, the consequences of the action.⁴⁹ What is noteworthy in relation to autonomy, or at least autonomy in the contemporary sense, is that its development has sometimes been attributed to classic utilitarian John Stuart Mill.⁵⁰ Accordingly, it is neither possible nor desirable to *escape* the presence of the normative ethical frameworks discussed. Rather, what the Georgetown Mantra has achieved to some extent is the combination of Deontology and Utilitarianism into an accessible system, which is more readily applicable to the practice-based medical context.

Autonomy

‘Autonomy’, coming from the Greek words *autos* meaning ‘self’ and *nomos* meaning law essentially came to mean ‘self-rule’ or ‘having its own laws’ and initially the term applied to cities, as distinct from individuals. An autonomous person is often thought to be one who is capable of freely making important decisions about her own life. Being autonomous seems, therefore, to be a relatively simple concept – the state of ruling oneself – and yet there has been difficulty in pinning down what that means, both inside and outside of the healthcare sphere. Autonomy has been explained as having freedom to act⁵¹ in accordance with a self-chosen

⁴⁸ Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) in ‘Part II: Moral Principles’.

⁴⁹ Emily Jackson, *Medical Law: Text, Cases and Materials* (4th edn, OUP 2016) 17.

⁵⁰ Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 30.

⁵¹ For example, see John Harris, ‘Euthanasia and the Value of Life’ in John Keown (ed) *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 1995) 11; he describes autonomy as ‘the ability and the freedom to make the choices that shape our

plan,⁵² as having capacity for self-determination,⁵³ as ‘a right to personal sovereignty’,⁵⁴ as freedom of choice and as being independent.⁵⁵ It has been explained as being a combination of some the above, as Joel Feinberg does:

When applied to individuals the word ‘autonomy’ has four closely related meanings. It can refer either to the capacity to govern oneself (...) to the actual condition of self-government (...) to an ideal of character derived from that conception (...) or to the sovereign authority to govern oneself, which is absolute within one’s own moral boundaries.⁵⁶

In typifying this lack of a single coherent definition, Gerald Dworkin notes:

It is used sometimes as an equivalent of liberty (...) sometimes as equivalent to self-rule or sovereignty, sometimes as identical with freedom of will. It is equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one’s own interests.⁵⁷

He contends that almost the only commonalities between the various accounts is that autonomy relates to individuals (persons) and that it is viewed to have value.

Autonomy has been described as standalone and as relational in nature, in the sense that it depends on an opposing force to exist.⁵⁸ It has been assigned versions and given ‘rules’ or conditions to be present.⁵⁹ John Coggon, for example, outlines three philosophical understandings of autonomy, or versions; (i) ideal desire autonomy (ii) best desire autonomy and (iii) current desire autonomy.⁶⁰ Within medical ethics, autonomy has primacy in some

lives’ which is ‘crucial in giving to each life its own special and peculiar value’. See also RS Downie and Elizabeth Telfer, ‘Autonomy’ (1971) 46 *Philosophy* 293, 293-295; they argue that an individual can be said to be autonomous by virtue of ‘his capacity to choose what to do, whether he will do X or refrain (...) a capacity to choose what to think (...) a capacity to “think what he likes on moral matters”, “make up his own mind on moral issues”(...)’. In summary, they opine that autonomy can be construed as the ability to plan and choose what to do, the ability to think for oneself or the freedom and the right to form one’s own opinions on moral questions.

⁵² Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) 99.

⁵³ For example, Tom Walker describes autonomy as ‘the capacity to think about what you want, to make decisions about what you want taking into account your aims and values, and then to act on those decisions’ - Tom Walker, ‘If they can consent, why can’t they refuse?’ in Mary Donnelly and Claire Murray (eds) *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester University Press 2016) 76. See also RS Downie and Elizabeth Telfer, ‘Autonomy’ (1971) 46 *Philosophy* 293. See Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 11-22 for a discussion of autonomy as self-determination, as rational self-determination and as moral rational self-determination.

⁵⁴ Bernadette J Richards, ‘Autonomy and the Law: Widely Used, Poorly Defined’ in David G Kirchhoffer and Bernadette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) 19.

⁵⁵ Onora O’Neill comments that many accounts of autonomy see it viewed as ‘a form of independence’, which she goes on to criticise quite strongly; ‘[i]ndividual autonomy is not a matter of mere, sheer independence, of the sort praised by pop-existentialists, or aspired to by my streaking student’ - Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 28.

⁵⁶ Joel Feinberg *Harm to Self* (OUP 1986) 28.

⁵⁷ Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press, 1988) 6.

⁵⁸ If one considers autonomy to be ‘a form of independence’, then in O’Neill’s view, it is relational in nature in that it is ‘independence from something or other’. Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 28. This is not to be confused with ‘relational autonomy’, which is exhibited by an individual who is ‘a free, self-governing agent who is also socially constituted and who possibly defines her basic value commitments in terms of inter-personal relations and mutual dependencies’; John Christmas, ‘Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves’ (2004) 117 *Philosophical Studies* 143.

⁵⁹ As per Walker, ‘[t]o be autonomous is to be self-governing’ and accordingly, ‘[i]n order to be self-governing an individual needs to be able to do certain things’; in other words autonomy has rules or conditions. Tom Walker, ‘If they can consent, why can’t they refuse?’ in Mary Donnelly and Claire Murray (eds) *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester University Press 2016) 76.

⁶⁰ John Coggon, ‘Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?’ (2007) 15 *Health Care Anal* 235, 240.

analysis, as the sole principle relevant to ethical decision-making in healthcare and a lesser importance in others, being described as one of a number of relevant considerations in modern medical ethics.⁶¹ Hoppe and Miola state:

Autonomy is a paramount principle of law as a whole (...) We can find aspects of autonomy in every area of law that touches upon free will of individuals (...) It is one of the law's foremost duties to protect and enable autonomous individuals and regulate the necessary trade-offs between autonomous actors.⁶²

Its primacy within medical law and ethics has been explored and questioned:

[S]hould we place limits on patient autonomy in defence of broader community interests (whether these be about public health, allocation of resources of the sort of society in which we want to live) (...) what, for example, of the autonomy of the patient face-à-face the autonomy of others, such as her parents, relatives or, even, her doctor?⁶³

Autonomy has been heavily critiqued in some instances.⁶⁴ It has been recognised as being fallible, susceptible to being diminished or reduced by particular circumstances.⁶⁵ Consequently, it is sometimes argued that 'one of the problems with autonomy is that there are almost as many different conceptions as there are commentators writing on the subject'.⁶⁶ This, Alasdair Maclean argues 'does not mean that there is no single concept' of autonomy.⁶⁷ Whether he is correct on that matter may be, to some extent, irrelevant. This research is neither going to propose a new understanding of autonomy, nor consider autonomy outside of the narrow circumstances of decision-making within healthcare. In that sense, autonomy can mean both freedom from interference and capacity for self-determination and choice, while always being viewed as valuable.

In *Life's Dominion*, Ronald Dworkin advances the most plausible account of autonomy (in his view) and in doing so, it is argued that he captures the essence of the importance of autonomy:

⁶¹ It is worth noting that Beauchamp and Childress explicitly state that autonomy does not have 'moral priority' over other principles. Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) 99.

⁶² Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 95.

⁶³ Graeme Laurie, 'The Autonomy of Others: reflections on the Rise and Rise of Patient Choice in Contemporary Medical Law' in Sheila McClean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 132 (in relation to the contribution of Professor Ken Mason to medical law).

⁶⁴ See, for example, Alexander McCall Smith, 'Beyond Autonomy' (1997) 14 J Contemp HL & Policy 23; Charles Foster, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics* (Hart Publishing 2009). Onora O'Neill, for example, is quite critical of individual notions of autonomy: 'By themselves (...) conceptions of individual autonomy cannot provide a sufficient and convincing starting point for bioethics, or even for medical ethics. They may encourage ethically questionable forms of individualism and self-expression and may heighten rather than reduce public mistrust in medicine, science and biotechnology. At most individual autonomy, understood merely as an inflated term for informed consent requirements, can play a minor part within a wider account of ethical standards'; Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 73.

⁶⁵ For example, circumstances such as drug addiction and social inequality; see Steve Matthews and Jeanette Kennett, 'Diminished Autonomy: Consent and Chronic Addiction' Defined' in David G Kirchhoffer and Bernadette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) and S Stewart Braun, 'Compromised Autonomy: Social Inequality and Issues of Status and Control' in David G Kirchhoffer and Bernadette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019).

⁶⁶ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 10.

⁶⁷ *ibid.*

[It] emphasizes the integrity rather than the welfare of the choosing agent; the value of autonomy, on this view, derives from the capacity it protects: the capacity to express one's own character – values, commitments, convictions, and critical as well as experiential interests – in the life one leads. Recognizing an individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives according to our own coherent or incoherent – but, in any case, distinctive – personality. It allows us to lead our lives rather than be led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what we have made of ourselves.⁶⁸

It is this idea, the vision of the individual shaping her existence, her life and her future in accordance with her values and in line with what is important to her that captures why respect for autonomy is so important.

In a healthcare context, autonomy is often synonymous with the ability of a competent adult to make decisions regarding her healthcare. In this context, it can be easily understood in line with its relationship to the potential for interference. As Bernadette Richards argues:

Autonomy (...) is best served when the law is focusing on other rights such as bodily integrity, freedom from assault (...) and privacy (...) [these rights] can be framed within the broader discussion of autonomy but represent other interrelated, rights, duties and interests.⁶⁹

Perhaps a symptom of its many understandings and constructs, adhering to principle of respect for autonomy is open to a broader or narrower interpretation. Within healthcare, the law has tended to support a narrower construction of autonomy in healthcare, perhaps reflecting what is argued by some as upholding 'the ethical minimum'.⁷⁰ The 'narrower' construction manifests as the general requirement that a physician seek consent prior to treating a competent patient, to facilitate and then respect the informed decision of that patient, once made and to refrain from treating a patient without her consent, save in exceptional circumstances.⁷¹ This is as opposed to the law requiring the physician to provide a particular treatment at the request of the patient. While a patient can choose between the treatment options provided by the doctor, or choose no treatment, or request to have a second opinion or transfer of care if she believes that other options should be made available to her, she cannot force a physician to provide her with her desired treatment against his judgement.⁷² As Coggon opines:

⁶⁸ Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Harper Collins 1993) 224.

⁶⁹ Bernadette J Richards, 'Autonomy and the Law: Widely Used, Poorly Defined' in David G Kirchhoffer and Bernadette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) 18.

⁷⁰ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 3; here they reference the work of Georg Jellinek, a German legal positivist from the early 1900s.

⁷¹ Naturally, there are some exceptions to this general principle i.e. treatment on the grounds of risk to public health, treatment of unconscious patients in an emergency, etc.

⁷² Even abortion, which is generally provided on the request of the woman and which is sometimes viewed as a 'right' in healthcare once in line with the jurisdictional legal framework, is subject to the constraints of conscientious objection.

‘Absolute’ rights of noninterference do not translate into absolute rights to claim, either against doctors in the face of contrary (and reasonable) professional judgment, or against the state in the face of lawful resource allocation decisions.⁷³

While this research would not necessarily accept the word ‘absolute’ in the context of the right to refuse treatment, his sentiment still stands.

In Chapter 3, the relationship between informed consent and autonomy will be discussed in more detail. For now, it is worth noting that many accounts of autonomy refer to making choices and self-determination. Consequently, it can be suggested that the physician has a key role to play in decision-making in the sense of information provision. Without the relevant information, an individual is unlikely to be capable of autonomous choice. The same can be said in relation to incompetence and involuntariness; they likely render the individual incapable of autonomous choice. Thus, in this context, respect for autonomy not only requires medical professionals to refrain from dispensing with the autonomous decision of the individual, but also requires them to assist in this exercise by providing the patient with information. It requires them to provide this information in a way that can be understood by the patient, where possible, thereby avoiding a declaration of incapacity purely because the patient did not understand something that she otherwise could have, were the information simplified or given more fully. Again, however, a narrower interpretation of the law in this regard can be seen; physicians are not required to give every last scrap of information to the patient and in some cases, may be permitted to withhold information if they consider it to be necessary to prevent harm to that particular patient given the circumstances (‘therapeutic privilege’).⁷⁴

One could opine that autonomy does not only generate obligations for physicians, but also perhaps for the patient herself. A patient’s responsibility to exercise her autonomy could be said to stem from the idea that autonomy is what gives the individual the best chance of achieving her aims, which promotes her well-being.⁷⁵ In that way, such responsibilities are ones towards oneself, or as Michael Meyer puts it ‘self-regarding obligations’.⁷⁶ John Keown argues that we have a responsibility to choose in such a way as to promote our chosen values and goals, in other words ‘human flourishing’.⁷⁷ Accordingly, if we do not act in a way

⁷³ John Coggon, ‘Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection’ (2016) 24 Med L Rev 396, 407.

⁷⁴ The differing standard of care with respect to information disclosure will be considered in Chapter 3, along with therapeutic privilege.

⁷⁵ See Ronald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press 1988); Tom Walker, ‘If they can consent, why can’t they refuse?’ in Mary Donnelly and Claire Murray (eds) *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester University Press 2016)

⁷⁶ Michael Meyer, ‘Patients’ Duties’ (1992) 17 J Med Philos 541, 541

⁷⁷ John Keown, *Euthanasia, Ethics and Public Policy* (Cambridge University Press 2002) 53; he argues that ‘[t]he capacity to choose brings with it the responsibility of making not just any old choice, but choices that (...) promote (...) human flourishing’.

consistent with human well-being, then we are not exercising our autonomy ‘in accordance with a framework of sound moral values’ and as such, our exercise of autonomy does not merit respect.⁷⁸ Whether or not one agrees with the idea that some decisions are undeserving of respect, there is certainly some merit to the idea that patients, too, have obligations, whether stemming from autonomy or from the idea that the physician-patient relationship is one of a contractual nature or from another concept altogether.⁷⁹

Heather Draper and Tom Sorrell, for example, argue that citizens may have a moral duty to follow measures designed to prevent serious illness or disease, not just to benefit themselves, but in order to limit demands on resources.⁸⁰ Accordingly they argue for more onerous responsibilities on patients, rather than equating the mere fact that the decision has been made by the patient herself with it being ‘good’.⁸¹ The notion that patients have duties is also more common than some might expect in practice; Asim Sheikh points out that this notion is reflected in healthcare guidelines, for example, the Royal College of Surgeons of England confers an obligation on patients to undertake certain actions, such as to attend appointments on time and to take medication as instructed.⁸² Meyer argues that patients have a duty to communicate openly with healthcare professionals, to co-operate with them and engage in and make responsible decisions about their self-care, including the duty to have an active interest in their condition and to collect information on available treatments and side-effects.⁸³ These duties, he argues, are ‘derivable from the idea which typically grounds the idea of patients’ rights [namely] patient autonomy’.⁸⁴ Other commentators go further again to suggest that it is reasonable to impose a duty on patients to participate in clinical research in publicly-funded health systems.⁸⁵ The idea of patient obligations and duties in the context of the pregnant patient will be considered as part of the analysis in Chapter 6. In any event, whether we think that patients have onerous or more moderate duties in respect of healthcare, it is fair to say that

⁷⁸ *ibid.*

⁷⁹ As will be discussed in a little more detail in the context of informed consent, Alexander Capron argues that the physician-patient relationship has a contractual nature; Alexander Morgan Capron, ‘Informed Consent in Catastrophic Disease Research and Treatment’ (1974) 123 U Pa L Rev 340, 364.

⁸⁰ Heather Draper and Tom Sorrell, ‘Patients’ Responsibilities in Medical Ethics’ (2002) 16 Bioethics 335, 343.

⁸¹ *ibid* 338.

⁸² Asim A Sheikh, ‘Patient autonomy and responsibilities within the patient-doctor partnership: two sides of the same unequal coin?’ in Mary Donnelly and Claire Murray (eds) *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester University Press 2016) 87-88; Some commentators go further than to impose a duty on patients in respect of their own healthcare; for example, HM Evans argues that a duty exists to participate in clinical research in publicly-funded health systems. See H Martyn Evans, ‘Should Patients be Allowed to Veto Their Participation in Clinical Research?’ (2004) 30 J Med Ethics 198.

⁸³ Michael Meyer, ‘Patients’ Duties’ (1992) 17 J Med Philos 541, 551

⁸⁴ *ibid* 541; crudely put, he opines that the patient has willingly entered into a partnership with the healthcare worker with a shared goal of improving his health and as such, obligations and duties arise by virtue of this partnership.

⁸⁵ See H Martyn Evans, ‘Should Patients be Allowed to Veto Their Participation in Clinical Research?’ (2004) 30 J Med Ethics 198.

where one wishes to exert some influence regarding one's healthcare, then one does have corresponding moral duties, even if they are not often legally enforceable.

As the research progresses, the relationship between autonomy and the law, as it applies to the various medical decision-making scenarios, will be examined. On the one hand, broad conversations regarding autonomy are limited in how far they can go towards assisting the core question in this research, however, on the other hand, failing to look at autonomy and its many understandings would give an artificial idea that matters, such as the meaning and importance of autonomy, are settled. As should be evident from this section, there is a wealth of debate on autonomy; its meaning, its value and its role. It is argued, however, that these differences do not form a substantial part of the reason why the law, both the courts and legislature, can face challenges in the context of medical decision-making and specifically within the area of decision-making in pregnancy. Thus, by giving an overview of autonomy within healthcare and by contending that one single definition is not specifically necessary for autonomy to be both valuable and worthy of protection, this research can progress unencumbered by the responsibility of redefining the concept of autonomy and of justifying one single understanding of it. Instead, it can proceed with a higher-level – and perhaps less detailed – understanding of autonomy, appropriate to a predominantly legal thesis.

Non-Maleficence

Coming from the Latin words *non* meaning 'not' and *maleficentia* meaning 'evildoing, mischievousness, injury', non-maleficence in medical ethics is widely considered to be the duty of a physician to avoid acting in a way that causes harm. Often in discussions of moral theory or medical ethics, beneficence and non-maleficence are considered together and if a distinction is drawn between them, it is quite subtle.⁸⁶ It is the position of this research, however, that the principles are distinct and must be treated as such. One justification for this is found in the nature of the two duties – positive and negative. Beneficence is the duty to act, in that one must act to promote good and prevent or remove harm, therefore it is a positive duty. Non-maleficence, by contrast, is the duty to refrain from acting in a way which causes harm or

⁸⁶ William Frankena, for example considers the duty 'not to inflict evil or harm' i.e. non-maleficence to be the first principle of beneficence. The other three principles being; the duty 'to prevent evil or harm', the duty 'to remove evil' and the duty 'to do or promote good' i.e. beneficence. William Frankena, *Ethics* (2nd edn, Prentice-Hall 1973) 47. He was discussing the general duty of beneficence, as opposed to beneficence in the specific context of professional ethics, however his tendency to consider the two principles as one, or at least as two sides of the same coin, is not uncommon in medical ethics too. Jonathan Herring argues that the principle of non-maleficence is best understood as the treatment, overall, does not cause harm, which he goes on to assert means that 'it appears to mirror the beneficence principle' – Jonathan Herring, *Medical Law and Ethics* (7th edn, OUP 2018) 28.

injury, thus it is a negative duty. Perhaps the difference between the two can be understood in the questions, which are generated for the physician by the two principles:

- One could opine that ‘am I causing harm if I do X?’ is the pertinent question for the principle of non-maleficence;
- Whereas, ‘am I achieving good if I do X?’ is more relevant for beneficence.⁸⁷

Often somewhat mistakenly attributed to the Hippocratic Oath, the maxim of *Primum non nocere* or ‘first do no harm’ could be considered to be an origin of the duty of non-maleficence.⁸⁸ There are various translations of the Hippocratic Oath, however, generally the reference to avoiding harm is considered to be encompassed in the statement that a doctor will ‘prescribe [a] regimen for the good of [my] patients according to my ability and my judgment and never do harm to anyone’.⁸⁹ According to Beauchamp and Childress, the Hippocratic oath creates an obligation of non-maleficence when, in the context of providing treatment to the sick, the oath states: ‘I will never use it to wrong or injure them’.⁹⁰

The principle of non-maleficence can be as stark and obvious as the duty of a physician not to intentionally kill one’s patients.⁹¹ It can be found in the duty of a physician not to administer unnecessary treatment for monetary gain. As Jonathan Herring points out, however, ‘[t]he principle of non-maleficence, if taken too literally, is absurd’ as the majority of medical treatment involves some physical harm.⁹² This is, perhaps, why commentators such as Gillon adopt a position of considering beneficence and non-maleficence together, in an almost mathematical way, in order to yield more benefit than harm in total:

Whenever we try to help others we inevitably risk harming them; health care workers (...) must therefore consider the principles of beneficence and non-maleficence together and aim at producing net benefit over harm.⁹³

In any event, in order to be consistent with the principle, a physician must refrain from medical intervention, which would cause harm overall, as distinct from looking at each action in isolation. Piercing the skin with a needle where the purpose is to stitch a wound could hardly

⁸⁷ It is acknowledged that if this formulation were taken in isolation, it may have negative effects for patients. Most every surgical intervention causes harm before they yield positive results. See the critique given by Jonathan Herring later in this section.

⁸⁸ The maxim ‘First Do No Harm’ can either be attributed to British surgeon, Thomas Inman – for further discussion, see Daniel K Sokol, ‘First Do No Harm Revisited’ (2013) 347 *BMJ* 23 – or British physician Thomas Sydenham; see Cedric Smith, ‘Origin and Uses of *Primum Non Nocere*— Above All, Do No Harm!’ 45 *J Clin Pharmacol* 371.

⁸⁹ Mary Donnelly, *Consent: Bridging the Gap between Doctor and Patient* (Cork University Press 2002) 1. Another possible translation which may have inspired the maxim is ‘[a]s to diseases, make a habit of two things—to help, or at least to do no harm’; Cedric Smith, ‘Origin and Uses of *Primum Non Nocere*— Above All, Do No Harm!’ 45 *J Clin Pharmacol* 371, 371.

⁹⁰ Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) 155.

⁹¹ This is distinguishable from circumstances such as legal euthanasia and physician assisted suicide at the request of the patient.

⁹² Jonathan Herring, *Medical Law and Ethics* (7th edn, OUP 2018) 28.

⁹³ Ranaan Gillon, ‘Medical Ethics: Four Principles Plus Attention to Scope’ (1994) 309 *BMJ* 184, 185.

be considered maleficent. Piercing the skin to trial an experimental drug without telling the patient, on the other hand, could certainly be viewed as breaching the principle.

The principle of non-maleficence is reflected in the law too, specifically the law of negligence, something which is discussed in more detail in the next chapter in the context of informed consent. In general medical negligence, the law obliges the physician to refrain from exposing his patients to the risk of harm, over and above the generally accepted risks associated with a particular treatment or refusal.⁹⁴

Beneficence

Beneficence derives its meaning from the Latin word *bene*, which means ‘in the right way’ or ‘good’ and came to be understood as the state of producing good. Although there is disagreement amongst philosophers as to whether a general obligation of beneficence exists, it is largely accepted that duty of beneficence is generated by specific roles, in this case, physicians.⁹⁵ Indeed, not only does the principle of beneficence have a long standing association with the Hippocratic Oath but also with the aspirations of domestic and international medical associations.⁹⁶ In professional and medical ethics, it is usually understood to mean the duty on a physician to act in a way that benefits his patients, whether by acting to prevent and remove harm or in a manner that maximises good or assists patients in achieving their legitimate interests. In other words, it can be explained as the dual obligations ‘to provide benefits and to balance benefits against risks’.⁹⁷ Maclean observes:

This duty, of acting to benefit the patient, is an important and reasonable duty that makes the healthcare professional-patient relationship a caring one and demands that the professional’s role is more than just salesman or technician.⁹⁸

The clash between autonomy and beneficence in situations where the patient desires something that is not in her best interests – for example, a Jehovah’s Witness wishes to refuse a life-saving

⁹⁴ To put this another way, the principle is reflected in the law of medical negligence in the form of the professional standard i.e. the expected level of care and behaviour, conduct below which on the part of the physician may mean that he has acted negligently. For further discussion see Chapter 4 and Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) 158-60.

⁹⁵ Kant believed in a general duty to be beneficent but that duty was imperfect in the sense that it allowed for times when an individual could decide not to be beneficent. Beneficence is also one of the seven *prima facie* duties devised by WD Ross. Philosophers such as Gert argue that individuals should ‘act impartially at all times in regard to all persons with the aim of not causing evil (...) but rational persons are not morally required to act impartially to promote the good for all persons at all times’. See Tom Beauchamp, ‘The Principle of Beneficence in Applied Ethics’ *The Stanford Encyclopaedia of Philosophy* (Spring edn, 2019) <<https://plato.stanford.edu/entries/principle-beneficence/>> accessed 24 May 2019.

⁹⁶ See the preamble to the Declaration of Helsinki, art 3: ‘The Declaration of Geneva of the WMA binds the physician with the words, “The health of my patient will be my first consideration,” and the International Code of Medical Ethics declares that, “A physician shall act in the patient’s best interest when providing medical care”.’ World Medical Association ‘Declaration of Helsinki: Ethical principles for medical research involving human subjects’ (1964). See also the World Medical Association ‘Declaration of Malta on Hunger Strikers’ (1991), which acknowledges the friction between beneficence and autonomy and the British Medical Association *Medical Ethics Today: Its practice and philosophy* (BMJ Publishing 1998).

⁹⁷ Tom Beauchamp, ‘Methods and principles in biomedical ethics’ (2003) 29 *J Med Ethics* 269.

⁹⁸ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 49.

blood transfusion⁹⁹ – has been acknowledged by many philosophers.¹⁰⁰ The best interests of the individual, when assessed objectively, dictate that she should receive the blood transfusion; it will, in all likelihood, save her life and is generally a straightforward, safe and low risk procedure.¹⁰¹ Gillon, however, opines that in adhering to the principle of beneficence, a physician must respect the autonomy of the patient as ‘what constitutes benefit for one patient may be harm for another’.¹⁰² He explains that ‘the patient’s own assessment of harms and benefits for himself’ has led him to conclude that ‘far more harm over benefit would result’ if he were given a life-saving blood transfusion, than if he were to die without it.¹⁰³

Ruth Macklin expands on this point as follows:

According to the patient’s calculus of values, the harm resulting from receiving a transfusion (denial of eternal salvation) is greater than the harm caused by refusing the transfusion (...) Arguably, this is a rational calculation for anyone who believes in the metaphysical scheme of the Jehovah’s Witness faith (...) From the perspective of the Jehovah’s Witness, refusal of a blood transfusion has a favourable balance of benefits over harms.¹⁰⁴

Thus, the individual has weighed up the two competing interests, namely preserving life on earth and maximising his chance at ‘eternal life’, and has chosen eternal life.¹⁰⁵ One difficulty with this analysis stems from an issue identified earlier in this research and as such, revisiting a core position is necessary; refraining from acting in a way which causes harm to a patient is more akin to the fulfilment of the duty of non-maleficence than the duty of beneficence. Administering a blood transfusion to a Jehovah’s Witness, who does not want it, would almost certainly breach the principle of non-maleficence, unless there was some other compelling justification for providing the treatment.¹⁰⁶ In some circumstances, providing the treatment may well be an act of beneficence, in that it saves the life of the patient. This is because, as

⁹⁹ For the purposes of the example, we are taking it that alternative therapies are unsuitable to treat the particular condition.

¹⁰⁰ Alasdair Maclean, for example, poses this as a question: ‘[D]oes the healthcare professional’s duty of beneficence affect the patient’s right to autonomy, or does the patient’s right to autonomy define the extent of the professional’s duty of beneficence?’ in Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 49. See also Ruth Macklin, ‘Applying the Four Principles’ (2003) 29 J Med Ethics 275.

¹⁰¹ There are some rare side effects associated with blood transfusion in developed countries such as the UK, Ireland, the USA, such as the recipient having an allergic reaction or immune reaction to the donor blood or suffers organ damage. It is important to distinguish these risks from the injuries previously suffered by recipients of blood transfusions and blood products, such as the contraction of HIV and Hepatitis. The contraction of these diseases were as a result of inadequate screening procedures and poor policies for the collection of blood, for example, the policy collecting blood from prisoners during the 1980s in France.

¹⁰² Ranaan Gillon, ‘Medical Ethics: Four Principles Plus Attention to Scope’ (1994) 309 BMJ 184, 185; This approach to ethical evaluation is in line with those commentators who believe that the autonomous choice of the patient forms part of their best interests and therefore part of the duty of beneficence, however, this blurring of duties is not desirable from the perspective of this research.

¹⁰³ Ranaan Gillon, ‘Four Scenarios’ (2003) 29 J Med Ethics 267.

¹⁰⁴ Ruth Macklin, ‘Applying the four principles’ (2003) 29 J Med Ethics 275, 275.

¹⁰⁵ Whether the individual is behaving morally in refusing treatment is a matter of debate and various factors influence such an evaluation; is he a (sole) parent, or caregiver to a relative? Is he leaving debts for others to pay?

¹⁰⁶ Perhaps that the Jehovah’s Witness has been subjected to coercion or undue influence or that there is uncertainty as to the true wishes of the patient; for example, if he is unconscious and family members and / or a spouse are in disagreement as to his commitment to the faith. Such justifications would be examples of ‘weak paternalism’, which can be morally justifiable. For further discussion of weak and strong paternalism, see Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn OUP 2019) 233-243.

outlined earlier, beneficence is a positive duty, in that it is an obligation to do something, such as promote good, remove or prevent harm. Accordingly, a more appropriate way to appraise that particular ethical dilemma – leaving aside any relevant legal framework – would be with reference to the principles of non-maleficence and autonomy. If the physician asks himself, *am I causing harm if I administer this blood transfusion?*, he will find that the answer is yes, as he is interfering with the autonomy of the patient and failing to give weight to the harm envisioned and his ‘calculus of values’.¹⁰⁷

One could opine that the principle of beneficence can be seen more clearly in something as simple as a physician informing a patient that she exhibits the early indicators of a disease and advising her on the best method of prevention. A patient suffering from high cholesterol and angina should be advised by her physician to reduce her cholesterol, control her blood pressure and maintain a healthy weight through diet and exercise. In giving this information and advice, the physician is fulfilling the duty generated by the principle of beneficence to avert harm by assisting the patient in the prevention of the development of heart disease. Now, should the patient decide to disregard the advice and subsequently go on to develop heart disease, then the principle of beneficence will go on to dictate that the physician treat the illness with medication or surgical intervention, thereby removing a present harm. Broadly speaking, the third obligation stemming from the principle of beneficence – the obligation to promote or maximise good for the individual patient – could be seen if the same patient and physician interacted during the patient’s teenage years and the physician spoke at length about the general benefits of a healthy diet and exercise without any specific concern that she may go on to develop heart disease.

Justice

The word justice comes from the Latin word *jus* meaning ‘law’ or ‘right’ and the Old English word *iustise* meaning the ‘administration of the law’ and has become synonymous with words like fairness, impartiality and egalitarianism. It has been identified as obligations of fairness in the distribution of benefits and risks.¹⁰⁸ In a legal sense, it is often thought of in the context of the vindication of the rights of the individual or the punishment of wrongs. In society, we often think of it as reward for merit or work done, or the way that Aristotle viewed fairness, namely

¹⁰⁷ Ruth Macklin, ‘Applying the four principles’ (2003) 29 J Med Ethics 275, 275

¹⁰⁸ Tom Beauchamp, ‘Methods and principles in biomedical ethics’ (2003) 29 J Med Ethics 269.

equals should be treated equally and unequals unequally with respect to their relevant inequality. Or, as Maclean opines:

[A]ll members of the relevant community should be treated as prima facie equals, which means that any different treatment of individuals must be justifiable on the basis of morally relevant differences between them. This also means that individuals should not be treated differently on the basis of morally irrelevant factors.¹⁰⁹

In other words, the principle gives individuals an entitlement to fair or proportionate treatment.¹¹⁰ Whether pregnancy is a morally relevant factor for differing treatment is certainly a matter worthy of debate.¹¹¹

The principle of justice can be seen at work across the law, not just in its obvious home – the criminal law – but also more broadly in matters such as equality protection and discrimination legislation and in constitutional articles guaranteeing that all persons are ‘equal before the law’.¹¹² If the principle of justice permeates almost every facet of society, this must be true for healthcare, not just in the obvious places such as resource allocation and access to medical care but also in less readily identifiable places, as will become apparent as this research progresses.¹¹³ It is a concept that is fundamental in dealings between individuals, where prioritisation of interests is required, particularly in circumstances where there is an inequality in bargaining power.¹¹⁴

Gillon subdivides justice in the healthcare context into three areas:

- (i) fair distribution of scarce resources, also known as ‘distributive justice’;
- (ii) respect for people's rights, also known as ‘rights based justice’;
- (iii) respect for morally acceptable laws, also referred to as ‘legal justice’.¹¹⁵

In Western society, we view distributive justice as the spreading of rights and responsibilities and of benefits and burdens across society. We see it in matters such as taxation, education and social welfare. Distributive justice is considered, by some, to be essential in healthcare, as it is an area in which there are limited means to fund the system;¹¹⁶ were this not the case, then

¹⁰⁹ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 57.

¹¹⁰ Ranaan Gillon, ‘Justice and Medical Ethics’ (1985) 291 BMJ 201, 201

¹¹¹ This will be discussed in Chapter 6.

¹¹² The *Magna Carta*; Bunreacht na hÉireann, art 40; 14th Amendment to the Constitution of the United States.

¹¹³ Ranaan Gillon, ‘Justice and Medical Ethics’ (1985) 291 BMJ 201, 201; he argues that resource allocation does not ‘exhaust the relevance of justice to medical ethics (...) Forensic psychiatrists, who concern themselves with the sanity (...) of clients charged with offences, are concerned with responsibility in the context of reparative justice. The (...) absolute prohibition of medical involvement in torture affirms a concept of justice based on rights that forbids certain things to be done to other people even if doing them may be of great social benefit. The General Medical Council (...) is concerned with specifically legal aspects of justice’.

¹¹⁴ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 12.

¹¹⁵ Ranaan Gillon, ‘Medical Ethics: Four Principles Plus Attention to Scope’ (1994) 309 BMJ 184, 185.

¹¹⁶ It is worth bearing in mind that, arguably, distributive justice in healthcare has considerably more practical prominence in Ireland and the United Kingdom – via the HSE and NHS respectively – than it has in the United States, where the system is dominated by free-market ideals.

there would be no need to fear the possibility of inequality. Given this is the case, however, it is important that there is justice in the allocation of scarce resources. Accordingly, justice in this sense can be considered to mean ‘fair adjudication between competing claims’.¹¹⁷

As was discussed previously, decisions on the allocation of scarce resources in healthcare are often broadly done in line with consequentialist principles. Resources are allocated to give the most benefit to the most people. However honourable the sentiment, in practice, such decisions are considerably more complex than ‘do the best for the most’. For example, is it better to restore the sight of ten people or save the life of one with an expensive experimental drug in light of resource scarcity? Upon what criteria does or should one make that decision? Does the answer change if the amount of lives that can be saved is increased to two or three? Gillon argues for the Aristotelian application of formal principles of justice.¹¹⁸ Even with that explanation of what is just, however, it still remains challenging to establish what criteria are relevant in assessing if an individual constitutes an equal or an unequal for the purpose of treatment. The answers to these questions can be viewed to depend on the particular theory of justice to which one subscribes.

The example of HLA matching in kidney transplantation given by Beauchamp and Childress highlight the different outcomes for different theories of justice.¹¹⁹ On the one hand, the use of human lymphocyte antigen (HLA) matching for kidney donation is argued to lead to a better long-term transplant outcome, thereby making it a ‘better’ use of donations. On the other hand, HLA matching can put those who have been waiting longer and those who more urgently need a transplant lower on the transplant list than those who happen to have a higher degree of HLA match to the donor. Given that the majority of organ donors are white, the likelihood is high that a white individual will be a better HLA match than a person of another ethnicity; this is problematic when one considers that a higher rate of end-stage renal disease is found in non-white individuals.¹²⁰ Thus, such a system could be considered unjust in that it breaches the fair equality of opportunity or it could be considered just as it yields the best overall results for the most amount of people.¹²¹

Criticisms of Principlism

¹¹⁷ Ranaan Gillon, ‘Medical Ethics: Four Principles Plus Attention to Scope’ (1994) 309 *BMJ* 184, 185.

¹¹⁸ Ranaan Gillon, ‘Justice and Medical Ethics’ (1985) 291 *BMJ* 201. This theme will reoccur in later chapters.

¹¹⁹ Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) 285.

¹²⁰ *Ibid.*

¹²¹ ‘Best overall result’ refers to the fact that, from a scientific perspective, HLA matching yields a higher chance of a successful transplant and long-term survival. Theoretically, this leads to less resources being needed as the transplant is more likely not to fail in the short and long term, thereby freeing up resources for other patients.

The Principles can be used effectively in decision-making in healthcare to resolve complex ethical dilemmas, however, Principlism is not without its critics. Accurate or not, issues cited are that the principles often conflict with each other with no guide as to how to resolve these conflicts,¹²² they do not actually give the individual clear instructions as to what he should do and they are inadequate to help people resolve complex dilemmas.¹²³ Perhaps the most well-known critics of Principlism, K Danner Clouser and Bernhard Gert, describe conflicts between the principles as unresolvable, ‘since there is no unified moral theory from which they are all derived’.¹²⁴ They argue that in discussing the principles, the reader merely gets ‘a description of several ways in which the authors think [the principle] is a relevant moral consideration’ but no ‘specific directive for action’.¹²⁵ The concepts of beneficence and non-maleficence have been described as ‘problematic’, as it is unclear if ‘good’ and ‘bad’ are to be assessed objectively or subjectively.¹²⁶ Furthermore, from whose perspective should they be assessed; should it be the patient or the doctor who assesses what is good or bad?¹²⁷ Arguments like these go to the core of the contention that Principlism doesn’t really tell the individual what the right action is.

Clouser and Gert also strongly criticise Principlism for its inclusion of beneficence as one of the principles – ‘duties’ as they argue – because they believe it ‘obscures the role that real duties play’.¹²⁸ It is their position that taking a ‘moral ideal’ of helping others and including it with actual – or ‘genuine’ – duties leads to confusion. In their view, beneficence cannot be treated the same as duties which are morally required, in other words genuine duties, such as ‘noninterference with the freedom of others’.¹²⁹ This line of reasoning is somewhat unsurprising given that there is much debate as to whether a duty of beneficence exists, as was discussed earlier in this chapter. Irrespective, however, if one agrees or disagrees with the

¹²² Jonathan Herring, *Medical Law and Ethics* (7th edn, OUP 2018) 29; it should be noted that he does not specifically say that this is his view of Principlism, as he opens the critique with ‘to some (...)’.

¹²³ Tom Walker, for example, argues that Principlism ‘must contain all the moral principles that are obligatory for us’ in order for it to be a framework, which helps individuals identify and resolve moral dilemmas. If it doesn’t contain all obligatory moral principles, then, he argues ‘it will blinker us so that we don’t see moral problems that are there’. Tom Walker, ‘What Principlism misses’ (2009) 35 *Journal of Medical Ethics* 229, 230. David Misselbrook, ‘Virtue Ethics – An Old Answer to a New Dilemma? Part 2. The Case for Inclusive Virtue Ethics’ (2015) 108 *J R Soc Med* 89; he argues that Principlism ‘may fail to capture the whole picture of the factors that are morally relevant’ in medical decisions and actions. See also Søren Holm, ‘Not Just Autonomy – The Principles of American Biomedical Ethics’ (1995) 21 *J Med Ethics* 332.

¹²⁴ K Danner Clouser and Bernard Gert, ‘A Critique of Principlism’ (1990) 15 *J Med Philos* 219, 219. Throughout the article, the authors describe Principlism as ‘quite disparate moral matters, unrelated by systematic considerations’, as ‘important aspects of morality [which] function mainly as a check list of considerations’ and as both practically and theoretically misleading at pages 222, 222 and 227 respectively.

¹²⁵ *ibid* 222

¹²⁶ Tuija Takala, ‘What Is Wrong with Global Bioethics? On the Limitations of the Four Principles Approach’ (2001) 10 *Camb Q Health Ethics* 72, 73-4.

¹²⁷ *ibid*.

¹²⁸ K Danner Clouser and Bernard Gert, ‘A Critique of Principlism’ (1990) 15 *J Med Philos* 219, 229.

¹²⁹ *ibid* 229.

criticisms of Principlism, it still remains the most widely used practical approach towards or framework for the identification and resolution of moral problems in healthcare.

The criticism of Principlism that it does not really tell the agent what to do in circumstances, while valid, is not exclusive to Principlism. There are many accounts of ethicists coming from the same normative ethical framework arguing on ‘opposite sides’ of the debate on the same issue, for example, euthanasia or abortion. In such situations, it is also clearly not the normative ethical framework that one subscribes to that dictates whether the action is right or wrong. Perhaps the wide use of Principlism is the opposite side of one of the primary criticisms, that it is not underpinned by a unified or single moral theory. In a sense, Principlism is a type of magpie, which picks from different normative ethical frameworks to create a more accessible mechanism for resolving ethical dilemmas. Arguably, it is that fluidity, flexibility and simplicity that makes it workable within the complex world of healthcare; perhaps such flexibility and generality are both positive and unavoidable. Principlism can orientate individuals toward how to think ethically, in time constraints and practical situations inherent in the healthcare context. Thus, while the principles are drawn from the common morality, they are not owned by any specific moral perspective. They are practical and allow for the fact that a physician and patient cannot feasibly conduct a lengthy consequentialist or deontological discussion at the bedside. Perhaps, best summed up by Dave Archard:

It would be lovely to think we can all be ethicists now. It would however diminish and misunderstand the project of bioethics to think that this can be achieved by denying what marks out ethics as a distinct discipline.¹³⁰

Arguably, it is a privilege of lawyers, scientists and medical professionals, indeed any role aside from ethicist, to choose the ethical framework that assists them in making a particular decision without the need to have completely subscribed to a particular normative framework and without the need fully understand every part of it.

Dignity

Although the predominant ethical framework throughout this thesis is Principlism, the concept of dignity is worthy of exploration, particularly in light of its position and prominence in legislation¹³¹, the preamble to the Constitution and case law.¹³² Dignity, however, much like

¹³⁰ Dave Archard, ‘The rise and fall and rise again of bioethics’ (*Nuffield Council on Bioethics*, 19 November 2019) <<https://nuffieldbioethics.org/blog/the-rise-and-fall-and-rise-again-of-bioethics>> accessed 19 November 2019. Archard contends that the interdisciplinarity is what defines the work of the Nuffield Council on Bioethics in that it is ‘a Council ‘on’ bioethics but not of bioethicists’. That acknowledges that ethics is a separate discipline.

¹³¹ Assisted Decision-Making (Capacity) Act 2015, s 8(6)(b); New York Public Health Law § 2994-d section 4(ii).

¹³² See for example *Simpson v The Governor of Mountjoy Prison* [2019] IESC 81; ‘When both rights [privacy and autonomy] are read as they must be, which is in the light of the value of dignity espoused in the preamble to the Constitution, it is not difficult to understand why torture,

autonomy presents challenges in ethical analysis because it often means different things to different people and is invoked in different ways. For example, proponents of euthanasia and physician assisted suicide appeal to the concept of dignity in arguing for its legalisation, however, so too do their opponents when they argue against it.¹³³ Thus, human dignity appears to simultaneously justify and make abhorrent the same act. Furthermore, dignity is not universally considered to have value; far from being that which gives every human being her fundamental value and far from being possessed by every rational human being, some view dignity as meaningless or useless.¹³⁴

Roger Brownsword and Deryck Beyleveld explain the concept of human dignity as *empowerment* and as *constraint* and discuss the implications of those understandings.¹³⁵ Broadly speaking, dignity as empowerment can be seen as providing a basis for the recognition of rights and as the source of fundamental human freedoms; the concept of dignity as constraint is more akin to duty and a responsibility not to act in a way that compromises dignity. For example, when articulating how dignity as constraint might manifest, Herring gives the example of one selling one's organs, conduct which would 'demean the individual's dignity as a human'.¹³⁶ Arguably, when one considers these two constructions of dignity, it is not difficult to see how it could be used to argue for and against the same thing; if ending one's life is considered a right, then dignity may be invoked in the 'empowerment sense'. If one considers the ending of life as an affront to the sanctity of human life and its inherent dignity, then ending life becomes an act that compromises human dignity.

Four competing concepts of dignity are outlined by Doris Schroeder, three of which form, to a greater or lesser extent, an appropriate basis for the discussion of dignity for the remainder of this research. These competing concepts are: Kantian Dignity, Compartment Dignity and Meritorious Dignity.¹³⁷ The first, Kantian Dignity, is inalienable and can be explained as the

or inhuman or degrading treatment, or indeed severely substandard prison conditions, can be an infringement of the constitutional rights of the individual. The fundamental rights, including the personal rights contained in Article 40, were adopted "so that the dignity and freedom of the individual may be assured" and must be interpreted in that light' (para 10). See also *Re a Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 IR 79, which will be discussed in Chapter 4. From England and Wales, see *Sheffield Teaching Hospitals NHS Foundation Trust v TH* [2014] EWCOP 4, para 53; 'I have no doubt that [TH] would wish to leave the hospital and (...) end his days quietly (...) and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it.' See also *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449, 460.

¹³³ Doris Schroeder, 'Dignity: Two Riddles and Four Concepts' (2008) 17 Camb Q Health Ethics 230.

¹³⁴ Ruth Macklin, 'Dignity is a Useless Concept' (2003) 327 BMJ 1419. Macklin argues that dignity is nothing more than respect for individuals and their autonomy and that consequently, that appeals to dignity add nothing to one's understanding of a particular topic. She gives the example of dying with dignity, which she argues is just respect for autonomy. A number of authors have challenged the idea that dignity is meaningless. See, for example, Doris Schroeder, 'Dignity: Two Riddles and Four Concepts' (2008) 17 Camb Q Health Ethics 230; Suzy Killmister, 'Dignity: Not Such A Useless Concept' (2010) 36 J Med Ethics 160.

¹³⁵ Deryck Beyleveld and Roger Brownsword, *Human Dignity in Bioethics and Biolaw* (OUP 2001). See chapters 1 and 2.

¹³⁶ Jonathan Herring, *Medical Law and Ethics* (7th edn, OUP 2018) 21.

¹³⁷ Doris Schroeder, 'Dignity: Two Riddles and Four Concepts' (2008) 17 Camb Q Health Ethics 230; The fourth is Aristocratic Dignity, which can be broadly explained as dignity based on rank or position.

belief that all human beings possess dignity by virtue of their ability to separate good and bad, in other words, their capacity for reason.¹³⁸ It centres on the belief that all rational human beings have intrinsic worth.¹³⁹ Arguably, however, this cannot be the concept of dignity invoked in case law, as such judgments refer to upholding or protecting dignity. This presupposes that dignity is capable of being stripped or violated, which would not be possible if the concept of dignity being discussed was inviolable or inalienable. Indeed, the Preamble to the Irish Constitution refers to *assuring* the dignity of the individual.

Comportment Dignity can be understood as the ‘dignity of appropriate and seemly comportment’,¹⁴⁰ in other words dignity as ‘outward displays of appropriate behaviour (...) [in] adherence to social norms and expectations’.¹⁴¹ Schroeder argues that ‘[c]ertain outward signs of dignified behavior are expected in most societies from most human beings’.¹⁴² Interestingly, Suzy Killmister reformulates Comportment Dignity as ‘upholding of one’s own standards and norms’, as opposed to those standards and norms being given by society.¹⁴³ The ideas of social expectations or ones’ own standards being a kind of barometer for dignity is will be returned to in Chapter 6 in the context of the pregnant women.

Finally, Meritorious Dignity can be understood as dignity, which is not automatic but instead deserved.¹⁴⁴ The means by which one deserves dignity is through being honourable, particularly when faced with challenges or difficulties. The competing concepts of dignity outlined above are certainly not exhaustive, however, they are viewed to have the most relevance to the topic of compelled medical treatment and advance decision-making. Accordingly, they will be revisited in relation to end-of-life decision-making and compelled obstetric interventions in Chapters 4 and 6.

Conclusion

To say that laws must reflect the morals and values of society is meaningless unless we can identify what those morals and values are. Furthermore, we must be capable of establishing where these morals and values, both individually held and society wide, have come from and how we use them, to decide what is the right decision in particular contexts. In order to do so,

¹³⁸ *ibid* 232.

¹³⁹ *ibid*.

¹⁴⁰ *ibid*.

¹⁴¹ Suzy Killmister, ‘Dignity: Not Such A Useless Concept’ (2010) 36 *J Med Ethics* 160, 161.

¹⁴² Doris Schroeder, ‘Dignity: Two Riddles and Four Concepts’ (2008) 17 *Camb Q Health Ethics* 230, 232.

¹⁴³ Suzy Killmister, ‘Dignity: Not Such A Useless Concept’ (2010) 36 *J Med Ethics* 160, 161. In the interest of clarity, this reformulation combines Comportment Dignity and Meritorious into a single concept.

¹⁴⁴ Doris Schroeder, ‘Dignity: Two Riddles and Four Concepts’ (2008) 17 *Camb Q Health Ethics* 230, 234.

this chapter gave an overview of two major normative ethical frameworks to demonstrate how they have contributed to more modern medical ethics. This chapter then introduced Principlism and highlighted why it is widely used as a system within complex medical decision-making. Despite its very vocal critics, Principlism will be used throughout this research to highlight and analyse some of the key ethical issues that arise in the context of life-sustaining treatment and advance decisions, particularly for pregnant women.

This chapter has undoubtedly been a building block and each subsequent chapter will add to the concepts and explanations provided when conducting the ethical analysis of the four core topics – informed consent, refusal of life-sustaining treatment, advance directives and compelled obstetric intervention and pregnancy exceptions to advance directive legislation. As this research progresses what will become apparent is that medical ethics is not only relevant to law-making but also key to the interpretation of those laws by the courts. Frequently, we see references in judgments to the ‘protection of autonomy’ and the duty to refrain from causing harm, thus it was important to understand the origin of these concepts in healthcare. The discussion of how robustly such concepts are protected when the individual is pregnant will unfold as this research progresses; questions as to whether the autonomy of the woman is less worthy of respect in pregnancy and whether concepts of justice permit physicians and the law to treat pregnant women ‘unequally’ will be posed. Furthermore, the connection between autonomy and ‘patient duties’ is also important; thus, it is a theme that will be picked up in the context of decision-making in pregnancy.

Chapter 3

Introduction

The conceptual basis for an advance refusal of treatment is the contemporaneous right to do so. Without the requirement that consent must be given before treatment is administered and the acceptance of the right of an individual to exercise her autonomy through medical decision-making, there would be no foundation upon which to base advance directives. Thus, an examination of consent to medical treatment is the natural starting point for a discussion on advance directives, as they are the clear exercise of that right in advance of a future loss of capacity. As outlined previously, this research is not only concerned with advance directives in general, but rather advance directives in pregnancy; accordingly, informed consent in pregnancy will be considered in detail. By considering informed consent in a more general way, the basis for advance directives in general can be established; then, by examining the interaction between informed consent and pregnancy – and specifically labour – the idea of the ‘pregnancy exception’ is first introduced. Furthermore, as Claire Murray argues; ‘by considering consent through the prism of labour we begin to identify shortcomings’ in the way that the law is constructed.¹

Medical professionals were not always duty bound to inform patients about their prognosis and treatment options. Furthermore, the duty to obtain consent from patients prior to treating them was not always enshrined in law. This chapter begins by exploring the impetus for the move away from the paternalism that traditionally defined the doctor-patient relationship, to a system that places informed consent and the will of the individual in a position of prominence. Logic dictates that if we are to discuss it, we should first seek to know what is meant by ‘consent’. As summarised by Ranaan Gillon, consent is ‘a voluntary, uncoerced decision, made by a sufficiently competent or autonomous person on the basis of adequate information and deliberation, to accept rather than reject some proposed course of action that will affect him or her’.²

It is often argued that informed consent has three functions; a legal, a clinical and a moral function.³ Therefore, it is imperative that this chapter not confine itself to solely considering the law, but also consider the ethical justification for requiring consent to treatment. The legal function will be discussed later in this chapter, whereas the other two functions – the clinical

¹ Claire Murray, ‘Troubling Consent: Pain and Pressure in Labour and Childbirth’ in Camilla Pickles and Jonathan Herring (eds) *Childbirth, Vulnerability and Law: Exploring Issues of Violence and Control* (Routledge 2019) 161.

² Ranaan Gillon, *Philosophical Medical Ethics* (John Wiley & Sons 1986) 113.

³ Emily Jackson, *Medical Law: Text, Cases and Materials* (4th edn, OUP 2016) 235.

and the moral – will be discussed in the ethics section. After considering the ethical issues, this chapter progresses to examining the legal development of informed consent in Ireland, England and Wales and New York. It was held by the US Supreme Court that ‘[t]he logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment’;⁴ accordingly, this chapter discusses the elements which must be present in order to have a valid consent to, and by extension, refusal of medical treatment:

- (i) The patient must be informed as to what the treatment involves, although what constitutes ‘informed’ varies by jurisdiction and can be unclear;
- (ii) The consent must be voluntarily given by an individual with the capacity to consent to treatment.⁵

As distinct from some of the other core areas of this thesis, pregnancy will be the lens through which the law and ethics of consent is viewed. Pregnancy presents some specific challenges and issues in informed consent, particularly in the context of capacity. These will be considered in this chapter, together with a more generalist legal and ethical examination of informed consent.

Traditionally, healthcare and medical treatment were defined by paternalism and perhaps the view that patients were ‘objects to be mended’ by medical professionals.⁶ The mantras of ‘it’s for your own good’ and ‘doctor knows best’ reigned supreme. As was discussed in the previous chapter, beneficence in medical ethics can be understood as a physician’s obligation to act in a manner that benefits his patients, whether by acting for the good of the patient or the prevention or elimination of harm. Non-maleficence is the duty of the physician to refrain from acting in a way that harms the patient. It can be argued, as Tom Beauchamp and James Childress have, that both of these principles actually provided a basis for paternalism in medical care.⁷ William Cody explains paternalistic acts as ones ‘carried out intentionally on behalf of a person (...) against that person’s wishes or without consent, with the explicit purpose of doing good for, or avoiding harm to, that person’.⁸ It can be argued, therefore, that paternalism is a kind of

⁴ *Cruzan v Director, Missouri Department of Health* 497 US 270 (1990).

⁵ Voluntariness is a key element of informed consent, however, it is not an issue which arises frequently in cases involving medical treatment. As such, it will not be considered in any more detail in this particular research, aside from to say that it is necessary in order for consent to be informed. For cases involving consideration of the voluntariness of consent to or refusal of medical treatment, see *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 and *Freeman v Home Office* [1984] 1 All ER 1036.

⁶ Jonathan Herring, *Medical Law and Ethics* (7th edn Oxford University Press 2018) 202.

⁷ Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (5th edn OUP 2001) 179.

⁸ William K Cody, ‘Paternalism in Nursing and Healthcare: Central Issues and their Relation to Theory’ (2003) 16 *Nurs Sci Q* 288. See also Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 52 where morally problematic acts of paternalism are defined as those which are for the benefit of the patient and done contrary to her will in such a way as undermines the person’s self-determination.

beneficence *gone wrong*. Or perhaps, as expressed in a more sophisticated manner by Alasdair Maclean: ‘beneficence is constrained by the beneficiary’s will, while paternalism is not’.⁹

Medical professionals are individuals in positions of power, with considerably more knowledge than almost all patients; therefore, what they believed to be the right course of action should have been accepted as such. His duty to do good, combined with his superior knowledge, justified the physician making decisions for the patient, or at the very least, making strong suggestions as to the best course of action, perhaps without even mentioning alternatives. More recently, however, while it is viewed as an exercise of autonomy to ‘acknowledge and rely on the expertise of others where there is a good reason to do so’, it has also been argued that ‘it smacks of the arrogance of infallibility to claim that simply because healthcare professionals are recognised as experts they should be allowed to override the patient’s agency’.¹⁰ This expresses, in quite clear terms, the difficulty with paternalism and why its rejection is justified. In part, at least, it comes down to the differences between people and individual values; what is an acceptable side effect for one person, may not be acceptable for another. The risk, for example, of being unable to procreate might be intolerable to one person, but an entirely acceptable outcome for another. Equally, a small risk to one’s own life or one’s foetus may be acceptable if the alternative goes against a clear tenet of one’s faith. As Jonathan Herring eloquently argues:

[I]t is the patient’s body, even if the doctor does know best. Anyway, even if we accept that a doctor has expertise in what works well in medicine generally, only the particular patient knows what is important to them and their body.¹¹

During the mid-late 20th century, a shift away from paternalism and towards patient autonomy began across Europe and the United States.¹² Commentators attribute this general move away from traditional medical paternalism to multiple events, predominantly healthcare and human subject research scandals, historical events and scientific developments. Jessica Berg *et al* assert that scientific developments, such as technological advances in life-sustaining treatment, contributed to America’s changing attitudes.¹³ They opine that patients began to evaluate their wishes with respect to treatment, particularly regarding life-sustaining measures, because of advancements in technology that resulted in patients being kept alive with very poor quality of

⁹ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 51.

¹⁰ *ibid* 24.

¹¹ Jonathan Herring, *Medical Law and Ethics* (7th edn Oxford University Press 2018) 202.

¹² That is not to say that there are no instances of obvious and arguably justified paternalism within medicine; for example, the immediate treatment of patients who have attempted suicide in order to leave open the possibility of later treating an underlying issue, which led to suicidal ideation.

¹³ Jessica W Berg and others, *Informed Consent: Legal Theory and Clinical Practice* (2nd edn, OUP 2001) 20.

life and prognosis.¹⁴ They also partly attribute the move in the US to the ‘atrocities revealed in the Nuremberg trial of Nazi doctors’, which they argue ‘called into question the trustworthiness of the medical profession’.¹⁵ Indeed, the cultural shift arising from the offences perpetrated by the Nazis was not unique to the US; the World Medical Association’s 1964 ‘Declaration of Helsinki’ demonstrated the approach of the international medical community to human subject research. Paramount in it was the right of each individual to safeguard his personal integrity and critically, the responsibility of the medical professional to seek free consent from the individual after he has been informed.¹⁶ Throughout the next four decades however, yet more events would shape the attitudes of individuals to informed consent.

Mary Donnelly cites the Tuskegee Syphilis Study in the US as a further impetus for the desire to be more informed regarding to medical treatment.¹⁷ In the 1970s, it was discovered that the United States Public Health Service, in conjunction with Tuskegee University, had been involved in a study of African-Americans with untreated syphilis for 40 years.¹⁸ The study was unethical for a number of reasons, most notably because the researchers never offered penicillin, which was recognised as the approved treatment for syphilis during the study.¹⁹ Furthermore, they never sought informed consent, as they never provided any information about the real nature and purpose of study, nor did they ever inform the participants that they were suffering from syphilis, thereby exposing others to contracting the disease.²⁰ In an article in the *New England Journal of Medicine*, Dr Henry Beecher gave 22 accounts of human subject experiments with questionable or unethical practices, including instances where there was absence of informed consent.²¹ Most notable amongst the accounts was the Willowbrook State School studies of hepatitis, in which staff infected developmentally disabled children with viral hepatitis in order to study the development of the disease.²²

The 1980-90s saw multiple blood scandals hit Europe and the US. During the 1970s and 1980s, thousands of haemophiliacs globally received Factor VIII or Factor IX,²³ which were contaminated with HIV and hepatitis C.²⁴ In 1985, two medical officials in France distributed

¹⁴ *ibid.*

¹⁵ *ibid.*

¹⁶ Articles 4a and 3a respectively of the Declaration. World Medical Association, ‘Declaration of Helsinki: Ethical principles for Medical Research Involving Human Subjects’ (1964) <www.wma.net/wp-content/uploads/2018/07/DoH-Jun1964.pdf> accessed 25 October 2018.

¹⁷ Mary Donnelly, *Consent: Bridging the Gap between Doctor and Patient* (Cork University Press 2002) 8.

¹⁸ Center for Disease Control, ‘The Tuskegee Timeline’ (Last reviewed March 2 2020) <www.cdc.gov/tuskegee/timeline.htm> accessed 26 October 2018.

¹⁹ *ibid.*

²⁰ *ibid.*

²¹ Henry Beecher, ‘Ethics and Clinical Research’ (1966) 274 *New Eng J Med* 1354.

²² *ibid* 1358.

²³ Proteins that help blood to clot.

²⁴ See Department of Health, *Tribunal of Inquiry into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters* (2002) <<https://health.gov.ie/wp-content/uploads/2014/04/Tribunal-of-Inquiry-into-the-Infection-with-HIV-and-Hep-C-of-persons-with->

products in the knowledge that they may be contaminated with HIV, to recipients who were unaware.²⁵ At the same time, the French government deliberately delayed the approval of a request by pharmaceutical company Abbott Laboratories to sell its HIV test, despite the being aware of the connection between contaminated blood products and contraction of HIV.²⁶ In 1991, the Blood Transfusion Service Board in Ireland was informed that a batch of anti-D²⁷ produced in 1977 may be contaminated with hepatitis.²⁸ Despite the warning, the BTSB made no attempt to find and inform the recipients of the anti-D that they may have been exposed; as a result, the widespread infection of 1,200 women was not discovered until 1994.²⁹ While all these scandals are seemingly unrelated incidents across different countries, a common thread links them; the possession of relevant medical information by states or individuals and the failure to impart that information to patients. It is posited that such failures could only serve to undermine the faith of patients in the healthcare industry and encourage patients to take a more active role in deciding what happens to their bodies. Although it is rare to find a reference to any of these historical events in the judgments of cases considering alleged lack of informed consent, they were certainly a driving force behind a change in perspective amongst the general public. The more aware people became about these morally questionable actions, the more patients' rights advocates began to demand that the imbalance of power be rectified in favour of patients.³⁰

Informed Consent and Ethics

This research favours describing the 'clinical function' and the 'moral function' as the 'ethical functions' of informed consent. As outlined earlier, the law on informed consent cannot be considered in a vacuum; it cannot be discussed without understanding the ethical justification for its existence. As discussed in Chapter 1, we generally expect that laws will reflect what we, as a society, perceive to be 'good' or 'bad' behaviours, but sometimes, there are no clear right answers from an ethical perspective. Be that as it may, it is important to consider informed

[Haemophilia-and-Related-Matters.pdf](#)> accessed 1 November 2018; Timothy J Dondero and others, 'Human Immunodeficiency Virus Infection in the United States: A Review of Current Knowledge' (1987) 36 CDC Morbidity and Mortality Weekly Report 1. In the United Kingdom, an independent public inquiry known as the 'Archer Inquiry' investigated the supply of contaminated blood products. The Rt Hon Lord Archer, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products* (2009) <https://archercbbp.files.wordpress.com/2017/01/76_lord-archer-report.pdf> accessed 1 November 2018.

²⁵ Alan Riding, 'Scandal Over Tainted Blood Widens in France' *The New York Times* (New York, 13 February 1994) <www.nytimes.com/1994/02/13/world/scandal-over-tainted-blood-widens-in-france.html> accessed 1 November 2018.

²⁶ *ibid.*

²⁷ The anti-D immunoglobulin injection (anti-D) is a medication which prevents Rhesus Disease, a condition which causes the pregnant woman's blood to destroy the blood cells of the foetus. It is routinely given to rhesus negative women during their first pregnancy to prevent Rhesus Disease from occurring in subsequent pregnancies.

²⁸ Caroline O'Doherty, 'Anti-D Scandal Was A Bloody Disgrace' *Irish Examiner* (Cork, 21 February 2014) <www.irishexaminer.com/viewpoints/analysis/anti-d-scandal-was-a-bloody-disgrace-259488.html> accessed 31 October 2018.

²⁹ *ibid.*

³⁰ For example, the Patients Association in the United Kingdom was established in 1963 in reaction to the thalidomide drug scandal and reports in the UK of tests being conducted on patients without informed consent. See <www.patients-association.org.uk/background>.

consent from both an ethical and legal perspective in order to get a full picture of the concept and its limitations.

As will become apparent in the following paragraph, the ‘clinical function’ of informed consent fits squarely within the notion of beneficence as explained in Chapter 2. It achieves the goal of ‘doing good’ through promoting the health and well-being of the patient, encouraging her compliance with medical advice and by contributing to a better diagnosis, prognosis and quality of care. It is supported by utilitarian reasoning; a patient who is informed about and has agreed to what is happening to her body, is unlikely to resist that treatment and any recommended aftercare; thus, she is more likely to benefit from the treatment and commit to the recommended aftercare.³¹ As Herring argues succinctly: ‘[f]orcing a treatment on an unwilling patient is likely to be counter-productive’, as at some point, the medical professional will not be able to compel the patient to behave in a certain manner, most likely when it comes to post-treatment recommendations.³² Thus, the act of seeking consent prior to administering treatment by adequately informing a patient as to the risks, benefits and alternatives leads to a positive outcome for the patient, hence the argument that it is an example of beneficence supported by utilitarian reasoning.

The ‘moral function’ of informed consent can be explained as the underpinning belief that respecting the self-determination and bodily integrity of an individual is the ‘right’ thing to do, in and of itself.³³ Or conversely, to interfere with them is the wrong thing to do and causes harm. In this sense, the moral function of informed consent sits within non-maleficence. Like the previous example, this principle is underpinned by normative ethical reasoning, in this case, deontology. Self-determination and bodily integrity are valuable concepts, which ought to be respected and promoted; this, in turn, generates a moral duty for the physician to refrain from interfering with or inhibiting them save in exceptional circumstances where there is a convincing and justifiable reason to do so.

Autonomy

³¹ See President’s Commission for the Study of Ethical Problems in Medicine and Behavioral Research, *Summing Up: Final Report on Studies of Ethical Problems in Medicine and Behavioral Research* (1983) <https://repository.library.georgetown.edu/bitstream/handle/10822/559377/summing_up.pdf?sequence=4&isAllowed=y> 18. The Commission conducted ‘an examination of the role of informed consent in promoting both communication between patients and health care professionals and “better” or “more autonomous” decisions by patients, as well as in improving therapeutic outcomes by increasing patient trust and decreasing provider anxiety over legal liability’. See also Emily Jackson, *Medical Law: Text, Cases and Materials* (4th edn, Oxford University Press 2016) 192.

³² Jonathan Herring, *Medical Law and Ethics* (7th edn Oxford University Press 2018) 149.

³³ It would be overly simplistic to suggest that the ‘moral function’ of consent does not also have utilitarian arguments. The utilitarian arguments in favour of informed consent will become apparent as the chapter progresses.

Principlism serves as a good framework upon which to consider ethical issues in healthcare.³⁴ Thus, an overview of the relationship between the principles and informed consent will be provided in this chapter. A natural starting point for an examination of the ethical justification for the requirement that medical professionals seek consent before administering treatment is autonomy. As outlined previously, autonomy encompasses the ability to freely make those important decisions that shape one's life and existence; intrinsically linked to this are one's interests in bodily integrity and self-determination. Without the ability to make autonomous choices and to be autonomous, we would move through life directed where to go by some other power. We would lose the ability to shape our own lives and have any say in its direction. Medical treatment clearly engages our interests in bodily integrity and self-determination. Furthermore, it is clearly an example of a context in which when we can shape our life in some way. An individual who battles cancer with aggressive treatment is shaping her life with an important choice; so too, is the individual who forgoes treatment in the belief that she will get the best from her remaining days by being free from the side effects of treatment. Critically, exercising one's autonomy in this way is impossible without informed consent. We cannot freely choose if we do not know what we are choosing, or what the alternatives are.

Thus, in supporting the decision-making of the individual by fulfilling the requirement to inform and to seek consent to treatment, the physician plays an active role in the exercise of patient autonomy.³⁵ As Onora O'Neill notes:

Respect for autonomy and for rights are often closely identified with medical practice that seeks individuals' informed consent to all medical treatment (...) Medical practice has moved away from paternalistic traditions, in which professionals were seen as the proper judges of patients' best interests. Increased recognition and respect for patients' rights and insistence on the ethical importance of securing their consent are now viewed as standard and obligatory ways of securing respect for patients' autonomy.³⁶

Sheila McLean argues that the purpose of having consent laws 'is to permit the patient the continued exercise of self-determination or autonomy'.³⁷ The corollary, it can be argued, is that an absence of (effective) rules on consent would deny patients the right to self-determination and autonomy. As was articulated in the opening paragraphs, two distinct aspects of the law on informed consent are relevant to this research: the consent must be informed and given by an

³⁴ The 'four principles' refers to Principlism as devised by Beauchamp and Childress. They are (respect for) autonomy, beneficence, non-maleficence and justice.

³⁵ An introduction to the principles of autonomy and non-maleficence was given in Chapter 2.

³⁶ Onora O'Neill *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 2. It is worth noting that she is somewhat critical of the prominence given to autonomy, seemingly at the expense of other principles and values.

³⁷ Sheila McClean, *A Patient's Right to Know* (Dartmouth 1989) 80.

individual with the capacity to do so. Maclean explains the relationship between autonomy and information disclosure as part of the consent process as follows:

[I]f patients require knowledge of the risks to make an ‘informed choice’ then they require that knowledge in order to maximise their autonomy. If the law of battery is to protect individual autonomy, at least in the liberal sense of rational self-determination, then it should require disclosure of those risks that are essential to informed choice.³⁸

As will be explained in more detail later in this chapter, informed consent cases are treated as matters coming within the scope of negligence and not battery. This does not mean, however, that the protection of autonomy is not an ethical justification for informed consent. Rather, it means that the law is doing a questionable job of protecting it; while the ‘theory of informed consent’ may be grounded in the ideal of autonomy, it is not adequately protected therein.³⁹ Thus, in order to truly respect the autonomy of the individual, the medical professional bears the responsibility, not only of seeking consent, but also of providing the information necessary to enable autonomous choices to be made.

Where informed consent is not given or refusal disregarded, the autonomy of the individual may be severely compromised. To an extent, this highlights the relationship between autonomy and the other principles, in this case non-maleficence. To diminish or disregard one principle, autonomy, is to breach the other, non-maleficence. In summarising the potential for negative effect when a patient is treated despite a competent refusal, Ian Kennedy argues:

[I]f the beliefs and values of the patient, though incomprehensible to others (...) have formed the basis for all the patient’s decisions about his life, there is a strong argument to suggest that the doctor should respect and give effect to a patient’s decision based on them (...) To argue otherwise would effectively be to rob the patient of his right to his own personality which may be far more serious and destructive than anything that could follow the patient’s decision as regards a particular proposed treatment.⁴⁰

While the quote appears to refer to the potential for damage in situations where the long-standing beliefs and values of the patient have informed her attitude to treatment, that is not quite the position of this research. Rather, it is submitted that changes to the circumstances of the patient can be just as much of a rationale as long-standing beliefs for a particular decision and can provide just as much of a justification for adhering to that decision. For example, an individual who recently converted to a particular religion may have changed her perspective regarding specific medical treatments; the fact that she converted, as opposed to being raised

³⁸ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 193.

³⁹ Bernadette J Richards, ‘Autonomy and the Law: Widely Used, Poorly Defined’ in David G Kirchhoffer and Bernadette J Richards *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) 25.

⁴⁰ Ian Kennedy, ‘Consent to Treatment: The Capable Person’ in Claire Dyer (ed) *Doctors Patients and the Law* (Blackwell Science 1992) 56.

as a member of that faith from childhood, should not make her decision any less worthy of respect nor should it render any disregard of that decision less damaging. Indeed, one could take the view that religious conversion is properly choice-based in a way that being raised in that faith may not be. Thus, it could be argued that conversion may be more, not less, worthy of respect. In any event, this research settles on *equally* worthy of respect.

If we consider Tom Walker's explanation of autonomy – 'the capacity to think about what you want, to make decisions about what you want taking into account your aims and values, and then to act on those decisions' – the doctor has an additional, vital role to play in the process, that of information provider.⁴¹ How this 'vital role' plays out in informed consent legislation and jurisprudence is inconsistent, as will be demonstrated in later sections. Either way, in order for a physician to discharge the moral duty he owes to seek informed consent prior to administering treatment, the patient must receive information; first, she must be informed as to what has led her to this point, in other words, the nature of her condition or illness. Second, she must be informed of her options, including likely recovery and success rates. Third, she must be informed of the risks associated with those options. To do anything less, may inhibit the ability of the individual to think and make decisions about what she wants, in other words the exercise of her autonomy.

Capacity is also key part to this ethical analysis, something that will be picked up in greater detail when this research considers end-of-life decisions. Still, some 'light coverage' is necessary for now. The relationship between capacity and autonomy is unavoidable. John Devereux argues that the ethical function of competence, is 'to operate as a guide to doctors as to whether the bioethical principle of autonomy or beneficence will be paramount'.⁴² Accordingly, when a patient has capacity, respect for autonomy should be the dominant principle in the vast majority of cases.⁴³ Where the patient is incompetent, the doctor should treat her in line with conferring the most benefit – whether this is based on best interests or previously expressed will and preference or some other method of assessment – in other words,

⁴¹ Tom Walker, 'If they can consent, why can't they refuse?' in Mary Donnelly and Claire Murray (eds) *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester University Press 2016) 76.

⁴² John Devereux, 'Continuing Conundrums in Competency' in Sheila McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 236. From a legal perspective, he argues: '[C]ompetency is one of the determining factors as to whether a patient may give a valid consent (...) A valid consent to treatment is a defence to a battery action. Battery protects the physical inviolability of a patient. It ensures that a patient is only administered treatment to which he or she has given consent. It pays no heed to whether the treatment is in the best interests or will benefit the patient. It simply asks the questions – did this patient consent to this procedure?' See also Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, OUP 2019) 112; they refer to capacity as having a 'gatekeeping role', in other words it distinguishes those decisions that should be accepted from those that should not.

⁴³ An exception to this could be a situation where failing to treat or isolate the individual would result in a grave risk to public health.

the principle of beneficence.⁴⁴ Were beneficence confined to just the health of the patient, then this construct may be problematic, however, as will be argued in more detail shortly, beneficence extends beyond mere health. Capacity also affects the interaction between the principles of autonomy and justice; to treat – in the general sense as opposed to the medical sense – incompetent individuals the same as their competent counterparts would result in incompetent individuals bearing the responsibility for the consequences of their decisions.⁴⁵ To treat competent individuals the same as their incompetent counterparts would also be unjust, as it would be to prevent individuals who have the ‘necessary ability to be rational’ and those who ‘are capable of making autonomous choices’ from doing so.⁴⁶ After all, the freedom to make one’s own decisions comes with it the ‘obligation to answer for the consequences of those decisions’, as autonomy has a clear association with ‘the notion of individual responsibility’.⁴⁷

Arguably, what has emerged from the discussion of autonomy in the context of informed consent is three distinct interactions. First, the relationship between the duty to seek informed consent itself and autonomy was discussed. Second, autonomy was explored in the context of non-consensual treatment, in other words where the refusal of a patient has been disregarded and third, it was discussed in the context of information provision.

Non-Maleficence

The maxim *Primum non nocere* or ‘first, do no harm’, from which the principle of non-maleficence can be derived, is widely considered to serve as moral guidance to physicians as to how to approach their relationship with their patients. Not only is it submitted that a failure to seek informed consent is wrong because it fails to respect the autonomy of the individual, but it is also wrong because of its failure to adhere to the principle of non-maleficence. Thus, two areas of the doctrine of informed consent will be considered through the lens of the duty of non-maleficence; first, non-consensual treatment and second, the provision of information. Separate to autonomy, it can be reasonably suggested that to treat a patient against her will is harmful because it has the potential to irreparably damage the physician-patient relationship, one in which trust and mutual respect is critical. As O’Neill argues:

⁴⁴ John Devereux, ‘Continuing Conundrums in Competency’ in Sheila McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 236.

⁴⁵ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 59.

⁴⁶ *ibid* 60.

⁴⁷ Alexander Morgan Capron, ‘Informed Consent in Catastrophic Disease Research and Treatment’ (1974) 123 U Pa L Rev 340, 365.

Trust is surely more important [than autonomy], and particularly so for any ethically adequate practice of medicine, science and technology. Trust – or rather loss of trust – is a constant concern in political and popular writing in all three areas.⁴⁸

Even if one does not accept that the breakdown of the physician-patient relationship is negative, in and of itself, it is also negative in terms of the consequences it generates. A breach of trust in the form of compelled treatment could well result in that patient not trusting the medical profession in the future, thereby leading to hesitance to seek medical care for related or different issues.⁴⁹ Given that there are arguments that health events themselves such as cardiac arrest can traumatise patients, it seems intuitive that an invasion in the form of non-consensual treatment has the same potential.⁵⁰ Thus, it can be argued that such treatment can expose the patient to a risk of developing PTSD or other mental health issues afterwards, a demonstrable harm. In a more general sense, if word emerges within particular communities or in the public domain of non-consensual treatment, others may shy away from seeking medical advice or care for fear of being compelled to receive treatment.

A range of information must be provided by the physician to fulfil his moral duty to seek informed consent. Aside from the obvious impingement on her autonomy if she does not receive the necessary information, the principle of non-maleficence is also engaged when there is a failure to adequately disclose information. First, if a patient is not adequately informed about her condition, she may not appreciate the severity of the situation in which she is, or the importance of strictly following any aftercare plan. For example, if an individual is suffering from liver fibrosis – a pre-cursor to cirrhosis – and is not adequately informed of the seriousness and causes of her condition, then she may continue drinking alcohol under the mistaken impression that the prescribed drug treatment is sufficient to prevent further liver damage, assuming that she is even aware that fibrosis constitutes ‘damage’. If the patient does not receive sufficient information about her treatment options and the risks associated with those options, then she may undergo treatment that she will later regret either because a risk materialises or because the treatment is unsuccessful. While more information cannot prevent a risk materialising or treatment failing, it can assist individuals to avoid the harm caused by being totally unprepared for such an eventuality.

⁴⁸ Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) ix.

⁴⁹ Alexander Capron, for example, makes a similar point; ‘the absence of such assurance [that the patient will not be forced into a decision that she does not want] would increase the inclination to delay seeking medical intervention even for serious conditions’; Alexander Morgan Capron, ‘Informed Consent in Catastrophic Disease Research and Treatment’ (1974) 123 U Pa L Rev 340, 365.

⁵⁰ Michelle Flaum Hall and Scott E Hall, *Managing the Psychological Impact of Medical Trauma: A Guide for Mental Health and Health Care Professionals* (Springer 2017) 19-21. See also the judgment in *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26, para 10, wherein Hayden J discusses the concept of ‘ICU syndrome’, which is comparable to Post Traumatic Stress Disorder and presents as violent and frightening dreams during ventilation.

In summary, a physician avoids causing harm to the patient by seeking consent because he avoids administering a treatment that may be against the will, preference or interests of the individual and avoids violating her bodily integrity. The ‘harm’ to the individual may arise because of the failure of the physician to provide sufficient information; it may be the administration of a particular treatment carries unacceptable risk to that individual, such as severe pain, nerve damage, loss of one of the five senses or impotence. It may be that the proposed course of action is simply not what the individual wants and that the alternative is preferable given her personal situation. If she is unaware of important information, then the choice she makes may be the wrong one. ‘Harm’ is also present in compelled medical intervention; it could be the treatment of an individual against her religious beliefs, such as administering certain treatment to a Christian Scientist or blood products to a person of Jehovah’s Witness faith. As discussed, such treatment can have the effect of discouraging that person or members of that faith from attaining assistance in the future for fear of receiving unwanted treatment. The harm could be the treatment with aggressive chemotherapy of an individual with terminal cancer, when her wish for her remaining time is to be unencumbered by intervention.

Beneficence

If it is accepted that the undermining of autonomy and self-determination is unethical, then it should also be apparent that the maximisation of these rights and interests is the right choice, in other words the beneficent one. Indeed, as Maclean argues:

Since the duty of beneficence subsumes the duty to prevent avoidable harm, and individual rights serve to protect the interests that all persons have, then the duty of beneficence requires the healthcare professional to protect and defend those rights.⁵¹

Aside from its relationship to autonomy, however, the duty of beneficence is an important consideration in informed consent. It does not just encompass the prevention of harm, but the maximisation of the welfare of the patient. In other words, it can be considered a positive duty to provide benefit, as has been argued:

As well as proscribing harmful interventions, the duty of beneficence also creates an obligation to provide benefit to the patient. This duty includes those interests that are protected by the patient’s rights and this requires healthcare professionals to act in a way that furthers those interests.⁵²

⁵¹ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 49.

⁵² *ibid* 49-50.

This duty or obligation to confer benefit is not confined to mere health, rather, it extends beyond that. As Nils Hoppe and José Miola argue:

The fundamental axiom of medicine is the welfare of the patient. The welfare of the patient does not necessarily mean (...) that the patient has to end up being well (in the sense of being better than before), but that his welfare (in the sense that his preferences are respected) is put first.⁵³

Welfare can certainly be seen to include health, but it should not be limited to health. Rather, it should be thought to include other, less quantifiable, interests, such as ‘peace of mind’, privacy and wellbeing. Given that the maximisation of welfare is considered positive, then it can be considered to fit with a notion of beneficence that a physician generally treats a patient in the way that she wants. As Alexander Capron argues, the doctrine of informed consent ‘assures the patient that in going to a physician he will not be trapped into decisions which he does not want’; this, he argues, promotes ‘trust and confidence between patient and physician’, which in turn ‘advance rational decisionmaking’.⁵⁴

If a physician fully embraces the concept of informed consent, as some commentators argue he should, rather than viewing it narrowly as a means of avoiding litigation, he can confer considerable benefit on the patient.⁵⁵ Irrespective of how (in)frequent this is in practice, by viewing the requirement to give information more fully, as an integral part of medical care and treatment, the physician plays a key role in preparing a patient for what is ahead of her. For example, by being made aware of risks of complications, what those complications entail and of likely recovery times for various treatments, the patient is enabled and supported in making any necessary plans. Different patients, who happen to have the same likely recovery time, may require very different supports during recovery depending on their personal situation. The additional stress of having to call on others unexpectedly to fulfil caring responsibilities ordinarily held by the patient, or to provide care to the patient herself, may cause undue distress and impede her recovery. The same can be said for patients with differing employment situations; individuals with permanent positions and sick leave entitlements are in a very different position to those employed on a casual basis. By having a full and frank discussion about what is entailed in treatment and what is ahead in the aftermath, the medical professional

⁵³ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 283.

⁵⁴ Alexander Morgan Capron, ‘Informed Consent in Catastrophic Disease Research and Treatment’ (1974) 123 U Pa L Rev 340, 365.

⁵⁵ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 50; ‘In the present context [of informed consent] this requires the professional to act in a way that not just respects the patient’s formal right to consent but also reflects the spirit behind that requirement.’

can play a significant role in preventing the avoidable harm in the form of increased anxiety, stress and worry.

Justice

Though most commonly associated with resource allocation and access to medical care within the healthcare sphere, the principle of justice does interact with informed consent. Justice is relevant to the rationale for why the decisions of individuals should or should not be respected and the limits that should legitimately be placed on this respect.⁵⁶ As the requirement to seek consent prior to medical treatment is viewed as sufficiently important to garner legal protection, then the principle of justice – requiring that unequal treatment to be coherently and adequately justified – gives rise to the contention that the consent or refusal of every individual deserves equal respect, all other things being equal.⁵⁷ Potential conflict with the principle arises when a policy dictates that the decisions of some individuals are to be respected but not the decisions of others and when that policy is not based on meaningful or morally relevant criteria.⁵⁸ While the principle of justice surely ought to determine the criteria used to decide whose choices deserve respect and whose do not, that might not always be the case, leading to a violation of the principle. It remains the basic premise of the principle is that those being treated unequally must be unequal in some meaningful way.⁵⁹

Though generally outside the focus of this research, one can question if the principle of justice is being upheld by the law when minors are almost invariably excluded by the courts from the refusing life-sustaining medical treatment. English law has accepted that minors can make decisions regarding their medical care and treatment if certain conditions are met – *Gillick* competence.⁶⁰ Time and time again, however, the courts have compelled the treatment of minors despite their refusal. In *Re E*, Ward J found the minor to be ‘a boy of sufficient intelligence to be able to take decisions about his own well-being’ capable of a ‘calm discussion of the implications’ of his refusal, yet he ruled that he did not have ‘a full understanding of the whole implication’ of what the refusal involved.⁶¹ One can legitimately question if the outcome

⁵⁶ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 58.

⁵⁷ This adapts an argument made by Alasdair Maclean, which states: If autonomy is judged worthy of legal protection, which it currently is, then the principle that the different treatment of certain individuals or groups must be justifiable means that, prima facie, each person deserves an equal respect for her autonomy. Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 58.

⁵⁸ *ibid.*

⁵⁹ See Chapter 2.

⁶⁰ Broadly speaking, a minor must be capable of: (i) comprehending the medical information including the nature and purpose of the treatment, its effects and side effects and the consequences of refusing such treatment on her health and the progression of the condition; (ii) retaining the information and (iii) being of sufficient intelligence and maturity to weigh up the information to arrive at a choice. See *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402.

⁶¹ *Re E (A Minor)(Wardship: Medical Treatment)* [1993] 1 FLR 386, 391.

could have been the same if an adult displayed the capabilities that the minor did in this case, namely obvious intelligence and an ability to calmly discuss the consequences of his refusal. Given that a different outcome is highly likely in that case, there are legitimate questions as to the adherence to the principle of justice in this case and others. Thus, it could be argued that a different standard seems to be applied to minors wishing to refuse life-sustaining medical treatment, without the accompanying morally relevant justification that is required by the principle of justice given that these minors possess what would be competence, were it not for their age.⁶² Additionally, were they attempting to consent to treatment at their age, they may well be considered to have the competence to do so.

Justice and fairness are also key to establishing who should bear the responsibility for the consequences of a decision.⁶³ This explains why competence is fundamental to the ethical analysis of informed consent. As previously mentioned briefly, not only does adherence to the principle of justice dictate that we ought not to treat individuals differently in the absence of morally relevant reasons, it also dictates that we may have a duty to treat individuals differently when they do have morally relevant differences. Capacity is one such morally relevant difference. There is a longstanding recognition that incompetent individuals should be protected, in varying degrees, from making poor decisions and from the consequences of their actions, something that is reflected in society and the law. It is evidenced by laws that provide for the finances of incompetent individuals to be administered by another with court or judicial oversight, in the voiding of contracts if one of the parties is incompetent and in diminished capacity defences in criminal law, among countless others. As the New York State Task Force on Life and the Law summarised the matter in relation to healthcare:

Society has a special duty to incapacitated patients — an obligation to respect them as individuals, to preserve their own religious and moral values in these intensely personal choices, and to promote their well-being by facilitating responsible decisions about their medical care.⁶⁴

⁶² *ibid*: Ward J specifically commented that the minor did not understand the pain he would suffer, the fear he would feel and the distress he would suffer by watching the distress of his family. It is questionable if an adult without medical training or specific experience, not to mind a minor, fully understands the pain that will be suffered at death. Second, whether or not there ought to be a moral obligation to do so, rarely does an adult appear to be required by the law to consider the distress that will be caused to her family by a refusal of treatment. In any event, though undoubtedly upsetting, the refusal is likely to be what the family would have wanted for the minor given that the family were devout members of the Jehovah's Witness faith.

⁶³ See Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 58, 63-67.

⁶⁴ New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (New York 1992) 73.

Thus, when one lacks decision-making capacity, to make them liable for the consequences of poor decisions seems patently unjust;⁶⁵ rather, it is submitted that such individuals should be protected from such negative consequences. While it may be argued by some that this line of argument is subsumed by the autonomy principle itself, it is the position of this research that they are distinct and that justice has an important role to play within informed consent. After all, justice has been explained in line with *fairness*.

Additionally, it is often argued that those with the requisite capacity should not be prohibited from making decisions and engaging in activities merely because they may be detrimental to life, health or well-being. Part of choice is bearing the responsibility for the consequences of that decision, both negative and positive. This is reflected in varying degrees across law and society. Mixed martial arts, boxing, car and motorcycle racing, the climbing of treacherous mountains and cliffs, sky diving and numerous other sports and recreational activities carry a risk to life and health. Yet, although sometimes regulated, they are not prohibited outright. Nor, for that matter, is holding a profession that carries a greater than typical risk. Nor are a multitude of other actions or activities that can affect life and health such as smoking, lack of compliance with medical advice⁶⁶ and overconsumption of alcohol or sugar. Rather, the decision to engage in any of these actions and activities rests with the individual, with their own moral values left to guide them as to whether they should participate and with them bearing the consequences.

Analysing informed consent in light of the four principles clearly demonstrates that seeking consent prior to treatment forms part of the ethical duty of the physician. In doing so, he has respected her autonomy, fulfilled his duties of beneficence and non-maleficence and adhered to the principle of justice. In other words, the principles do not conflict. The situations that lead to the greatest ethical challenges are not as clear cut, however; they are not the cases concerning an average adult patient with capacity. Instead, the challenging cases from the perspective of the physician often concern adults with borderline or fluctuating capacity, patients who have been unduly influenced or coerced or, directly relevant to this research, pregnant patients.

To be clear, it is the position of this research that the obligation to seek informed consent from a patient does not change merely because the patient is pregnant, a contention which appears

⁶⁵ See Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 58, 63-67.

⁶⁶ Save in exceptional circumstances, such as pandemics.

to be strongly supported by various ethical guidelines.⁶⁷ Unwanted and non-consensual treatment do not suddenly become more beneficent because a woman is pregnant. They do not suddenly maximise her welfare in a way that they would not have, prior to pregnancy. Unwanted treatment does not become less of a violation of bodily integrity, nor less of an interference with her interests in self-determination. Such treatment does not become less harmful nor maleficent because of pregnancy. Critically, the principle of justice does not sit unengaged because of pregnancy, rather non-consensual treatment in pregnancy goes to its very heart. The question the principle poses is whether pregnancy is a morally relevant reason to treat a woman differently. It is argued that it is not and the justification for this viewpoint will be explained throughout this research. Finally, neither the autonomy of the woman nor her dignity suddenly become less relevant or worthy of respect because she is pregnant, despite the potential for – though not guaranteed presence of – competing interests. As this research progresses, these contentions will be expanded and defended. For the time being, they are designed to indicate the position of this research towards compelled treatment and invalidating advance directives in pregnancy.

The Law

The ‘legal function’ of consent has a criminal and tortious facet;⁶⁸ it is to convert into lawful contact what would, without consent, be unlawful physical contact. In other words, non-consensual touching can amount to the crime of assault or battery depending on the domestic criminal statutes. When one considers major surgical procedures and even minor procedures such as taking blood, it is evident that were these actions to be committed outside of the physician-patient relationship, they would constitute assault within the meaning of jurisdictional criminal statutes.⁶⁹ Criminal statutes, for example the Non-Fatal Offences Against the Person Act 1997 in Ireland, refer to a person committing the act ‘without lawful excuse’, therefore demonstrating the legal function of informed consent to medical treatment.

⁶⁷ For example, see generally the Health Service Executive National Consent Policy, which will be discussed in more detail later in this chapter. National Consent Advisory Group of the Health Service Executive ‘National Consent Policy’ (2019) <<https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf>> accessed on 6 August 2020.

⁶⁸ Commentators such as Alexander Capron argue that informed consent also has a contract law dimension: ‘Protection of the patient’s autonomy [in the context of the requirement to seek consent prior to treatment] is accomplished by means of a treatment contract between the physician and patient. Even though the terms of such a contract are usually not reduced to writing, its existence is a prerequisite for therapy.’ Alexander Morgan Capron, ‘Informed Consent in Catastrophic Disease Research and Treatment’ (1974) 123 U Pa L Rev 340, 364.

⁶⁹ Ireland: Section 28 of the Non-Fatal Offences Against the Person Act 1997, abolished the common law offence of ‘assault & battery’. Instead the crimes of ‘assault’ (s 2), ‘assault causing harm’ (s 3) and ‘assault causing serious harm’ (s 4) are recognised. England and Wales: Both battery and assault are crimes under the law in England and Wales; the former is a common law offence with no statutory definition and the latter is governed by sections 20 and 47 of the Offences Against the Person Act 1861, which criminalise ‘assault occasioning bodily harm’ and ‘inflicting bodily injury, with or without a weapon’ respectively. New York: New York does not refer to battery in the context of the criminal law, however Penal Code § 120 – 120.15 covers offences such as ‘assault’, ‘reckless assault’, ‘aggravated assault’ and ‘menacing’.

The intentional touching of another person without her consent can also amount to battery under the law of torts, as proof of injury or damage to the plaintiff is not necessary for a successful action thereunder. Rather, what is required is awareness on the part of the defendant that her actions were ‘objectionable’ in some way or beyond the bounds of generally accepted physical contact without lawful excuse.⁷⁰ As will be evident as this chapter progresses, battery is generally not the action pursued against a medical professional when there is alleged lack of informed consent.⁷¹ Instead, such matters come within the remit of medical negligence, something which has been criticised.⁷² While some early informed consent jurisprudence treated the matter as coming within the scope of battery,⁷³ there was a shift in approach as time passed, reflecting the reluctance of the judiciary to tar medical professionals with the same brush as criminals, or *batterers*.⁷⁴ The purpose of the law of consent is often lauded as being the protection of individual autonomy, however, this belief has been challenged by informed consent cases sitting within medical negligence. Given that informed consent provides a defence to the tort of battery, the purpose of which, in turn, is to protect individual rights to bodily integrity, self-determination and autonomy, it seems inconsistent with the goal of protecting autonomy for informed consent cases to be treated as medical negligence. Accordingly, there is a school of thought that the law of informed consent ‘is not, despite

⁷⁰ *Collins v Wilcock* [1984] 3 All ER 374, 378; *Wilson v Pringle* [1986] 3 WLR 1. According to the court in *Wilson*, the touching by the defendant had to be ‘hostile’ in order to constitute battery [11]. In *F v West Berkshire Health Authority* [1989] All ER 545, however, Lord Goff opined that such a word was unsuitable [563-564], instead preferring to define battery in line with the principle that ‘any touching of another’s body is, in the absence of lawful excuse, capable of amounting to a battery and a trespass’ [564]. See also Eoin Quill, *Torts in Ireland* (4th edn, Gill & Macmillan 2014) Chapter 4; he utilises the word ‘objectionable’ to describe the conduct and argues that it is similar to the American approach of ‘offensive’ conduct constituting battery.

⁷¹ Battery will usually only be pursued if there was an absence of consent, for example, if a patient consents to amputation of the right leg but while under anaesthetic, the surgeon decides to also remove the left (see *Mohr v Williams* 104 NW 12 (Minn 1905) for a similar scenario). Battery is not pursued in situations where consent was given but it is subsequently alleged that it was insufficiently informed.

⁷² See for example, *Dries v Gregor* 72 AD 2d 231 (NY 1980); 235: ‘To encapsulate in a medical malpractice case such divergent legal theories as an intended wrong predicated on a battery and a negligent or unintended wrong is at the very least confusing, if not erroneous’. See also Emily Jackson, ‘Informed consent’ to Medical Treatment and the Impotence of Tort’ in Sheila McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006).

⁷³ *Schloendorff v New York Hospital* 211 NY 125 (1914) 129.

⁷⁴ See comments of O’Flaherty J in *Walsh v Family Planning Services* [1992] 1 IR 496, 531: ‘[inadequate information] would not involve the artificial concept of an assault’, instead ‘[a] claim of assault should be confined to cases where there is no consent to the particular procedure and where it is feasible to look for a consent’. See the judgments of Bristow J in *Chatterton v Gerson* [1981] QB 432 and Hirst J in *Hills v Potter* [1984] 1 WLR 641 for authority from England and Wales. For New York, see *Williams v Cordice* 418 NYS 2d 995 (1979). In advocating the approach taken in *Murriello v Crapotta* 51 AD 2d 381 (NY 1976), Egeth J found that ‘a breach by a doctor of his professional duty to properly inform his patient is more akin to malpractice, even though this uninformed consent might lead to the commission of a technical assault and battery’. It was the view of the court that this was because ‘[i]ntent to do injury is an essential element in an assault and battery action’. Egeth J went on to state that ‘the consent to treatment (...) has been elicited as a result of the failure of the physician to supply the patient with the required information while in the process of discharging his obligation to so do. Such failure constitutes an act of negligence or malpractice, rather than an assault or battery which would result from a totally non-consensual exercise of dominion over the body of the patient.’ The Appellate Division of the Supreme Court of the State of New York in the case of *Dries v Gregor* 72 AD 2d 231 (NY 1980) also found that the law relating to malpractice was appropriate to cases involving an alleged lack of informed consent. For criticism of the treatment of informed consent cases as medical negligence, see Emily Jackson, ‘Informed consent’ to Medical Treatment and the Impotence of Tort’ in Sheila McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006). She argues that being treated without consent is harm in and of itself i.e. a ‘dignitary harm’. She contends that an action in battery ‘more accurately protects the patient’s interest in self-determination, because it is the violation of the patient’s right to make an informed choice which is being compensated, rather than the materialisation – through nobody’s fault – of some remote risk’ [275]. See also Bernadette J Richards, ‘Autonomy and the Law: Widely Used, Poorly Defined’ in David G Kirchhoffer and Bernadette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) and Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) Chapter 6.

judicial assertions to the contrary, actually about [protection of] autonomy’ and instead is about ‘professional standards of care’, logic which is difficult to dispute.⁷⁵

Furthermore, if the purpose of the law is to protect autonomy, then why is the materialisation of a known complication necessary for a successful action for lack of informed consent? The ‘harm’ is non-consensual touching, or so dictates the law of battery. Emily Jackson argues:

[A] successful action in battery will lead to compensation for the dignitary harm of being treated without consent. This more accurately protects the patient’s interest in self-determination, because it is the violation of the patient’s right to make an informed choice which is being compensated, rather than the materialisation – through nobody’s fault – of some remote risk (...)⁷⁶

Indeed, the right to make an informed choice may have been compromised ‘regardless of whether she also happens to have suffered physical injury’.⁷⁷ Arguably, the autonomy of the individual has already been compromised by treatment without informed consent, the lack of which has been caused by insufficient information. It is just a fact of life that some people are luckier than others and a risk will materialise for some but not others. Although a detailed analysis of this issue is outside the remit of this research, the discrepancy is certainly worth keeping in mind when intervention in pregnancy and labour is being considered later in this research, given the intimacy of the situation and substantial power imbalance. Alleged conceptual weaknesses of the law aside, it still remains that there is a requirement on medical professionals to seek consent prior to administering treatment, as to do otherwise may result in a successful action in battery.

Capacity

There are three distinct approaches to assessments of capacity; the functional approach, the status approach and the outcome approach.⁷⁸ The functional approach is a subjective, issue-specific and time-specific method of capacity assessment in that it relates to the decision-making ability of a particular patient in relation to a particular decision at a specific point in time. Thus, this approach displays some appreciation of the fluidity of mental capacity; for

⁷⁵ Bernadette J Richards, ‘Autonomy and the Law: Widely Used, Poorly Defined’ in David G Kirchhoffer and Bernadette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) 18. See also Emily Jackson, ‘Informed Consent and the Impotence of Tort’ in Sheila A McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate Publishing, 2006) 273-286; Alasdair Maclean *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 193.

⁷⁶ Emily Jackson, ‘Informed consent’ to Medical Treatment and the Impotence of Tort’ in Sheila McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 275.

⁷⁷ *ibid.*

⁷⁸ The outcome approach assesses the capacity of an individual based on an evaluation of the consequences of their choices. This means that where the decision conforms with usual practice or conventional wisdom i.e. has a ‘good outcome’, it would be found that the person has capacity. The status and functional approaches will be explained in the following sentences.

example, a patient suffering from dementia may alternate between incompetence and competence, therefore there are times when it is appropriate to treat her as a competent decision-maker and times when it is not. Equally, patients with learning difficulties may lack capacity to make certain large or significant decisions but may actively participate in other areas of their healthcare. In both instances, it would not demonstrate respect for the person, nor be in line with the law, to assume that she lacks capacity because she has a particular condition. Such an assumption would be an example of the ‘status approach’; this approach dictates that certain groups or statuses of patients *en masse* lack the capacity to consent to medical treatment. This can be by virtue of these individuals lacking certain characteristics or having certain conditions.

On the face of it, pregnancy does not alter this view of capacity and there are no laws stating that pregnant women should be considered incapable of making decisions based on pregnancy. Nor are there any laws that states that women in labour are incompetent. Still, after the general overview of the jurisdictional approaches to capacity is given, a slew of cases will be discussed that seem to indicate that labour often results in questions as to capacity.

*England and Wales*⁷⁹

As far back as the 1700s, the English common law recognised that consent must be sought before treatment was administered.⁸⁰ In more recent times, this requirement was defined:

[E]very person’s body is inviolate (...) the effect of this principle is that everybody is protected not only against physical injury but against any form of physical molestation (...) The general rule is that consent is necessary to render such [medical] treatment lawful. If such treatment administered without consent is not to be unlawful, it has to be justified on some other principle.⁸¹

As explained in the introduction, consent is only valid if it is voluntarily given by a person with the requisite capacity to do so after being given sufficient information. In approaching capacity to consent to medical treatment, England and Wales utilises a layering of the ‘functional approach’ on top of a very basic ‘status approach’; this can be seen in the rebuttable presumptions that all adults have capacity to consent to medical treatment by virtue of their ‘status’ as adults and that all minors below the age of 16 lack capacity by virtue of their ‘status’

⁷⁹ Because Irish law borrows so heavily from the law in England and Wales, it is preferable to begin with its legal position and development and then progress to Ireland. For all other sections, Ireland will be considered first.

⁸⁰ *Slater v Baker and Stapleton* 2 Wils KB, 95 ER 850 (1767).

⁸¹ *F v West Berkshire Health Authority* [1989] 2 All ER 545, 563-4.

as children. Arguably, however, this may be more of a reflection that the law must have some starting point or constant, rather than an endorsement of the status approach.

In stark contrast to Ireland, which will be discussed in due course, England and Wales has considerable case law pertaining to capacity to refuse medical treatment, both before and after the introduction of the Mental Capacity Act 2005 ('MCA 2005'). There is a rebuttable legal presumption that all adults have the capacity to consent to or refuse medical treatment;⁸² this is irrespective of the wisdom of or reasons behind their choice and notwithstanding the fact that negative consequences may flow from that decision.⁸³ As Jackson J expressed in *Heart of England NHS Foundation v JB*:

The temptation to base a judgement of a person's capacity upon whether they seem to have made a good or bad decision, and (...) upon whether they have accepted or rejected medical advice, is absolutely to be avoided.⁸⁴

Or perhaps, more renowned are the words of Lord Donaldson in *Re T*;

Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment (...) Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent (...)⁸⁵

Lord Donaldson goes on to clarify, however, that the 'presumption of capacity to decide, which stems from the fact that the patient is an adult, is rebuttable'.⁸⁶ In other words, all adults are taken as having decision-making capacity, unless the contrary is demonstrated. It is important to note the distinction between a rebuttable presumption of capacity and a requirement to demonstrate capacity; the latter places the onus on the patient to prove that she has capacity to make medical decisions, whereas the former places the burden of demonstrating incapacity on the medical professionals. This point is important in the context of advance decisions, particularly where the directive-maker suffers from fluctuating capacity; this will be returned to in Chapter 5.

In England and Wales, medical professionals have a common law duty to treat incompetent patients in their 'best interests', which was codified by the MCA 2005.⁸⁷ It is accepted that a competent individual is best placed to judge whether a particular treatment is in her interests; where she is incompetent, she will be treated in line with her best interests. In this way, the law reflects Devereux's contention that capacity dictates which ethical principle should receive

⁸² Mental Capacity Act 2005 (MCA 2005), s 1(2).

⁸³ MCA 2005, s 1(2); *Re T (Adult: refusal of treatment)* [1993] Fam 95.

⁸⁴ *Heart of England NHS Foundation Trust v JB* [2014] EWHC (COP).

⁸⁵ *Re T (Adult: refusal of treatment)* [1993] Fam 95, 115 ('*Re T*').

⁸⁶ *ibid.*

⁸⁷ *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1; MCA 2005, s 1(4).

paramountcy.⁸⁸ Previously determined, albeit it with limited analysis, by the common law, section 4 of the MCA 2005 details how the ‘best interests’ of the patient should be assessed.⁸⁹ Amongst several other relevant factors, it includes the requirement to consider the wishes, feelings, beliefs and values of the individual.⁹⁰ As authors such as Jackson note, however, while ‘the wishes, values and beliefs of P are important, they do not have primacy over other considerations’;⁹¹ this, she contends was ‘deliberate’ in order to avoid what the then government believed would ‘unnecessarily fetter’ the operation of the factors ‘in the many and varied circumstances’ in which they might require application.⁹²

What constitutes ‘best interests’ has led to debate over the years, however, the settled legal position is that it extends beyond and encompasses more than mere medical benefits.⁹³ Accordingly, the courts have interpreted the interests of the individual quite broadly; for example, in *A NHS Trust v DE* it was held to be in the best interests of a man with a learning disability to have a vasectomy for contraceptive purposes.⁹⁴ After his girlfriend became pregnant, their relationship almost broke down and DE lost much of the independence that he had gained with the support of family and disability services. As he was clear that he did not want any more children, his parents felt that it was in his best interests to ensure that another pregnancy did not occur, thus they approached the Trust to carry out the procedure; the Trust, in turn, applied for a declaration as to DE’s capacity and for authorisation to carry out the vasectomy.⁹⁵ The pre-MCA 2005 judgment in *Re Y (Mental Patient: Bone Marrow Donation)*, which garnered considerable commentary and criticism, also demonstrated the willingness of the court to consider factors outside of medical benefit when authorising a procedure.⁹⁶ In this

⁸⁸ John Devereux, ‘Continuing Conundrums in Competency’ in Sheila McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 236.

⁸⁹ For comment on the conceptual basis for the ‘best interests’ standard, see Mary Donnelly, ‘Best Interests, Patient Participation and the Mental Capacity Act 2005’ (2009) 17 *Med L Rev* 1.

⁹⁰ MCA 2005, s 4(6).

⁹¹ *ITW v Z and M* [2009] EWHC 2525 (Fam); *Re M (Statutory Will)* [2009] EWHC 2525 (Fam); *A NHS Trust v DE* [2013] EWHC 2562 (Fam). The primacy and importance of the views (wishes, feeling, values, beliefs) of the individual will be considered in more detail in the course of the next chapter in the context of end-of-life decision-making.

⁹² Emily Jackson, ‘From ‘Doctor Knows Best’ to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment’ (2018) 81 *MLR* 247, 253. Quoted in her text; Department of Constitutional Affairs, *Government Response to the Scrutiny Committee’s Report on the Draft Mental Incapacity Bill* (Cm 6121, 2004).

⁹³ See *Re MB (Medical Treatment)* [1997] 2 *FLR* 426, 439: ‘Best interests are not limited to best medical interests’ (Butler-Sloss LJ). See also Butler-Sloss LJ in *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 *FLR* 549, 555: She cited the understanding of ‘best interests’ in *Re MB* with approval and added: ‘In my judgment best interests encompasses medical, emotional and all other welfare issues’.

⁹⁴ [2013] EWHC 2562 (Fam).

⁹⁵ Despite initial ‘legitimate concerns’ as to DE’s competence to consent to sexual intercourse in the aftermath of the pregnancy, King J found that there was universal agreement as to DE’s capacity in this regard [34]. In view of the consistent position of all the experts and his parents, it was unnecessary for King J to devise any particular test in relation to sexual contact. It can be discerned from the judgment that she only made a declaration as to his capacity in this regarding because the Official Solicitor sought one [34]. For more recent jurisprudence in the area of consent to sexual contact and a more adversarial example, see *B v A Local Authority* [2020] *Fam* 105, 122-26.

⁹⁶ [1996] 2 *FLR* 787. Deirdre Madden, for example, criticises this judgment for being ‘an unsatisfactory application of a best-interests test in a case in which there was no obvious tangible benefit to the woman in undergoing a medical procedure to which she did not consent’. Deirdre Madden, *Medicine, Ethics and the Law* (2nd edn, Bloomsbury Professional 2011) 376. For other comments on and critiques of the *Re Y* judgement, see Penney Lewis, ‘Procedures that are Against the Medical Interests of Incompetent Adults’ (2002) 22 *Oxford J Legal Stud* 575; Richard Huxtable, ‘Autonomy, Best Interests and the Public Interest: Treatment, Non-Treatment and the Values of Medical Law’ (2014) 22 *Med L Rev* 459; Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 219-20.

case, a bone marrow donation from a severely mentally disabled woman to her sister was ordered. The court found that if the woman's sister was terminally ill, her mother would be too upset to visit her; thus, the basis for the order was the benefit to the disabled woman's mother, which in turn would benefit the woman herself.

Notwithstanding any challenges in identifying what amounts to 'best interests' in the case of a particular individual or more generally, for the purpose of this part of the research, the system of differentiating between those with and without capacity is most important.⁹⁷ As should be apparent from the jurisprudence above, prior to the introduction of MCA 2005, it was the common law that guided physicians on how to treat incompetent patients. Upon its introduction, the MCA 2005 made a number of necessary reforms when read in concert with the Code of Practice associated with the Act. Both appeared to give doctors, patients and healthcare facilities at least some of the much-needed clarity in the area. While there is considerably more that could be said about the best interests standard, it is beyond the scope of this piece to get into a detailed debate about its merits and weaknesses;⁹⁸ for current purposes, it should suffice to say that treating incompetent patients in line with best interests is the current legal position.⁹⁹

The MCA 2005 provides that an individual does not possess capacity if 'at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain'.¹⁰⁰ Two separate considerations are clearly laid out in section 2; first, the presence of a disturbance or impairment and second a resulting inability to make a 'decision for himself'. Merely possessing a disturbance or impairment does not in and of itself mean a patient lacks capacity, however, the presence of the disturbance or impairment may indicate that capacity is absent.¹⁰¹ The standard of proof

⁹⁷ As will become evident in Chapter 5, which pertains to advance directives, capacity or lack thereof arises frequently in the context of advance decision-making. For example, decision-making competence is a pre-requisite to drafting a valid advance directive, the advance directive only becomes effective upon incompetence of the individual, etc. The relevance of the previously articulated views of the individual to best interests assessments will be considered in more detail in the next chapter.

⁹⁸ For some commentary on the use of best interests see, for example, Emily Jackson, 'From 'Doctor Knows Best' to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment' (2018) 81 MLR 247; Helen J Taylor, 'What are 'Best Interests'? A Critical evaluation of 'Best Interests' Decision-Making in Clinical Practice' (2016) 24 Med L Rev 176; Mary Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 Med L Rev 1; Søren Holm and Andrew Edgar, 'Best Interest: A Philosophical Critique' (2008) 16 Health Care Anal 197.

⁹⁹ It remains to be seen if the MCA 2005 will be amended in order to come into line with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, as interpreted by the Committee on the Rights of Persons with Disabilities in General Comment No. 1, which dictates that 'best interests' should be replaced with 'will and preference'. For discussions on the interaction between 'will and preference' and the MCA, see Paul Skowron, 'Giving substance to 'the best interpretation of will and preferences' (2019) 62 Int'l J L & Psychiatry 125; Alex Ruck Keene and Cressida Auckland, 'More Presumptions Please? Wishes, Feelings and Best Interests Decision-Making' (2015) 5 Eld LJ 293; Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye' (2016) 24 Med L Rev 318.

¹⁰⁰ MCA 2005, s 2(1). Section 2(2) confirms the irrelevance of whether the impairment or disturbance is permanent or temporary.

¹⁰¹ MCA 2005, s 2(3)(b). See also *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 29 ('*Re C*') – the judgment in which contains the capacity test that was eventually codified by the MCA – where Thorpe J found that C's diagnosis of schizophrenia or his incompetence in relation to other decisions was not sufficient to render him incompetent to make the decision to refuse surgery.

required in matters of mental capacity is the balance of probabilities, in others words the physician must show that it is more likely than not, that the patient is currently incompetent to make the decision in question.¹⁰² The original 3-stage test for assessing the capacity of an individual was devised by Thorpe J in the *Re C* case in the 1990s.¹⁰³ It was refined by Butler-Sloss LJ in *Re MB* – which will be discussed in more detail in a later section in the context of capacity in pregnancy – wherein she stated that the individual is unable to make a decision if she is:

- (i) unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question;
- (ii) unable to use the information and weigh it in the balance as part of the process of arriving at the decision.¹⁰⁴

Section 3 of the MCA 2005 codified the common law test providing that a person is unable to make a decision if she is unable to meet the following criteria:

- (i) to understand the information relevant to the decision;¹⁰⁵
- (ii) to retain that information;¹⁰⁶
- (iii) to use or weigh that information as part of the process of making the decision, or;¹⁰⁷
- (iv) to communicate his decision (whether by talking using sign language or any other means).¹⁰⁸

It also states that patients must not be considered unable to make a decision if the information is not provided to them in a way that sufficiently facilitates their understanding, therefore the method of communication should be tailored to the needs of the individual.¹⁰⁹ While this requires that a patient not be considered incompetent just because the information has not been provided in an accessible manner, it does not follow that a physician will have liability in

¹⁰² Code of Practice accompanying the Mental Capacity Act 2005 ('Code of Practice'), para. 4.10.

¹⁰³ *Re C* [1994] 1 WLR 290. To have capacity, the person must comprehend and retain the relevant information, believe it and weigh it in the balance, so as to arrive at a choice.

¹⁰⁴ *Re MB (Medical Treatment)* [1997] 2 FLR 426, 437; Butler-Sloss LJ did not include the requirement to believe the information. In *Local Authority X v MM* [2007] EWHC 2003 (Fam), Munby J opines that the omission of the requirement to believe the information is inconsequential, as 'if one does not "believe" a particular piece of information then one does not, in truth, "comprehend" or "understand" it, nor can it be said that one is able to "use" or "weigh" it. In other words, the specific requirement of belief is subsumed in the more general requirements of understanding and of ability to use and weigh information.'

¹⁰⁵ MCA 2005, s 3(1)(a).

¹⁰⁶ MCA 2005, s 3(1)(b).

¹⁰⁷ MCA 2005, s 3(1)(c).

¹⁰⁸ MCA 2005, s 3(1)(d).

¹⁰⁹ MCA 2005, s 3(2). See also section 4.18 of the Code of Practice, which gives suggestions as to how to present information to those with learning difficulties and conditions such as anxiety. Furthermore, paragraph 4.16 states that 'quick or inadequate explanations are not acceptable unless the situation is urgent'.

negligence if a patient misunderstands information and refuses treatment on foot of a misapprehension.¹¹⁰ Section 3(3) cautions that the ability to retain the relevant information for a short period of time only, does not render the patient unable to make the decision.¹¹¹ Paragraph 4.20 of the Code of Practice reaffirms this section and supports medical professionals utilising ‘items such as notebooks, photographs, posters, videos and voice recorders’ in order to help people record and retain the relevant information.¹¹²

After the introduction of the MCA 2005, the meaning of ‘relevant to the decision’, in the context of the information to be understood, retained and assessed to reach a choice, was considered by the court. The relevant section of the Code of Practice states that the information must include the nature of the decision and the reason why the decision is necessary, together with the likely consequences of deciding one way or another or not deciding.¹¹³ In *Heart of England NHS Foundation v JB*, the court assessed the meaning of ‘information relevant to the decision’, wherein Jackson J found that a ‘broad, general understanding’ of the ‘nature, purpose and effects of the proposed treatment’ was sufficient.¹¹⁴ Furthermore, he opined that the respondent was ‘not required to understand every last piece of information about her situation and her options’, further emphasising that a general understanding was the legal requirement.¹¹⁵

As was articulated previously, it is irrelevant if the decision being made by the person is unwise. In *Heart of England NHS Trust v JB*, Jackson J stated:

[Medical] decisions are intensely personal (...) There are no right or wrong answers. The freedom to choose for oneself is a part of what it means to be a human being (...) anyone capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom or consequences of the decision. The decision does not have to be justified to anyone.¹¹⁶

Perhaps the clearest rejection of the conflation of ‘unwise’ or ‘immoral’ decisions with incapacity on the part of the decision-maker was found in *King’s College Hospital NHS*

¹¹⁰ *Al Hamwi v Johnston and another* [2005] All ER (D) 278: Counsel for the plaintiff had suggested that the duty of a clinician was to ensure that the information given to the patient is understood. At para 69, the learned judge stated: In my view that is to place too onerous an obligation on the clinician. It is difficult to see what steps could be devised to ensure that a patient has understood, short of a vigorous and inappropriate cross-examination. A patient may say she understands although she has not (...) or has a clear understanding of something other than what has been imparted. It is common experience that misunderstandings can arise despite reasonable steps to avoid them. Clinicians should take reasonable and appropriate steps to satisfy themselves that the patient has understood the information which has been provided; but the obligation does not extend to ensuring that the patient has understood.

¹¹¹ MCA 2005, s 3(3).

¹¹² Code of Practice, para 4.20.

¹¹³ Code of Practice, paras 4.19 and 4.16 respectively.

¹¹⁴ [2014] EWHC (COP), paras 24-5.

¹¹⁵ [2014] EWHC (COP), para 25. See also *LBL v RYJ* [2011] FLR 1279 at 1284 where Macur J stated that he ‘read s 3 [of the MCA 2005] to convey (...) that it is envisaged that it may be necessary to use a variety of means to communicate relevant information, that it is not always necessary for a person to comprehend all peripheral details and that it is recognised that different individuals may give different weight to different factors’.

¹¹⁶ [2014] EWHC (COP), paras 1-2.

Foundation Trust v C.¹¹⁷ MacDonald J, in finding for a woman who wished to refuse dialysis, stated:

To introduce into the assessment of capacity an assessment of the probity or efficacy of a decision to refuse life saving treatment would be to introduce elements which risk discriminating against the person making that decision by penalising individuality and demanding conformity at the expense of personal autonomy in the context of a diverse, plural society which tolerates a range of views.¹¹⁸

Although C's long-term prognosis was viewed to go from 'cautiously optimistic' to 'excellent with survival fully anticipated', she refused dialysis for a variety of reasons. She was concerned that she would be dependent on it for the rest of her life, but critically, did not view her life positively if it lacked socialising, drinking and partying with friends.¹¹⁹ Furthermore, she was concerned about the effect that dialysis and aging generally would have on her appearance.¹²⁰ Although it may be incomprehensible to many that an individual possessing what are objectively considered 'good' things in life – family, children, friends, a good prospect of recovery – would put minimal value on such a life, were it to be without socialising and partying and with aging and decreased material possessions, such a value system is not overridden by law. In affirming that C had capacity to refuse, MacDonald J stated:

C was recorded (...) as being clear in her understanding that without dialysis (...) she would die and (...) fully understood the risk of refusing treatment (...) It is clear from the medical records that C appears (...) to have undertaken an exercise of using or weighing information as it is recorded that an hour was spent talking to C about her grave medical condition, her chances of recovery, and her prognosis for the future.¹²¹

Consistent with the legislative interpretation above is the more recent judgment of MacDonald J in *Cambridge University Hospitals NHS Foundation Trust v BF*, wherein the learned judge found that the psychosis suffered by the respondent had resulted in incompetence.¹²² First, BF disbelieved that she had a tumour and thought that the scans were false and second, despite 'compelling evidence to the contrary', she persisted in a view that she would not suffer any negative consequences by refusing surgery.¹²³ Therefore, it is apparent that the law in England and Wales generally protects the interests in bodily integrity and self-determination of the individual, even when her decision may be unpalatable, unconventional or ill-advised.¹²⁴

¹¹⁷ [2015] EWCOP 80.

¹¹⁸ *ibid* para 30.

¹¹⁹ *ibid* paras 17, 20 and 74.

¹²⁰ *ibid* para 74

¹²¹ *ibid*.

¹²² *Cambridge University Hospitals NHS Foundation Trust v BF* [2016] EWCOP 26.

¹²³ *ibid* 52. See also *A Hospital NHS Trust v K* [2012] EWHC 2922 (COP).

¹²⁴ The right to refuse life-saving treatment or have it withheld or withdrawn will be considered in more detail in the next chapter.

Ireland

Medical treatment may not be given to an adult person of full capacity without his or her consent (...). This right arises out of civil, criminal and constitutional law. If medical treatment is given without consent it may be a trespass against the person in civil law, a battery in criminal law, and a breach of the individual's constitutional rights. The consent which is given by an adult of full capacity is a matter of choice. It is not necessarily a decision based on medical considerations. Thus, medical treatment may be refused for other than medical reasons, or reasons most citizens would regard as rational, but the person of full age and capacity may make the decision for their own reasons.¹²⁵

The statement of Denham J in *Re a Ward of Court* is clear and unambiguous in theory, however when we delve deeper to ask what constitutes *full capacity*, or more accurately what constitutes incompetence, we must look to a mix of legislation and case law. It must be stated from the outset, however, that Irish jurisprudence is limited.

Prior to the drafting of Assisted Decision-Making (Capacity) Act 2015, which will be discussed in more detail in the coming paragraphs, a small number of cases considered the issue of decision-making capacity in healthcare; *Fitzpatrick v FK* case (hereafter 'the *K case*') was one such case.¹²⁶ It concerned a Congolese woman who had refused a post-partum blood transfusion, an order for which was granted in an *ex tempore* High Court hearing. In *ex tempore* judgment, Abbot J found that K was competent to refuse treatment but ruled that the interests of her newborn child in not being abandoned outweighed her interests.¹²⁷ After the transfusion was administered and K recovered, she alleged *inter alia* that the transfusion was unlawful and breached her constitutional rights. Laffoy J stated that 'it could not be argued that a competent adult is not free to decline medical treatment' and proceeded to endorse the approach taken to capacity assessment in the English case of *Re C*.¹²⁸ In doing so, Laffoy J established the capacity test to be used in Ireland:

- (i) K must understand the information given to her regarding the necessity of a blood transfusion to preserve her life and retain it;
- (ii) she must believe it;

¹²⁵ *Re a Ward of Court (withholding medical treatment)* (No. 2) [1996] 2 IR 79 ('*Re a Ward of Court*').

¹²⁶ [2009] 2 IR 7.

¹²⁷ It subsequently emerged that this conclusion was factually unsound and that Ms K had misrepresented the whereabouts of the child's father on her hospital admission form.

¹²⁸ [2009] 2 IR 7, 14; *Re C* [1994] 1 All ER 819.

- (iii) she must weigh that information in the balance, balancing the risk of death inherent in that decision against the availability of a blood transfusion.¹²⁹

The learned judge ruled, on the facts of the case, that K lacked capacity to refuse the blood transfusion.¹³⁰ This test has now been codified by the ADM(C)A 2015.¹³¹

The legal position was neatly summarised in *Nolan v Carrick*:

[T]here is a presumption as to the capacity of an adult patient (...) but that presumption can be rebutted. The test in [the *K*] case was stated to be whether the patient's cognitive ability has been impaired to the extent that (...) she does not sufficiently understand the nature, purpose and effect of the proffered treatment and the consequences of accepting or rejecting in the context of the choices available at the time the decision is made.¹³²

A similar approach to the assessment of capacity was taken by Baker J in *Governor of X Prison v PMcD*:

Having heard the evidence (...) I am of the view that he has the capacity to make the decision he has (...) and that the decision was made by him in the full understanding of its consequences and of the alternatives, and that his decision-making capacity is not vitiated by any frailty arising from his current living conditions or from his personality traits. I consider that Mr. McD has fully and freely chosen his path (...) and that his decision has been fully informed.¹³³

In Ireland, capacity assessments for the purpose of medical treatment will be governed by the ADM(C)A 2015, once commenced. From the outset, the Act dictates that capacity must be presumed unless there is a reason to suspect its absence.¹³⁴ It outlines how the issue of capacity should be approached; first, it states that capacity is to be assessed functionally and proceeds:¹³⁵

[A] person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time.¹³⁶

As discussed previously, the MCA 2005 dictates that a person lacks capacity if he is unable to make the relevant decision by virtue of a 'mental impairment or disturbance in the functioning of the mind or brain'.¹³⁷ The ADM(C)A 2015 attaches no such condition to incapacity, instead

¹²⁹ *Fitzpatrick v FK* [2009] 2 IR 7, 48. Applied as the three-stage test for capacity assessments under common in *Health Service Executive v R (A person of unsound mind not so found represented by his Solicitor) and ors* [2016] IEHC 445, paras 40, 85 and 93. See also *Health Service Executive v KW* [2015] IEHC 215.

¹³⁰ Ms K had indicated her belief that her condition could be treated with a diet of Coca Cola, eggs and milk, something which Laffoy J stated 'could only ring alarm bells as to Ms K's appreciation of the gravity of her situation and what was required to be done to preserve her life [75]. Thus, Ms K did not understand the information regarding the necessity of the blood transfusion, nor did she believe it.

¹³¹ Assisted Decision Making (Capacity) Act 2015, s 3(2).

¹³² [2013] IEHC 523, para 153.

¹³³ *Governor of X Prison v PMcD* [2016] 1 ILRM 116, 142.

¹³⁴ Assisted Decision Making (Capacity) Act 2015, s 8(2). See also National Consent Policy, ss 5.3 and 5.4.

¹³⁵ The heading of section 3 of the Assisted Decision Making (Capacity) Act 2015 reads 'Person's capacity to be construed functionally'. See also National Consent Policy, s 5.1.

¹³⁶ Assisted Decision Making (Capacity) Act 2015, s 3(1).

¹³⁷ MCA 2005, s 2(1).

the Act virtually mirrors section 3 of the MCA 2005 by stating that ‘a person lacks capacity to make a decision if he or she is unable—

- (a) to understand the information relevant to the decision;
- (b) to retain that information long enough to make a voluntary choice;
- (c) to use or weigh that information as part of the process of making the decision; or
- (d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.¹³⁸

In the same fashion as the MCA 2005, section 3(7) of the ADM(C)A 2015 explains ‘information relevant to a decision’ as including information about the reasonably foreseeable consequences of the available options and of declining to make the decision.

Insofar as possible, it appears that the legislation has attempted to protect the autonomy and self-determination of the individual. For example, there is an onus to explain the information to the individual ‘in a way that is appropriate to his or her circumstances (whether using clear language, visual aids or any other means)’, thereby requiring medical professionals to take all steps to ensure that they are communicating effectively with the patient.¹³⁹ Furthermore, the mere fact that an individual can only retain the relevant information for a short time does not render her incompetent.¹⁴⁰ The guiding principles make quite strong statements protecting individual interests of self-determination; as outlined in Chapter 1, this section requires that an individual not be considered to be unable to make a decision because the decision is, or a past decision was, unwise and it mandates that no intervention be made in respect of an individual unless necessary.¹⁴¹ It remains to be seen, however, if the Irish courts will interpret the legislation in a manner as supportive of autonomy and self-determination, as their counterparts in England and Wales have generally done.

New York

New York Public Health Law states that any adult, married person or parent ‘may give effective consent for medical, dental, health and hospital services’.¹⁴² This right is explicitly extended to pregnant women by virtue of § 2504 section 3, however, the text of the section limits this

¹³⁸ Assisted Decision Making (Capacity) Act 2015, s 3(2). See also National Consent Policy, s 5.5.

¹³⁹ Assisted Decision Making (Capacity) Act 2015, s 3(3).

¹⁴⁰ Assisted Decision Making (Capacity) Act 2015, s 3(4).

¹⁴¹ Assisted Decision Making (Capacity) Act 2015, s 8(2) (4) and (5) respectively. See generally, National Consent Policy, s 5.3.

¹⁴² New York Public Health Law § 2504 section 1 (‘Public Health Law’).

right to prenatal care, an issue that will be picked up again in Chapter 6. New York has a long tradition of supporting the right of competent adults to make decisions as to their medical care:

In our system of a free government, where notions of individual autonomy and free choice are cherished, it is the individual who must have the final say in respect to decisions regarding his medical treatment in order to insure that the greatest possible protection is accorded his autonomy and freedom from unwanted interference with the furtherance of his own desires.¹⁴³

When Cardozo J stated that '[e]very human being of adult years and sound mind has a right to determine what shall be done to his body', he enshrined in New York law, the right of a competent adult to consent to or refuse medical treatment.¹⁴⁴ As a federalised system, New York law does not exist in a vacuum but rather local decisions and statute must exist harmoniously with federal law and judgments of the United States Supreme Court. Not only has the right of an individual to consent to or refuse treatment been vindicated by state judgments but also by the Supreme Court:

No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law (...) The right to one's person may be said to be a right of complete immunity: to be let alone.¹⁴⁵

Although this case concerned a determination that a court could not order a plaintiff involved in a personal injury action to submit to a pre-trial surgical examination, the sentiment expressed appears to be clear; although not absolute, there is an inviolability associated with the human body.¹⁴⁶

In *Re Storar*, Watchler J acknowledged the legitimate interest of the state in protecting the lives of its citizens and identified instances in which the state may step in and order treatment to be administered, for example, public health grounds. He stated, however, that there existed 'no statute which prohibits a patient from declining necessary medical treatment or a doctor from honoring the patient's decision'.¹⁴⁷ Opining on the position of the legislation and case law regarding refusal of treatment, he stated:

To the extent that existing statutory and decisional law manifests the State's interest on this subject, they consistently support the right of the competent adult to make his own

¹⁴³ *Rivers v Katz* 67 NY 2d 485 (1986); 493.

¹⁴⁴ *Schloendorff v New York Hospital* 211 NY 125 (1914); 129. Early cases outside New York also upheld the right to refuse medical treatment for example, *Mohr v Williams* 104 NW 12 (Minn 1905); *Pratt v Davis* 79 N.E. 562 (Ill 1906); *Rolater v Strain* 39 Okla 572 (1913).

¹⁴⁵ *Union Pacific Railway Company v Botsford* 141 US 250 (1891); 251.

¹⁴⁶ This judgment has been cited extensively including in *Superintendent of Belchertown State School v Saikewicz* 373 Mass 728 (1977); *Satz v Perlmutter* 362 So 2d 160 (Fla 1978), both cases concerning withdrawal or withholding medical treatment.

¹⁴⁷ *Re Storar* 52 NY 2d 363 (1981); 377.

decision by imposing civil liability on those who perform medical treatment without consent, although the treatment may be beneficial or even necessary to preserve the patient's life (...) The current law identifies the patient's right to determine the course of his own medical treatment as paramount (...)¹⁴⁸

Naturally, the capacity of the individual is critical to her ability to exercise this right. *Rivers v Katz* demonstrates the approach of the highest New York court when the competence of the adult is called into question.¹⁴⁹ The respondents in the case, the Harlem Valley Psychiatric Center and Commissioner of the New York State Office of Mental Health, argued that the plaintiffs, who were involuntarily committed mental patients, are presumptively incompetent to make decisions and refuse medication.¹⁵⁰ They argued this on the grounds that by virtue of ordering involuntary retention, the court has 'implicitly determined that the patient's illness has so impaired his judgment as to render him incapable of making decisions regarding treatment and care'.¹⁵¹ The Court of Appeals of the State of New York unanimously rejected this, with Alexander J stating:

[N]either the fact that appellants are mentally ill nor that they have been involuntarily committed (...) constitutes a sufficient basis to conclude that they lack the mental capacity to comprehend the consequences of their decision to refuse medication.¹⁵²

Thus, *Rivers* established that in order for treatment to be compelled, a determination of the patient's incompetence must be made by a court.¹⁵³ The only exception to this general rule advanced by the court is if 'the patient presents a danger to himself or other members of society or engages in dangerous or potentially destructive conduct within the institution'.¹⁵⁴ Alexander J was unequivocal regarding the burden of proof in such cases, stating that the state 'would bear the burden of demonstrating by clear and convincing evidence the patient's incapacity to make a treatment decision'. He continued:

If, after duly considering the State's proof, the evidence offered by the patient, and any independent psychiatric, psychological or medical evidence that the court may choose to procure (...) the court determines that the patient has the capability to make his own treatment decisions, the State shall be precluded from administering antipsychotic drugs.¹⁵⁵

¹⁴⁸ *ibid.*

¹⁴⁹ 67 NY 2d 485 (1986).

¹⁵⁰ *Rivers v Katz* 67 NY 2d 485 (1986); 493.

¹⁵¹ *ibid.*

¹⁵² *ibid* 494.

¹⁵³ The court ruled that the court determination should follow the exhaustion of out of court options i.e. the administrative review provided for in 14 NYCRR 27.8, which governs the right of patients in institutions to object to treatment or appeal treatment decisions.

¹⁵⁴ 67 NY 2d 485 (1986); 495-6: In such cases, the state may be warranted in temporarily administering treatment as the legitimate exercise of its police powers.

¹⁵⁵ *ibid* 497.

If, after hearing the evidence, the court was of the view that the individual was incompetent, then it must determine if the treatment in question should to be administered. In order to do so, the court must consider the treatment in light of the liberty interest of the patient, her best interests and the benefits and side effects associated with the treatment and alternatives.¹⁵⁶

What *Rivers* did not establish, however, was what would constitute clear and convincing evidence of incapacity; in other words, no criteria for determining incapacity was given. Thus, a series of Appellate Court decisions appeared ‘to fill the blanks’, so to speak. In *Re Harvey U*, it was held that an individual must be capable of understanding the reality of his condition, which extends to its severity and the consequences of refusing treatment.¹⁵⁷ Thus, Levine J found the individual in this case incompetent because he was ‘incapable of making an informed, rational decision on the basis of the risks and benefits of the surgery’ and of ‘comprehending the seriousness of his condition and the consequences of not having the procedure performed’.¹⁵⁸ In short, the court viewed the patient’s lack of ‘any realistic insight into the nature of his condition or capability of understanding the risks and benefits of surgery or the consequences of his refusal to accept treatment’ as the decisive factor.¹⁵⁹ Accordingly, evidence that the patient was in denial as to the severity of his condition and his belief that his condition would improve without intervention was sufficient to demonstrate incompetence.

Subsequent cases appear to generally apply the criteria laid out in *Re Harvey U*; in *S v Kingsboro Psychiatric Center*, denial by a patient suffering from chronic paranoid schizophrenia that she needed medication and her belief that her condition was improving without treatment was sufficient to find her incompetent.¹⁶⁰ A denial that medication was required to improve her condition was easily distinguishable from *Rivers*, in which no evidence of alleged incapacity, other than their involuntary admission to a psychiatric facility, was provided. Thus, broadly speaking, it can be said that in determining incapacity, the court should consider the ability of the individual to understand and accept her condition, including its reality and severity and her ability to appreciate the consequences of refusing treatment.

¹⁵⁶ The State also bears the burden of establishing that the proposed treatment meets the aforementioned criteria, again with the ‘clear and convincing’ standard.

¹⁵⁷ 116 AD 2d 351 (NY 1986); 353.

¹⁵⁸ *ibid.* It is worth noting that this decision was reversed on appeal on other grounds and a redetermination of capacity in the court of first instance was ordered. With that said, it does not appear that this was because Levine J had erred in any way in the factors he deemed necessary to consider as part of the capacity determination.

¹⁵⁹ *Matter of Harvey U* 116 AD 2d 351 (1986); 353.

¹⁶⁰ 149 AD 2d 424 (NY 1989). See also *Re McConnell* 147 AD 2d 881 (NY 1989) for a similar factual scenario and conclusion i.e. the illness suffered by the individual was debilitating and caused him to disbelieve its existence. Accordingly, he was found incapable of making a reasoned treatment decision. See also *Mausner v William E.* 264 AD 2d 485 (NY 1999) and *Re William S* 31 AD 3d 567 (NY 2006).

It is interesting to note the repeated requirement of ‘rational’ and ‘reasoned’, which is placed on healthcare decision-making by the New York courts in comparison with England and Wales and Ireland.¹⁶¹ As articulated previously, in *Re T*, Lord Donaldson stated that the reasons behind a particular decision may be ‘rational’, ‘irrational’ or ‘non-existent’.¹⁶² The ADM(C)A 2015 provides that treatment may be refused even if the decision is ‘unwise’ or not grounded in ‘sound medical principles’.¹⁶³ One could argue that the standard in New York equates ‘rational’ or ‘reasoned’ decision-making with decision-making capacity; this, it is argued, is problematic. There are undoubtedly people who view religious beliefs to be lacking in logic or rationality, yet medical decision-making based on religious belief has been upheld by the New York courts.¹⁶⁴ It is questionable if the pursuit of a particular course of action for religious reasons is any more rational or logical than for another reason.

The Family Health Care Decisions Act, pending since 1994 and introduced in 2010, inserted Article 29-CC into New York Public Health Law and dictates *inter alia* how people without capacity should be treated and how capacity should be assessed. Somewhat emulating the common law position, capacity is defined as ‘the ability to understand and appreciate the nature and consequences of proposed health care, including the benefits and risks of and alternatives to proposed health care, and to reach an informed decision’.¹⁶⁵ What is worthy of note is what is not required, namely an ability to reach a ‘rational’ or ‘reasoned’ decision. Despite this, some case law post-2010 seems to retain the requirement that the decision be ‘reasoned’, where capacity determinations are being made by the court.¹⁶⁶ It is worth bearing in mind that such judgments are from the mid-level or county courts – as distinct from the Court of Appeal – meaning that they may still be bound by the ruling in *Rivers*.

Similar to England and Wales and Ireland, the law in New York is that ‘every adult shall be presumed to have decision-making capacity unless determined otherwise’.¹⁶⁷ In contrast to the aforementioned jurisdictions, however, New York law requires both an initial determination of incapacity and an independent concurring determination in hospital and residential health care facility settings, with both determinations including ‘an assessment of the cause and extent of

¹⁶¹ In *Matter of Harvey U* 116 AD 2d 351 (1986) and in *Mausner v William E.* 264 AD 2d 485 (N.Y. 1999), there are statements regarding an inability to make ‘rational’ decisions. In *Rivers v Katz* 67 NY 2d 485 (1986), *S v Kingsboro Psychiatric Center* 149 AD 2d 424 (NY 1989), *Paris M v Creedmoor Psychiatric Center* 30 AD 3d 425 (NY 2006) and others there is a reference to the (in)ability of the individual to make a ‘reasoned’ decision. See also *Re Storar* 52 NY 2d 363 (1981) – which will be discussed in more detail in the next chapter – where there is a reference to Mr Storar’s totally inability to understand or making ‘a reasoned decision about medical treatment’ [380].

¹⁶² *Re T* [1993] Fam 95, 115. See also MCA 2005, s 1(4).

¹⁶³ Assisted Decision-Making (Capacity) Act 2015, s 83(2)(a)(b).

¹⁶⁴ For example, *Fosmire v Nicoleau* 75 NY 2d 218 (1990).

¹⁶⁵ Public Health Law § 2994-a section 5.

¹⁶⁶ See for example, *Re Marietta* 125 AD 3d 581 (NY 2015).

¹⁶⁷ Public Health Law § 2994-c section 1.

the patient's incapacity and the likelihood that the patient will regain decision-making capacity'.¹⁶⁸ The functional approach to capacity clearly favoured by New York, can also be seen in § 2994-c section 5; it states that a determination of incapacity cannot be interpreted to mean that the individual lacks capacity for other decisions. Decisions separate to the one for which the capacity assessment is being conducted require a confirmation of continued incapacity.¹⁶⁹

Section 6 of § 2994-c dictates that if an individual objects to the determination of incapacity, her objection should prevail unless a court has determined that the patient lacks capacity.¹⁷⁰ This is interesting, as it places a clear burden on the physician to get a declaration of incapacity, rather than exercising his judgment that the patient is incompetent and treating accordingly. Furthermore, section 6 states that should an individual disagree with the healthcare decision made on her behalf by a medical professional in accordance with § 2994-g, the decision of the individual should prevail unless a court declares her incompetent and authorises the treatment, or there exists another legal basis for overriding her decision.¹⁷¹ § 2994-g allow *inter alia* specified medical professionals¹⁷² to make routine decisions on behalf of incompetent patients where there is no surrogate decision-maker. These sections also allow major medical decisions to be made for a patient if the specified professional consults with the hospital staff involved in the patient's care and another relevant medical professional concurs that the course of action is appropriate.

Section 4 of § 2994-d dictates that medical professionals must treat the incompetent patient in accordance with her wishes, including religious and moral beliefs. Where those wishes and beliefs are not ascertainable, then the appropriate decision-making standard is 'best interests'.¹⁷³ Thus, New York and Ireland appear broadly in line on this point, with England and Wales occupying a different position, at least in theory.¹⁷⁴ While wishes and religious beliefs often form part of an evaluation of patient 'best interests' in England and Wales, it appears that if known or ascertainable, wishes and beliefs are the only pertinent factor in decision-making in New York. Interestingly, however, 'best interests' is the applicable

¹⁶⁸ Public Health Law § 2994-c sections 2 and 3. Section 3(d) dictates that where there is disagreement between the initial and concurring determiners, the case should be referred to the relevant ethics review committee

¹⁶⁹ Public Health Law § 2994-c section 7. Section 7 also requires a concurring determination of incapacity to be made where the decision pertains to life-sustaining treatment.

¹⁷⁰ Public Health Law § 2994-c section 6.

¹⁷¹ *ibid.*

¹⁷² Attending physicians or nurse practitioners.

¹⁷³ Public Health Law § 2994-d section 4.

¹⁷⁴ As discussed in relation to 'best interests' in England and Wales, there are articles that discuss the similarities between best interests and will and preference, wishes, etc.

standard in New York for healthcare decisions made by guardians on behalf of persons with long term incapacity, in other words those who never had decision-making capacity.¹⁷⁵ For previously competent individuals, an assessment of ‘best interests’ only seems relevant if the wishes and beliefs of that individual, when competent, are unclear or incapable of determination.¹⁷⁶ For what constitutes ‘best interests’ in the context of medical treatment, one can also look to § 2994-d:

An assessment of the patient’s best interests shall include: consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient’s life; the preservation, improvement or restoration of the patient’s health or functioning; the relief of the patient’s suffering; and any medical condition and such other concerns and values as a reasonable person in the patient’s circumstances would wish to consider.¹⁷⁷

Decision-Making Capacity in Pregnancy

Where capacity is concerned, one could not be faulted for thinking that the situation of pregnant women should be no different to a non-pregnant individual. In general, however, disputes as to capacity frequently arise in pregnancy, particularly in labour, as will be evidenced by the following English cases. In *Rochdale NHS v C*, Ms C wished to refuse a Caesarean section having undergone one previously.¹⁷⁸ As expressed during the emergency hearing, the view of the court was that the ‘throes of labour with all that is involved in terms of pain and emotional stress’ was sufficient to render Ms C incompetent to refuse.¹⁷⁹ Critically, this was despite the fact that her obstetrician considered her to have decision-making capacity, an opinion not contradicted by a mental health professional.¹⁸⁰ This factor is particularly noteworthy; the basis for compelled obstetric interventions is generally medical opinion, in other words, the obstetrician believes that without intervention, the foetus and / or the woman will be (fatally) harmed, or similar formulation.¹⁸¹ In this instance, the judge appears to simultaneously disregard medical opinion and enforce treatment on the basis of it. One could certainly question this rationale and indeed, as stated in *Re MB*:

¹⁷⁵ New York Surrogate’s Court Procedure Act § 1750-b section 2(a): ‘The guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the person who is intellectually disabled and, when reasonably known or ascertainable with reasonable diligence, on the person who is intellectually disabled’s wishes, including moral and religious beliefs.’

¹⁷⁶ See *Matter of Doe* 53 Misc 3d 829 (Sup Ct, King’s County 2016); in making a decision on behalf of an incompetent person, the special guardian began with trying to ascertain Ms Doe’s religious beliefs and then progressed to her values. After finding that her wishes could not be reasonably ascertained from these inquiries, the special guardian made the decision in Ms Doe’s best interests.

¹⁷⁷ Public Health Law § 2994-d section 4(ii).

¹⁷⁸ [1997] 1 FCR 274.

¹⁷⁹ *ibid* 275.

¹⁸⁰ There was no time for a mental health professional to carry out a capacity assessment.

¹⁸¹ Cases with such rationale are discussed in considerably more detail in Chapter 6. For the moment, this analysis confines itself to matters related to decision-making capacity in labour.

One may question whether there was evidence before the court which enabled the judge to come to a conclusion contrary to the opinion of the obstetrician that she was competent. Nonetheless he made the declarations sought.¹⁸²

In assessing her competence, Johnson J concluded:

[A] patient who could, in those circumstances [the pain and emotional stress associated with the throes of labour] speak in terms which seemed to accept the inevitability of her own death, was not a patient who was able properly to weigh-up the considerations (...) so as to make any valid decision.¹⁸³

A clear interpretation of this statement is that the learned judge concluded that a patient, who accepted that death may be a consequence of refusal, was not competent to refuse. Shaun Pattinson remarks that her ‘willingness to accept her own death over another caesarean was not regarded as evidence of the firmness and sincerity of her views, but of her failure to be able to weigh up the relevant considerations’.¹⁸⁴ Furthermore, Samantha Halliday argues:

If C was competent, and there was no evidence to suggest that she was not, her best interests were irrelevant and she was entitled to refuse (...) and to expect that refusal to be respected (...) There was no threat to her own life, but there was a threat to the foetus and so she was deemed to be incapable of weighing the information given to her on the basis of the reason she gave for refusing treatment (‘I’d rather die’) and because of the context in which she made the decision (during labour).¹⁸⁵

The judgment certainly seems to go against the earlier jurisprudence; Lord Donaldson states in *Re T* that the right to refuse must be respected ‘even if a refusal may risk permanent injury (...) or even lead to premature death’.¹⁸⁶ Though *Re MB* occurred after *Rochdale*, it is also worth contrasting the judgment with the statement of Butler-Sloss LJ regarding understanding the information material to the decision, namely that one must comprehend information ‘especially as to the likely consequences of having or not having the treatment in question’.¹⁸⁷ Arguably, it was a ‘no win’ situation for Ms C; her willingness to accept her death demonstrated incompetence, however, so too would any denial of or an unwillingness to accept that death was a consequence of her decision. Arguably, she was going to be found incompetent either way. Had she not accepted the consequences of her decision, she would most likely have been found incompetent on the basis that she did not understand or believe the information.¹⁸⁸ As

¹⁸² [1997] 2 FLR 426, 435.

¹⁸³ *Rochdale Healthcare (NHS) Trust v C* [1997] 1 FCR 274, 275.

¹⁸⁴ Shaun D Pattinson, *Revisiting Landmark Cases in Medical Law* (Routledge 2019) 141.

¹⁸⁵ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 50-1.

¹⁸⁶ *Re T* [1993] Fam 95, 115; Furthermore, Butler-Sloss LJ remarked during the course of her judgment in *Re MB* that ‘[o]ne may question whether there was evidence before the court which enabled the judge to come to a conclusion contrary to the opinion of the obstetrician that she was competent’.

¹⁸⁷ *Re MB* [1997] 2 FLR 426, 437. This case will be discussed in more detail in the coming paragraphs.

¹⁸⁸ *Re C* [1994] 1 WLR 290. The inclusion of the requirement to understand the consequences of the decision were added by *Re MB* [1997] 2 FLR 426, which occurred after *Rochdale*, however, it is reasonable to speculate that a court would have made a finding of incompetence where an individual refused to accept a particular consequence of a decision.

an aside, Ms C changed her mind and did consent to the Caesarean, once again calling the finding of incapacity into question.¹⁸⁹

Norfolk and Norwich Healthcare (NHS) Trust v W presents somewhat of a confusing picture.¹⁹⁰ In that case, Johnson J commented that the ‘acute emotional stress and physical pain in the ordinary course of labour’ were exacerbated by the patient’s history of psychiatric history.¹⁹¹ What is unclear, however, is whether this stress and pain rendered Ms W incompetent to refuse, or if there was another factor that eroded her capacity. This is because her incompetence is not attributed to anything in particular and certainly not labour. Perhaps a feature of an emergency hearing, but very little analysis was given to decision-making capacity; the psychiatrist opined that Ms W could not weigh up the considerations involved in the decision, however the basis for this conclusion was not explained. While the patient did deny she was pregnant despite being in labour – which could indicate incapacity in line with the *Re C* test –¹⁹² the psychiatrist could not state that her denial was due to a lack of understanding on her part. Therefore, a question remains as to what the ‘acute emotional stress and physical pain in the ordinary course of labour’ actually had to do with Ms W’s capacity. Assuming that it had nothing to do with her incompetence, then the reference in the judgment is inappropriate. If it was directly relevant to her incapacity, then it is argued that it could set quite a dangerous precedent regarding fairly routine occurrences in labour.

Even *Re T*, which is lauded as one of the strongest vindications of the right of a competent person to refuse treatment, leaves uncertainty where the competence of a pregnant woman is to be assessed. Lord Donaldson stated that capacity to refuse is a rebuttable presumption and opined an otherwise competent individual could lose capacity when encountering the ‘effects of shock, severe fatigue, pain or drugs being used in their treatment’.¹⁹³ Although the capacity of a pregnant woman has not been at issue in the Irish courts, a similar conclusion was reached by Laffoy J in *Fitzpatrick v FK*.¹⁹⁴ The learned judge included ‘the effects of fatigue, stress, pain or drugs’ in the list of temporary factors, which may affect capacity.¹⁹⁵ This position is echoed in the National Consent Policy with section 5.2 stating that individuals ‘may be able to make decisions at certain times but not at other times, because of (...) factors such as confusion, panic, shock, fatigue, pain or medication temporarily affect their ability to understand, retain

¹⁸⁹ This aspect of the case was noted in *Re MB* [1997] 2 FLR 426, 435.

¹⁹⁰ [1996] 2 FLR 613.

¹⁹¹ *ibid* 616 (emphasis added).

¹⁹² *Re C* [1994] 1 WLR 290.

¹⁹³ *Re T* [1993] Fam 95, 113.

¹⁹⁴ [2009] 2 IR 7.

¹⁹⁵ [2009] 2 IR 7, 8. This was somewhat unsurprising, as *Re T* was cited in the course of her judgment.

or weigh up information, or communicate their wishes'. Though such factors are not exclusive to labour, in that they can affect patients in a range of situations, they are very often present during in labour.

In *Re MB*, a severe needle phobia was grounds to find the woman incompetent, as it rendered her 'incapable of making a decision'.¹⁹⁶ The woman in question consented to the Caesarean section a number of times but revoked consent once it came time to administer the anaesthetic. This coupled with the fact that there was no indication that she did not want her baby to be born, or that she wished to accept the risk to her foetus of not undergoing surgery, led to the conclusion that she could not consent by virtue of being paralysed by fear. In some sense, one can distinguish this from a situation where there is a clear attempt to circumvent the will of the woman, particularly in view of the strong pronouncements made as to the right of a competent pregnant woman to refuse.¹⁹⁷ With that said, the reference by Bulter-Sloss LJ to the ability of Lord Donaldson's 'temporary factors' in *Re T* – confusion, shock, fatigue, pain or drugs – to completely erode capacity is noteworthy, despite the higher bar set by her statement that such factors must be 'operating to such a degree that the ability to decide is *absent*'.¹⁹⁸ *Re L* had a similar fact pattern, in that the woman had a severe needle phobia, which resulted in her being judged incompetent.¹⁹⁹

A curious spin on the traditional compelled treatment situation can be found in *Bolton Hospitals NHS Trust v O*.²⁰⁰ Post-traumatic stress disorder, which manifested as 'overwhelming psychological fear and anxiety' when it came time to undergo the Caesarean section was considered sufficient to find Ms O incompetent. It was accepted that she had decision-making capacity the majority of the time, however, her PTSD rendered her incompetent at the crucial moment. What is certainly noteworthy about *Bolton* is that Ms O did not oppose the order, rather it appeared that she was in favour of it. What Ms O almost appeared to seek was a kind of advance *consent* to treatment, which, like any other advance decision, would apply when she lost capacity in the future, irrespective of any behaviour on her part that could be considered contrary to it.²⁰¹

¹⁹⁶ [1997] 2 FLR 426, 438.

¹⁹⁷ *ibid* 436: 'A competent woman who has the capacity to decide may, for religious reasons, other reasons, for rational or irrational reasons or for no reason at all, choose not to have medical intervention, even though the consequence may be the death or serious handicap of the child she bears, or her own death.'

¹⁹⁸ [1997] 2 FLR 426, 437.

¹⁹⁹ *Re L (Patient: non-consensual treatment)* [1997] 2 FLR 837.

²⁰⁰ [2003] 1 FLR 824.

²⁰¹ This case is pre-MCA 2005, but such a legal construct still does not exist in English law, as will become apparent in Chapter 5 when advance decisions are discussed. See for example *R (Burke) v The General Medical Council and Others* [2004] EWHC 1879, wherein the claimant sought to make an advance request that treatment – in the form of artificial hydration and nutrition – to be continued once he lost the ability to communicate. The Court of Appeal declined to make such a binding order. With that said, advance consent or the expression of

Perhaps Murray sums up the difficulty with the current law best:

The pain of labour is very real, but not necessarily incapacitating. Women in labour are both powerful and vulnerable. Because pregnancy and labour occupy a space like no other, when we consider the pregnant woman in labour, she may not always sit clearly within one or other side of the binaries which underpin the legal framework for consent (...) [B]ecause we are familiar with the existing binary model of consent it is difficult to concede that pain or pressure might have an impact on decision-making because to do so *feels like* defeat and *appears to be* accepting that pregnant women in labour are less autonomous than other subjects.²⁰²

Thus, the challenge going forward for women is that precedent dictates that their competence may be called into question because of some very routine occurrences within labour, such as stress or pain. This is despite the strong pronouncement from Lady Hale in *Montgomery* that '[g]one are the days when it was thought that, on becoming pregnant, a woman lost, not only her capacity, but also her right to act as a genuinely autonomous human being'.²⁰³ Either way, questions as to capacity are unlikely to arise in practice unless the woman wishes to go against medical advice and refuse intervention, irrespective of whether she has a general right to refuse in pregnancy. In New York, the additional persistence of the equation of 'rational' or 'reasoned' with competence could indicate that the capacity of a woman refusing intervention in labour may be doubted by the courts. Perhaps then, the best way to ensure that a firm refusal will be honoured in labour is to have an advance directive to that effect; as will be discussed in Chapter 6, however, that may not be as straight forward as it appears.²⁰⁴

Information Disclosure

As was stated early in the introduction, in order for consent to or refusal to be valid it must be voluntarily given by a person with capacity after her or she has been informed as to what the treatment involves. At the outset, it may seem unusual to dedicate time to discussing information disclosure in a thesis primarily focused on advance refusals, however, the rules surrounding informed consent are important in this context. Primarily, this is because in Chapter 5, some of the arguments against advance directives are that individuals are

wishes in advance are often considered as part of a best interests assessment by the court. A recent Court of Protection judgment pertained to a man suffering from emotionally unstable personality disorder and end-stage kidney failure who appeared before the court when competent to request restraint, general anaesthetic and the administration of treatment when he loses capacity. While competent he wishes to accept treatment, however, while incompetent he rejects it and the only way to administer it is to restrain and anaesthetise him, presenting serious risks to his life. See Celia Kitzinger, 'Advance Requests for Restraint and Compulsory Treatment' (*Open Justice: Court of Protection Project*, 28 September 2020) <<https://openjusticecourtofprotection.org/2020/09/28/advance-requests-for-restraint-and-compulsory-treatment/#comments>> accessed 28 September 2020.

²⁰² Claire Murray, 'Troubling Consent: Pain and Pressure in Labour and Childbirth' in Camilla Pickles and Jonathan Herring (eds) *Childbirth, Vulnerability and Law: Exploring Issues of Violence and Control* (Routledge 2019) 161-2.

²⁰³ [2016] 1 LRC 350, 383.

²⁰⁴ See also Claire Murray's suggestion of 'Stretching the Temporal Context' as a means of making consent 'meaningful' for women in labour - Claire Murray, 'Troubling Consent: Pain and Pressure in Labour and Childbirth' in Camilla Pickles and Jonathan Herring (eds) *Childbirth, Vulnerability and Law: Exploring Issues of Violence and Control* (Routledge 2019) 168-70.

insufficiently informed when drafting them, meaning they acquire a ‘lower’ standard than contemporaneous refusal. This argument will be challenged at that point, however, before doing so, it is necessary to understand how the law operates in relation to information disclosure. What constitutes ‘informed’ for the purpose of giving or refusing consent to medical treatment is certainly a matter of debate. The Honourable Mr Justice Kirby, writing extrajudicially, provided an astute explanation:

An informed consent is that consent which is obtained after the patient has been adequately instructed about the ratio of risk and benefit involved in the procedure as compared to alternative procedures or no treatment at all.²⁰⁵

Even this explanation still leaves questions, primarily as to the meaning of ‘adequate’. As will be evident from this chapter, there have been challenges in answering this very question in Ireland and elsewhere. Despite these challenges, what does not appear to vary within or between the chosen jurisdictions is the extent of the requirement to provide information in pregnancy. In other words, there is no indication that a physician has less of a duty to disclose information in pregnancy than at any other time.

Before progressing to the law on information disclosure in Ireland, it is worth making a note on summary judgments, which are often the type of judgments in jurisprudence from New York. Such judgments result in the defendant having ‘the initial burden of establishing that he or she did not depart from good and accepted practice, or if there was such a departure, that it was not a proximate cause of the plaintiff’s injuries’ as distinct from the plaintiff bearing the burden of proof in a typical trial.²⁰⁶ These judgments often merely require that the plaintiff has a *prima facie* case, thus the defendant will not discharge his burden unless he demonstrates that he did not depart from accepted practice. Anything less will have the effect of a summary judgment denied to the defendant or in favour of the plaintiff.²⁰⁷ The effect of this is that the analysis coming from New York does not appear to be quite as detailed as that found in the cases coming from Ireland and England and Wales; naturally, if summary judgment is granted in favour of the plaintiff, settling rather than going to full trial would be preferable for the defendant. If granted in favour of the defendant, it may be preferable for the plaintiff not to pursue the action.

Ireland

²⁰⁵ Michael D Kirby, ‘Informed consent: what does it mean?’ (1983) 9 J Med Ethics 69.

²⁰⁶ *Dyckes v Stabile* 153 AD 3d 783 (NY 2017) 784.

²⁰⁷ This includes where conflicting evidence is produced as to whether the defendant(s) adhered to good or accepted practice. See *Feinberg v Feit* 23 AD 3d 517 (2005); *Kovacic v Griffin* 170 AD 3d 1143 (2019).

In order to accurately trace the approach of the Irish courts to establishing the standard of care applicable to risk disclosure, one must start with examining the standard of care in cases of general medical negligence. The seminal Irish case in this regard is *Dunne v National Maternity Hospital*, wherein the Supreme Court favoured the ‘professional standard’.²⁰⁸ In his judgment, Finlay CJ applied *O’Donovan v Cork County Council*²⁰⁹ and *Daniels v Heskin*²¹⁰ holding:

The true test for establishing negligence (...) on the part of a medical practitioner is whether he has been proved to be guilty of such failure as no medical practitioner of equal specialist or general status and skill would be guilty of if acting with ordinary care. If the allegation of negligence (...) is based on proof that he deviated from a general and approved practice, that will not establish negligence unless it is also proved that the course he did take was one which no medical practitioner of like specialisation and skill would have followed (...)²¹¹

He further clarified that ‘an honest difference of opinion between doctors as to which is the better of two ways of treating a patient’ does not satisfy the criteria for negligence, thus the act of choosing the option that led to the unfortunate consequence alone, does make the medical practitioner negligent.²¹² It is worth noting however, that the learned judge stopped short of applying the *Bolam* test completely.²¹³ He opined:

If a medical practitioner charged with negligence defends his conduct by establishing that he followed a practice which was general, and which was approved of by his colleagues of similar specialisation and skill, he cannot escape liability if in reply the plaintiff establishes that such practice has inherent defects which ought to be obvious to any person giving the matter due consideration.²¹⁴

Thus, while a high burden of proof lies with the plaintiff, the Supreme Court was of the opinion that the required standard would not be met by the practitioner if he employed a practice, which would be considered patently defective on reflection.²¹⁵ Accordingly, it can be seen that the standard of care for general negligence in Ireland is the ‘professional standard’ – also known as the ‘reasonable doctor’ test – and the plaintiff, in order to succeed in an action, must demonstrate that the defendant, by action or inaction, either failed to adhere to generally

²⁰⁸ *Dunne v National Maternity Hospital* [1989] IR 91.

²⁰⁹ *O’Donovan v Cork County Council* [1967] IR 173.

²¹⁰ *Daniels v Heskin* [1954] IR 73.

²¹¹ *Dunne v National Maternity Hospital* [1989] IR 91, 109.

²¹² *ibid.*

²¹³ The *Bolam* test will be discussed in more detail in the section pertaining to England and Wales. For the current purposes, it can be summarised as whether or not the (in)action of the medical professional is in line with the standard established by a responsible body of medical opinion, in other words, a profession led standard.

²¹⁴ *Dunne v National Maternity Hospital* [1989] IR 91, 109.

²¹⁵ *Dunne* has been upheld in a number of cases including *Wolfe v St. James’s Hospital* [2002] IESC 10, *Warnock v National Maternity Hospital* [2010] IEHC 25, *Pyne & Anor v Western Health Board & Anor* [2005] IEHC 415; *Shuit v Mylotte* [2006] IEHC 89 and more recently, in *Morrissey v Health Service Executive* [2020] IESC 6.

accepted practice, or that the generally accepted practice within the medical community to which he adhered, is so flawed as to be obvious, were it given sufficient thought.

It was not always clear how the Irish courts approached the standard of disclosure, that is, the information that must be given by the medical professional in order to ensure valid consent. There is a limited amount of early case law in Ireland which addressed the issue of risk disclosure; the 1954 Supreme Court decision in *Daniels v Heskin* considered whether the defendant owed a duty to disclose to a plaintiff that a broken part of a needle had been left in her body during stitching after childbirth.²¹⁶ In this instance, the majority of the court found that there was no duty to disclose, however, as Deirdre Madden notes, the judgment is of ‘limited value’ and was rarely referred to by the courts in subsequent cases.²¹⁷ In any event, one could opine that this matter would be decided quite differently over 60 years on for a variety of reasons, most notably the advancement of the rights of women and patients in Ireland.²¹⁸

The first case in Ireland to give any real consideration to the question of ‘how much is enough’ in the context of risk disclosure, was that of *Walsh v Family Planning Services*.²¹⁹ The plaintiff elected to have a vasectomy for contraceptive purposes and encountered a number of post-operative issues, including severe pain and impotence, eventually culminating in the removal of one of his testicles. He subsequently brought an action against the defendants for negligence and assault. Although the Supreme Court found in favour of the defendants by a margin of 3:2, there was considerable disagreement amongst the judges as to the appropriate standard of care and whether it had been reached in this instance. Finlay CJ endorsed the professional standard approach applied in *Dunne*:

I am satisfied (...) that the standard of care to be exercised by a medical practitioner in the giving of the warning of the consequences of proposed surgical procedures is not in principle any different from the standard of care to be exercised by medical practitioners in the giving of treatment or advice, and that there are not good grounds for suggesting that the issue of negligence arising under this heading is outside the general principles which have been enunciated by this Court (...)²²⁰

²¹⁶ *Daniels v Heskin* [1954] IR 73.

²¹⁷ Deirdre Madden, *Medicine, Ethics and the Law* (3rd edn, Bloomsbury Professional 2016) 462; she argues that the judgment by Lavery J that there is a duty to disclose risks where a ‘dangerous operation’ is concerned isn’t particularly useful as there is no clarity as to what a ‘dangerous operation’ means. It is worth noting however, that the dissenting judgment of Maguire CJ and the judgments of Lavery J and Kingsmill Moore J in *Daniels v Heskin* are referred to by McCarthy J in *Walsh v Family Planning Services* [1992] 1 IR 496.

²¹⁸ In light of the ‘Cervical Check controversy’ in 2018, for example, questions still persist as to whether there is full commitment within the Health Service Executive to making disclosures to patients. The ‘Cervical Check controversy’ refers to the failure of the Health Service Executive to inform women who had been diagnosed with cervical cancer of the findings of an audit, which revealed that the women had received incorrect results of earlier smear tests. See also *Morrissey v Health Service Executive* [2020] IESC 6 and the CervicalCheck Tribunal Act 2019.

²¹⁹ *Walsh v Family Planning Services* [1992] 1 IR 496.

²²⁰ *ibid* 510.

With that said, the learned judge did note that the standard of disclosure related to an elective procedure may be higher than the standard for a necessary one.²²¹ Although McCarthy J refers to a ‘prudent medical doctor’ during his judgment, he adopts a patient-centred approach:

In determining whether or not to have an operation (...) it seems to me that to supply the patient with the material facts is so obviously necessary to an informed choice on the part of the patient that no reasonably prudent medical doctor would fail to make it (...) This is not a question of merely determining that a particular outcome is so rare as not to warrant such disclosure that might upset a patient but, rather, that those concerned (...) if they knew of such a risk, however remote, had a duty to inform those so critically concerned with that risk (...) In my view it is inescapable that the defendants...were in breach of their duty to the plaintiff (...) for failing to identify the risk of impotence (...)²²²

O’Flaherty J, endorsing the approach taken by the Supreme Court of Canada and remarking on the elective nature of the procedure in question, stated:

[W]here there is a question of elective surgery (...), if there is a risk – however exceptional or remote – of grave consequences involving severe pain stretching for an appreciable time into the future and involving the possibility of further operative procedures, the exercise of the duty of care owed by the defendants requires that such possible consequences should be explained in the clearest language to the plaintiff.²²³

Although lack of clarity as to the appropriate approach to information disclosure endured post-*Walsh*, there was general agreement that there existed a requirement on a medical practitioner to give a warning of any material risk of a ‘known complication’ of a procedure.

It is worth noting that an attribution of a higher standard of disclosure to elective procedures is not without criticism. Margaret Brazier argues that distinguishing between therapeutic and non-therapeutic procedures, however ‘well-intentioned and designed to promote patient autonomy, is fraught with difficulty and uncertainty’.²²⁴ She further opines:

Female sterilisation is itself a prime example of where drawing the line will be nigh on impossible in many cases. If a woman of 37 requests sterilisation after giving birth without complications to two healthy babies, will surgery on her be classified as therapeutic because of the increasing risk to mother and baby of pregnancy at that age (...) [or] (...) a convenient means of contraception and so non-therapeutic? Will the test be whether the initiative comes from the woman wanting no more children or the doctor judging that she should have no more children?²²⁵

²²¹ *ibid* 511.

²²² *ibid* 521.

²²³ *ibid* 535.

²²⁴ Margaret Brazier, ‘Patient Autonomy and Consent to Treatment: The Role of the Law?’ (1987) 7 *LS* 169, 183.

²²⁵ *ibid*.

Arguably, there are many procedures which could qualify as elective or non-elective, depending on the circumstances of the patient in question. Rhinoplasty is most commonly known as a cosmetic surgery procedure, however, it is also an appropriate surgical treatment for certain conditions such as vestibular stenosis.²²⁶ Amongst other symptoms, this condition often affects the appearance of the nose, thus there may be both medical and cosmetic reasons for the choice. In that instance, consideration of the patient's motivation for having the treatment would be required in order to ascertain if the lower or higher standard of disclosure was required.²²⁷ It could certainly be suggested that the imposition of a requirement on physicians to thoroughly examine the motives of patient prior to treatment would constitute an undue burden, or at the least be considered somewhat arduous.

It is also interesting to note the discrepancy within Irish law as to the meaning of 'elective'. In *Walsh*, O'Flaherty J considered an elective procedure to be one which was 'not essential to health or bodily well-being'. McCarthy J, however, defined it as:

All surgery, in a sense, is elective although the election may have to be implied from the circumstances rather than determined as express. The gravely wounded, the gravely ill may be unconscious but in urgent need of surgery. A patient's condition may be such as to demand surgical intervention as the only hope for survival. Such may be called non-elective surgery. The patient given the choice between enduring pain and having limb replacement surgery or fusion surgery may technically be electing as between the pain and the surgery but the election may be more apparent than real. An extreme of elective surgery would be what is purely cosmetic - simply to improve the natural appearance rather than to remedy the physical results of injury or disease.²²⁸

In *Bolton v Blackrock Clinic & Others*, Hamilton CJ considered the treatment at the centre of the case to be elective 'in the sense that it was a matter for the Appellant to decide whether or not she would undergo such an operation and to give or withhold her consent thereto'.²²⁹ Such an understanding of elective seems to mean that any treatment to which an individual freely consents is elective, even if that treatment is necessary for health or well-being. Arguably, this could suggest that anything other than emergency treatment is elective. Perhaps, it is worth stating that the lack of agreement as to what constitutes 'elective' lends further weight to the

²²⁶ Vestibular stenosis is where the nasal valve has collapsed. It can be caused by trauma or infection and is sometimes seen in patients with cleft palate deformities. Rhinoplasty may also be an appropriate treatment for patients suffering from excessive snoring and recurring sinus infections.

²²⁷ If the primary desire of the patient suffering from nasal collapse is to improve the aesthetics of the nose, it would be difficult for a physician to argue that the treatment was anything but elective, however, if the primary goal of the treatment is to alleviate the symptoms and known complications of the condition – rendering any aesthetic improvement an ancillary bonus – then the treatment may be considered non-elective, thereby incurring a lower standard of disclosure requirement.

²²⁸ *Walsh v Family Planning Services* [1992] IR 496, 517.

²²⁹ (SC, 23 January 1997) 4.

criticism of the law distinguishing between it and essential treatment for the purposes of determining the relevant standard of care.²³⁰

The uncertainty regarding the standard of disclosure required to produce informed consent continued for the best part of a decade, with the cases of *Farrell v Varian*²³¹ and *Bolton*.²³² The question of the appropriate standard of disclosure was laid to rest in *Geoghegan v Harris*, wherein Kearns J sharply departed from the professional standard.²³³ In applying the decision in *Walsh*, he held that there was an obligation to warn the patient of the remote risk of neuropathic pain, despite the fact that the medical experts were of the opinion that no warning was necessary.²³⁴ In advocating for the reasonable patient test, the learned judge stated:

This approach, at the other end of the spectrum, concentrates on the patient's right to determine what is to be done to his body. It requires full disclosure of all material risks incident to the proposed treatment, so that the patient, thus informed, rather than the doctor, makes the real choice as to whether treatment is to be carried out.²³⁵

It could perhaps be discerned from this judgment that the self-determination of the patient and her right to bodily integrity rest on her knowledge of all material risks. Without those, her interests are compromised. The learned judge further expands his judgment to profess that the appropriate test to assess if the standard of disclosure has been met is the reasonable patient test:

The application of the reasonable patient test seems more logical in respect of disclosure. This would establish the proposition that (...) the patient has the right to know and the practitioner a duty to advise of all material risks associated with a proposed form of treatment (...) 'Materiality' includes consideration of both (a) the severity of the consequences and (b) statistical frequency of the risk (...) Each case it seems to me should be considered in the light of its own particular facts, evidence and circumstances to see if the reasonable patient in the Plaintiff's position would have required a warning of the particular risk.²³⁶

The departure of the Irish Courts from the 'professional standard' approach was stated more vehemently by Kearns J in the case of *Fitzpatrick v White*:

²³⁰ In this case, the surgery in question was a sleeve resection, which was suggested to treat an obstruction in Mrs Bolton's left bronchus.

²³¹ *Farrell v Varian* (1995) MLJI 29: Curiously, this seemed to uphold the judgment in the English case of *Sidaway v Board of Governors of Bethlem Royal Hospital*. At 51: 'I agree with the view expressed by the House of Lords in the *Sidaway* case that "the decision what degree of disclosure of risks is best calculated to assist a particular patient to make a rational choice as to whether or not to undergo a particular treatment must primarily be a matter of clinical judgment", although (...) a case might arise where a judge could conclude that disclosure of a particular risk was so obviously necessary to an informed choice (...) that no reasonably prudent medical man would fail to make it'.

²³² In *Bolton v the Blackrock Clinic, Wood & Cumiskey* (SC, 23 January 1997), the approach in *Walsh* advanced by Finlay CJ, namely a professional standard tempered by the obvious defects exception, was found to be the correct one.

²³³ *Geoghegan v Harris* [2000] 3 IR 536.

²³⁴ *ibid.*

²³⁵ *ibid* 539-540.

²³⁶ *ibid* 549.

I am thus fortified to express, in rather more vigorous terms than I did in *Geoghegan v. Harris* (...) my view that the patient centred test is preferable, and ultimately more satisfactory from the point of view of both doctor and patient alike, than any ‘doctor centred’ approach favoured by part of this Court in *Walsh v. Family Planning Services*.²³⁷

In assessing the materiality, the Court was of the opinion that ‘a risk may be seen as material if, in the circumstances (...) a reasonable person in the patient’s position, if warned of the risk, would be likely to attach significance to it’.²³⁸ The question of the ‘validity’ of the risk disclosure arose due to the somewhat unusual progression of this case; in the High Court, the plaintiff claimed that he had not been warned of the material risk arising from eye surgery muscle slippage causing diplopia – and made his unsuccessful negligence claim on that basis. In the Supreme Court, the plaintiff accepted that he had been warned of the risk but argued that the timing of the warning rendered it invalid. This contention was based on the undisputed fact that the conversation between the plaintiff and his surgeon took place a mere 30 minutes before he was due to undergo surgery. Kearns J rejected the argument that the warning was invalid on the basis that there was no clear evidence that the plaintiff was actually disadvantaged by the lateness of the warning.²³⁹

Therefore, the current law in Ireland is that information disclosure is to be approached from the perspective of the reasonable patient. As with any action in negligence, however, the plaintiff must also prove that had she known of the risk, she would not have undergone treatment, in other words causation. In order to be successful, the medical practitioner must fail to advise the plaintiff of a material risk associated with a proposed treatment and that risk must materialise. With that said, the National Consent Policy appears to endorse a more subjective approach to information disclosure. For example, according to the NPC, the volume of information that a patient will want and require varies ‘depending on their individual circumstances’; thus, discussions should be tailored insofar as possible according to ‘[t]heir needs, wishes and priorities, [t]heir level of knowledge about, and understanding of, their condition, prognosis and the treatment options, [t]heir ability to understand the information

²³⁷ *Fitzpatrick v White* [2008] 3 IR 551, 563.

²³⁸ *ibid* 564. See also National Consent Policy, s 3.3: ‘A general rule is to provide information that a reasonable person in the service user’s situation would expect to be told... Such information includes the likelihood of: side effects or complications of an intervention; failure of an intervention to achieve the desired aim; and the risks associated with taking no action or with taking an alternative approach’.

²³⁹ [2008] 3 IR 551, 564; With that said, the judge did note the undesirability of warnings issued ‘late in the day’ and cautioned that a late disclosure of risk could very well constitute an invalid warning in the case of a different patient. For further discussion, see Eoin Quill, ‘Ireland’, in Helmut Koziol and Barbara C Steininger (eds) *European Tort Law 2007* (Springer 2008) 15–17. Applied in *Buckley v O’Herlihy & the National Maternity Hospital* [2010] IEHC 51, 143-55 and *Healy v Buckley* [2010] IEHC 191, paras 4.1-4.22. See also the National Consent Policy, s 7: The provision of information and the seeking and giving of consent ‘should not be a once-off, sometimes “eleventh hour” event, exemplified by getting a hurried signature on a consent form’.

provided/language used and [t]he nature of their condition'.²⁴⁰ Furthermore, the 'amount of information about risk that staff should share (...) will depend on the individual (...) and what they want or need to know'.²⁴¹ Therefore, 'common, even if minor, side effects should be disclosed as should rare but serious adverse outcomes'.²⁴²

Again, this appears to advocate for a more subjective approach towards information disclosure. Thus, it will be interesting to see how the apparently more onerous requirements contained in the NPC affect future court judgments on information disclosure, particularly in view of the recent legal shift in England and Wales, which will be discussed in the next section. The Medical Council also provides an extensive list of information that a patient may want or 'should know' before they make a decision regarding a particular treatment.²⁴³ Interestingly, aside from fairly typical information such as the diagnosis and prognosis and treatment options, this list also includes 'details of the procedures or therapies involved, including methods of pain relief', 'any lifestyle changes which may be caused or required by the treatment for each option' and 'a reminder that patients can change their minds (...) at any time'.²⁴⁴

While there is no case that considers information disclosure specific to pregnancy, one can again look to the NPC for guidance on that particular issue. Should such a case arise, one can reasonably assume that a court would consider it to be quite persuasive. Section 3.5 provides that pregnant patients must receive 'sufficient information in a manner that is comprehensible to them about the nature, purpose, benefits and risks of an intervention or lack thereof on their health and life'. It also states:

Service users who are pregnant will need to receive sufficient information about the benefits and risks of an intervention or lack thereof on the viability and health of a foetus (...) They will also need sufficient information on the benefits and risks of an intervention or failure to intervene on the viability and health of the child that will be delivered.²⁴⁵

Thus, no lower standard of information disclosure is warranted where the patient is pregnant. By contrast, when read in conjunction with the previous sections, there are additional requirements where the patient is pregnant. Not only must she receive sufficient information

²⁴⁰ National Consent Policy, s 3.1.

²⁴¹ National Consent Policy, s 3.3.

²⁴² *ibid.*

²⁴³ Medical Council 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners (Amended)' (2019) 50 <<https://www.medicalcouncil.ie/news-and-publications/reports/guide-to-professional-conduct-and-ethics-8th-edition-2016-.pdf>> accessed on 6 August 2020.

²⁴⁴ *ibid.*

²⁴⁵ National Consent Policy, s 3.5.

relating to the risks and benefits of the various interventions and of no intervention as they relate to her health but also as they relate to the foetus and the child, if born.

England and Wales

The approach of our ‘nearest neighbour’ to the standard of disclosure has been more complex and meandering than Ireland’s. The first English case of real significance in this area was that of *Bolam v Friern Hospital Management Committee*.²⁴⁶ In this case, the plaintiff was being voluntarily treated for depression and when undergoing electro-convulsive therapy (ECT)²⁴⁷ without a muscle relaxant, suffered a fractured pelvis amongst other injuries. Mr Bolam alleged *inter alia* that the hospital was negligent in not properly informing him of the risks of the treatment.²⁴⁸ In directing the jury, McNair J stated that the issue before them was to consider if the practice employed by the doctor of ‘saying very little and waiting for questions from the patient’ had fallen below ‘a proper standard of competent professional opinion on this question of whether or not it is right to warn’.²⁴⁹ Thus, the *Bolam* test was born.

Almost 30 years later, the House of Lords considered the relevance of the *Bolam* test in the case of *Sidaway v Board of Governors of Bethlem Royal Hospital*, which solely assessed the standard of risk disclosure for informed consent.²⁵⁰ A known risk of the surgery estimated to be at 1% materialised and Mrs Sidaway was left severely disabled. The majority of the bench held that a modified *Bolam* test was appropriate for risk disclosure cases, however, there was a complete lack of clarity as to how the test should be formulated. For example, Lord Bridge advocated for a seemingly modified *Bolam* test; this dictated that disclosure was predominantly a matter of clinical judgment, but in certain circumstances the courts may decide that a risk should have been disclosed, despite a body of responsible medical opinion indicating otherwise.²⁵¹ He opined that where there was a ‘substantial risk of grave adverse consequences’, the court may find that a doctor owed a duty to disclose.²⁵² Lord Templeman was of the view that a doctor should make a patient aware of dangers which are ‘special in kind

²⁴⁶ *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

²⁴⁷ ECT is the passing of small electric currents through the brain to intentionally trigger a brief seizure, while the patient is under general anaesthetic. It is thought that ECT causes changes in brain chemistry, which can reverse the symptoms of certain mental illnesses.

²⁴⁸ He also contended that the hospital has been negligent in not administering muscle relaxants and for failing to restrain him.

²⁴⁹ [1957] 1 WLR 582, 590.

²⁵⁰ *Sidaway v Board of Governors of Bethlem Royal Hospital* [1985] 1 All ER 643.

²⁵¹ [1985] 1 All ER 643, 663: ‘[E]ven in a case where (...) no expert witness in the relevant medical field condemns the non-disclosure as being in conflict with accepted and responsible medical practice, I am of opinion that the judge might (...) come to the conclusion that disclosure of a particular risk was so obviously necessary to an informed choice on the part of the patient that no reasonably prudent medical man would fail to make it.’

²⁵² He cited a 10% risk of stroke, as was the case in the Canadian case of *Reibl v Hughes* (1980) 114 DLR (3d) 1. One could view the choice of case by the learned Law Lord as somewhat ironic, given that the Supreme Court of Canada in *Reibl* endorsed the reasonable patient test.

or magnitude or special to the patient'. As a consequence of the lack of clarity, the judgment garnered widespread criticism and has been described by Rachael Mulheron as 'possibly the most confusing and unsatisfactory House of Lords decision in recent history'.²⁵³ Subsequent cases did little to clarify matters; the Court of Appeal in the case of *Gold v Haringey Health Authority* applied the *Bolam* test, as it was of the view that the Court in *Sidaway* had done the same.²⁵⁴ Furthermore, the distinction between elective and non-elective procedures was held to be incorrect and that the principle laid down in *Bolam* was the correct interpretation of the law.

Arguably, cases in the late 1990s and early 2000s, such as *Bolitho*, *Pearce* and *Wyatt*, demonstrated a slow shift away from the classic paternalistic approach, a sort of gradual encroachment on the professional standard.²⁵⁵ *Bolitho*, though concerning general negligence as opposed to informed consent, established that the action of a medical professional must also be logically supportable in addition to being accepted practice.²⁵⁶ Though the Irish case of *Dunne* was not referenced in *Bolitho*, Lord Brown-Wilkinson appeared to approach his judgment in a similar fashion to Chief Justice Finlay, in that the court reserves the right to find that a medical professional has breached the standard of care in circumstances where the generally accepted practice fails to stand up to logical scrutiny.²⁵⁷ The judgment in *Pearce* exhibits somewhat of a contradiction; on the one hand Lord Woolf refers to a 'significant risk which would affect the judgement of a reasonable patient', implying that the significance of a risk should be assessed from the perspective of the reasonable patient.²⁵⁸ Later in the judgment, however, Lord Woolf defers to the opinion of the medical community as to the significance of the particular risk, in this case, stillbirth.²⁵⁹ As Jackson points out, however, given the trauma associated with a stillbirth, it is fair to say that many women in Ms Pearce's situation would

²⁵³ Rachael Mulheron, 'Has Montgomery Administered the Last Rites to Therapeutic Privilege? A Diagnosis and a Prognosis' (2017) 70 CLR 149, 150. For other critiques, see Margaret Brazier 'Patient Autonomy and Consent to Treatment: The Role of the Law' (1987) 7 LS 169. See also Emily Jackson, *Medical Law: Text, Cases and Materials* (3rd edn OUP 2013) 179.

²⁵⁴ *Gold v Haringey Health Authority* [1988] QB 481.

²⁵⁵ *Bolitho v City and Hackney Health Authority* [1997] 4 All ER 771; *Pearce v United Bristol Healthcare NHS Trust* [1998] 48 BMLR 118; *Wyatt v Curtis* [2003] EWCA Civ 1779.

²⁵⁶ *Bolitho v City and Hackney Health Authority* [1997] 4 All ER 771, 779: '[I]f, in a rare case, it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold that the body of opinion is not reasonable or responsible. I emphasise that, in my view, it will very seldom be right for a judge to reach the conclusion that views genuinely held by a competent medical expert are unreasonable'.

²⁵⁷ *ibid*: 'In the vast majority of cases the fact that distinguished experts (...) are of a particular opinion will demonstrate the reasonableness of that opinion. But if (...) it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold that the body of opinion is not reasonable or responsible'. It is worth noting, however, that the learned judge opined that such a finding would be a seldom occurrence.

²⁵⁸ *Pearce v United Bristol Healthcare NHS Trust* [1998] 48 BMLR 118, 124.

²⁵⁹ *ibid* 125. Rachael Mulheron also argues given that 'the obstetrician was entitled to take account of the effect that disclosure might have on "the state of the patient at the particular time, both from the physical point of view and an emotional point of view"', Lord Woolf clearly applied therapeutic privilege in the case, 'although not by that name'. Rachael Mulheron, 'Has Montgomery Administered the Last Rites to Therapeutic Privilege? A Diagnosis and a Prognosis' (2017) 70 CLR 149, 159.

have wanted to be informed of such a risk and would likely attach significance to it.²⁶⁰ The view of Lord Sedley in the Court of Appeal judgment in *Wyatt* was that the opinion of the patient as to the seriousness of a risk was relevant, thus an assessment of the gravity of a risk should be from that standpoint.²⁶¹ It is unsurprising, therefore, that there was considerable ambiguity as to whether a particular risk would be assessed from the perspective of the patient or the doctor in a given case, with later cases doing little to clarify that matter.²⁶²

Montgomery v Lanarkshire Health Board settled the near 40 year old question of whom, doctor or patient, should assess the significance of a particular risk, the court finding the latter to be the appropriate judge.²⁶³ As *Montgomery* concerned the failure of an obstetrician to inform Mrs Montgomery of the risk of her baby having shoulder dystocia²⁶⁴ – a condition suffered by 9-10% of babies whose mothers suffer from diabetes – the case highlighted the issue of information disclosure through the lens of pregnancy and labour. If present, the condition carries numerous risks to the baby, including a broken shoulder, an avulsion of the brachial plexus,²⁶⁵ cerebral palsy and death, with the latter two arising from the umbilical cord becoming trapped against the pelvis causing the baby to suffer from prolonged hypoxia. Naturally, it also poses risks to the woman. Mrs Montgomery argued *inter alia* that, as an insulin dependent diabetic of small stature who had expressed concern about her ability to deliver vaginally, she should have been advised of the risk of her baby having shoulder dystocia and presented with the alternative, namely Caesarean section. Both the Outer House and the Inner House of the Court of Session in Scotland found in favour of the defender, finding that Dr McLellan – and consequently the Lanarkshire Health Board – owed no duty to disclose the particular risk to the pursuer. Mrs Montgomery appealed the decision to the Supreme Court of the United Kingdom – meaning the judgment applies in both Scotland and England and Wales – where her claim was upheld. Lord Kerr and Lord Reed rejected the majority view in *Sidaway* opining:

²⁶⁰ Emily Jackson, *Medical Law: Text, Cases and Materials* (4th edn, OUP 2013) 205.

²⁶¹ *Wyatt v Curtis* [2003] EWCA Civ 1779, para 16: '[W]hat is substantial (...) and grave are questions on which the doctor's and the patient's perception may differ, and in relation to which the doctor must therefore have regard to what may be the patient's perception'. The learned judge contended: 'To the doctor, a chance in a hundred that the patient's chickenpox may produce an abnormality in the foetus may well be an insubstantial chance (...) To the patient, a new risk which (...) enhances the background risk of a potentially catastrophic abnormality may well be both substantial and grave, or at least sufficiently real for her to want to make an informed decision about it.'

²⁶² *Chester v Afshar* [2005] 1 AC 134, 144: While Lord Steyn states that a patient has the right to be made aware of 'a small, but well-established risk' of a procedure, it is unclear who should be assessing its seriousness.

²⁶³ *Montgomery v Lanarkshire Health Board* [2016] 1 LRC 350.

²⁶⁴ Shoulder dystocia is a mechanical problem or obstruction experienced during vaginal delivery. Most commonly, it is where the anterior shoulder of the baby cannot pass below the pubic symphysis after the head has passed through. It is often caused by a large concentration of the weight of the baby on its shoulders, though the estimated size / weight of the baby is not thought to be a good predictor of the condition.

²⁶⁵ An injury resulting in the nerve root of the arm being torn from the spinal cord.

[T]he analysis of the law by the majority in *Sidaway* is unsatisfactory, in so far as it treated the doctor's duty to advise her patient of the risks of proposed treatment as falling within the scope of the *Bolam* test, subject to two qualifications of that general principle, neither of which is fundamentally consistent with that test.²⁶⁶

While arguably a considerable shift from a legal standpoint, some commentators argue that *Montgomery* merely cemented a position that had been adopted in practice for some time.²⁶⁷ Mark Campbell observes that the hesitance of the lower courts to continue applying *Bolam* to cases concerning information disclosure combined with the reasonable patient test being utilised in the majority of common law countries made the decision in *Montgomery* an almost *fait accompli*.²⁶⁸ In further distancing itself from the judgment in *Sidaway*, the Court remarked that it was 'unsurprising that courts have found difficulty in the subsequent application of *Sidaway*, and that the courts (...) have in reality departed from it'.²⁶⁹ In fully endorsing patient-centred standard, they stated:

An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment (...) The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved (...) and of any reasonable alternative or variant treatments. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.²⁷⁰

In rejecting the approach taken by the Court of Session, the Supreme Court found that the focus on the relatively small risk that the baby might suffer a grave injury, as distinct from the substantial risk of shoulder dystocia from which the more serious consequences flowed, was incorrect. In applying the 'new' standard to the facts before them, the judges were of the view that the exercise of reasonable care undoubtedly required that the risk of shoulder dystocia be disclosed:

[A]part from the risk of injury to the baby (...) it is apparent (...) that shoulder dystocia is itself a major obstetric emergency, requiring procedures which may be traumatic for the mother, and involving significant risks to her health. No woman would, for example, be likely to face the possibility of a fourth degree tear (...) or a symphysiotomy with equanimity. The contrast of the risk involved in an elective caesarean section, for the mother extremely small and for the baby virtually non-existent, is stark and illustrates

²⁶⁶ *Montgomery v Lanarkshire Health Board* [2016] 1 LRC 350.

²⁶⁷ Emma Cave, 'The Ill-Informed: Consent to Medical Treatment and the Therapeutic Exception' (2017) 46 CLWR 104, 141. Mark Campbell argues that *Montgomery* does not mark a significant shift in legal approach at all, but rather 'confirms the general direction of travel'. Mark Campbell, 'Case Note: *Montgomery v Lanarkshire Health Board*' (2015) 44 CLWR 222, 224.

²⁶⁸ Mark Campbell, 'Case Note: *Montgomery v Lanarkshire Health Board*' (2015) 44 CLWR 222, 223-3. He also argues that the *Sidaway* itself was inconsistent with accepted medical standards as evidenced by the GMC submission in *Montgomery*.

²⁶⁹ *Montgomery v Lanarkshire Health Board* [2016] 1 LRC 350.

²⁷⁰ *ibid* 376.

clearly the need for Mrs Montgomery to be advised of the possibility, because of her particular circumstances, of shoulder dystocia.²⁷¹

The learned Law Lords further stated:

[T]he ‘therapeutic exception’ is not intended to enable doctors to prevent their patients from taking an informed decision. Rather, it is the doctor’s responsibility to explain to her patient why she considers that one of the available treatment options is medically preferable to the others, having taken care to ensure that her patient is aware of the considerations for and against each of them.²⁷²

Emma Cave summarises the effect of the *Montgomery* judgment as:

Henceforth, unless patients do not want to be so informed, physicians must discuss the risks of treatment and make patients aware of alternatives. Gone is the single comprehensive legal standard that applied to both treatment and advice. *Montgomery* separates those aspects of medical decision-making that require expert knowledge (such as treatment) and those that do not (such as advice on the risks of treatment and its alternatives).²⁷³

Arguably, the ‘pregnancy lens’ is highlighted most clearly in the judgment of Lady Hale, wherein she states that pregnancy is a ‘particularly powerful illustration’ of the fact that ‘it is not possible to consider a particular medical procedure in isolation from its alternatives’.²⁷⁴

She continued:

That is not necessarily to say that the doctors have to volunteer the pros and cons of each option [vaginal birth versus Caesarean section] in every case, but they clearly should do so in any case where either the mother or the child is at heightened risk from a vaginal delivery. In this day and age, we are not only concerned about risks to the baby. We are equally, if not more, concerned about risks to the mother. And those include the risks associated with giving birth, as well as any after-effects. One of the problems in this case was that for too long the focus was on the risks to the baby, without also taking into account what the mother might face in the process of giving birth.²⁷⁵

Furthermore, the learned Law Lady was quite critical of Dr McLelland, stating that her limited testimony appeared to indicate that she had not made ‘a purely medical judgment’ on the desirability of a Caesarean section, but instead seemed to have made ‘a judgment that vaginal delivery is in some way morally preferable to a caesarean section’, which justified ‘depriving the pregnant woman of the information needed for her to make a free choice in the matter’.²⁷⁶

²⁷¹ *ibid* 377.

²⁷² *ibid* 377.

²⁷³ Emma Cave, ‘The Ill-Informed: Consent to Medical Treatment and the Therapeutic Exception’ (2017) 46 CLWR 140, 142.

²⁷⁴ [2016] 1 LRC 350, 381.

²⁷⁵ *ibid* 381-2.

²⁷⁶ *ibid* 382.

Thus, two things can be drawn from this judgment. First, the Court demonstrated, through the judgment of Lady Hale, the importance of information disclosure within pregnancy. Like Ireland, pregnancy does not lower the standard of care in information disclosure; if anything, increased responsibilities appear to come with it. Second, it condemned the ‘professional standard’ to the past, establishing that the legal test for materiality is whether a reasonable person in the patient’s position would likely attach significance to the particular risk, or critically, whether that particular patient would be likely to attach significance to the risk and the doctor is or ought to be aware of that.²⁷⁷ This is arguably an expansion past the ‘reasonable patient’ test to encompassing a subjective element, bringing the law on informed consent one step closer to maximising patient autonomy and protecting interests in self-determination.

One step forward and one step back, perhaps; despite its existence, though rare use, in other common law countries, the retention of the therapeutic privilege – referred to as ‘therapeutic exception’ in *Montgomery* – has not gone without criticism, or at the very least, comment. For example, Cave argues that in comparison to the newly articulated test for materiality, ‘the TE has received much less attention, despite its seemingly incongruous place in a judgement that professes to adopt a patient-focused position intended to uphold autonomy rights’.²⁷⁸ She goes on to argue that therapeutic exception is ‘obfuscatory, unnecessary and unjustified’ given that neither of the justifications for its existence are present in England and Wales;²⁷⁹ these justifications are where the defence ‘mitigates the effects of a broadly objective test of materiality by enabling clinicians in exceptional circumstances to protect the autonomy interests of the particular patient’ and where ‘it protects those incapable of an autonomous decision from harm’.²⁸⁰ Mulheron contends that following on from *Montgomery*, ‘the defence of “therapeutic privilege” remains as unsettled and obscure as it has ever been in English jurisprudence’.²⁸¹ She argues that not only have neither UK courts, nor other common law courts, adequately articulated the elements which underpin therapeutic privilege but also that there is a complete lack of clarity as to whether the defence ‘precludes a duty of care from arising altogether’ or ‘rebutts a patient's complete cause of action’.²⁸² To have a full theoretical and practical discussion about therapeutic privilege is beyond the scope of this research, however, it is important to draw attention to the fact that, while England and Wales has adopted

²⁷⁷ As is the case in Ireland, the plaintiff must also demonstrate causation in order to be successful.

²⁷⁸ Emma Cave, ‘The Ill-Informed: Consent to Medical Treatment and the Therapeutic Exception’ (2017) 46 CLWR 140, 142.

²⁷⁹ *ibid.*

²⁸⁰ *ibid.* 142.

²⁸¹ Rachael Mulheron, ‘Has Montgomery Administered the Last Rites to Therapeutic Privilege? A Diagnosis and a Prognosis’ (2017) 70 CLR 149, 150.

²⁸² *ibid.* 160-1.

a considerably more patient-centred approach in more recent years, it does not follow that it has completely abandoned all vestiges of paternalism.

New York

Historically, the 1914 case of *Schloendorff v New York Hospital*, is of critical importance as it acknowledged, for the first time, the existence and importance of consent to medical treatment in New York.²⁸³ In the words of Cardozo J:

Every human being of adult years and sound mind has a right to determine what shall be done to his body; and a surgeon who performs an operation without his patient's consent, commits an assault, for which he is liable in damages.²⁸⁴

Logically, it must follow that an individual cannot determine what 'shall be done with' her body, if she is unaware of what is being proposed to be done to her body.²⁸⁵ Accordingly, she must be sufficiently informed. In contrast to Ireland and England and Wales, the standard of disclosure in New York State has been governed by statute for more than 40 years. Prior to its introduction, however, there appeared to be a tendency within the mid-level appellate courts towards the reasonable patient test. In *Fogal v Genesee Hospital*, it was acknowledged that the standard of care in the context of information disclosure had yet to be explored by the New York courts.²⁸⁶ Simons J cited the case of *Canterbury v Spence* with approval:

We consider the *Canterbury* rule [the duty and scope of disclosure are not governed by the profession's standards of due care but by the general standard of conduct reasonable under all the circumstances] preferable and hold that a doctor is obliged to divulge to his patient the risks which singly or in combination, tested by general considerations of reasonable disclosure under all the circumstances, will materially affect the patient's decision whether to proceed with the treatment.²⁸⁷

This approach to information disclosure was also taken in *Zelevnik*, where Martuscello J stated firmly:

Risk disclosure is based on the patient's right to determine what shall be done with his body (...) Such right should not be at the disposal of the medical community (...) The jury should not be bound by the conclusions of the medical community (...) Testimony

²⁸³ *Schloendorff v New York Hospital* 211 NY 125. It was also widely cited across the United States making it a seminal informed consent case for the country, not just New York.

²⁸⁴ *ibid* 129; as discussed earlier, the law shifted away from considering the act of operating without consent to be a battery and instead finds it to be an action in negligence or malpractice.

²⁸⁵ *Schloendorff* applied to a complete absence of consent but was extended to situations where consent was insufficiently informed; see, for example, *Di Rosse v Wein* 24 AD 2d 510 (NY 1965) and *Darrah v Kite* 32 AD 2d 208 (NY 1969).

²⁸⁶ 41 AD 2d 468 (NY 1973); 473.

²⁸⁷ *ibid*.

of a specific medical community standard as to the risks to be divulged is necessarily permeated with self-interest in its attempt to state as concrete what is so nebulous.²⁸⁸

The clear condemnation of the professional standard by members of the judiciary was severely tempered by the introduction of the Medical Malpractice Act in 1975. This Act inserted section 2805-d entitled 'Limitation of medical malpractice action based on lack of informed consent' into the New York Public Health Law. At that time, the United States was embroiled in a 'medical malpractice crisis' – rapid increases in the number of medical malpractice cases, burgeoning cost of malpractice insurance, the reluctance of some insurance companies to provide malpractice insurance and substantial compensation being awarded in successful lawsuits – and commentators such as Zuckerman *et al* and Feagels *et al* argue that the legislation was passed as a reaction to this crisis.²⁸⁹ While the impetus for 1975 Act is generally discussed in the context of the United States as a whole, there were some distinct 'New York' reasons for the legislation; in 1974, the Argonaut Insurance Company, which provided malpractice insurance to approximately 80 percent of the physicians in New York announced it would be increasing its rates by 196.8%, however, before the increase became effective, the company announced that it was going to cease malpractice insurance altogether. It is widely viewed that faced with the possibility that physicians would simply leave the state and practice elsewhere and of severe service disruption, New York opted to legislate.²⁹⁰

The approach taken by the Act was way out of step with the common law position as evidenced by *Fogal* and *Zelesnik*.²⁹¹ Additionally, the seminal case of *Canterbury v Spence* had been decided a mere 3 years previously, wherein the court clearly advocated for a patient-centred approach to risk disclosure and informed consent by stating that 'the patient's right of self-decision shapes the boundaries of the duty to reveal', a right that could only be 'effectively exercised' he possesses 'enough information to enable an intelligent choice'.²⁹² Therefore, the court held that 'the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked'.²⁹³

²⁸⁸ *Zelesnik v Jewish Chronic Disease Hospital* 47 AD 2d 199 (NY 1975); 205-6.

²⁸⁹ Steven Zuckerman and others, 'Information on Malpractice: A Review of Empirical Research on Major Policy Issues' (1986) 49 L Contemp Probl 85, 91-94; Prentiss E Feagels and others, 'An Analysis of State Legislative Responses to the Medical Malpractice Crisis' (1975) 24 Duke LJ 1417.

²⁹⁰ See for example, *Retkwa v Orentreich* 154 Misc 2d 164 (Sup Ct, NY County 1992); 166; Booth Glen J stated '[t]he statutory codification of the doctrine of informed consent was the result of legislative pressure to limit or abolish the doctrine in New York (...) and was passed in response to the threat of a physicians' strike in 1975'.

²⁹¹ *Fogal v Genesee Hospital* 41 AD 2d 468 (NY 1973); *Zelesnik v Jewish Chronic Disease Hospital* 47 A.D.2d 199 (NY 1975).

²⁹² *Canterbury v Spence* 464 F.2d 772 (D.C. 1972); 786.

²⁹³ *ibid* 787.

The contrast is obvious, as lack of informed consent is clearly in line with the professional standard defined by the 1975 Act:

[T]he failure of the person providing the professional treatment or diagnosis to disclose to the patient such alternatives thereto and the reasonably foreseeable risks and benefits involved as a reasonable medical, dental or podiatric practitioner under similar circumstances would have disclosed, in a manner permitting the patient to make a knowledgeable evaluation.²⁹⁴

Thus, it is evident that full disclosure is not expected by the law; rather it is required that the physician discloses the reasonably foreseeable risks and benefits of the treatment and its alternatives. Thus, a determination that a physician has discharged his duty will often rest on a written record of the discussion with the patient and the relevant information given.²⁹⁵ The legislation further limits the ability of patients to recover damages to instances where the lack of informed consent relates to non-emergency treatment and diagnostic procedures that involve invasion of bodily integrity; thus, where a medical professional fails to properly disclose the risks associated with emergency medical treatment, the patient appears to be barred from pursuing for alleged lack of informed consent.²⁹⁶ While an action is not prohibited under the law in Ireland and England and Wales, a plaintiff is unlikely to succeed owing to the difficulty she would face in proving causation. The requirement that the diagnostic procedure involves invasion of bodily integrity is said to stem from the origins of the doctrine of informed consent, in other words, its root in battery and assault;²⁹⁷ however, it is worth noting that it excludes the possibility of procedures such as mammograms from requiring informed consent, despite the risk of injury to the patient.²⁹⁸

The statute expands further to state available defences; first, if the medical professional demonstrates that the risk he failed to disclose is commonly and universally known, then it may

²⁹⁴ Public Health Law § 2805-d section 1.

²⁹⁵ *Lynn G v Hugo* 96 NY 2d 306 (2001); 309. In this case, the Court of Appeals of the State of New York held that the defendant had 'made a prima facie showing of informed consent by submitting (...) medical records establishing that he had informed plaintiff of the risks associated with the procedures, including scarring, and that she had signed written consent forms indicating her understanding of those risks'. See also *Viera v Khasdan* NY Slip Op 03717 (NY App 2020), where it was held that the '[d]efendants failed to meet their prima facie burden by providing any documentary evidence demonstrating that they informed plaintiff of the foreseeable risks associated with Clindamycin use'. The defendants had failed to prove that they advised the patient of a well-known, though rare, adverse reaction to the antibiotic. It is worth noting that this hearing concerned a motion for summary judgment, thus it is highly unlikely that it will proceed to a full trial. It is cited as a recent example of the legal position regarding documentation and proof of informed consent.

²⁹⁶ Public Health Law § 2805-d section 2.

²⁹⁷ For an explanation of such a limitation see *Karlsons v Guerinet* 57 AD 2d 73 (NY 1977) 82: '[A] cause of action based upon this theory of liability [an offshoot of the law of assault and battery] exists only where the injury suffered arises from an affirmative violation of the patient's physical [sic] integrity and, where nondisclosure of risks is concerned, these risks are directly related to such affirmative treatment'.

²⁹⁸ See a discussion by two practising attorneys - Daniel Freidlin and Thomas Mobilia – regarding their successful defence of a case concerning a ruptured breast implant. They state mammograms do not require informed consent, as they are not invasive diagnostic studies. With that said, it is often custom for warnings to be given. Daniel L Freidlin and Thomas A Mobilia, 'Informed Consent Considerations for Mammography in Women with Breast Implants' (2019) <https://www.martindale.com/legal-news/article_martin-clearwater-bell-llp_2522638.htm> accessed 27 July 2020.

warrant not disclosing that risk.²⁹⁹ Second, he may elect not to inform the patient of a particular risk if, after considering all of the facts and circumstances, he used reasonable discretion to conclude that such a disclosure would be expected to adversely and substantially affect the patient's condition, in other words, therapeutic privilege.³⁰⁰

Thus, despite its shortcomings, it is readily apparent that New York has advocated for the 'reasonable doctor' standard in cases of informed consent for the last 45 years.³⁰¹ As such, the patient will bear the burden of demonstrating that the information – whether volume or type thereof – provided by the physician was inconsistent with what a reasonable doctor would have disclosed in similar circumstances. Arguably, however, the language used – namely 'permitting the patient to make a knowledgeable evaluation' – suggests that the way in which the discussion is conducted should be of an accessible nature to the patient. Indeed, the American Medical Association Code of Ethics states that physicians should assess the patient's ability to understand relevant information and implications and then present the relevant information accurately and sensitively.³⁰² In section 2.1.3, it is stated that 'information may be conveyed over time in keeping with the patient's (...) ability to comprehend'.³⁰³ It is worth noting, however, that the AMA places a disclaimer at the beginning of that section of the Code: 'The Opinions in this chapter are offered as ethics guidance for physicians and are not intended to establish standards of clinical practice or rules of law'.³⁰⁴

This very issue was considered in *Nisenholtz v Mount Sinai Hospital*:³⁰⁵ in interpreting the requirement that disclosures be made 'in a manner permitting the patient to make a knowledgeable evaluation', Gammerman J acknowledged that, in some cases, a physician may

²⁹⁹ Public Health Law § 2805-d section 4a.

³⁰⁰ Public Health Law § 2805-d section 4(d): Parts 4(b) and 4(c) provide further defences (i) (b) states that there is a defence available to the medical professional where the patient assured the medical professional that (s)he would undergo the treatment irrespective of the risks or that (s)he did not wish to be informed of the risks (ii) (c) states that there is a defence where consent by the patient was not reasonably possible. It is interesting to note that in the American Medical Association Code of Ethics Opinions on Consent, Communication & Decision Making Opinion 2.1.3 entitled 'Withholding Information from Patients' the AMA advises that '[w]ithholding pertinent medical information from patients in the belief that disclosure is medically contraindicated creates a conflict between the physician's obligations to promote patient welfare and to respect patient autonomy'. The same section goes further to state that '[e]xcept in emergency situations in which a patient is incapable of making an informed decision, withholding information without the patient's knowledge or consent is ethically unacceptable'. Available: <<https://www.ama-assn.org/delivering-care/ethics/withholding-information-patients>>.

³⁰¹ See for example the view of the professional standard expressed by the Supreme Court of New Jersey in *Largey v Rothman* 110 NJ 204 (1988); 214: 'In contrast [to the prudent patient test] the arguments for the "professional" standard smack of an anachronistic paternalism that is at odds with any strong conception of a patient's right of self-determination'.

³⁰² American Medical Association Code of Ethics Opinion 2.1.1 'Informed Consent' <<https://www.ama-assn.org/delivering-care/ethics/informed-consent>>

³⁰³ American Medical Association Code of Ethics Opinion 2.1.3 'Withholding Information from Patients' <<https://www.ama-assn.org/delivering-care/ethics/withholding-information-patients>>.

³⁰⁴ Although the guidelines set by the AMA could arguably serve as an indication of generally accepted practice amongst physicians, it may still be challenging for a plaintiff to prove that a physician fell below the reasonable standard because the legislation expressly provides for therapeutic exception.

³⁰⁵ 126 Misc 2d 658 (Sup Ct, NY County 1984).

be required to do more than identify the risks and their statistical frequency in order to discharge his duty.³⁰⁶ He stated:

Physicians have a duty to provide a reasonable explanation of the available alternatives and potential dangers of a medical procedure. When a plaintiff alleges that such an explanation was not reasonable, this question is an issue of fact to be determined by a jury (...) In assessing the reasonableness of the explanation provided by a physician, the issue is whether, under the facts and circumstances of a given case, the physician's description of the risks and alternatives to the proposed procedure would enable a reasonably prudent patient to make a knowledgeable evaluation of whether to submit to that procedure.³⁰⁷

He continued that while it may be that 'merely identifying the risks and their likelihood of occurrence' would be sufficient for a physician to discharge his duty, there undoubtedly existed cases which necessitated 'a more detailed description of the causes of potential harm'.³⁰⁸ He continued that by '[u]nderstanding the mechanism by which a potential harm may occur' a patient is provided with 'a clearer view of the procedure being recommended, the nature of the risks, and the extent to which the risks are within the control of the physician'.³⁰⁹ The learned judge expressed that a patient 'who was confident in the physician's skills would quite reasonably want to know whether an undesired result of surgery was beyond the physician's control or solely dependent upon the physician's skills'.³¹⁰ Thus, it was '[o]nly through receiving a more thorough explanation of the mechanisms by which a proposed procedure could result in undesired effects may (...) patients adequately evaluate whether (...) to undergo treatment'.³¹¹ It was the view of the learned judge that it would be 'unwise to hold that a physician need never provide more information than a mere identification of the risk and its likelihood of occurrence'.³¹²

While this case resulted in a favourable outcome for the plaintiff, it hinged on the fact that there was expert medical testimony that the disclosure made by the defendant was inadequate.³¹³ Accordingly, patients in New York currently face a considerably tougher burden than their counterparts in Ireland, England and Wales and indeed, other US states. With that said, a Bill

³⁰⁶ *ibid* 661.

³⁰⁷ *ibid*.

³⁰⁸ *ibid*.

³⁰⁹ *ibid*.

³¹⁰ *ibid* 661-2.

³¹¹ *ibid* 662.

³¹² *ibid*.

³¹³ See also *Retkwa v Orentreich* 154 Misc 2d 164 (Sup Ct, NY County 1992); 169: 'Here, plaintiff has made an offer of proof that an expert witness will testify that a doctor working with liquid silicone in the fields of dermatology and/or plastic surgery in 1982 or 1983 would, as a regular matter, have informed the patient that liquid silicone was not approved by the FDA. Such testimony, assuming it is given at trial, would make out a prima facie case of lack of informed consent'.

drafted in 2019 that would change some aspects of New York informed consent law is currently making its way through the various stages; as of July 2020, it was sitting with the Assembly for approval having passed the Senate.³¹⁴ Arguably, its predecessor was far more extensive; it provided for an entirely new article pertaining to informed consent to be inserted into New York Public Health Law, however, it was amended considerably before being presented to the Senate for approval.³¹⁵ If passed, this amended Bill would require hospitals to adopt and publicise a statement on the rights of patients pertaining including:

- (i) the right ‘to receive all information necessary to give informed consent for any proposed procedure or treatment, and alternate treatment options including the possible risks and benefits of the procedure or treatment taking into consideration any known preconditions’;³¹⁶ and
- (ii) the right to ‘be informed of the name, position and functions of any hospital staff including medical students and physicians exempt from New York State [education law], involved in a patient’s care and refuse their treatment, examination or observation’.³¹⁷

While these are undoubtedly helpful obligations for hospitals to bear, it remains to be seen what the practical and legal implications will be.

Where informed consent in pregnancy is concerned, the Appellate Division of the Supreme Court of the State of New York has held that an independent cause of action exists on behalf of the foetus against a physician for failure to obtain informed consent from the woman.³¹⁸ Thus, the courts have imposed liability on a physician for injuries sustained by a foetus arising from the failure to disclose. Additionally, New York Public Health Law contains two sections relating to the informed consent of pregnant women; first, § 2503 requires pregnant women be informed of the drugs to be administered during pregnancy and birth and any related side effects for the foetus and woman. Second is § 2504, which was discussed previously.³¹⁹ Thus, it is argued that it would be challenging for a medical professional to demonstrate that a failure

³¹⁴ An Act to Amend the Public Health Law, in relation to the Provision of Informed Consent Senate Bill (2019) S1029A (hereafter ‘Informed Consent Senate Bill 2019’).

³¹⁵ *ibid*: In the justification for the amendment, it is stated that the amended version of the bill ‘preserves those protections identified in the original bill, and clearly articulates those rights in the existing hospital patient’s bill of rights’.

³¹⁶ Informed Consent Senate Bill 2019, s 1(g)(ii), which is proposed to amend Public Health Law § 2803 section 1(g).

³¹⁷ *ibid* s 1(g)(iii).

³¹⁸ *Hughson v St. Francis Hospital* 92 AD 2d 131 (NY 1983).

³¹⁹ ‘Any person who is pregnant may give effective consent for medical, dental, health and hospital services relating to prenatal care.’

to disclose risk because a patient is pregnant is generally accepted practice. Indeed, nothing in the law points to a lower standard for pregnant patients; if anything, the opposite is true.

Conclusion

Although a seemingly straightforward concept, informed consent has proved to be anything but in the common law. What constitutes competence and incompetence and sufficiently ‘informed’ and the divergence between jurisdictions as to how incompetent individuals should be treated, demonstrates the complexity of this issue. Key to this chapter was contrasting how New York treats informed consent and how Ireland and England and Wales do; the fact that the New York judiciary appeared to make the move to a reasonable patient test far earlier than the other two, only to have it reversed by the legislature was worthy of note. For a variety of reasons, one would be forgiven for assuming that the same *pro-patient* tendencies seen in Ireland and England and Wales would be seen in New York. First, New York is often viewed as a bastion of human and individual rights; it is home to the headquarters of the United Nations and the American Civil Liberties Union, it legalised gay marriage prior to the Defense of Marriage Act (DOMA) being struck down by the United States Supreme Court.³²⁰ As discussed in Chapter 1, it had legal abortion prior to the decision in *Roe v Wade*³²¹ and it was the location of one of the earliest cases establishing the doctrine of informed consent, *Schloendorff*.³²² Yet clear paternalism can be seen, not only in the standard of disclosure required in informed consent cases but perhaps also in the requirement that individuals be capable of rational or reasoned decisions in order to have capacity, which has yet to be overturned. Highlighting this early difference between how refusal of medical intervention is generally treated in these jurisdictions will be built upon in the coming chapters, with the next considering end-of-life decision-making and the refusal of life sustaining treatment.

Pregnancy, as outlined throughout this chapter, seems to be an outlier. On the one hand, it appears that the capacity of a woman going against medical advice can be more readily challenged in labour than in other healthcare contexts. On the other hand, information disclosure requirements appear to be as onerous, if not more so, in pregnancy. The relationship between these early differences and advance directives in pregnancy will be discussed in due course.

³²⁰ *United States v Windsor* 570 US 744 (2013); *Obergefell v Hodges* 576 US 644 (2015).

³²¹ *Roe v Wade* 410 US 113 (1973).

³²² *Schloendorff v New York Hospital* 211 NY 125 (1914).

Chapter 4 Introduction

The right to a natural death is one outstanding area in which the disciplines of theology, medicine and law overlap; or, to put it another way, it is an area in which these three disciplines convene.

Medicine with its combination of advanced technology and professional ethics is both able and inclined to prolong biological life. Law with its felt obligation to protect the life and freedom of the individual seeks to assure each person's right to live out his human life until its natural and inevitable conclusion. Theology with its acknowledgment of man's dissatisfaction with biological life as the ultimate source of joy ... defends the sacredness of human life and defends it from all direct attacks.¹

The previous chapter considered informed consent at a more generalised level, focusing on its building blocks, so to speak.² It progressed to considering whether those requirements varied or ought to vary if the decision-maker is pregnant. It did not, however, consider the ethical and legal challenges encountered by the court, legislature and healthcare professionals in the context of refusing life-sustaining medical treatment in any great detail. This aspect is important in the context of advance directives, as it is those advance decisions to decline life-sustaining intervention that are the most ethically challenging and those most likely to require court adjudication. It is worth stating, however, that this chapter will look at end-of-life decision-making generally, rather than in the context of pregnancy; that discussion will be conducted in Chapter 6 wherein compelled intervention in pregnancy is examined. This is a deliberate decision, as it is felt that it highlights one of the key issues with medical intervention in pregnancy. End-of-life decision-making in pregnancy is almost never just about the pregnant woman, as it would be in the case of non-pregnant people. Rather, judgments often lack clarity as to what the risk is to the woman's life and what it is to the foetus' life; her life, health and wellbeing are often merged with that of the foetus, with little discussion of why this ought to be the case.³ Thus, it was felt that to discuss them fully, all interventions in pregnancy should be discussed together. Accordingly, this chapter and the next pertaining to Advance Directives serve as building blocks for Chapter 6.

¹ Hughes CJ in *Re Quinlan* 70 NJ 10 (1976); 32.

² Chapter 3 looked at the two primary criteria necessary to establish informed consent to or refusal of medical treatment, namely that the patient be competent and informed. As discussed in the previous chapter, consent must also be voluntary, however, it is suggested in the medical context that the other two criteria are more likely to be at issue and consequently, worthy of more discussion.

³ This will become evident when some of the blood transfusion cases are discussed in Chapter 6.

Rosamond Scott neatly summarises the legal aspects of the refusal of life-sustaining medical treatment:

In the early days of medical law, a patient's right to refuse medical treatment was typically subject to four potentially countervailing state interests in: the preservation of life, the prevention of suicide, the protection of the ethical integrity of the medical profession, and the protection of innocent third parties. With the exception of the last, the strength of these has waned over time, so that in general a competent adult can now refuse any treatment for any reason.⁴

As time progressed, greater respect was accorded to the self-determination of the individual and greater deference was shown to her choice; it was widely acknowledged that refusing life-sustaining treatment was not equivalent to suicide.⁵ Norman Cantor argues succinctly that the 'main distinction is that suicide involves initiation of a self-destructive course' whereas refusal of treatment allows 'a fatal affliction follow its natural course'.⁶ It was widely accepted that respect for the sanctity of life should not prevail over respect for the decision of a competent person to refuse life-sustaining treatment, save in the most exceptional circumstances.⁷ The ethical integrity of the medical profession is generally no longer at issue, as guidance from the relevant professional bodies now advocates respecting patient choice and self-determination, even in life-saving situations.⁸ The protection of innocent third parties, however, remains a different matter and one that will be considered in more detail in Chapter 6 in the context of compelled obstetric interventions.

It is important at this juncture to clarify what this chapter will not consider in the context of end-of-life decision-making. While there is a body of law concerning euthanasia and assisted suicide, it will not be considered as part of this research.⁹ Rather, this research focuses on the individual's pursuit of unassisted death on their own terms, referred to by some as 'death with dignity', 'a

⁴ Rosamund Scott, 'The Pregnant Woman and the Good Samaritan: Can a Woman Have a Duty to Undergo a Caesarean Section?' (2000) 20 Oxford J Legal Stud 407, 409.

⁵ See *Re Conroy* 98 NJ 321 (1985); 350; *Re Storar* 52 NY 2d 363 (1981); fn 6; *Re a Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 IR 79, 93-94 ('*Re Ward of Court*'). Contrast with the judgment of Justice Scalia in *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990); 292-300.

⁶ Norman L Cantor, 'Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying' (2001) 29 J L Med Ethics 182, 184.

⁷ *Airedale NHS Trust v Bland* [1993] 1 All ER 821, 851-2; *Re Conroy* 98 NJ 321 (1985); 349.

⁸ For example, the World Medical Association International Code of Medical Ethics signed in 1949 obliged physicians to 'always bear in mind the obligation of preserving human life'; World Medical Association, 'International Code of Medical Ethics' (1949) <<https://www.wma.net/wp-content/uploads/2018/07/International-Code-of-Medical-Ethics-1949.pdf>> accessed on 8 May 2020. The most recent version, signed in 2006, still requires that a physician 'always bear in mind the obligation to respect human life' but also requires that she 'respect a competent patient's right to accept or refuse treatment'. World Medical Association, 'International Code of Medical Ethics' (2006) <<file:///C:/Users/afinnerty/Downloads/wma-international-code-of-medical-ethics.pdf>> accessed on 8 May 2020.

⁹ It is worth noting, however, that some of the ethical arguments made in relation to euthanasia and physician assisted suicide will be relevant and accordingly, included in this ethical analysis.

natural death' or a 'good death'.¹⁰ This research accepts the distinction between acts undertaken with the intention of ending life and treatment that is withheld or withdrawn, which has the consequence of ending life.¹¹ As this research ultimately focuses on advance healthcare directives, it is outside its scope to give a detailed account of why the distinction between withholding medical treatment and withdrawing treatment is accepted.¹² In advance directives, both a rejection of treatment and the cessation of treatment already commenced can be articulated, therefore they apply to withholding and withdrawing. Upon making those distinctions, it is necessary to exclude a further subset of cases, namely those where failure to treat was either negligent or unlawful. Advance directives, by their nature, are exhibitions of the will of the individual; accordingly, there is little to be gained by considering cases where treatment was withheld unlawfully, against the will of the individual or in the absence of an appropriate justification.

This chapter discusses how end-of-life matters are treated in Ireland, England and Wales and New York. In clear contrast to the previous chapter, there will be fuller discussion of the approach of other states in the United States to this issue. The law as it pertains to matters at the end of life can be sharply contrasted with informed consent, as the former sees significant and substantial variances in how the issue is treated from state to state, whereas the same cannot necessarily be said for the latter.¹³

Disorders of Consciousness

Before discussing the ethics of end-of-life decisions, it is important to discuss the terminology that will be used throughout this chapter and the reason why it may change at times. Persistent vegetative state¹⁴ ('PVS') is a term first coined by Fred Plum and Bryan Jennet to describe patients that had suffered brain injuries but not brain death; these patients presented with periods of

¹⁰ Norman L Cantor, 'Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying' (2001) 29 J L Med Ethics 182.

¹¹ For arguments as to why active euthanasia can and ought to be distinguished from withdrawal of life-preserving medical intervention, see for example, Norman L Cantor, 'The Permanently Unconscious Patient, Non-Feeding and Euthanasia' (1989) 15 AJLM 381, 427-435.

¹² For discussions on withdrawal versus withholding, see Philip Levin and Charles Sprung, 'Withdrawing and Withholding Life-sustaining Therapies are Not The Same' (2005) 9 Crit Care 230; Gunilla Melltorp and Tore Nilstun, 'The Difference Between Withholding and Withdrawing Life-sustaining Treatment' (1997) 23 Intensive Care Med 1264.

¹³ The primary difference in informed consent law from state to state is the standard of care used to determine breach of duty to disclose. New York, as discussed, legislated for the professional standard, whereas states such as California use the reasonable patient standard.

¹⁴ For the avoidance of confusion, there are sometimes references to 'Permanent Vegetative State' also abbreviated to 'PVS'. The difference between the two is explained as follows. 'The adjective "persistent" refers only to a condition of past and continuing disability with an uncertain future, whereas "permanent" implies irreversibility. Persistent vegetative state is a diagnosis; permanent vegetative state is a prognosis.' Thus, despite the precise use of language by Jennett and Plum, who originally defined 'persistent' in the context of a vegetative state, confusion arose over the exact meaning of the term 'persistent'. See The Multi-Society Task Force on PVS, 'Medical Aspects of the Persistent Vegetative State' (1994) 330 N Engl J Med 1499, 1501. In 2018, the US guidelines replaced the term 'permanent' with 'chronic', as there was evidence that a small number of patients were showing some improvement after the point at which improvement was deemed 'improbable' thus rendering 'permanent' misleading. Joseph Giacino and others, 'Practice Guideline Update Recommendations Summary: Disorders of Consciousness' (2018) 91 Neurology 450.

wakefulness with open eyes and movement, limited responsiveness and some reflex movements.¹⁵ It subsequently became apparent that there were patients suffering from long term ‘severe alteration[s] in consciousness’ that could not be diagnosed as being in a persistent vegetative state, in other words, they did not meet the established diagnostic criteria; the term that was used in the case of such patients was a minimally conscious state (MCS).¹⁶ While ‘PVS’ has been utilised extensively in jurisprudence and in academic commentary for over four decades, it is used with considerably less frequency in medical circles today; in order avoid confusion between *persistent* and *permanent* vegetative states, the UK National Clinical Guidelines for Prolonged Disorders of Consciousness (PDOC) issued by Royal College of Physicians advised that ‘persistent’ be replaced with ‘continuing’ in 2013.¹⁷ A diagnosis of a *permanent* disorder of consciousness is still possible.¹⁸ It still remains, however, that much of the historical academic commentary and jurisprudence referred to ‘PVS’. While the term ‘MCS’ is still in used in medical circles, it is worth bearing in mind that both vegetative and minimally conscious states are collectively referred to as Prolonged Disorders of Consciousness (PDOC) or if the circumstances are present, Terminal Decline of Consciousness (TDOC).¹⁹ Accordingly, more modern jurisprudence and literature may simply refer to a ‘disorder of consciousness’, focusing on the symptoms of the disorder, the quality of life of the individual and their prospect for improvement, rather than diagnosing either vegetative or minimally conscious state.²⁰ Arguably, such an approach brings jurisprudence more in line with the medical guidance, which describes consciousness as a continuum.²¹

Ethical Issues in End-of-Life Decision-Making

¹⁵ Bryan Jennett and Fred Plum, ‘Persistent Vegetative State after Brain Damage: A Syndrome in Search of a Name’ (1972) 299 *The Lancet* 734.

¹⁶ Joseph Giacino and others, ‘The Minimally Conscious State: Definition and Diagnostic Criteria’ (2002) 58 *Neurology* 349.

¹⁷ Royal College of Physicians, *Prolonged Disorders of Consciousness: National Clinical Guidelines* (London 2013) 9-10.

¹⁸ Royal College of Physicians, *Prolonged Disorders of Consciousness following Sudden Onset Brain Injury: National Clinical Guidelines* (London 2020) 37.

¹⁹ See Royal College of Physicians, *Prolonged Disorders of Consciousness following Sudden Onset Brain Injury: National Clinical Guidelines* (London 2020) 20. The former applies is the disorder of consciousness arises from a sudden brain injury, whereas the latter applies where the disorder is as a result of a condition causing progressive brain damage such as Parkinson’s Disease

²⁰ See Alexander Ruck Keene and Annabel Lee, ‘Withdrawing Life-Sustaining Treatment: A Stock-Take of the Legal and Ethical Position’ (2019) 45 *J Med Ethics* 794, 794-5. Contrast with the definition given in *Re M (Adult Patient)(Minimally Conscious State: Withdrawal of Treatment)* [2012] 1 All ER 1313, 1320 (hereafter ‘*Re M*’): ‘A patient in this condition [MCS] is above the vegetative state and is aware to some extent of herself and her environment but does not have full consciousness’. Arguably, there is a significant difference between having a person having ‘minimal consciousness’ and not having ‘full consciousness’. For a discussion of the decreasing importance of a definite definition of either MCS or PVS in jurisprudence, see *NHS Cumbria CCG v Rushton* [2018] EWCOP 41, paras 29-30.

²¹ Royal College of Physicians, *Prolonged Disorders of Consciousness following Sudden Onset Brain Injury: National Clinical Guidelines* (London 2020) 27. For the avoidance of doubt, however, ‘continuing VS’ can be understood as when the patient ‘continues to demonstrate complete absence of behavioural evidence for self or environmental awareness for more than 4 weeks’ and ‘continuing MCS’ can be understood as when the patient ‘continues to demonstrate inconsistent, but reproducible, interaction with their surroundings (above the level of spontaneous or reflexive behaviour) for more than 4 weeks’ (37).

The ethical issues underpinning end-of-life decision-making must be considered and teased out in order to understand the challenges faced by judges deciding matters of life and death and the challenges that legislators face when trying to coherently address such matters. It is a legitimate aim of society, the medical profession, the legislature and the courts to mitigate against the harm that can be caused to individuals by both undertreatment – the failure to provide needed beneficial treatment – and overtreatment – the provision of futile or harmful treatment. The assessment of whether a failure to treat is *undertreatment* or the administration of treatment is *overtreatment* is a challenging matter for the law, something that will be evidenced by the differing outcomes reached in cases with similar facts. Clearly, it is also challenging for members of the medical profession, as evidenced by the differing opinions contained in the medical testimony in such cases. The balance between treatment, overtreatment and undertreatment is critical to understanding whether treating an incompetent patient is an act of beneficence or maleficence on the part of the physician; in other words, is the provision of treatment beneficial or detrimental to her? Both overtreatment and undertreatment also concern matters of justice; for overtreatment, justice in the sense of scarcity of resources is a consideration and for undertreatment, justice in the sense of equality of access to healthcare has relevance. These issues will be considered in more detail in the succeeding paragraphs.

In order to ascertain the ethical issues underpinning the refusal, withholding or withdrawal of life-sustaining medical treatment, it is beneficial to return to Principlism; Autonomy, Beneficence, Non-Maleficence and Justice. While the ethical issues pertaining to consent to and refusal of treatment were analysed in Chapter 3, it is submitted that there are distinct ethical issues when the administration of treatment preserves the life of the individual. This research divides end-of-life situations in two; first, there are those end-of-life cases concerning individuals with capacity and second, those cases concerning individuals who are incapable of consenting to or refusing treatment. For the latter type of patient, there will be a further subdivision into those who never had capacity and those who had, but have lost it. Perhaps it goes without saying that the weight given to the principles must change where the patient is incompetent, thus while the ethical principles remain the same, the prominence given to one over another must vary in line with individual capacity. As was discussed in the previous chapter, society and the law reflect the idea that incompetent individuals must be protected in a variety of ways. Because of the differences between competent and incompetent persons, it is worth considering the four principles separately

in both contexts, then further differentiating between lifelong incompetence and sudden but persistent incompetence caused by trauma or illness.

The subdivision advanced in this chapter is not to suggest that there is no grey area within medical decision-making or that it is always clear that an individual is competent or incompetent. Naturally, there are cases everyday where individuals have fluctuations in capacity either because of degenerative diseases or because they are recovering from trauma or some other reason. Thus, rather than implying that capacity is a completely clear-cut matter, the format of the analysis is designed to highlight clear points on a spectrum of decision-making capacity.

Autonomy

While ‘autonomy’ is often referenced in the course of judgments considering refusals of treatment, its analysis and application by judges has sometimes been criticised.²² Despite this criticism – and what could be considered patchy application of the principle of respect for autonomy by the law – this research would be incomplete were it to consider the law without respect for autonomy from an ethical perspective. Where the death of the individual is a likely consequence of her competent refusal of medical treatment, what is the right action cannot be discerned until the ethical questions themselves are. Tom Beauchamp laid out the two competing premises:

It is morally prohibited to risk death for a patient whose life threatening condition can be medically managed by suitable medical techniques.

It is morally prohibited to disrespect a first party refusal of treatment.²³

He provided a caveat to the second point, namely ‘unless the refusal is non-autonomous and presents a significant danger to the patient’, which he argues has the ‘simple but powerful effect of informing medical officials (indeed, everyone) that all truly autonomous refusals of treatment must be respected, no matter the consequences’.²⁴ Perhaps it goes without saying that a legal framework that protects the right of the individual to refuse unwanted life-sustaining medical treatment is one that respects the autonomy of the individual. While, as Ruth Faden and Tom Beauchamp point out, early court decisions may not have referred to terms such as ‘autonomy’ or

²² See for example, Bernadette J Richards, ‘Autonomy and the Law: Widely Used, Poorly Defined’ in David G Kirchhoffer and Bernadette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) 18.

²³ Tom Beauchamp, ‘Methods and principles in biomedical ethics’ (2003) 29 *J Med Ethics* 269, 270.

²⁴ *ibid.*

‘self-determination’, they did refer to ideals such as ‘the free citizen’s ... right to himself’, something which they argued was ‘functionally equivalent’.²⁵

In explaining the importance of autonomy and the right to decide for oneself in the context of end-of-life matters, Chris Docker argues that it is ‘not difficult to recognise in each of us a desire to exercise control over our own destiny and to have a chance to finish our own “work of art” in the manner of our own choosing’.²⁶ Or, as Nils Hoppe and José Miola argue: ‘everyone should be allowed to live the life they want, and die the death they want’.²⁷ While this research does not make any statement about choosing one’s death in the sense of assisted dying, sometimes the autonomy arguments stemming from those issues can illuminate the debate in relation to refusing life-sustaining treatment. To adapt an argument made by Peter Singer: if one’s future life, if compelled to undergo life-sustaining treatment, ‘would hold more negative elements than positive ones – more unhappiness than happiness, more frustration of preferences than satisfaction of them’, then honouring the autonomous wish of that person to refuse treatment and exercise some control over their existence is morally justified.

This kind of thinking is not unusual in healthcare. It seemed to start with more straightforward situations such as accepting the decisions of terminally ill patients to refuse life-lengthening treatments and progressed to more complicated ones, such as accepting the decision of otherwise healthy individuals to refuse medical treatment for religious reasons.²⁸ Arguably however, if we are to accord the autonomy of the individual with the respect it deserves, then the measure of ‘negative elements’ must not be objective, it must be subjective. It must be based on what the competent individual views as positive or negative and not on what members of the medical profession, other individuals or society perceive as positive or negative. This, we have also seen borne out in some jurisprudence with courts permitting individuals to refuse treatment even when their prognosis was good and their reasoning for refusal unconventional, in that it was not objectively logical or rational or based on religious reasons.²⁹ After all, there is not necessarily any convincing reason why religious beliefs should garner more protection than any other kind of

²⁵ Ruth Faden and Tom Beauchamp, *A History and Theory of Informed Consent* (Oxford University Press 1986) 121.

²⁶ Chris Docker, ‘Advance Directives / Living Wills’ in Sheila McLean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996) 180-1.

²⁷ Nils Hoppe and José Miola, *Medical Law and Medical Ethics* (Cambridge University Press 2014) 283.

²⁸ There is a body of literature in which it is argued that decisions based on religious conviction are not autonomous, however, such contentions are not being considered by this research.

²⁹ See *King’s College Hospital NHS Foundation Trust v C* [2015] EWCOP 80, discussed in more detail in the previous chapter.

conviction, whether moral, political, or aesthetic;³⁰ as Julian Savulescu argues, religious values are one of several sets of values relevant within ethics.³¹ The rationale for granting religious belief a special level of protection in more recent history is more likely a reaction to our shared global history of religious persecution, a way of undoing the past wrongs committed in the name of religion, or at the very least, preventing their reoccurrence. Furthermore, some version of freedom of religion has a place in many domestic foundational rights documents and in international provisions, which makes it challenging to ‘ignore’ it in a medico-legal context.

Thus, if an individual views their current or future existence with life-sustaining treatment as negative – even if objectively speaking, it could be considered positive – then it is the view of the individual that is paramount. Or to put it another way, the protection of the future autonomy of an individual does not justify overriding her autonomy in the here and now, irrespective of how honourable that aim may be. Emily Jackson notes that the priority given to autonomy has been criticized ‘on the grounds that it is an excessively individualistic value’.³² She continues:

Giving the competent adult patient an absolute right to reject life-saving medical treatment ignores the impact that this might have upon other people, such as her dependent children. The principle of patient autonomy gives the individual a right to make decisions that could have a profoundly negative impact upon those close to her.³³

Clearly, the protection of children is a legitimate aim of any society and one that is pursued by the law, in the criminalisation of child abuse, the requirement that children be educated up to a certain age, prohibition on child labour and so forth. With that said, it is argued that preventing competent adults from refusing treatment for themselves in the interest of their children is an illegitimate interference. Any decision to accept treatment for the benefit of ‘those close to her’ must be because the individual feels that is her duty to do so, not because she is forced to do so by the law. Individuals are not prevented from having hazardous professions – fire and rescue services, police or armed forces – just because they are parents. While this may not be a completely fair comparison – the risk of death with refusal of treatment is more likely, if not almost certain, whereas the same cannot be said for having any of the aforementioned occupations – it remains that we do trust individuals to decide for themselves if they wish to continue working in these environments after they become parents. Arguably, this is because society recognises the value and importance of

³⁰ For a similar argument, see Tom Beauchamp, ‘Methods and principles in biomedical ethics’ (2003) 29 J Med Ethics 269, 270.

³¹ Julian Savulescu, ‘Two Worlds Apart: Religion and Ethics’ (1998) 24 J Med Ethics 382, 383.

³² Emily Jackson, *Medical Law: Text, Cases, and Materials* (4th edn, OUP 2016) 239.

³³ *ibid.*

these activities to individuals and collectively. The same argument can be made in relation to autonomy and individual choice. We may disagree with the decision of the individual and think it ethically questionable, but it does not follow that we should remove the choice for everyone, or a subset of society, such as parents.

Shimon Glick, however, might disagree:

[A]utonomy is of no value to a dead person. By permitting a patient to die avoidably, when it is virtually certain that were he saved against his present protest he would be grateful, one is granting that person his short term 'autonomous' wish while depriving him of his long term autonomy.³⁴

He argues that 'stressed' or 'upset' patients may not be fully autonomous and accordingly that their refusals should be assigned 'less weight'.³⁵ He goes on to argue in favour of the model of consent in Israel, which provides that a competent refusal may be overruled by a hospital ethics committee once the committee is satisfied that 'the patient's welfare demands a particular treatment, and that the patient, too, will subsequently be grateful for such intervention'. In other words, retroactive consent will subsequently be given.³⁶ This is clearly premised on the patient being grateful for treatment after it is administered; arguably, that is a very high burden for a hospital to bear and one must question what criteria a hospital ethics board would use to predict subsequent *patient gratitude*. It is contended that the very existence of this clause is problematic, even if, as Glick concedes, that it 'is not intended for frequent or routine use' and even were it to have sound and consistent evaluation criteria.³⁷ This is for two reasons: first, its presence tells patients within that society that their wishes may not be respected if a hospital board can be convinced of their future gratitude by their treatment team. To only honour choice that is considered *right*, is to permit no choice at all in a medical context. While one person may be grateful for the extension of her life, another may not; the view one has of one's own life is unique. Were it not, we would all make the same decisions and pick the same option with the same set of circumstances. Time and time again, humans have shown this not to be the case. Therefore, it is argued that autonomy and the decision we wish to make for ourselves, though not absolute, should not be contingent on receiving the approval of medical professionals. Second, as will be discussed in more detail later in this chapter, where a patient goes against medical advice, there is nothing

³⁴ Shimon Glick, 'The Morality of Coercion' (2000) 26 J Med Ethics 393, 395.

³⁵ *ibid.*

³⁶ *ibid* 393-395; Patients' Rights Law 1996, Laws of State of Israel.

³⁷ Shimon Glick, 'The Morality of Coercion' (2000) 26 J Med Ethics 393, 394.

stopping her physician from having a full and frank conversation with her about the matter; rather, he may even have a duty to have such a conversation. Where the patient persists in refusing, then that should be honoured and not overruled in the interest of future gratitude; consequently, Glick's ideal is rejected for its interference with the autonomy of the individual.

Autonomy: The Incompetent Patient

As was articulated previously, considerations justifiably change when the patient is incompetent. Merely referring to 'the incompetent patient', however, is still insufficient to capture both the range of ethical issues and the appropriate balance that must be struck between those issues. Some patients never had decision-making capacity, nor will they ever attain it; others have capacity for some or most of their lives, only to lose it because of illness or trauma. To assume that the ethical considerations are the same for all incompetent patients would be to oversimplify the issue. Furthermore, an individual who has never had capacity is one who is unable to make an advance directive; as will be detailed further in the next chapter, the anticipatory refusal must be made by an individual with the requisite capacity to do so. In Chapter 3, it was argued that the relevance of decision-making capacity, at least in part, is that it indicates to the medical professionals which of the two principles, autonomy or beneficence, should be paramount in a given situation.³⁸ Beneficence having the paramount position, however, does not mean that autonomy is irrelevant or non-existent for all incompetent patients, though it has been argued that it is irrelevant for some. Nancy Rhoden contends:

[T]o view incompetent patients as just like us – autonomous choosers ... helps (a bit) to mask the fact that in life or death decisions third parties are making quality of life judgments for incompetents. It is an approach that is ludicrous if the patient was never competent, and far from satisfactory if the patient was competent but never discussed the matter or at any rate never chose.³⁹

It is difficult to argue with her contention if one briefly returns to the understanding of autonomy advanced in Chapter 2 or failing that, most accepted constructs of autonomy. If an individual has never been competent in the sense that she has never possessed the capacity for self-determination, the ability to participate in deciding matters for herself or been independent in any meaningful way, then arguably, it may be a misrepresentation to speak of her autonomy and autonomous

³⁸ Chapter 3. See also John Devereux, 'Continuing conundrums in competency' in Sheila McLean *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 236.

³⁹ Nancy Rhoden, 'How Should We View the Incompetent?' (1989) 17 *L Med & Health Care* 264, 267.

choice. This clearly applies to quite a specific subset of incompetent patients, however, namely those who have never been capable of making decisions about their health or life. It is the view of this research that it does not extend to those who have intermittent capacity or fluctuating decision-making capabilities. Such individuals were at some point and may still be capable of autonomous choice, therefore they may be capable of choosing (or refusing) in advance. Where they have previously made an autonomous choice in relation to the circumstances in question, it is argued that such a choice should be respected. In doing so, the individual is being ‘regard[ed] as a person, rather than simply as an object of concern’.⁴⁰

Benevolence and Non-Malevolence

Traditionally, perhaps it was understandable that administering life-sustaining treatment to patients was viewed as upholding the principle of benevolence and that failing to do so breached the principle of non-malevolence. This reflected a view that patients were, to some extent, *things to be fixed* and that the physician had the toolbox; indeed, the greatest ‘fixing’ of all was to prevent death. This ideal motivated scientific and medical developments and inspired researchers and medical professionals to invent life-sustaining treatments such as defibrillators and ventilators. In turn, such developments also created many of the ethical dilemmas inherent in healthcare; where once, one would be dead, now technology made death more of a choice. Arguably, these developments also reflected a failure to abide Ambroise Paré’s honourable ideal from the 16th Century that the role of a physician was ‘to cure sometimes, to relieve often, and to comfort always’.⁴¹ Or what has been defined in more modern times by Alasdair Maclean as the failure to ‘distinguish between the individual as a biological being and the individual as a person’.⁴² As medicine modernised, the idea that the duties of benevolence and non-malevolence were restricted to just the health of the patient fell out of favour.⁴³

But what of the decision that seems to go against maximising the welfare of the patient, when outcomes would be negative for the patient and not positive? One may legitimately ask what a physician ought to do if the decision of the patient to refuse treatment seems destructive or

⁴⁰ Samantha Halliday and Lars Witteck, ‘Decision - Making At The End Of Life and The Incompetent Patient: A Comparative Approach’ (2003) 22 Med & L 533, 540.

⁴¹ This quote is generally attributed to Ambroise Paré, a French surgeon who lived in the 16th Century, however it is also attributed to Sir William Osler, a Canadian physician and one of the founding professors of Johns Hopkins Hospital.

⁴² Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 50.

⁴³ As discussed in Chapter 3.

irrational. What ought he do when the administration of treatment in such circumstances would preserve life, meaning it would, in his assessment, confer benefit? While the instinct of the physician may be to preserve a life capable of preservation, the administration of treatment may still compromise the welfare of the individual, not only failing to confer benefit but causing detriment. Shaping one's death, insofar as that is possible, is a legitimate exercise in self-determination. It can help an individual to be the person in death that she was in life, whether that has been shaped by her religious faith or her independence or her family situation. For some patients, it may be infinitely more beneficial to provide them with comfort care and respect for their wishes, than life-sustaining treatment. For others, the thought of death may be welcome when faced with choosing between persistent pain or lack of awareness caused by pain relief measures. Death may be a way of rescuing an individual with degenerative condition from the humiliation she foresees in her future existence. As was argued in the previous chapter, the prevention of avoidable harm, which is encompassed in the principle of beneficence, extends to the protection and vindication of the rights and interests of the individual.⁴⁴ Refraining from causing harm, understood as the duty of non-maleficence, encompasses the duty to refrain from breaching such rights and interests.

Overriding a seemingly irrational decision prevents the individual from being responsible for her actions and diminishes her to a level where she is only permitted to make decisions if she picks the *right answer*. After all, as was argued in relation to the Israeli model: to prohibit a person to make the choice that is considered wrong is really to permit no choice at all. Such action diminishes all patients to this level and spreads the message that individuals are not trusted to decide, potentially discouraging individuals from seeking assistance and increasing fear and anxiety amongst the ill. Again, it must be borne in mind that there is a substantial difference between overriding the decision of the individual and questioning and openly discussing it. Nothing in this research should be construed as arguing that the physician should not make an attempt to discuss the matter further with the patient if his professional judgment is at odds with her decision. Such a respectful conversation is not maleficent, rather it is beneficent in that it ensures that she has all the information that she may need to choose and ensures that the information she has received has

⁴⁴ Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 49.

been comprehended. In other words, it eliminates any doubt that the course of action is really what the patient wants and eliminates a preventable harm, thereby benefitting the patient.

Beneficence and Non-Maleficence: The Incompetent Patient

In-keeping with the trend first started in the discussion of autonomy, incompetent patients provide a more challenging picture where beneficence and non-maleficence are concerned. The principle of beneficence takes centre stage for incompetent patients, as they lack the ability to make a contemporaneous decision; '[w]hen a patient is incompetent to exercise control over her medical care, the moral principle of beneficence instructs others to protect the patient's well-being'.⁴⁵ The way by which this 'protection of well-being' is given effect, its form so to speak, is the subject of much debate. What constitutes the beneficence should be – and generally is – assessed on a case by case basis; some jurisdictions advance the position that the right decision is the one that the patient would have made for herself, what is often referred to as 'substituted judgment'. Other jurisdictions advocate for a 'best interests' standard, the beneficent decision is the one that is in the best interests of the patient in question taking all relevant factors, including what she would have wanted, into consideration. In relation to withdrawing treatment from patients in minimally conscious or vegetative states, several commentators have been unequivocal about the benefit, or lack thereof, that can be achieved by treating. Perhaps Ranaan Gillon summarises this most aptly in relation to clinically assisted hydration and nutrition (CAHN) for patients in PVS:

[T]he moral obligation of the doctor is to provide care, which entails the intention and prospect of benefit, and the mere prolongation of unconscious life is not a benefit. The doctor therefore has no moral obligation to provide hydration and nutrition, and his or her partial role in causing the patient's death is not of moral significance.⁴⁶

Rhoden argues:

[I]n a significant sense, we are not stopping treatment for the *good* of the vegetative or barely conscious patient: such a patient is beyond caring. We are stopping because the treatment seems meaningless (as does the patient's life), and because the family is wracked with anguish at the artificially prolonged death.⁴⁷

Arguably, if the treatment 'seems meaningless' as Rhoden contends, then it cannot be said that it is conferring any benefit on the individual, in other words, the principle of beneficence is not being pursued by such treatment. The continuation of treatment that is not conferring benefit has the

⁴⁵ Rebecca Dresser, 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law' (1986) 28 *Ariz L Rev* 373, 383.

⁴⁶ Ranaan Gillon, 'Patients in The Persistent Vegetative State: A Response to Dr. Andrews' (1993) 306 *BMJ* 1602, 1603.

⁴⁷ Nancy Rhoden, 'How Should We View the Incompetent?' (1989) 17 *L Med & Health Care* 264, 266. (emphasis added)

potential to cause harm in the case of some minimally conscious individuals – for example, pain or distress – thus the principle of non-maleficence must be a consideration. Joel Feinberg contends that in the absence of ‘awareness, expectation, belief, desire, aim, and purpose, a being can have no interests’ and further argues that ‘without interests, he cannot be benefited’.⁴⁸ Thus, if the only life to be sustained is a one in complete lack of awareness, then harm to the incompetent individual is not being avoided in any real sense; he cannot sense life or death.⁴⁹ Such patients cannot benefit, in any meaningful sense, from the treatment in question as medical opinion as to their condition has concluded that they will never regain consciousness. Though bleak in some senses, it is very difficult to disagree with this summary of the situation of the unconscious, brain-damaged individual with no prospect of improvement. To some extent, it makes the matter more clear-cut.

Arguably, the greater challenge arises in relation to patients where their incompetence is not coupled with the lack of consciousness synonymous with disordered consciousness, but instead a considerably lower quality of life than they had previously, something that constitutes a considerable change in circumstances for them. Some commentators argue that decisions made by such patients when they were competent ought to be determinative, even if insufficiently formal to comply with advance directive requirements. Cantor argues that withholding of life-sustaining treatment should be permitted where it is clear that the patient would have so chosen in the circumstances:

This approach correctly seeks to implement a competent person’s right of self-determination, to the extent feasible, even after the patient has lost competence to make further determinations. Even if the patient is too insensate to appreciate the honoring of his choice, effectuation of that choice is important. American society values human dignity, and an essential component of that human dignity is the making of intimate decisions according to personal priorities and preferences.⁵⁰

One matter should be borne in mind in relation to Cantor’s argument; while it may be a reflection of the age of the piece, he treats the decision the person would have made (substituted judgment) as the same as the decision she did make (advance decision).⁵¹ Thus, the inclusion of the word

⁴⁸ Joel Feinberg, ‘The Rights of Animals and Unborn Generations’ in William T Blackstone (ed) *Philosophy and Environmental Crisis* (University of Georgia Press 1974) 61.

⁴⁹ See for example the judgment of Lord Browne-Wilkinson in *Bland* where he described Anthony Bland in the following terms: ‘If artificial feeding is continued, he will feel nothing; if artificial feeding is discontinued and he dies he will feel nothing’. *Airedale NHS Trust v Bland* [1993] 1 All ER 821, 883.

⁵⁰ Norman L Cantor, ‘*Conroy*, Best Interests, and the Handling of Dying Patients’ (1985) 37 Rutgers L Rev 543, 555-6.

⁵¹ *ibid* 555: He contends that effectuating the course of conduct that the patient would have desired ‘requires examination of any prior instructions left by the patient, whether in the form of a written document, or more formal “living will”, or oral expressions’.

‘choice’ may be a little misleading, given the position adopted by this research in relation to the difference between substituted judgment and advance decisions. Accordingly, this research would replace ‘choice’ with ‘wish’ to give the quote the desired contextual meaning. Thus, his point stands; it is important to people and society as a whole to know that their wishes will be honoured. It is harmful for them to fear that they will not. Harm in the context of a physician overriding the competent wishes of a patient was discussed in Chapter 3 and it is fair to contend that similar, or graver, harm is caused when individuals receive the message that their competent choice will be honoured, but only if others agree with it at the relevant point in time.⁵² Furthermore, such a policy would clearly be at odds with the respect and position given to contemporaneous competent decisions – in other words, the respect afforded to competent persons. As was also argued previously, part of adhering to the principle of beneficence is supporting and respecting the autonomous decision of the person, whether wise or unwise.

Other commentators, such as Rebecca Dresser, however, argue the opposite:

Incompetent patients are no longer capable of valuing their prior exercise of these rights. As a result, they can receive no present benefit from treatment decisions in accord with their former preferences; indeed, they could now be burdened by such decisions.⁵³

While Dresser undoubtedly has a point about the benefit to the patient of adhering to their previously expressed wishes, there are some issues with her contention. First, it rests to a large extent on the idea that the competent person and the incompetent person are two different *people*.⁵⁴ While people’s views, preferences, desires and values may change over time, it is not accepted that this generates a ‘new person’, rather it is argued that the incompetent person is the competent person, just at a later stage of her life. Samantha Halliday notes this in the context of advance directives:

The temporal and psychological distance that separates the anticipatory decision from the time at which it should be implemented differentiates anticipatory choices from

⁵² Nancy Rhoden makes this point in relation to living wills: ‘How Should We View the Incompetent?’ (1989) 17 L Med & Health Care 264, 266.

⁵³ Rebecca Dresser, ‘Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law’ (1986) 28 Ariz L Rev 373, 381.

⁵⁴ She argues that the assumption that ‘if we can identify what the formerly competent patient once wanted, we will know what she would want in her present incompetent state (...) can be challenged on the grounds that person’s interests can change radically over time, so radically that in some cases it could be said that a different person exists by the time the life and death treatment situation arises.’ As a result, she argues that ‘[c]ompelling justification is lacking for according greater respect to the wishes of the earlier person (no longer in existence) than to the interests of the existing one.’ Rebecca Dresser, ‘Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law’ (1986) 28 Ariz L Rev 373, 379-81. See also Rebecca Dresser, ‘Dworkin on Dementia: Elegant Theory, Questionable Policy (1995) 25 Hastings Center Report 32, 35: ‘Substantial memory loss and other psychological changes [in a patient with dementia] may produce a new person, whose connection to the earlier one could be less strong, indeed, could be no stronger than that between you and me.’

contemporaneous ones, and the asymmetries between such decisions will be particularly important where there has been a significant change in circumstances.⁵⁵

Thus, while changes in circumstances are hugely important in the context of decisions based on the wishes of the previously competent person, it is not accepted that the possibility of them occurring is a sufficient reason for ignoring such wishes outright.

Second, it affords insufficient respect to the ‘future-oriented autonomous choice of competent persons’;⁵⁶ the very premise of these kinds of conversations and conditional decisions is that they will have effect at a later point in time, otherwise they would be contemporaneous decisions. They are made in the knowledge that if certain circumstances arise at a future point in time, they will have effect. Rhoden questions this with the example of the hypothetical now incompetent pregnant woman with terminal cancer, who wanted, when competent, to give birth even if her life would be sacrificed:

If this cherished goal must be discounted once she becomes incompetent and is viewed only in the present, something morally relevant has (...) been lost (...) Does protecting the now-incompetent person by excluding her former values compromise too severely the cherished goals of the formerly competent person?⁵⁷

Furthermore, given the gravity of end-of-life decisions, society demands considerable clarity in such situations; mere vague statements or musings are insufficient to authorise the cessation of treatment. This level of control, so to speak, is something that will become readily apparent from the jurisprudence discussed later in this chapter.

Third, while the individual may receive ‘no present benefit from treatment decisions in accord with their former preferences’, it must be questioned if the corollary is accurate, namely that they would receive present benefit from treatment. Cases concerning the withdrawal or withholding of life-sustaining measures usually do not concern otherwise healthy but incompetent people.⁵⁸ They concern seriously ill and debilitated individuals with some combination of terminal physical illness, limited life expectancy, poor quality of life, limited or no expectation of improvement,

⁵⁵ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 30.

⁵⁶ Nancy Rhoden, ‘How Should We View the Incompetent?’ (1989) 17 *L Med & Health Care* 264, 266.

⁵⁷ *ibid* 267.

⁵⁸ That is not to say that they cannot.

poor awareness, poor communication or poor cognitive function. Preserving their life requires the administration of invasive treatment, which they neither have the capacity to understand and nor perhaps, the cognitive function to recognise is taking place. Thus, it is questionable what benefit is being conferred. Even if some benefit is conferred, it is debatable that it ought to be sufficient to override their prior competent wishes. Moreover, there is obvious potential for harm to be caused to the individual by continuing to administer treatment, as it may cause pain and distress given her limited capacity.

Finally, it is submitted that the honouring of the competently expressed wishes of the individual demonstrates respect ‘not only for the patient as a sick person, but for the patient as a person integrally connected to (...) her previous healthy self — the goals, preferences, and beliefs by which the patient defined (...) herself’.⁵⁹ To do otherwise would arguably be to allow a minor snapshot of the life of the individual to have a disproportionate role in shaping that life; without respect both for the patient as a sick person and as a previously healthy person, ‘patients are severed from their former lives, and stripped of the values and beliefs they had embraced’.⁶⁰ Or as Rhoden opines, albeit in relation to advance directives, ‘elevating incompetents over competents’.⁶¹

Justice

It is accepted that resources within healthcare systems are scarce or at least, not infinite. While the notion that a resource shortage may have an impact on whether or not a decision to refuse life-sustaining treatment should be honoured may be considered somewhat unsavoury, arguably, that does not stop it from being a legitimate factor, just perhaps a factor of lesser weight than the other principles.⁶² Put a little bluntly, is it the ethical decision to utilise limited resources on the person who has actively expressed a desire not to have such resources, when there are others experiencing challenges, in varying degrees, to accessing healthcare? During the Covid-19 outbreak in 2020, Suzanne Hoylaerts, a 90-year old Belgian woman, was lauded around the world for her decision to refuse ventilation on the grounds that she had ‘had a beautiful life’ and instead asked that it be

⁵⁹ New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (New York 1992) 104.

⁶⁰ *ibid.*

⁶¹ Nancy Rhoden, ‘How Should We View the Incompetent?’ (1989) 17 *L Med & Health Care* 264, 266.

⁶² Tom Beauchamp argues that distributive justice is not relevant to the refusal of life-sustaining medical treatment and that ‘any rights at stake are rights of autonomy, not rights grounded in distributive justice’. While he may be correct that the *rights* at stake are connected to autonomy and self-determination, that does not mean that aspects of the principle of justice are not engaged or unworthy of consideration. Tom Beauchamp, ‘Methods and principles in biomedical ethics’ (2003) 29 *Journal of Medical Ethics* 269, 270.

kept for younger patients.⁶³ It is argued that the acceptance by both medical professionals and the international community of her refusal demonstrated the clear link between the refusal of life-sustaining treatment and the principle of distributive justice.⁶⁴

It is worth saying that it is not only distributive justice that interacts with the refusal of life-sustaining treatment, but other aspects of justice too. As was argued in the previous chapter, differing levels of respect for the wishes of individuals must be justified by morally relevant criteria. If we allow one to refuse life-sustaining treatment, then we must allow all unless there is a morally relevant reason not to. Yet, if we briefly look ahead to some of the case law that forms the basis of this chapter, it is argued that the principle of justice has been violated. This is because morally irrelevant criteria were used in deciding whether to honour the wishes of the patient. For example, in the *O'Connor* case, which will be discussed in more detail in this and the next chapter, the previously expressed wishes of an older person were summarily dismissed by the court as statements ‘that older people frequently, almost invariably make’.⁶⁵ It is difficult to see how the age of the person who made the statements was a morally relevant criterion in assessing whether or not her wishes should be respected. It is worth saying that Mrs O'Connor was incompetent at the time of the court hearing, however, the quote taken from the judgment is to highlight the attitude of the court to the statements she made while competent. One would hope that the matter would be decided differently were she standing before the court competently making such statements.

The Incompetent Patient

It is generally considered unjust to treat a patient against his competently expressed wishes and furthermore, competent, autonomous individuals should be responsible for the consequences of their actions. Thus, conflict arises with the principle of justice arising when the previously expressed competent wish of the individual is overridden once she becomes incompetent, in order to protect her. While some might argue that such a position is subsumed within the principle of autonomy, the concept of justice advanced in previous chapters has a broader definition, thereby

⁶³ Maïthé Chini, ‘Belgian Woman (90) Dies after Refusing Ventilator’ *The Brussels Times* (Brussels, 1 April 2020) <<https://www.brusselstimes.com/belgium/104108/coronavirus-belgian-woman-90-dies-after-refusing-ventilator/>> accessed on 17 April 2020.

⁶⁴ Acceptance of such a decision by the medical community was unsurprisingly, given that euthanasia is legal in Belgium. It was the reaction around the world that seems to demonstrate and acknowledge the existence of a link between distributive justice and the refusal of life-sustaining treatment.

⁶⁵ *Re Westchester County Medical Center [O'Connor]* 72 NY 2d 517 (1988); 532.

encompassing this aspect of justice. Such interference clearly breaches the principle because it prohibits her from being responsible for her previously articulated autonomous choice. This is not to be confused with situations where a patient lacks decision-making capacity and attempts to make a *bad* decision; justice requires that she be protected from unfairly suffering the consequences of a decision that she was incompetent to make. In other words, there is a morally relevant reason for treating her differently.⁶⁶

This element of the principle of justice is particularly acute where the treatment advised is life-sustaining and therefore the likely consequence of withholding or withdrawing that treatment is death. Arguably therefore, the relevance of this particular aspect of justice must rest on there being something significant to protect, as there would be in the case of an incompetent person making the wrong decision for herself. Perhaps this is one aspect of what makes end-of-life cases involving seriously ill or comatose patients, who cannot or have not decided for themselves, challenging; whose role is it and ought it to be to decide what is and is not deserving of preservation and protection? It will become apparent that the courts have occasionally struggled with this question. As outlined earlier, in relation to PVS patients, Gillon argues that there is no medio-moral obligation on a physician to provide treatment where intervention is unlikely to provide benefit and withholding or withdrawing treatment does not infringe the doctor's duty.⁶⁷ In other words, this function of justice, namely to protect incompetent people from bearing the responsibility of negative consequences of their 'wrong' decision is irrelevant in that context. The person has not made any decision, nor will they ever be capable of doing so. With this in mind, the dominant principle when deciding whether or not to treat the incompetent person should be beneficence and as discussed previously, treatment should be administered only if it benefits the patient.

A further aspect of the principle of justice is relevant in cases involving the administration of nonbeneficial treatment of incompetent individuals, namely resource shortage. Gillon argues that there may actually be a moral obligation to withhold or cease treatment in such circumstances given the scarcity of resources within health systems.⁶⁸ There can be a tendency in some circles to

⁶⁶ See Chapter 3. See also Alasdair Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009) 60.

⁶⁷ Ranaan Gillon, 'Persistent Vegetative State, Withdrawal of Artificial Nutrition and Hydration, and the Patient's "Best Interests"' (1998) 24 *J Med Ethics* 75.

⁶⁸ *ibid.*

conflate an obligation to withdraw treatment arising from resource shortage with a statement that certain lives cost ‘too much’ or they are not worth living. When Mrs Hoylaerts refused ventilation during the COVID-19 outbreak, her reasoning for doing so was that she had had a good life – not that her life was no longer worth living – and that somebody younger should be ventilated. In other words, she was aware of the scarcity of resources. Her decision was that of a living, conscious, competent person who had the possibility of extending her life; thus, she was someone who was capable of deriving benefit from such treatment. If her decision and reasoning can be accepted and celebrated, then it seems implicit that we should adopt the same reasoning in relation to patients who cannot derive benefit from treatment but who cannot express that. Nothing here should be construed as implying that elderly, gravely ill or mentally disabled patients should be denied treatment in order to efficiently use resources. Rather, when such a patient has no clear previously expressed wishes on treatment, the burden and particularly benefit of such treatment must be examined thoroughly, without the automatic assumption that continuing to live, in the biological sense, is positive.

Law at the End-of-Life

Courts have recognised that intrinsic to informed consent is informed refusal.⁶⁹ Without the right to refuse treatment, the right to consent is virtually meaningless, however, that does not mean that end-of-life situations are devoid of challenges for the courts. As will be clear from the discussion of the jurisprudence, two veins of case law have tended to emerge under the umbrella heading of ‘end-of-life decisions’; those concerning express refusal of life-saving treatment and those that concern incompetent individuals incapable of expressing consent or refusal at the relevant time. The former often rest on a finding as to the capacity of the individual. The latter are considerably more complex; in the first instance, it depends on the nature of the incompetence of the individual, in other words, whether the individual has always lacked capacity or whether the incompetence has been caused by a change in circumstances, such as an accident or illness. Where the person never had capacity or where their prior thoughts on end-of-life matters are not ascertainable, the

⁶⁹ For example, *Re Conroy*, 98 NJ 321 (1985); 348: ‘The patient’s ability to control his bodily integrity through informed consent is significant only when one recognizes that this right also encompasses a right to informed refusal’; *Cruzan v Director, Missouri Department of Health* 497 US 266 (1990); 270: ‘The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment’. *Re a Ward of Court* [1996] 2 IR 79, 129. *Re T (Adult: refusal of treatment)* [1993] Fam 95, 99 (hereafter ‘*Re T*’).

court will determine the best course of action for that person in line with the relevant domestic legal standard. Where the person had capacity at one time, the judgment sometimes rests on a determination as to if, while competent, she actually made the relevant decision. As will be evident as this chapter progresses, the rules applicable to determining if a decision has been made varies between jurisdictions and has been extensively developed.

One might reasonably question why some of the cases being discussed are relevant to this research, as in many of these end-of-life cases, the person never had capacity, or they were competent at some point but never made the relevant decision. After all, the focus of the research is advance decisions, which clearly require the decision-maker to have capacity when the decision is being drafted. The purpose of considering such cases is two-fold; first, such cases give important context to the legal and ethical issues surrounding the refusal of life-saving medical treatment. In some jurisdictions, cases involving incompetent individuals established the right of the individual to decline life-sustaining medical treatment, despite the inability of the individual at the heart of the case to assert that right. Thus, they are of value in a historical sense but also in the sense of articulating what interests and rights the law was attempting to protect when ordering the cessation of treatment. Second, they highlight the alternative; in other words, they demonstrate how individuals are treated by the law in the absence of a valid advance decision.

Finally, before considering the jurisprudence and statutes in the various jurisdictions, it is worth briefly bearing in mind the applicability of Articles 3 and 8 of the European Convention on Human Rights to medical decision-making in Ireland and England and Wales.⁷⁰ Respect for the private life of the individual is guaranteed by Article 8 and it has been held *inter alia* that this right is engaged where the case concerns the refusal of medical intervention by a competent individual.⁷¹ Thus, cases involving non-consensual medical treatment are solidly within its ambit. The relationship between Article 3 – prohibition of inhuman or degrading treatment – and medical treatment is a little less clear. Degrading treatment is understood to mean conduct that ‘grossly humiliates [the individual] before others or drives him to act against his will or conscience’.⁷² Thus, Article 3 may be applicable to compelled intervention depending on the circumstances and

⁷⁰ It has been suggested that articles aside from 3 and 8 may also be relevant to non-consensual medical treatment; for discussion on the relevance of Articles 2, 9 and 12, see Deirdre Madden, *Medicine, Ethics and the Law* (3rd edn, Bloomsbury 2016) 470-1.

⁷¹ *X v Austria* [1980] 18 DR 154; *Pretty v United Kingdom* [2002] 35 EHRR 1.

⁷² *Denmark, Norway, Sweden and the Netherlands v Greece* [1969] 12 YB 1, 186. See also *East African Asians v United Kingdom* [1973] EHRR 76, para 195.

severity of the case. Andrew Grubb *et al* posit that Article 3 may be engaged ‘where treatment humiliates or debases an individual showing a lack of respect for, or diminishing, his or her human dignity’, which it could be argued may occur in the context of certain unwanted medical intervention.⁷³ Deirdre Madden argues, on the one hand, that ‘the emphasis on humiliation’ and the ‘leaning towards the protection of human dignity as opposed to the concept of autonomy’ may render non-consensual medical treatment outside the ambit of Article 3.⁷⁴ On the other hand, she acknowledges that as ‘non-consensual medical treatment deprives a person of the freedom of choice over his own body, which is a fundamental part of individual dignity’, Article 3 may be engaged.⁷⁵

Once again, the concept of human dignity and specifically its protection has arisen. Though abstract, individual dignity has been in receipt of protection in the Irish courts under the Constitution (as distinct from the ECHR).⁷⁶ In Chapter 2, various concepts of dignity were outlined and in the same chapter, some of the challenges associated with dignity as a concept were briefly discussed. Dignity, however, insofar as the case law has indicated, is both worthy of protection and capable of being diminished by external factors. In the legal context, it may be useful to view it as Roger Brownsword’s and Deryck Beyleveld’s *empowerment* or Suzy Killmister’s *aspirational dignity*, which is ‘the quality held by individuals who are living in accordance with their principles’.⁷⁷ Such a concept of dignity is valuable but prone to attack and therefore worthy of protection. Accordingly, situations such as an individual being forced to manually empty human waste from his prison cell for a prolonged period of time and the life of an individual being artificially sustained with no prospect of meaningful recovery have been seen as affronts to human dignity.⁷⁸

Ireland

Ireland is no different to the vast majority of jurisdictions in that a competent adult has a right to refuse medical treatment, even if that refusal will result in death, however there is comparatively

⁷³ Andrew Grubb, *Principles of Medical Law* (3rd edn, OUP 2010) 259.

⁷⁴ Deirdre Madden, *Medicine, Ethics and the Law* (3rd edn, Bloomsbury 2016) 470.

⁷⁵ *ibid.*

⁷⁶ See *Simpson v The Governor of Mountjoy Prison* [2019] IESC 81; *Re a Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 IR 79.

⁷⁷ Suzy Killmister, ‘Dignity: Not Such A Useless Concept’ (2010) 36 J Med Ethics 160, 161.

⁷⁸ *Re a Ward of Court* [1996] 2 IR 79. For England and Wales, see *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449, 460 (‘Re B’) and *Re M* [2012] 1 All ER 1313 where this appeared to be the concept of dignity being advanced by the patients at the centre of those cases, or on their behalf.

less case law coming from Ireland than the United Kingdom or United States. As Denham J stated in *Re a Ward of Court (withholding medical treatment) (No. 2)* ('*Re a Ward of Court*')

Medical treatment may not be given to an adult person of full capacity without his or her consent (...) This right arises out of civil, criminal and constitutional law (...) The consent which is given by an adult of full capacity is a matter of choice.⁷⁹

Even if Denham J had been less unequivocal, the very fact that medical negligence cases alleging a lack of informed consent, wherein the accepted method of demonstrating causation was to show that the plaintiff would not have undergone the treatment, existed, presupposed that informed consent to treatment was a legal requirement.⁸⁰ Indeed, O'Flaherty J as much as makes this contention in the course of *Re a Ward of Court*, where he states:

The next matter that is not in dispute is that consent to medical treatment is required in the case of a competent person (...) and, as a corollary, there is an absolute right in a competent person to refuse medical treatment even if it leads to death.⁸¹

Although the use of the word 'absolute' is questionable in the context of the right to refuse medical treatment, the intention of this judgment is clear; generally speaking, a competent adult has the right to refuse unwanted life-sustaining medical intervention.

Right to Refuse Treatment: The Constitution

The right to refuse medical treatment is not only a right at common law but is also said to flow from various articles of the Irish Constitution. Both fundamental and unenumerated personal rights included in Bunreacht na hÉireann have been considered as the foundation of this right. Unenumerated rights such as the right to bodily integrity, as established in *Ryan v Attorney General*⁸² is a clear basis for the right to refuse treatment. As acknowledged in *AB v CD*:

[O]rdering medical treatment and especially surgical treatment contrary to the wishes of an adult patient impinges upon the bodily integrity of the individual, so in the case of a patient of full age and capacity (...) it normally needs to be clear that the person does indeed lack such capacity.⁸³

⁷⁹ [1996] 2 IR 79, 156.

⁸⁰ O'Flaherty J as much as makes this point in the course of *Re a Ward of Court*, where he states that '[t]he next matter that is not in dispute is that consent to medical treatment is required in the case of a competent person (cf *Walsh v Family Planning Services Ltd* [1992] 1 IR 496) and, as a corollary, there is an absolute right in a competent person to refuse medical treatment even if it leads to death'.

⁸¹ [1996] 2 IR 79, 129.

⁸² [1965] IR 294.

⁸³ [2016] IEHC 541, para 8.

The unenumerated right to privacy has also be construed as encompassing the right to refuse medical treatment.⁸⁴ In her judgment in *Re a Ward of Court*, Denham J acknowledged that part of the right to privacy, which is an unenumerated right under the Constitution, is ‘the giving or refusing of consent to medical treatment’.⁸⁵ Furthermore, she added that ‘[a] constituent of the right of privacy is the right to die naturally, with dignity and with minimum suffering’.⁸⁶

It has also been accepted by the court that the autonomy to choose or refuse treatment is derived from the right to life, a fundamental right guaranteed by article 40.3 of Bunreacht na hÉireann. The consequence of this right is a correlating duty on the state to respect autonomous decisions, in order to protect that right.⁸⁷ In *Fleming v Ireland*, it was stated by the High Court that:

[O]ne necessary feature of the Constitution’s protection of the ‘person’ in art 40.3.2 is that the competent adult cannot be *compelled* to accept medical treatment and that our constitutional traditions have firmly set their face against the compulsion of the competent adult in matters of this kind.⁸⁸

This interpretation was also clear in the case of *Governor of X Prison v PMcD*, which concerned a man on hunger strike wished to refuse food and related medical assistance. In the words of Baker J:

The sentence of imprisonment lawfully imposed upon Mr McD has of course deprived him of his right to personal liberty, but it (...) cannot be suggested as a matter of law, that he has thereby lost all of his constitutional rights including the right of personal autonomy, and the right of bodily integrity (...) A person has under the Constitution certain fundamental rights including the right to life, the right to personal autonomy, the right to bodily integrity, and the right to self-determination, the right to live one’s life as one wishes provided those wishes do not impact upon or harm others, and provided no conflict arises between that individual right and the interests of society.⁸⁹

This conclusion was also reached in *Re a Ward of Court*, where Hamilton CJ stated:

As the process of dying is part, and an ultimate, inevitable consequence, of life, the right to life necessarily implies the right to have nature take its course and to die a natural death and, unless the individual concerned so wishes, not to have life artificially maintained.⁹⁰

Right to Refuse: Irish Jurisprudence

⁸⁴ *McGee v Attorney General* [1974] IR 284; *Norris v Attorney General* [1984] IR 36.

⁸⁵ *Re a Ward of Court* [1996] 2 IR 79, 162-3.

⁸⁶ *ibid* 163.

⁸⁷ *Governor of X Prison v PMcD* [2016] 1 ILRM 116, 118.

⁸⁸ *Fleming v Ireland* [2013] 131 BMLR 30, 54.

⁸⁹ *Governor of X Prison v PMcD* [2016] 1 ILRM 116, 142-3.

⁹⁰ [1996] 2 IR 79, 124.

As was previously discussed, two veins of case law have emerged in Ireland under the broad heading of ‘end-of-life decisions’; where treatment is or has been refused or where individuals are unable to consent to or refuse treatment. The seminal Irish authority on the latter type of end-of-life decision-making is *Re a Ward of Court*, in which the mother of a severely brain damaged woman petitioned the court to have artificial nutrition withdrawn.⁹¹ As distinct from many of the renowned early end-of-life cases – for example, *Airedale NHS Trust v Bland*⁹² and *Cruzan v Director Missouri Department of Health*⁹³, which will be discussed later in this chapter – the woman was not in PVS, but was acknowledged to be quite close to it in the judgment. Although this case primarily focused on the right of the individual to refuse medical treatment as stemming from an exercise of constitutional rights, the common law right of the individual to refuse was recognised. Citing American law, O’Flaherty J stated that ‘it would be correct to describe the right in our law as founded both on common law as well as the constitutional rights of bodily integrity and privacy’.⁹⁴ Denham J adopted a similar approach stating that medical treatment could not be given to a competent adult without consent, save in rare exceptions, a right which ‘arises out of civil, criminal and constitutional law’.⁹⁵

The court held that, whilst the right to life was a pre-eminent personal right, the requirement of the State to defend and vindicate that life is not absolute.⁹⁶ One can appreciate why this interpretation was taken by the court given that the wording of Article 40.3.1 of the Constitution is ‘as far as practicable’ and not, ‘at all costs’ or equivalent.⁹⁷ This is why, as Denham J explained, the state’s respect for the life of the individual ‘encompasses the right of the individual to (...) refuse a blood transfusion for religious reasons’; by recognising the autonomy of the individual, ‘life is respected’.⁹⁸ In adopting an approach similar to jurisprudence in England and Wales, the court identified ‘best interests’ of the incompetent woman as the relevant test and ruled those to be paramount. In assessing her best interests, the Supreme Court affirmed the decision of the High Court and found that the continuation of ‘invasive’ medical treatment – as distinct from basic care

⁹¹ *ibid.*

⁹² [1993] 1 ER 821.

⁹³ 497 US 261 (1990).

⁹⁴ [1996] 2 IR 79, 130.

⁹⁵ *ibid* 156. See also Denham J at 146: ‘These matters have not been addressed by the Oireachtas so it falls to be decided by this Court in accordance with the Constitution and the *common law*’ (emphasis added).

⁹⁶ *ibid* 160.

⁹⁷ Denham J makes this very point; [1996] 2 IR 79, 160.

⁹⁸ *ibid.*

– and the accompanying ‘loss of bodily integrity and dignity’ with ‘no curative effect’ was not in her best interests.⁹⁹

It is worth explaining the focus that this research gives to the categorisation of CAHN as medical treatment, a theme which will be picked up again in more detail when the law from England and Wales is considered. That distinction is relevant for the purpose of this research, as there is a difference in how advance refusals of CAHN are treated in different jurisdictions, something that will be considered in more detail in the next chapter. In short, certain US states have opted to exclude it from being specified in an advance directive and others require that it is specifically stated in the advance directive that CAHN is to be refused.¹⁰⁰ In *Re a Ward of Court*, Blayney J found that Lynch J in the High Court was entitled to find that artificial nutrition constituted medical treatment in view of judgments from other jurisdictions.¹⁰¹ Hamilton CJ stated that he had ‘no doubt but that the treatment being afforded to the ward, constituted “medical treatment” and not merely “medical care”’.¹⁰² Perhaps such conclusions reflects what Cantor describes as the acknowledgement that ‘the need for artificial nutrition and hydration is prompted by disease or other pathology and that the patient is entitled to control their provision just as with any other medical response to bodily dysfunction’.¹⁰³

Although *Re a Ward of Court* concerned withdrawing existing treatment, the rationale has been applied to cases concerning the withholding of future treatment. In *HSE v JM*, the court found that it was not in the best interests of a minimally conscious man to be resuscitated¹⁰⁴ or for ventilator support to be increased beyond the level at which it was at the time of the hearing.¹⁰⁵ Kelly J stated:

The risks involved in [increased ventilator support] are substantial. No doctor supports the provision of the therapy. No improvement of his underlying condition will be effected. No lessening of the burden of J.M.'s illness will be brought about. No clear medical benefit will be achieved. The burden of the treatment outweighs such limited benefits as may accrue from it.¹⁰⁶

⁹⁹ *ibid* 158 and 128.

¹⁰⁰ Given the way the law is written in both Ireland and England and Wales, it is also the case that CAHN must be specified, however, it is not treated any differently to any other treatment in Ireland or England and Wales as it is in some parts of the United States.

¹⁰¹ [1996] 2 IR 79, 143-4; *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990).

¹⁰² [1996] 2 IR 79, 126.

¹⁰³ Norman L Cantor, ‘Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying’ (2001) 29 J L Med Ethics 182, 184.

¹⁰⁴ Receive CPR, cardioversion, defibrillation.

¹⁰⁵ [2017] IEHC 399.

¹⁰⁶ *ibid* para 125.

The second type of case identified previously under the heading of end-of-life cases concern an express refusal of treatment, whether contemporaneously expressed or expressed in advance. *JM v The Board of Management of Saint Vincent's Hospital* concerned the application of a man of Jehovah's Witness faith to have a blood transfusion and liver transplant performed on his wife, who adopted his religion upon marriage.¹⁰⁷ The evidence was the woman had consented to treatment, then refused to sign the consent form. Although the judgment refers to her being 'visibly weaker', 'not as clear in speech' and 'not as clear of mind' when she made the decision, Finnegan P appears not to focus on whether or not she had capacity to make a decision at the time. Instead, the judgment focuses on whether, prior to lapsing into a coma, she had made a decision at all. On this matter, he found that she 'did not make a clear final decision to have, or not to have the treatment' and attributed her apparent refusal to 'her cultural background and her desire to please her husband and not offend his sensibilities'.¹⁰⁸ Accordingly, an order was made to admit the woman to wardship and authorise the liver transplant and blood transfusion.

Understandably, the judgment has been described by Madden as difficult to reconcile with legal principle.¹⁰⁹ The woman had refused to sign the consent form for the procedures, thereby indicating a refusal to be treated, as it was not the case that she lost consciousness before she could sign the form. Thus, while she may have changed her mind about the procedures, it is argued that it was not accurate of the learned judge to say that she had not made 'a final decision'. Arguably, the issue ought to have been decided on the principles of informed consent, which may well have yielded the same outcome but with different reasoning. Perhaps, the appropriate question ought to have been: was a voluntary decision made by a person with the capacity to do so having received the relevant information? Had the decision of the court been made in line with the precedent from England and Wales at the time, which was discussed in the previous chapter,¹¹⁰ or were it being made today, the same outcome may well have occurred. In any event, if there were any lack of clarity as to the law on refusing medical treatment arising from the judgment in *JM*, it has been clarified by *Fitzpatrick and Another v K and Another*, wherein Laffoy J applied *Re a Ward of Court*:

¹⁰⁷ [2003] 1 IR 321.

¹⁰⁸ *ibid* 325.

¹⁰⁹ Deirdre Madden, *Medicine, Ethics and the Law* (3rd edn, Bloomsbury 2016) 481.

¹¹⁰ *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290.

In the light of the decision of the Supreme Court (...) it could not be argued that a competent adult is not free to decline medical treatment. While that case concerned the withholding of medical treatment in the case of a person who had been found to be incompetent, the foundation of the ratio decidendi is the court's exposition of the position of a competent adult.¹¹¹

The legal position regarding the ability of a competent adult to refuse medical treatment is now settled.¹¹² The jurisprudence has been codified by the Assisted Decision-Making (Capacity) Act 2015, with section 83(2) stating that a competent adult may refuse treatment for any reason irrespective of the life-threatening consequences.

England and Wales

Competent Individuals

The right of a competent adult to refuse medical treatment has been embedded in English law for quite some time. As articulated by Lord Scarman in *Sidaway*:

The right of 'self-determination', the description applied by some to what is no more and no less than the right of a patient to determine for himself whether he will (...) accept the doctor's advice, is vividly illustrated where the treatment recommended is surgery (...) The existence of the patient's right to make his own decision, which may be seen as a basic human right protected by the common law, is the reason why a doctrine embodying a right of the patient to be informed of the risks of surgical treatment has been developed (...) The profession (...) should not be judge in its own cause; or, less emotively but more correctly, the courts should not allow medical opinion as to what is best for the patient to override the patient's right to decide (...) whether he will submit to the treatment offered him.¹¹³

Somewhat inevitably, this right to refuse was extended to life-saving medical treatment, or in the words of Lord Donaldson, refusals which may even 'lead to premature death'.¹¹⁴ As Lord Mustill opined in *Airedale NHS Trust v Bland*:

If the patient is capable of making a decision (...) and decides not to permit it his choice must be obeyed, even if on any objective view it is contrary to his best interests. A doctor has no right to proceed in the face of objection, even if it is plain to all, including the patient, that adverse consequences and even death will or may ensue.¹¹⁵

¹¹¹ [2009] 2 IR 7, 13. The *K* case is discussed in more detail in the previous chapter in relation to the development of Irish law in relation to capacity assessments.

¹¹² Provided that person is not pregnant.

¹¹³ [1985] 1 All ER 643, 649-650.

¹¹⁴ *Re T* [1993] Fam 95, 115. See also for example, *King's College NHS Foundation Trust v C* [2015] EWCOP 80.

¹¹⁵ [1993] 1 ER 821, 889.

Thus, the decision of a patient undergoing life-sustaining treatment ‘that it would be preferable to die’ must be honoured.¹¹⁶ The categorisation of end-of-life, described in the introductory paragraph on the law will be continued in this section, with the cases concerning express refusals being considered first.

Re T concerned a woman who required a blood transfusion following a car accident and Caesarean section. Although she was brought up in accordance with the tenets of the Jehovah’s Witness faith, she never became a member. Prior to going into labour and while under the influence of narcotics, she stated to a nurse that she did not want a blood transfusion, that she had been a Jehovah’s Witness and retained some beliefs. Prior to undergoing the Caesarean section, Ms T again stated her opposition to a blood transfusion. Both refusals were expressed after Ms T had been alone with her mother, who was a practicing member of the faith. After being informed that transfusions were usually unnecessary and that other procedures were available, Ms T signed the hospital refusal form. Following the Caesarean section, her condition deteriorated to such an extent that a blood transfusion was necessary to preserve her life. Her father petitioned the court for an order permitting a blood transfusion, which was granted. At the subsequent hearing, however, the judge found that Ms T’s decision-making capacity was unimpaired. The Court of Appeal upheld the right of an individual to refuse life-saving medical treatment, but ‘for such a refusal to be effective his doctors had to be satisfied that (...) his capacity to decide had not been diminished by illness or medication or by false assumptions or misinformation’ and ‘that his will had not been overborne by another’s influence’.¹¹⁷ The court found on the facts that the refusal was invalid and that treatment was warranted.

Lord Donaldson made a point of opining that *Re T* was not about the ‘right to die’, but instead about the ‘right to choose how to live’.¹¹⁸ While it contained a strong statement about the right of the individual to refuse life-saving medical treatment, it rested on whether Ms T had made a voluntary and valid decision at the relevant point in time. In explaining the balancing act between sanctity of life and individual self-determination, Lord Donaldson states:

The patient’s interest consists of his right to self-determination – his right to live his own life how he wishes, even if it will damage his health or lead to his premature death.

¹¹⁶ *ibid.* The learned judge did apply a proviso, which was that ‘all necessary steps have been taken to be sure that this is what he or she really desires’.

¹¹⁷ *Re T* [1993] Fam 95, 96.

¹¹⁸ *ibid* 102.

Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount. But this merely shifts the problem where the conflict occurs and calls for a very careful examination of whether (...) the individual is exercising that right. In case of doubt, that doubt falls to be resolved in favour of the preservation of life for if the individual is to override the public interest, he must do so in clear terms.¹¹⁹

Thus, this case enshrined the common law right of the competent person to refuse life-sustaining medical treatment, a position that has been reiterated on a number of occasions.¹²⁰

Re B concerned a woman who suffered an intramedullary cervical spine cavernoma, which led to paralysis below the neck and reliance on a ventilator.¹²¹ She wanted ventilation to be removed and gave instructions to the hospital to this effect. Prior to this, she had drawn the attention of staff to an advance directive, wherein she stated that she did not want to be ventilated; she was, however, informed at the time that it was insufficiently specific to permit her ventilation to be withdrawn. When her capacity was assessed initially, she was found to be competent, however, the psychiatrists subsequently amended their determinations. After she was prescribed anti-depressants, Ms B said that she was relieved that the ventilator had not been switched off and agreed to attempt spinal rehabilitation. When her capacity was reassessed by the hospital psychiatrists in the months that followed, they were unable to determine her capacity, however, an independent reassessment at her request resulted in her being found to have decision-making capacity. Although Ms B was requesting that the ventilator be withdrawn, the hospital staff proposed to attempt the gradual reduction of ventilator support with the eventual aim of enabling her to breathe unassisted ('weaning'). This suggestion was rejected by Ms B for a variety of reasons, including her fear that it would result in a 'slow and painful death' and result in her being 'robbed of a certain amount of dignity', but critically because she viewed it as being devoid of benefit because of her level of disability.¹²²

Butler-Sloss LJ stated with clarity that 'the right of the competent patient to request cessation of treatment must prevail over the natural desire of the medical and nursing profession to try to keep

¹¹⁹ *ibid* 112.

¹²⁰ For example, see Jackson J in *Heart of England NHS Trust v JB* 137 BMLR 232, 235; '[A]nyone capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom *or consequences* of the decision' (emphasis added).

¹²¹ *Re B* [2002] 2 All ER 449 ('*Re B*').

¹²² *ibid* 460.

her alive'.¹²³ Arguably, it would have been patently inconsistent with the existing common law position for the court to rule any other way. The learned judge continued:

One must allow for those as severely disabled as Ms B, for some of whom life in that condition may be worse than death. It is a question of values and (...) we have to try inadequately to put ourselves into the position of the gravely disabled person and respect the subjective character of experience. Unless the gravity of the illness has affected the patient's capacity, a seriously disabled patient has the same rights (...) to respect for personal autonomy. There is a serious danger, exemplified in this case, of a benevolent paternalism which does not embrace recognition of the personal autonomy of the severely disabled patient.¹²⁴

Ms B was found to be competent to decide to have ventilation withdrawn, which was duly carried out after she was transferred to a different hospital. In doing so, the court seemed to strike a balance between Ms B's autonomy and self-determination and the integrity of the medical professionals that had been treating her, who had clear reservations about withdrawing ventilation.¹²⁵

Furthermore, as Ms B was determined to have decision-making capacity from the point in time at which the independent assessment was conducted, the Trust was considered to have administered treatment unlawfully after this point. On this matter, however, Bulter-Sloss LJ added that it was important to distinguish between the duties of the team who cared for Ms B 'to the highest standards of medical competence and with devotion' and the duties of the Trust.¹²⁶ The former, she found, received a request from Ms B, which although understandable 'in a palliative care situation', was 'outside the experience of the intensive care unit in relation to a mentally-competent patient'; thus, it was 'seen by some as killing the claimant or assisting her to die', thereby breaching their ethical duties.¹²⁷ Thus, the learned judge emphasised that it was the failure of the Trust to take steps to resolve the dilemma with the necessary urgency that was the reason behind the finding of unlawful treatment and not the actions of the treating professionals.¹²⁸ Indeed, perhaps what made it more challenging for the staff in this case was the fact that Ms B was refusing a treatment not with mere acceptance that it may lead to her death, rather '[h]er expectation – indeed her hope

¹²³ [2002] 2 All ER 449, 457.

¹²⁴ [2002] 2 All ER 449, 472.

¹²⁵ Norman Cantor describes this balancing act between patient autonomy and the integrity of the medical profession as follows: 'While the courts acknowledge a health-care provider's interest in maintaining personal scruples or following one's conscience, the judicial solution is to allow the provider asserting a conscientious objection to refer the patient to another provider and withdraw from the case, thus not overriding the patient's preference to forgo treatment.' Norman L Cantor, 'Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying' (2001) 29 J L Med Ethics 182, 184.

¹²⁶ [2002] 2 All ER 449, 451.

¹²⁷ *ibid.*

¹²⁸ Ms B was awarded a small amount in damages in recognition of the unlawful treatment; [2002] 2 All ER 449, 474.

– was that she would subsequently die’.¹²⁹ As Sheila McLean contends, she ‘chose, effectively, death over a quality of life she regarded as unacceptable’.¹³⁰

The law has, however, developed to protect individual choice and to mitigate against situations where individual choice gets overridden because it may go against ‘the norm’. John Coggon argues:

[E]ven where medical law gives special value to continued life, medico-legal norms have developed to protect a system of value pluralism, where it is recognised that perspectives on a person’s moral, social, spiritual, and other interests legitimately vary. Respect should be given to the specific patient’s conception of her interests including when her life is at stake.¹³¹

One could certainly argue that this case makes it abundantly clear that the refusal of treatment by a competent adult will almost invariably stand. Indeed, Butler-Sloss LJ stated as much in the course of the judgment when she said that ‘if (...) that patient, having been given the relevant information and offered the available options, chooses to refuse the treatment, that decision has to be respected by the doctors’.¹³² As will be discussed in Chapter 6, this also appears to be the case for competent pregnant patients, at least in principle, notwithstanding any increased scrutiny that their capacity may garner.

Incompetent Individuals

The second ‘type’ of case arising in the context of end-of-life decision-making are those when the individual cannot make the relevant decision, nor is it likely that they will be able to do so in the future. Perhaps the seminal case, or certainly one of the most well-known, on the withdrawal of life-saving medical treatment from an individual who was incapable of exercising his right to choose was *Airedale NHS Trust v Bland*.¹³³ Anthony Bland suffered catastrophic injuries and was left in a permanent vegetative state (PVS) as a result of a crush at the Hillsborough football ground in Sheffield. He was capable of breathing and had some reflex responses to stimuli but was in ‘a

¹²⁹ Sheila AM McLean, ‘Decisions at the End of Life: An Attempt at Rationalisation’ in Catherine Stanton and others (eds) *Pioneering Healthcare Law; Essays in Honour of Margaret Brazier* (Routledge 2016) 58.

¹³⁰ *ibid.*

¹³¹ John Coggon, ‘Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection’ (2016) 24 *Med L Rev* 396, 399.

¹³² [2002] 2 All ER 449, 474.

¹³³ [1993] 1 ER 821.

complete state of unawareness' with no prospect of improvement or recovery of cognitive function.¹³⁴

He has no feeling, no awareness, nor can he experience anything relating to his surroundings. To his parents and family he is 'dead' (...) all that remains is the shell of his body. This is kept functioning as a biological unit by the artificial process of feeding through a mechanically operated nasogastric tube.¹³⁵

Airedale General Hospital, with the support of his parents, applied to the court to have artificial hydration and nutrition withdrawn and for authorisation to withhold antibiotics, when the need arose. Opposed to the initial application was the Official Solicitor, alleging that such withdrawal and withholding was 'both a breach of the doctor's duty to care for his patient, indefinitely if need be, and a criminal-act'.¹³⁶ The decision of Sir Stephen Brown P, which permitted the lawful discontinuation of all life-sustaining treatment including hydration and nutrition, was subsequently appealed to the Court of Appeal and thereafter, the House of Lords.

The issue of substance for the appeal courts was if a physician was obliged to continue treating a patient who was incapable of giving or refusing consent to treatment, irrespective of the circumstances or quality of that patient's life.¹³⁷ In the Court of Appeal, Sir Thomas Bingham MR was keen to emphasise what the case was and was not about, stressing that it was not about euthanasia – 'the taking of positive action to cause death' – nor was it about 'putting down the old and infirm, the mentally defective or the physically imperfect'.¹³⁸ Instead, the learned judge articulated that the case was about 'whether artificial feeding and antibiotic drugs may lawfully be withheld from an insensate patient with no hope of recovery when it is known that if that is done the patient will shortly thereafter die'.¹³⁹ The issue of criminal liability in circumstances such as

¹³⁴ *Airedale NHS Trust v Bland* [1993] 1 ER 821, 825; 'EEG and CT scans reveal no evidence of cortical activity. Indeed recent scans which have been photographed and produced to the court show that there is more space than substance in the relevant part of Anthony Bland's brain. There is simply no possibility whatsoever that he has any appreciation of anything that takes place around him.'

¹³⁵ [1993] 1 All ER 821, 832.

¹³⁶ *ibid* 822.

¹³⁷ *ibid* 883: Lord Browne-Wilkinson described the critical decision to be made by the Court as 'whether it is in the best interests of Anthony Bland to continue the invasive medical care involved in artificial feeding'. He continued: 'The (...) question assumes that it is lawful to perpetuate the patient's life; but such perpetuation of life can only be achieved if it is lawful to continue to invade the bodily integrity of the patient by invasive medical care. Unless the doctor has reached the affirmative conclusion that it is in the patient's best interest to continue the invasive care, such care must cease.'

¹³⁸ *ibid* 835. See also Hoffman LJ concurring at 856. The House of Lords also distinguished the case from active euthanasia; see Lord Lowry for example: 'I consider that the court, when intent on reaching a decision according to law, ought to give weight to in-formed medical opinion both on the point now under discussion and also on the question of what is in the best interests of a patient and I reject the idea, which is implicit in the appellant's argument, that informed medical opinion in these respects is merely a disguise for a philosophy which, if accepted, would legalise euthanasia.' [1993] 1 All ER 821, 876.

¹³⁹ *ibid*.

Anthony Bland's had been somewhat sidestepped by the court of first instance.¹⁴⁰ Both the House of Lords and the Court of Appeal were clear that no criminal liability should attach for the withdrawal of medical treatment in the circumstances.¹⁴¹ Bulter-Sloss LJ stated in the Court of Appeal:

I do not consider that there remains a duty of care upon the doctors to continue the artificial feeding and (...) there is no actus reus and no unlawful act or omission. The issue of mens rea does not arise (...) My view is supported ... by the decision of the Superior Court of the State of California (...) in *Barber* (...) The court held that the doctors' omission to continue treatment though intentional and with knowledge that the patient would die was not unlawful failure to perform a legal duty.¹⁴²

Sir Thomas Bingham MR stated that inapplicability of the criminal liability was highlighted by the attempted analogy with *R v Stone*; in that case, the defendant convicted of manslaughter had failed to supply food to a conscious, elderly and infirm patient who was capable of feeding herself had food been supplied.¹⁴³ Thus, that case was in no way comparable with that of Anthony Bland.

An argument initially advanced on behalf of the Official Solicitor was that artificial hydration and nutrition (CAHN) formed basic care and did not amount to medical treatment. To the extent that it was actually relevant to do so, all three courts considered CAHN to constitute a form of 'medical treatment' or 'medical care'.¹⁴⁴ Some of the learned justices were also keen to point out the difficulty with drawing fine distinctions between medical care, basic care and medical treatment in this context.¹⁴⁵ In the Court of Appeal, Sir Thomas Bingham MR stated:

The overwhelming consensus of medical opinion (...) is that artificial feeding by nasogastric tube is also medical treatment (...) The insertion of the tube is a procedure calling for skill and knowledge, and the tube is invasive of the patient's body to an extent

¹⁴⁰ *ibid* 833: Sir Stephen Brown P stated: 'I do not consider it appropriate to make any declaration with regard to any possible consequences so far as the criminal law is concerned. In my judgment the declaration that the course proposed is lawful is sufficient to give to the doctors and to the hospital the necessary assurance as to the lawfulness of what is proposed'.

¹⁴¹ Lord Browne-Wilkinson expressed his views regarding criminal liability in detail at 880-2. Lord Goff: '[T]here is no longer any duty upon the doctors to continue with this form of medical treatment or care in his case, and it follows that it cannot be unlawful to discontinue it'. [1993] 1 All ER 821, 873.

¹⁴² *ibid* 848-9.

¹⁴³ *ibid* 841-2.

¹⁴⁴ *ibid* 861. For example, Lord Keith stated: 'regard should be had to the whole regime, including the artificial feeding, which at present keeps Anthony Bland alive. That regime amounts to medical treatment and care, and it is incorrect to direct attention exclusively to the fact that nourishment is being provided. In any event, the administration of nourishment by the means adopted involves the application of a medical technique'.

¹⁴⁵ See, for example Lord Hoffmann's judgment at 857-8: 'Some have felt that the issues in this case could not depend upon a semantic point like that. I agree... There is in my view no distinction between medical treatment and other kinds of care for the purposes of deciding the central issue in this case.' Lord Browne-Wilkinson opined: 'In these circumstances, it is perfectly reasonable for the responsible doctors to conclude that there is no affirmative benefit to Anthony Bland in continuing the invasive medical procedures necessary to sustain his life. Having so concluded, they are neither entitled nor under a duty to continue such medical care.' The circumstances to which the learned judge was referring were that of Anthony Bland's condition, which he described as follows: 'If artificial feeding is continued, he will feel nothing; if artificial feeding is discontinued and he dies he will feel nothing'.

which feeding by spoon or cup is not. An intubated patient certainly looks as if he is undergoing treatment, and the mechanical pumping of food through the tube is a highly unnatural process. It does not, however, seem to me crucial whether this is regarded as medical treatment (...) since whether or not this is medical treatment[,] it forms part of the patient's medical care and I cannot think the answer to this problem depends on fine definitional distinctions.¹⁴⁶

Butler-Sloss LJ opined that there was 'overwhelming evidence upon which Sir Stephen Brown P was entitled to conclude' that CAHN constituted medical treatment, however, similarly she stated:

If we describe what is being done by the doctors and nurses for Anthony Bland (...) as medical care rather than treatment, it may to the layman make more sense and avoid the uncomfortable attempt to draw a line between different forms of feeding such as spoon-feeding a helpless patient or inserting a tube through the nose or direct into the stomach.

The definition of medical treatment does not, (...) resolve the problem. The underlying issue is whether, under the extreme circumstances of this case, there is a duty upon his doctor to continue to provide to Anthony Bland nutrition and hydration by an artificial method.¹⁴⁷

Particularly interesting in the context of legislative decisions to exclude CAHN from being refused in advance, Hoffmann LJ approached the matter differently in his judgment in the Court of Appeal. Rather than distinguishing between types of care and treatment, the learned judge tackled the question of whether it was ever ethical to 'deny food to a patient'.¹⁴⁸ He stated:

It is of course hard to imagine a case in which it could be humane to deny food to a patient (...) To deny someone food is wrong because it causes suffering and death. But Anthony Bland cannot suffer and his condition is such that it is right that he should be allowed to die. His interest in the manner of his death (...) is that it should not be distressing or humiliating. If therefore, withdrawal of nourishment would produce distressing symptoms of which Anthony Bland was unconscious but which were visible to the nursing staff and family, this would be a good reason for allowing him to die in some other way. But the medical evidence is that suitable sedation can prevent any untoward symptoms and that withdrawal of nourishment is the most gentle and controlled way in which to allow him to die.¹⁴⁹

Noting the emotive language used by Counsel for the Official Solicitor – the Court of Appeal had considered it lawful for 'a doctor to starve his patient to death' – the learned judge opined that the

¹⁴⁶ [1993] 1 All ER 821, 837.

¹⁴⁷ *ibid* 844.

¹⁴⁸ *ibid* 856. At 870-1, Lord Goff approached the matter distinguishing 'the vision of an ordinary person slowly dying of hunger, and suffering all the pain and distress associated with such a death' from Anthony Bland's situation.

¹⁴⁹ *ibid* 856. It is interesting to contrast the exception given by Lord Hoffmann to 'distressing symptoms' visible to medical staff with the case of *Re B*, discussed earlier. In that instance, the likelihood of the medical staff being distressed at withdrawing ventilation from Ms B was insufficient to justify her continued treatment. It is highly unlikely, however, that Lord Hoffman intended his comments to apply to individuals with capacity, as was the case with Ms B.

images evoked by that language - cruelty, suffering and unwelcome death – were false and inapplicable to the case of Anthony Bland. One could argue, perhaps, that such images do underpin the rationale for some legislatures in the United States prohibiting advance refusals of CAHN.¹⁵⁰

The House of Lords was unanimous in dismissing the appeal against Court of Appeal ruling, thereby permitting the withdrawal of treatment from Anthony Bland. In doing so, the Court found that prolonging his life in this manner was no longer in his best interests. This conclusion is interesting when it is juxtaposed with the view from the United States that the best interests standard is ‘unworkable’ where PVS patients are concerned.¹⁵¹ David English, for example, cites a series of cases where the court found it ‘impossible’ to apply the best interests standard to PVS patients.¹⁵² Post-*Bland*, other cases considered the circumstances in which life-sustaining treatment should be administered to (or withdrawn from) incompetent patients, using a ‘patient-centred best interests standard’, which focused ‘on the values of the patient, and her global rather than just her medical interests.’¹⁵³ In other words, *Bland* was a starting point and the current law has developed considerably since then.

First, it became necessary to determine if the Human Rights Act 1998, which had not been in force at the time of *Bland*, now resulted in the withdrawal of CAHN from patients in PVS unlawful.¹⁵⁴ In *NHS Trust A v M, NHS Trust B v H*, the hospital trusts with the support of the families of two patients – Mrs M and Mrs H, who had been in PVS for 3 years and 9 months respectively – petitioned the court for a declaration that withdrawal of CAHN was compatible with the Act, which gave effect to Article 2.1 of the European Convention on Human Rights (ECHR), the protection of the right to life.¹⁵⁵

In finding that ceasing to treat a patient in PVS did not violate the Act, Butler-Sloss P eloquently stated:

Although the intention in withdrawing artificial nutrition and hydration in PVS cases is to hasten death, in my judgment the phrase ‘deprivation of life’ must import a deliberate act, as opposed to an omission, by someone acting on behalf of the state, which results in death.

¹⁵⁰ For contrast, see *Re Conroy* 98 NJ 321 (1985). See also *Barber v Superior Court* 147 Cal App 3d 1006 (1983).

¹⁵¹ David M English, ‘Defining the Right to Die’ (1993) 56 L Contemp Probl 255, 257.

¹⁵² *ibid.* See for example *Re Jobes* 529 A 2d 434 (NJ 1987); *Re Peter* 529 A 2d 419 (NJ 1987).

¹⁵³ John Coggon, ‘Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection’ (2016) 24 Med L Rev 396, 409.

¹⁵⁴ *NHS Trust A v M, NHS Trust B v H* [2001] Fam 348.

¹⁵⁵ Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

A responsible decision by a medical team not to provide treatment at the initial stage could not amount to intentional deprivation of life by the state. Such a decision based on clinical judgment is an omission to act. The death of the patient is the result of the illness or injury from which he suffered and that cannot be described as a deprivation. It may be relevant to look at the reasons for the clinical decision in the light of the positive obligation of the state to safeguard life, but, in my judgment, it cannot be regarded as falling within the negative obligation to refrain from taking life intentionally.¹⁵⁶

Furthermore, although pre-dating the Human Rights Act, Butler-Sloss P established the compatibility of the decision in *Bland* with Article 2.¹⁵⁷ Consequently, the legal position regarding the treatment of patients in PVS could be summarised as follows: if a patient is in PVS with no prospect of recovery, then treatment will not be considered to be in his best interests. Sometimes, this is argued to be so because the patient has ‘no interests’, as was the contention made in *St George’s Healthcare NHS Trust v P*.¹⁵⁸ Other times, it is argued that inherent in PVS is a lack of sentience and an absence of any prospect of recovery and accordingly, medical treatment cannot be of any benefit to patients in that state.¹⁵⁹ Irrespective of the reasons why further treatment is determined not to be in the best interests of the patient, it remains the case that court orders approving the withdrawal or withholding of treatment from patients in PVS are almost automatic. As Baker J stated in *Re M*, ‘the balance falls in one direction in every case—in favour of withdrawal’.¹⁶⁰ Despite this, medical professionals still appeared to be prevented from exercising their judgement and withdrawing CAHN in PVS cases until recently. Instead, such cases had to be brought before the Court of Protection, a rule which has been criticised as ‘an expensive rubber-stamping exercise’.¹⁶¹ As Alex Ruck Keene and Annabel Lee comment, decisions to withdraw CANH from a much larger group of patients, with diagnoses other than PVS and MCS, are made on a regular basis without the requirement for court approval, so the logic for such a requirement is questionable.¹⁶²

¹⁵⁶ [2001] Fam 348, 358.

¹⁵⁷ *ibid* 359; ‘The analysis of these issues by the House of Lords in *Bland’s* case ... is entirely in accordance with the Convention case law on article 2 and is applicable to the distinction between negative and positive obligations. An omission to provide treatment by the medical team will (...) only be incompatible with article 2 where the circumstances are such as to impose a positive obligation on the state to take steps to prolong a patient’s life’.

¹⁵⁸ [2015] EWCOP 42, para 13: Newton J states this is the case because ‘a person in a continuing vegetative state has no interests and therefore no best interests’.

¹⁵⁹ *A Primary Care Trust v CW* [2010] EWHC 3448.

¹⁶⁰ *Re M* [2012] 1 All ER 1313, 1328.

¹⁶¹ Court of Protection Rules 2007, Practice Direction 9E, Paragraph 5. For criticisms, see Jonathan Herring, *Medical Law and Ethics* (7th edn OUP 2018) 526; Penney Lewis, ‘Withdrawal of Treatment from a Patient in a Permanent Vegetative State: Judicial Involvement and Innovative “Treatment”’ (2007) 15 Med L Rev 392, 396-7.

¹⁶² Alexander Ruck Keene and Annabel Lee, ‘Withdrawing Life-Sustaining Treatment: A Stock-Take of the Legal and Ethical Position’ (2019) 45 J Med Ethics 794.

Interestingly, in the 2017 case of *Re M*, the court found that it was unnecessary to bring the matter of withdrawal of CAHN from Ms M, a patient suffering from a disorder of consciousness as a result of Huntington's Disease.¹⁶³ Jackson J did so on two key grounds; first, he differentiated between the court rendering an act lawful and merely confirming that it is. Second, he highlighted the inconsistency of medical professionals and families being obliged to bring cases of withdrawal of CAHN to court, where there is no such requirement in other areas of medical decision-making; in short, he argued that medical professionals make decisions regarding life-sustaining treatment on a daily basis, with no court oversight. The opinion of the learned judge seems to strike a far better balance than requiring that all of these kinds of cases must be brought to court; it eliminates the costly and frankly unnecessary 'automatic' approval process, but leaves ample room for a court application if there is a difference of opinion between the care team and the family or indeed within the care team itself or the wider facility.

Aside from compliance with the HRA 1998, it also became necessary post-*Bland* to clarify the legal position of patients who were not in PVS. The jurisprudence suggests that treatment will be withheld or withdrawn from an incompetent individual when that treatment is considered futile,¹⁶⁴ overly burdensome or both.¹⁶⁵ The withdrawal or cessation of treatment from incompetent patients has also been authorised on the basis of a previously articulated wish to refuse treatment, even if such a preference is not expressed in the form of a valid advance decision;¹⁶⁶ it must be stated, however, that the courts have been clear that wishes and feelings are not determinative of best interests, though they may help to establish the best interests of the particular individual.¹⁶⁷ As Lady Hale DP stated in relation to the wishes of the individual in *Aintree University Hospital Foundation Trust v James*:

The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail (...) But insofar as it is possible to ascertain the patient's wishes and feelings,

¹⁶³ *Re M (Withdrawal of Treatment: Need for Proceedings)* [2017] EWCOP 19.

¹⁶⁴ '[B]eing ineffective or being of no benefit to the patient'; *Aintree University Hospital Foundation Trust v James* [2014] 1 All ER 573.

¹⁶⁵ See for example, *NHS Trust v L* [2012] EWHC 2741 (COP) where, despite the law's strong presumption in favour of the preservation of life, force-feeding under sedation was considered to be contrary to the best interests of Ms L because it was viewed to be futile and overly burdensome in light of its low chance of saving her life; *NHS Trust v L and Ors* [2012] EWHC 4313 (Fam) where the court ruled that it would not be in the best interests of Mr L – who had multiple co-morbidities and brain damage – to receive active resuscitation if he suffered a cardiac or respiratory arrest or a serious deterioration in his condition.

¹⁶⁶ See for example in *An NHS Trust v X* [2005] EWCA Civ 1145, para 59 where Waller LJ commented that the views of the individual were 'highly material', though 'not the governing factors when considering best interests'. See also *Sheffield Teaching Hospitals NHS Foundation Trust v TH* [2014] EWCOP 4; *Re D (Withdrawal of Treatment)* [2012] EWCOP 885; *Barnsley Hospitals NHS Foundation Trust v MSP* [2020] EWCOP 26. Contrast these decisions with the judgment in *Re M* [2012] 1 All ER 1313, which will be discussed in due course.

¹⁶⁷ See for example, *M v N and Ors* [2015] EWCOP 9, para 28: 'where the wishes, views and feelings of P can be ascertained with reasonable confidence, they are always to be afforded great respect. That said, they will rarely, if ever, be determinative of P's "best interests"'.

his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.¹⁶⁸

Thus, as Jackson argues:

Post-*Aintree* (...) if the patient's wishes can be ascertained, they should be central to the decision as to what is in her best interests. And in cases that have followed *Aintree*, judges sitting in the Court of Protection have been emboldened to take P's wishes very seriously indeed, even when they are contrary to an 'objective' view of what is in P's clinical best interests.

Since *Aintree*, it appears that the courts are taking a more active role in giving effect to the (precedent) autonomy of the individual and their interests in self-determination, provided that there is clear evidence that the course of action is what the patient would have wanted. Coggon, however, appears to argue that this is insufficient to some extent and contends that where 'a patient's reflectively endorsed view on her interests is known, legally this should hold equal weight regardless of whether she has capacity or not'.¹⁶⁹ This research would agree, as to do otherwise in the face of reliable and credible evidence as to the prior wishes of the individual appears to treat incompetent individuals less favourably than their competent counterparts without justification, thus undermining their autonomy.

Arguably, however, pregnancy may be an example of a situation where the views of the woman towards the cessation or withholding of treatment could be considered indiscernible by a court or appear to hold less weight. For her views to be considered clear by the court, the woman would almost certainly have had to express them during pregnancy or have factored pregnancy into the conversation. Otherwise, the decision to continue the pregnancy¹⁷⁰ and its circumstances may well be viewed as indicating a desire to give birth to a healthy child – which in turn may be viewed as altering her previous views – unless there is cogent evidence to the contrary.¹⁷¹ After all, there is an expectation inherent within society that the woman will sacrifice herself for her pregnancy,

¹⁶⁸ [2014] 1 All ER 573, 588-9.

¹⁶⁹ John Coggon, 'Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection' (2016) 24 Med L Rev 396, 398. Contrast with the comments made by Hayden J in *M v N and others* [2015] EWCOP 9.

¹⁷⁰ This assumes that the pregnancy had been detected and that a termination had not been planned by the woman.

¹⁷¹ As has occurred in cases concerning elective Caesarean section cases, thus generally not live-saving for the woman, the previously expressed wishes of the woman can become secondary to other factors and therefore the unwanted procedure can be determined to be in her best interests even though it is not what she wants. See Chapter 6 for further discussion of such cases. See also *University Hospitals NHS Trust v CA* [2016] EWCOP 51 para 44: 'The court must (...) pay careful attention to CA's expressed wishes and feelings and her experience of trauma in the past which, I infer, is the cause (...) of her deep-seated aversion to medical procedures. But looking at the evidence overall, it is manifestly clear that the balance comes down decisively in favour of a planned Caesarean section.'

whether that is borne out in the expectation that she will abstain from cigarettes and alcohol,¹⁷² or by labelling routine or prescription drugs as ‘not safe in pregnancy’¹⁷³ or in the expectation that she will eat a particular diet.¹⁷⁴ For example, Anne Lyerly *et al* assert:

A second cup of coffee, the occasional beer, the medication that treats a woman’s severe allergies but brings a slight increase in the risk of cleft palate, the particular SSRI that best treats a woman’s severe recalcitrant anxiety disorder but brings a small chance of heart defects—all are off limits, or nearly so, to a ‘good mother’.¹⁷⁵

If expectations of this nature are casually levelled at women, then likely also would the expectation that she would want to sacrifice her wishes in respect of her interests in bodily integrity and self-determination. It should be said, however, that this does not preclude the possibility of a court deciding that the withholding of (further) treatment is in the best interests of the patient in light of futility or burdensomeness, just that any prior opinions expressed by her may be considered unreliable unless expressed specifically in relation to pregnancy. In other words, it is possible that what would have been the wishes of the pregnant individual may be circumvented by the law pertaining to best interests.

A corollary of *Aintree* and its progenies has also been the case, in other words, treatment may be continued (partly) on the basis of previously expressed wishes of the patient. It still remains that wishes and values cannot be determinative; indeed, as discussed in Chapter 2, although a patient has the right to refuse treatment, it does not follow that she has a corresponding right to demand it against the professional judgement of the physician.¹⁷⁶ Accordingly, the benefit or futility of any treatment will be of considerable relevance in a court’s determination of whether it should be withdrawn, withheld or maintained. Treatment will not be continued or administered if it is futile, irrespective of the previously expressed wishes of the patient; arguably, *futility* in such instances will have a very high bar if there is strong evidence that the individual would have wanted

¹⁷² For example, not only do the Chief Medical Officers (UK) and the Health Service Executive in Ireland recommend abstaining from alcohol while pregnant but also if a woman is planning on becoming pregnant. See National Health Service, *Drinking Alcohol While Pregnant* (2020) <<https://www.nhs.uk/conditions/pregnancy-and-baby/alcohol-medicines-drugs-pregnant/>> accessed 28 Jul 2020; Health Service Executive *Alcohol During Pregnancy* (2018) <<https://www2.hse.ie/wellbeing/child-health/alcohol-during-pregnancy.html>> accessed 28 Jul 2020.

¹⁷³ Greer Donley, ‘Encouraging Maternal Sacrifice: How Regulations Governing the Consumption of Pharmaceuticals during pregnancy Prioritize Fetal Safety over Maternal Health and Autonomy’ (2015) 39 NYU Rev L & Soc Change 45, 66-81.

¹⁷⁴ Denise A Copelton, ‘“You Are What You Eat”: Nutritional Norms, Maternal Deviance, and Neutralization of Women’s Prenatal Diets’ (2007) 28 Deviant Behav 467, 468-9: ‘Prenatal nutritional norms concretize the link between prenatal nutrition and cultural ideals of “the good mother”, which include self-sacrifice and undying devotion to one’s child (...) To be considered good mothers, women attempt to follow maternal norms, both during and following pregnancy, including nutritional norms.’

¹⁷⁵ Anne Lyerly and others, ‘Risk and the Pregnant Body’ (2009) 39 The Hastings Center Report 34, 40.

¹⁷⁶ See also John Coggon, ‘Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection’ (2016) 24 Med L Rev 396, 407; ‘“Absolute” rights of noninterference do not translate into absolute rights to claim, either against doctors in the face of contrary (and reasonable) professional judgment, or against the state in the face of lawful resource allocation decisions.’

treatment to continue. In *St George's Healthcare NHS Trust v P*, for example, a combination of Mr P's religious beliefs and his previously expressed opinions and wishes resulted in life-preserving treatment being administered despite his 'profound and prolonged disorder of consciousness', effectively MCS.¹⁷⁷ While acknowledging that many others would not consider the circumstances of Mr P's life to be 'worthwhile', Newton J was of the opinion that Mr P, himself, would have:

In the light of his previously expressed strong views, coupled with his strong religious beliefs, the weight of the evidence all falls heavily to one side which is that the preservation of any life would be considered by P to be of significant value. His present circumstances are a life which P would find worthwhile, even though I entirely accept many others would not (...)¹⁷⁸

It is axiomatic that the corollary must also be the case, in other words, it is not for others to say that a life that they would regard as tolerable and acceptable would be viewed the same by the individual in question.¹⁷⁹

In discussing the relevance of Mr P's wishes and values, the learned judge stated:

The quality of life should be judged not by the values of others but from the particular perspective of the patient. In considering what the patient himself might regard as worthwhile P's prior statement and behaviours (...) his wishes, his beliefs, his feelings and his values are all relevant (...) the very strong available evidence from P's family and friends is highly relevant (...) All those matters point strongly to P wishing to ensure that life preserving treatment should continue whatever may befall him.¹⁸⁰

In the course of the judgment, the court considered statements, beliefs and opinions – such as Mr P's disagreement with assisted dying, his opinion that chronic disability or illness did not render a life any less valuable, his religious beliefs regarding predestination and God's role in death and his desire to receive the best possible treatment for his kidney condition – to be relevant in determining his best interests.¹⁸¹ It should be emphasised, however, that Newton J did not find the treatment in question to be futile or overly burdensome, despite the fact that Mr P was suffering from a serious disorder of consciousness with poor prospects of functional recovery.¹⁸² It is worth observing the

¹⁷⁷ [2015] EWCOP 42.

¹⁷⁸ *ibid* para 41.

¹⁷⁹ *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26, para 28.

¹⁸⁰ [2015] EWCOP 42, para 38.

¹⁸¹ *ibid*.

¹⁸² [2015] EWCOP 42, para 37: The learned judge remarked that the treating physician, Dr Khan, had stated that there was no prospect of 'meaningful recovery', by which he meant that 'there is no chance consciousness will improve from its current state. He may well deteriorate further'. He then remarked that another physician, Mr Badwan, 'could not yet rule out the possibility of a further increase in consciousness' but that his initial views were 'also that P would not likely recover from his present condition and the prospects of recovery were remote'.

specific distinction between no prospect of recovery and no prospect of returning to ‘good health’ that was made by the court; the former, it was argued, could not be equated with the latter.¹⁸³

It is interesting to contrast the decision in *P* with the one reached in the first MCS case in England and Wales some 4 years earlier, namely *Re M*.¹⁸⁴ Although both decisions resulted in the preservation of life being favoured, the reasons for the decisions and specifically the weight attached to the evidence of family members as to the wishes of the individual varied significantly. Despite evidence from her family as to what Ms M would have wanted – or more accurately, what she would not have wanted – the court ruled that the continuation of treatment was in her best interests. In reaching this conclusion, Baker J used the ‘balance-sheet test’ advocated by Thorpe LJ in *Re A*; this amounted to the process of ‘setting out the actual benefits to be gained from the medical procedure and any “counterbalancing disbenefits”’.¹⁸⁵ The facts of *Re M* were as follows: Ms M suffered extensive and irreparable brain damage as a result of contracting viral encephalitis and while it initially appeared that she was in PVS, it was subsequently accepted that Ms M was in MCS.¹⁸⁶ As she was immobile and doubly incontinent, she was completely dependent on others or medical intervention for her care and the consensus was that she had ‘no realistic prospect’ of improvement.¹⁸⁷ She could experience pain, distress and discomfort and did so on a regular basis.

Although Baker J acknowledged that ‘the law rightly requires the court to take into account (...) wishes and feelings when determining (...) best interests’, he categorised the statements made by Ms M as ‘informal’.¹⁸⁸ Furthermore, he stated:

[W]hilst I take those statements into account, they are not binding and in all the circumstances I do not consider they carry substantial weight in my decision. The factor which does carry substantial weight, in my judgment, is the preservation of life. Although not an absolute rule, the law regards the preservation of life as a fundamental principle.¹⁸⁹

¹⁸³ *ibid*: ‘Here (as the Supreme Court held in *Aintree*) the concept of no prospect of recovery is not to be equated with having the prospect of a return to good health.’

¹⁸⁴ *Re M* [2012] 1 All ER 1313.

¹⁸⁵ Mary Donnelly, ‘Best Interests, Patient Participation and the Mental Capacity Act 2005’ (2009) 17 Med L Rev 1, 4-5.

¹⁸⁶ [2012] 1 All ER 1313, 1323: Following the diagnosis of PVS, the family petitioned to have life-sustaining measures discontinued. As part of this process, the Official Solicitor was given permission to instruct an expert witness. The expert in question found that ‘whilst there was some evidence that M would meet the accepted criteria for the diagnosis of vegetative state, there were doubts about the diagnosis that suggested it remained possible that she was in fact in a condition above the vegetative state generally known (...) as the “minimally conscious state”’. Following a SMART (Sensory Modality Assessment and Rehabilitation Technique) assessment, this diagnosis of MCS was confirmed.

¹⁸⁷ *ibid* 1322.

¹⁸⁸ *ibid* 1320.

¹⁸⁹ *ibid*.

Given the importance of the sanctity of life, and the fatal consequences of withdrawing treatment (...) it would be in my judgment be wrong to attach significant weight to those statements made prior to her collapse.¹⁹⁰

It is worth contrasting the above with a later statement made by the learned judge in which he opined that '[t]he proper assessment of best interests in this context requires great weight to be given to M's wishes and feelings and those of her family, past and present'.¹⁹¹

Consequently, one could not be criticised for being unsure as to what weight was being attached to the statements of Ms M's regarding her wishes and beliefs and what weight ought to be. Consequently, it is worth bearing in mind that the court appears to distance itself somewhat from *Re M* in subsequent judgments.¹⁹² Perhaps in trying to reconcile his seemingly inconsistent views, Baker J later stated:

It is important to note that, while any decision-maker, including a judge, is under an obligation to consider P's wishes and feelings, and the beliefs, values and other factors that he would have taken into account if he had capacity, the decision must be based on P's best interests and not on what P would have decided if he had capacity.¹⁹³

It is interesting to note the apparent conflict in this passage; patients with capacity are entitled to decide for themselves and that decision will almost invariably stand, yet what a patient would have decided for herself in particular circumstances cannot be considered determinative.¹⁹⁴ One could argue that the apparent mutual exclusivity of the two factors – best interests and what would have been decided – is problematic. It should not be beyond the realms of possibility that what an individual would have decided if competent, once clearly ascertainable by the court, should be treated as being in the best interests of that patient.¹⁹⁵ This is not to be conflated with including the wishes and feelings of the patient as part of a best interests assessment, where it is *unclear* what a

¹⁹⁰ *ibid* 1383.

¹⁹¹ *ibid* 1328.

¹⁹² In *Briggs v Briggs* [2016] EWCOP 53, Charles J opined that the opinion expressed in *Re M* that caution should be shown in relation to attaching 'significant weight' to M's previously expressed wishes 'runs counter to the holistic approach that the Supreme Court confirms is to be taken to enabling P to do what he would have wanted if of full capacity'. Also contrast *Re M* with *ITW v Z & Ors* [2009] EWHC 2525 (Fam) ('*ITW v Z*'), paragraph 35 where Munby J states: 'First, P's wishes and feelings will always be a significant factor to which the court must pay close regard (...) Secondly, the weight to be attached to P's wishes and feelings will always be case-specific and fact-specific (...) Thirdly, in considering the weight and importance to be attached to P's wishes and feelings the court must of course, and as required by section 4(2) of the 2005 Act, have regard to all the relevant circumstances.' For a more recent example of the weight that should be placed on the views and feelings of the individual, see the judgment of Hayden J in *Barnsley Hospitals NHS Foundation Trust v MSP* [2020] EWCOP 26, para 24-25, 41-47.

¹⁹³ *ibid* 1345.

¹⁹⁴ For a more detailed critique of this judgement, see John Coggon where he argues, inter alia, that is that Baker J actually appears to misunderstand the passage from the Code of Practice and its relationship, or lack thereof, to substituted judgment. The former, John Coggon argues, details that a best interests decision is partly informed by the patient's values, whereas the latter has no basis or means of introduction in English law; John Coggon, 'Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection' (2016) 24 *Med L Rev* 396, 410-13.

¹⁹⁵ See Munby J in *ITW v Z* [2009] EWHC 2525 (Fam).

patient would have decided if she had capacity.¹⁹⁶ Furthermore, with all due respect to the learned judge, it is debateable if that passage is an accurate reflection of the law or its intent; if it were, it would be questionable what basis, if any, advance directives would have for being legally binding. They are, after all, a written representation of ‘what P would have decided if he had capacity’. Perhaps further emphasising a somewhat questionable interpretation of the law, Baker J goes on to distinguish advance decisions:

[T]he crucial distinction between an advance decision (...) and other expressions of wishes and feelings is that an advance decision must address specifically the circumstances in which it will be binding and is made in the knowledge that it will be decisive if those circumstances arise. In other words, an adult who makes an advance decision knows that it will be decisive in the event that he or she becomes incapacitated and is unable to communicate their current *wishes and feelings*.¹⁹⁷

At the risk of overstating the point, ‘wishes and feelings’ are not the same as ‘what the patient would have decided if he had capacity’, though the former may aid a conclusion as to the latter.

As part of the balancing exercise, Baker J considered the views of the family of Ms M. They argued that she had always said that ‘she would rather shorten her life by ten years rather than have someone look after her’ and ‘was fiercely independent and (...) would have hated to have been looked after’.¹⁹⁸ This was in response to witnessing both her grandmother and father being cared for and in response to the *Bland* case. It was the view of her partner that Ms M ‘would be horrified that she was carrying on in this undignified manner’, stating that ‘she was a very proud person and very conscious of how she presented herself’.¹⁹⁹ He added that ‘she wouldn’t want to continue with this burdensome life with a lack of dignity’.²⁰⁰ In refusing the application of the family, however, Baker J found that the life of Ms M was ‘not without positive elements’.²⁰¹ He determined that that she had ‘positive experiences and that, although her life [was] extremely restricted, it [was] not without pleasures, albeit small ones’.²⁰²

Jackson contends that more recent cases concerning patients with a disorder of consciousness have demonstrated a trend towards ‘considerable’ weight being attached to the opinion of the family as

¹⁹⁶ Arguably, this was the case in *Re M*, however, it is argued that this does not render the criticism of the passage moot.

¹⁹⁷ [2012] 1 All ER 1313, 1382 (emphasis added).

¹⁹⁸ *ibid* 1353.

¹⁹⁹ *ibid* 1356.

²⁰⁰ *ibid*.

²⁰¹ *ibid* 1329.

²⁰² *ibid* 1388. Some of the benefits listed by the learned judge were the preservation and continuation of her life, her being spared the effect of the withdrawal of CAHN and her continued ability ‘to gain pleasure from the things which, as described by her carers, give her pleasure at present – company, listening to conversation, music and the sensory experience of the “snoozeroom”’ (1387).

to what the individual would have wanted.²⁰³ For example, in *Cumbria Clinical Commissioning Group v S*, Hayden J in states:

I cannot over-emphasise the importance of listening to the family who ultimately know the patient's personality best. That is not to say that their wishes and views should be determinative, but it is extremely important that they are heard and their observations given appropriate weight.²⁰⁴

Citing *Abertawe Bro Morgannwg University Local Health Board v RY*, however, Herring argues that the court remains 'wary of putting too much weight on the views of relatives'.²⁰⁵ In the context of this case, Mary Donnelly contends that it seems that family evidence 'weighs more heavily when it accords with medical evidence'.²⁰⁶ In any event, this judgment has subsequently been described by the court as one where the evidence was 'not sufficiently cogent to be relied on'.²⁰⁷ In short, it can be suggested that the court appears to have struck an appropriate balance regarding the opinion of the family; it has demonstrated a willingness to listen to and consider the views of family as to the wishes of the individual but also requires that those views are adequately evidenced and balanced against other relevant factors. Arguably, as stated previously, where the law has not struck quite as good of a balance is where giving effect to the wishes and feelings of the individual is concerned.

New York

As with the majority of areas of law in New York, law at the end-of-life must be understood in the broader context of legal developments in the United States. In 1976, Joseph Quinlan petitioned the Supreme Court of New Jersey to be appointed guardian of his daughter Karen.²⁰⁸ Ms Quinlan was described as being in a 'chronic persistent vegetative state', having lapsed into a coma in the previous year.²⁰⁹ The court acknowledged the consensus of medical professionals to be that '[n]o form of treatment which can cure or improve that condition is known or available' and with due regard for the 'uncertainties characteristic of most medical science predictions', Karen could

²⁰³ Emily Jackson, *Medical Law: Text, Cases, and Materials* (4th edn, OUP 2016) 1006.

²⁰⁴ [2016] EWCOP 32, para 13.

²⁰⁵ Jonathan Herring, *Medical Law and Ethics* (7th edn, OUP 2018) 529; *Abertawe Bro Morgannwg University Local Health Board v RY* [2017] EWCOP 2.

²⁰⁶ Mary Donnelly, 'Decisions at the End of Life: "The Inimitable Hallmark of the Lawyer"?' (2017) 26 *Med L Rev* 531, 536.

²⁰⁷ *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26, para 31.

²⁰⁸ *Re Quinlan* 70 NJ 10 (1976).

²⁰⁹ 70 N.J. 10 (1976); 24: A patient in chronic PVS was described as a 'subject who remains with the capacity to maintain the vegetative parts of neurological function but who no longer has any cognitive function'.

‘never be restored to cognitive or sapient life’.²¹⁰ In view of her prognosis, Mr Quinlan sought, as part of being appointed guardian over his daughter, that he would receive express power to authorise the withdrawal of life-sustaining medical treatment, in this case, mechanical ventilation. In assessing Mr Quinlan’s appeal, the court was required to answer two key questions:

- First, was the decision of the trial court to refuse the specific relief requested by Mr Quinlan – authorisation for termination of life-sustaining measures – correct?
- Second, was the decision of court to refuse to appoint Mr Quinlan guardian correct?²¹¹

In the view of the Court paramount in answering these questions, was the constitutional right of privacy established in *Griswold v Connecticut*.²¹² The court was of the view that the interest of the State weakened and the right of the individual to privacy grew ‘as the degree of bodily invasion increases and the prognosis dims’.²¹³ In relation to Ms Quinlan, Hughes CJ, speaking on behalf of the court, stated:

Ultimately there comes a point at which the individual’s rights overcome the State interest. It is for that reason that we believe Karen’s choice, if she were competent to make it, would be vindicated by the law.²¹⁴

The analysis undertaken by the learned judge is not without criticism, however; Alan Meisel and Kathy Cerminara comment:

The *Quinlan* court’s balancing test did not do justice to the significance of the individual’s interests at stake. The problem might be seen as only a procedural one: the court began with the state’s interests and claimed that they weaken as the individual’s right grows. Standard analysis would begin with the individual’s interest, which is presumed to predominate unless overcome by a sufficient state interest. In other words, there should be a presumption of a right to refuse treatment that countervailing state interests might overcome, rather than a presumption that treatment must be administered that grows weaker as the patient’s interests grow stronger.²¹⁵

This argument certainly has appeal given the jurisprudence as far back as the early 1900s, which dictated, not that the state had an interest in administering treatment to all, but that ‘[e]very human being of adult years and sound mind has a right to determine what shall be done with his own

²¹⁰ *ibid* 26.

²¹¹ *ibid* 34.

²¹² 381 US 479 (1965).

²¹³ 70 NJ 10 (1976); 41.

²¹⁴ *ibid*.

²¹⁵ Alan Meisel and Kathy L Cerminara, *The Right to Die: The Law of End-of-Life Decision Making* (3rd edn, Aspen 2004) 5-39.

body'.²¹⁶ This was then subject to certain state interests, which may be considered countervailing depending on the circumstances. In any event, the New Jersey Supreme Court appears to have clarified the issue of how this balancing should be approached in subsequent cases.²¹⁷

The court acknowledged that Ms Quinlan was unable to make a choice given her incapacity, however, it found that her right to privacy could be asserted on her behalf by her father, as guardian.²¹⁸ In explaining how the court had reached its decision, Hughes CJ was unequivocal:

We perceive no thread of logic distinguishing between such a choice on Karen's part [no State interest could compel her to endure treatment, only to vegetate a few measurable months with no realistic possibility of meaningful recovery] and a similar choice which (...) could be made by a competent patient terminally ill, riddled by cancer and suffering great pain; such a patient would not be resuscitated or put on a respirator (...) and *a fortiori* would not be kept against his will on a respirator.²¹⁹

In addition to the two primary questions at the heart of the case, it was also necessary for the court to address the issue of criminal liability and what the Court termed 'The Medical Factor' – in other words, the assertion that the substantive legal basis upon which Mr Quinlan's rights as Karen's representative are predicated 'unwarrantably offends prevailing medical standards'.²²⁰ On the former; the court was of the firm view that criminal liability would not attach in such circumstances because 'the implementation of a patient's constitutional entitlement to resist life-sustaining medical intervention could not be deemed unlawful homicide'.²²¹ The latter contention of offence to prevailing medical standards was rejected in view of the recognition within medical ethics that individuals are entitled to choose their own course of treatment.²²²

Accordingly, the judgment given by the court was that once Mr Quinlan and the relevant physicians agreed on there being no reasonable possibility of a meaningful recovery²²³ and that the life-sustaining treatment should be withdrawn, the matter should be referred to the hospital

²¹⁶ *Schloendorff v New York Hospital* 211 NY 125 (1914); 129.

²¹⁷ See *Re Jobes* 108 NJ 394 (1987); 427: '[A] competent patient's right to make [the] decision [to refuse life sustaining treatment] generally will outweigh any countervailing state interests (...) An incompetent patient does not lose his or her right to refuse life-sustaining treatment. Where such a patient has clearly expressed her intentions about medical treatment, they will be respected.'

²¹⁸ This was described in the judgment of the Supreme Judicial Court of Massachusetts in *Superintendent of Belchertown State School v Saikewicz* 373 Mass 728 (1977); 749: 'The court thus recognized that the preservation of the personal right to privacy against bodily intrusions, not exercisable directly due to the incompetence of the rightholder, depended on its indirect exercise by one acting on behalf of the incompetent person'.

²¹⁹ 70 NJ 10 (1976); 39.

²²⁰ *ibid* 42.

²²¹ Norman L Cantor, 'Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying' (2001) 29 J L Med Ethics 182. 70 NJ 10 (1976); 52: 'We conclude that there would be no criminal homicide in the circumstances of this case. We believe, first, that the ensuing death would not be homicide but rather expiration from existing natural causes. Secondly, even if it were to be regarded as homicide, it would not be unlawful.'

²²² Norman L Cantor, 'Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying' (2001) 29 J L Med & Ethics 182.

²²³ In other words, 'emerging from her present comatose condition to a cognitive, sapient state' (70 NJ 10 (1976); 55).

Ethics Committee for determination. Provided the Committee concurred, then treatment could be withdrawn without any civil or criminal liability. After the judgment, ventilation was withdrawn from Ms Quinlan, however, she began breathing unaided and survived for a further 9 years, as her family neither sought the withdrawal of artificial hydration and nutrition (CAHN) from the care facility nor by court application.²²⁴

New Jersey subsequently adjudicated the matter of withdrawal of CAHN from an 84-year-old incompetent woman with irreversible mental and physical ailments.²²⁵ In that case, however, the Supreme Court of New Jersey based its decision on the common law doctrine of informed consent and right to self-determination, though it did recognise that a federal right of privacy might also be relevant.²²⁶ Although Ms Conroy died before the Supreme Court judgement, it ruled in favour of withdrawing treatment and overturned the judgment of the Appellate Court. The Court was of the view that the right of self-determination was not lost just because the individual was not aware that what is being violated, thus incompetent individuals have a right to refuse treatment; this right, it was held, could be exercised by a surrogate decisionmaker using a 'subjective' standard when there was clear evidence that the incompetent person would have exercised it. In the absence of such evidence, this right could still be invoked in certain circumstances under objective 'best interest' standards. Accordingly, if credible evidence existed that the individual would have wanted to refuse treatment or have it withdrawn and the burden of continuing treatment and prolonging life markedly outweighed its benefits, treatment could be terminated under a 'limited-objective' standard. Where no credible evidence existed and the continuation of life-sustaining treatment was viewed to be inhumane, a 'pure-objective' standard could be used to terminate treatment. If none of the standards could be met, then the court must err on the side of preserving life.

Other state courts, for example Indiana, California and Illinois, have answered the question of withdrawal of CAHN from incompetent patients, with Indiana deciding that the family of an incompetent patient could lawfully withdraw it on behalf of the patient in *Lawrence*.²²⁷ The Court

²²⁴ Ravi Nessman, 'Karen Ann Quinlan's Parents Reflect on Painful Decision 20 Years Later' *Los Angeles Times* (Los Angeles, 7 April 1996) <<https://www.latimes.com/archives/la-xpm-1996-04-07-mn-55744-story.html>> accessed 9 March 2020.

²²⁵ *Re Conroy* 98 NJ 321 (1985).

²²⁶ *ibid* 348: 'While this right of privacy might apply in a case such as this, we need not decide that issue since the right to decline medical treatment is, in any event, embraced within the common-law right to self-determination'.

²²⁷ 79 NE 2d 32 (Ind 1991) 39-40: Respect for patient autonomy does not end when the patient becomes incompetent. In our society, health care decision making for patients typically transfers upon incompetence to the patient's family (...) This right to consent to the patient's course of

of Appeals of California ruled that California probate statute permitted the conservator²²⁸ of the patient to order the withdrawal of life-sustaining treatment on behalf of that patient provided that the decision was made in good faith based on medical advice and in the best interests of the patient.²²⁹ Similarly, in *Longeway*, the Supreme Court of Illinois based the right to refuse treatment on the doctrine of informed consent and ruled that Illinois probate law permitted a guardian to exercise the right of the incompetent individual to refuse CAHN in the event that the patient was terminally ill and irreversibly comatose.²³⁰

In 1981, the New York cases of *Storar* and *Eichner* were combined and heard as one, as both cases concerned patients with no reasonable chance of recovery, rendered incompetent because of profound mental disability (*Storar*) and PVS (*Eichner*) respectively.²³¹ Their guardians were opposed to the continuation of life-sustaining treatment; in the case of Brother Fox, the patient in *Eichner*, that was ventilation and in the case of Mr *Storar*, that was blood transfusions after his diagnosis of terminal bladder cancer.²³² Brother Fox was a member of a Catholic religious order, who had discussed the *Quinlan* case as part of his community work. At that time and in line with Catholic teachings on the matter, he expressed the firm view that he would not want extraordinary measures if he were in circumstances similar to Ms *Quinlan*, a view that he repeated several years later prior to hospital admission. Wachtler J delivering the majority opinion stated:

[T]here is no statute which prohibits a patient from declining necessary medical treatment or a doctor from honoring the patient's decision. To the extent that existing statutory and decisional law manifests the State's interest on this subject, they consistently support the right of the competent adult to make his own decision by imposing civil liability on those who perform medical treatment without consent, although the treatment may be beneficial or even necessary to preserve the patient's life (...) The current law identifies the patient's right to determine the course of his own medical treatment as paramount to what might otherwise be the doctor's obligation to provide needed medical care. A State which imposes civil liability on a doctor if he violates the patient's right cannot also hold him criminally responsible if he respects that right. Thus a doctor cannot be held to have violated his legal or professional responsibilities when he honors the right of a competent adult patient to decline medical treatment.²³³

treatment necessarily includes the right to refuse a course of treatment (...) we conclude that artificial nutrition and hydration is treatment that a competent patient can accept or refuse, that the family of an incompetent patient can accept or refuse it on behalf of the patient.

²²⁸ Refers to a type of guardian under California law.

²²⁹ *Conservatorship of Drabick* 200 Cal App 3d 185 (1988).

²³⁰ *Re Estate of Longeway* 133 Ill 2d 33 (1989).

²³¹ 52 NY 2d 363 (1981).

²³² *ibid* 381: It was accepted that the transfusions would not cure Mr *Storar*'s cancer, but they could prevent him from dying from 'another treatable cause'.

²³³ *ibid* 377.

The court found that Brother Fox had made the decision to refuse prior to becoming incompetent through his statements and treatment was withdrawn.²³⁴ In coming to this conclusion Wachtler J upheld the determination made in the lower courts that the evidence provided as to the statements of Brother Fox combined with his incapacity and negligible chance of recovery satisfied the standard of being ‘clear and convincing’.²³⁵ This is the higher standard of proof utilised in ‘exceptional civil matters’.²³⁶

The learned judge continued:

The finding that he carefully reflected on the subject, expressed his views and concluded not to have his life prolonged by medical means if there were no hope of recovery is supported by his religious beliefs and is not inconsistent with his life of unselfish religious devotion. These were obviously solemn pronouncements and not casual remarks made at some social gathering, nor can it be said that he was too young to realize or feel the consequences of his statements.²³⁷

Mr Storar, by contrast, was profoundly mentally disabled from childhood. His mother was appointed his guardian in 1979 after his cancer diagnosis as the hospital were unwilling to treat him without the consent of a legal guardian. After a brief period in remission he was diagnosed with terminal cancer, which included considerable blood loss as a symptom. The hospital sought to administer blood transfusions in order to compensate for the loss of blood and petitioned the court for an order to do so, however, Mrs Storar cross-petitioned for an order prohibiting the transfusions. On the one hand, Mr Storar found the transfusions and their after-effects distressing; on the other hand, he was observed as having more energy after them and a much-improved ability to undertake his usual daily activities, such as feeding himself, bathing and exercising. In refusing the application by Mrs Storar, Wachtler J, on behalf of the majority, stated:

Although we understand and respect his mother’s despair, as we respect the beliefs of those who oppose transfusions on religious grounds, a court should not in the circumstances of this case allow an incompetent patient to bleed to death because someone (...) feels that this is best for one with an incurable disease.²³⁸

²³⁴ *ibid* 379.

²³⁵ See also *Re Westchester County Medical Center [O'Connor]* 72 NY 2d 517 (1988), which will be discussed in detail in the next chapter in the context of advance directives.

²³⁶ 52 NY 2d 363 (1981); 379: ‘Clear and convincing proof should also be required in cases where it is claimed that a person, now incompetent, left instructions to terminate life sustaining procedures when there is no hope of recovery.’

²³⁷ *ibid* 379-80.

²³⁸ *ibid* 382.

In short, there was no clear and convincing proof that Mr Storar did not want the blood transfusions, as he did not have the capacity to contemplate such a decision at any time in his life. It was argued by some that the clear result of judgments such as *Storar* was that patients who were incapable of decision-making ‘would have to be sustained no matter how much suffering or debilitation was being endured’.²³⁹ In other words, it appeared that individuals with permanent or long-term incapacity could never have treatment withdrawn at the request of a family member. In that context, it is interesting to contrast *Storar* with the judgment of the Supreme Judicial Court of Massachusetts in *Saikewicz*, in which life-prolonging chemotherapy was withheld from a severely mentally disabled man.²⁴⁰ Undoubtedly, the legal challenges in relation to the withdrawal of treatment from patients with long term incapacity was one of the impetuses for the change to New York law given effect by the Health Care Decisions Act for Persons With Mental Retardation (HCDA).²⁴¹

Returning briefly to the emotive language used by Wachtler J, namely allowing ‘an incompetent patient to bleed to death’, one could argue that it resonates with the emotive language seen in relation to withdrawal of CAHN, of *allowing patients to starve to death*. The Court seemed somewhat preoccupied with the blood loss that could be mitigated by the treatment and the resulting temporary improvement to his ability to undertake some tasks and less concerned with the fact that Mr Storar was terminally ill with no more than a few months to live. In his dissenting judgment, Jones J was persuaded by the combination of the incurable cancer, the short life expectancy and the negative effects of the blood transfusions – what could perhaps be described as the *futility* or *burdensomeness* of the treatment in question.²⁴² In particular, he noted that the ‘the transfusions did not serve to reduce John’s pain or to make him more comfortable’ nor did they ‘serve a curative purpose or offer a reasonable hope of benefit’ and therefore he viewed them to constitute ‘extraordinary treatments’, which could be ceased in the circumstances.²⁴³

²³⁹ Norman L Cantor, ‘Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying’ (2001) 29 J L Med & Ethics 182, 190. See also New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (New York 1992) 75: ‘[N]either a health care proxy nor clear evidence of wishes is a possibility for (...) many mentally ill and developmentally disabled adults. Existing New York law does not clearly authorize and guide (...) decisions by parents or others for developmentally disabled adults.’

²⁴⁰ *Superintendent of Belchertown State School v Saikewicz* 373 Mass 728 (1977).

²⁴¹ Surrogate’s Court Procedure Act § 1750-b (‘SCPA’). For commentary, see Christy A Coe, ‘Beyond Being Mortal: Safeguarding the Rights of People with Developmental Disabilities to Efficacious Treatment and Dignity at the End of Life’ (2016) 88 NYSBA Journal 9.

²⁴² 52 NY 2d 363 (1981); 391.

²⁴³ *ibid*.

Consequently, it could be argued that the approach of the learned justice seems to be more similar to the approach taken in England and Wales and Ireland than to that taken by his fellow justices.

Although honourably intended and likely ‘grounded in the apprehension that helpless patients would otherwise be abused by insensitive quality-of-life decisions on the part of prejudiced or self-interested decision-makers’,²⁴⁴ the challenges created by the ‘clear and convincing’ standard were highlighted in the subsequent case of *O’Connor*.²⁴⁵ This case will be examined in considerably more detail in the next chapter in light of its relevance to advance directives, however, for the purpose of this chapter, it set the test for withdrawal of treatment as ‘clear and convincing proof that the patient had made a firm and settled commitment, while competent, to decline this type of medical assistance’ under the particular circumstances.²⁴⁶ In the absence of such proof, it appeared that life-sustaining treatment could not be withdrawn. Thus, the standard effectively prevented termination of treatment unless the patient had made a living will or had the good fortune to make an oral statement open to no other interpretation.²⁴⁷ Indeed, John Regan argued that based on *O’Connor* ‘[i]f no advance directive exists and a DNR order is not at issue, the Court of Appeals has held that no one - neither family nor physician nor court - can authorize the withholding or withdrawal of life-sustaining treatment from an incapacitated patient’.²⁴⁸ In other words, the input of the family regarding the care of a loved one was limited to resuscitation,²⁴⁹ a legal position amended by the introduction of the Family Health Care Decision Act in 2010, which will be discussed in more detail later in this chapter.

Despite evidence of several conversations where Mrs O’Connor had expressed her opposition to life-sustaining treatment, the court found that she had not made a ‘firm and settled commitment’ to refuse. Rather, her statements were viewed as a type of statement ‘that older people frequently, almost invariably make’ and as ‘immediate reactions to the unsettling experience of seeing (...) another’s unnecessarily prolonged death’.²⁵⁰ These were contrasted with the statements made by

²⁴⁴ Norman L Cantor, ‘Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying’ (2001) 29 J L Med & Ethics 182, 190.

²⁴⁵ NY 2d 517 (1988).

²⁴⁶ *ibid* 522.

²⁴⁷ Nancy Rhoden, ‘How Should We View the Incompetent?’ (1989) 17 L Med & Health Care 264.

²⁴⁸ John J Regan, ‘Refusing Life-Sustaining Treatment for Incompetent Patients: New York’s Response to *Cruzan*’ (1991) 19 NYU Rev L & Soc Change 341, 343.

²⁴⁹ See *People v Eulo* 63 NY 2d 341 (1984); the right to decline treatment is personal and under New York law, could not be exercised by a third party in circumstances where the patient is unable to do so.

²⁵⁰ 72 NY 2d 517 (1988); 532.

Brother Fox regarding ventilation, which were viewed to amount to his ‘moral and personal views concerning the use of a respirator on persons in a vegetative state’ following careful reflection on the subject;²⁵¹ thus, his decision was one that was grounded in his faith and consistent with the way he had lived his life in the view of the court. The restrictiveness of the ‘*O’Connor* standard’ is evident and can be contrasted sharply with cases from other states such as *Conroy*, which was discussed earlier. Indeed, as was contended by the New York State Task Force on Life and Law:

[T]he clear and convincing evidence standard is often unworkable and inhumane. It is a legal standard that translates poorly at the bedside where families and health care professionals must confront the hard choices that incurable illness and medical advances present (...) It is simply unrealistic and unfair for the vast majority of the public.²⁵²

English argues that patients who have satisfied restrictive standards like *O’Connor* have generally managed to do so because they ‘made their views known only following the onset of a terminal illness’ – as was the case in the Ohio case of *Couture*²⁵³ – or where the professional background of the individual added extra credibility to their statements – as was the situation in the Connecticut case of *McConnell*²⁵⁴ and indeed, *Eichner*.²⁵⁵ Samantha Halliday and Lars Witteck argue that a further problem with such high standards is that they may ‘simply encourage families to manufacture evidence of the patient’s view, for example, by recalling conversations where the patient purportedly said she would not wish a particular treatment to be given to her in the circumstances she now finds herself in’.²⁵⁶ Even if the family have not manufactured the evidence, it is entirely possible that their recollection of the conversation may be different to what really took place. Unconsciously, what they recall may be coloured by their own views on the matter, or they may have forgotten important contextual aspects of the conversation or they may simply put more weight on particular statements made by the patient, forgetting others.

In 1990, the Supreme Court of the United States had its first opportunity to consider the withdrawal of life-sustaining measures from a patient in PVS. In 1983, Nancy Cruzan was involved in a car

²⁵¹ *ibid* 529.

²⁵² New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (New York 1992) 74.

²⁵³ *Couture v Couture* 549 NE 2d 571 (Ohio 1989).

²⁵⁴ *McConnell v Beverly Enterprises-Connecticut, Inc.* 553 A 2d 596 (Conn 1989).

²⁵⁵ David M English, ‘Defining the Right to Die’ (1993) 56 LCP 255, 256.

²⁵⁶ Samantha Halliday and Lars Witteck, ‘Decision-Making at the End-of-Life and the Incompetent Patient: A Comparative Approach’ (2003) 22 *Med & L* 533, 540; they argue this point in relation to the standard in Germany, where ‘presumed wishes’ are determinative. It is argued, however, that the point is equally relevant to the situation in New York where conversations with family are taken as evidence of whether or not a decision has been made by the individual.

accident; she was found face-down in a water-logged ditch with no detectable respiratory or cardiac function. Efforts to revive her at the scene were successful, in that cardiac function and spontaneous respiration were restored, however she did not regain consciousness and suffered severe and irreversible brain damage as a result of prolonged oxygen deprivation. She was subsequently diagnosed as being in a persistent vegetative state, namely ‘a condition in which a person exhibits motor reflexes but evinces no indications of significant cognitive function’.²⁵⁷ A number of efforts were made to rehabilitate her, however, they were unsuccessful. Among other results of the condition, Ms Cruzan was ‘oblivious to her environment except for reflexive responses to sound and perhaps painful stimuli’ and had ‘no cognitive or reflexive ability to swallow food or water to maintain her daily essential needs’, nor would she ever recover such ability.²⁵⁸ Some 5 years after the accident, Ms Cruzan’s parents requested that artificial hydration and nutrition be terminated by the hospital. The hospital employees refused to do so in the absence of a court order, so Mr and Mrs Cruzan sought a declaratory judgment to authorise the cessation of CAHN. The trial court made the order to remove the feeding tube from Ms Cruzan;²⁵⁹ the Supreme Court of Missouri, however, reversed the order in a split decision finding that the State had ‘expressed a strong policy favoring life’ meaning that the Court had to ‘err on the side of preserving life’.²⁶⁰ While the Court recognised a right to refuse treatment stemming from the common law doctrine of informed consent, it found that the right to refuse rested with the individual herself and that neither the formalities required under Missouri’s Living Will statute nor clear and convincing evidence of Ms Cruzan’s wishes were present.²⁶¹

The trial court found statements made by Ms Cruzan to her housemate that if she were ever sick or injured, she would not want to continue her life unless she could live ‘halfway normally’ were considered to indicate that she would not have wanted treatment to be continued in such circumstances. The Supreme Court of Missouri, however, viewed these statements to be unconvincing and ruled that the interest of the State in preserving life was paramount in this case:

[T]he evidence (...) as to Nancy’s wishes is inherently unreliable and thus insufficient to support the co-guardian’s claim to exercise substituted judgment on Nancy’s behalf. The

²⁵⁷ *Cruzan v Director, Missouri Department of Health* 497 US 266 (1990).

²⁵⁸ *Cruzan v Harmon* 760 SW 2d 408 (Mo 1988); 411.

²⁵⁹ *Estate of Cruzan* Estate No. CV384-9P (P Div Cir Ct, Jasper County 1988).

²⁶⁰ *Cruzan v Harmon* 760 SW 2d 408 (Mo 1988); 426.

²⁶¹ *ibid* 425: ‘Just as the State may not delegate to any person the right to veto another’s right to privacy choices, no person can assume that choice for an incompetent in the absence of the formalities required under Missouri’s Living Will statutes or the clear and convincing, inherently reliable evidence absent here. Nor do we believe that the common law right to refuse treatment (...) is exercisable by a third party absent formalities.’

burden of continuing the provision of food and water, while emotionally substantial for Nancy's loved ones, is not substantial for Nancy. The State's interest is in the preservation of life, not only Nancy's life, but also the lives of persons similarly situated yet without the support of a loving family. This interest outweighs any rights invoked on Nancy's behalf to terminate treatment in the face of the uncertainty of Nancy's wishes and her own right to life.²⁶²

Chief Justice Rehnquist summarised the question before the United States Supreme Court in *Cruzan* as whether the United States Constitution prohibited the state of Missouri from choosing the rule that it did, namely the 'clear and convincing' rule. In doing so, Rehnquist CJ stated that *Cruzan* was 'the first case in which we have been squarely presented with the issue whether the United States Constitution grants what is in common parlance referred to as a "right to die".'²⁶³ The Supreme Court ruled that the Fourteenth Amendment of the Constitution, which provides that no State shall 'deprive any person of life, liberty, or property, without due process of law', could be interpreted as conferring a competent person with a constitutionally protected liberty interest in refusing unwanted medical treatment.²⁶⁴ As the Court noted, however, the inquiry did not end at 'determining that a person has a "liberty interest"'.²⁶⁵ Rather, it must be established that one's constitutional rights have been violated by balancing one's liberty interests against the relevant state interests.²⁶⁶ In the context of this research, it is interesting to note that the Court did not view the right to refuse medical treatment as one grounded in the constitutional right to privacy – as it had done with reproductive healthcare matters such as abortion and contraception²⁶⁷ – opting instead to ground the right in a liberty interest. Anne Marie Gaudin suggests explanations for the Court veering away from the right to privacy: first, the Court 'felt uncomfortable in giving the right to die the substantive protection of the right to privacy because the exercise of this right leads to death, whereas the typical exercise of the right to privacy does not have such extreme consequences'.²⁶⁸ Second and the 'most probable possibility' was, in her view, that 'the conservative Court wanted to tighten the reins on the growing right to privacy'.²⁶⁹

²⁶² *ibid* 426.

²⁶³ 497 US 261 (1990); 277.

²⁶⁴ *ibid* 278; citing *Jacobson v Massachusetts* 197 US 11 (1905); *Washington v Harper* 494 US 210 (1990); *Breithaupt v Abram* 352 US 432 (1957).

²⁶⁵ 497 US 261 (1990) 279; quoting *Youngberg v Romeo* 457 US 307 (1982); 321.

²⁶⁶ *ibid*.

²⁶⁷ *Eisenstadt v Baird* 405 US 438 (1972); *Roe v Wade* 410 US 113 (1973).

²⁶⁸ Anne Marie Gaudin, '*Cruzan v. Director, Missouri Department of Health: To Die or Not to Die: That is the Question - But Who Decides?*' (1991) 51 *La L Rev* 1307, 1318.

²⁶⁹ *ibid*.

In balancing the ‘liberty interests against the relevant state interests’, the Supreme Court found, by majority, that the procedural requirement in the state of Missouri that ‘clear and convincing’ evidence of the incompetent’s wishes as to the withdrawal of treatment be provided was not unconstitutional:

The choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements (...) we think a State may properly decline to make judgments about the ‘quality’ of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual (...) In our view, Missouri has permissibly sought to advance these interests through the adoption of a ‘clear and convincing’ standard of proof to govern such proceedings.²⁷⁰

(...) Missouri may permissibly place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual’s life-sustaining treatment. An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science (...) or simply the unexpected death of the patient (...) at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision (...) is not susceptible of correction.²⁷¹

For the reasons outlined previously in this chapter, it is interesting to note the apparent acceptance of the United States Supreme Court of CAHN as medical care or treatment.²⁷²

Critically for New York, *Cruzan* solidified its entitlement to require ‘clear and convincing’ proof of a settled decision to refuse treatment, as it had done in *O’Connor*. Post-*Cruzan*, the US Supreme Court upheld the right of the individual to refuse life-sustaining treatment, however, this right could not be understood as a right to assisted suicide; in other words, it was not unconstitutional for Washington state to prohibit assisted suicide.²⁷³ Following on from the jurisprudence in New

²⁷⁰ 497 US 261 (1990); 282.

²⁷¹ *ibid* 283.

²⁷² O’Connor J stated: ‘I agree that a protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions ... and that the refusal of artificially delivered food and water is encompassed within that liberty interest (...) Artificial feeding cannot readily be distinguished from other forms of medical treatment’ (497 US 261 (1990); 287-7). Brennan J, with whom Marshall J and Blackmun J concurred, stated: ‘No material distinction can be drawn between the treatment to which Nancy Cruzan continues to be subject (...) and any other medical treatment (...) The artificial delivery of nutrition and hydration is undoubtedly medical treatment. The technique to which Nancy Cruzan is subject—artificial feeding through a gastrostomy tube—involves a tube implanted surgically into her stomach through incisions in her abdominal wall’ (497 US 261 (1990); 307).

²⁷³ *Washington v Glucksberg* 521 US 702 (1997); 703; ‘The constitutionally protected right to refuse lifesaving hydration and nutrition that was discussed in *Cruzan* (...) was not simply deduced from abstract concepts of personal autonomy, but was instead grounded in the Nation’s history and traditions, given the common-law rule that forced medication was a battery, and the long legal tradition protecting the decision to refuse unwanted medical treatment’. At 720: ‘We have also assumed, and strongly suggested, that the Due Process Clause protects the traditional right to refuse unwanted lifesaving medical treatment’.

York the 1980s, only one thing was clear, namely that a patient with decision-making capacity had the right to consent to or decline life-sustaining treatment in the state. The position of incompetent individuals was considerably more uncertain. Consequently, the New York Governor at the time, Mario Cuomo, identified the need for public discussion and consultation on end-of-life matters and advancements in medical technology and the associated ethical and legal considerations. Consequently, he convened the New York State Task Force on Life and Law in 1985, which was tasked with considering ‘the determination of death, the withdrawal and withholding of life-sustaining treatment, organ transplantation, the treatment of disabled newborns and new technologies and practices to assist reproduction’ among other issues.²⁷⁴ In its 1992 report, ‘When Others Must Choose: Deciding for Patients Without Capacity’, the Task Force recognised that because of the ‘legal precedents established by the New York Court of Appeals, only the legislature can authorize family members and others close to [a] patient to decide about life-sustaining treatment’.²⁷⁵ In acknowledging the serious problems with New York law, the Task Force proposed a model of surrogate decision-making, which it hoped found a middle ground between the ‘medical model of informal decisions at the bedside and the judicial model with all its procedural and evidentiary requirements’.²⁷⁶ This framework for surrogate decision-making saw almost 20 years of debate, eventually being passed as the Family Health Care Decision Act in 2010.²⁷⁷

After its introduction, the FHCDA changed matters considerably in New York. It may be remembered that in the wake of *O’Connor*, it was argued by commentators that neither family nor physician had the power to authorise the withholding or withdrawal of life-sustaining treatment from an incapacitated patient, save in very narrow circumstances.²⁷⁸ After its introduction, the FHCDA introduced a range of provisions to regulate medical decision-making for patients who have lost capacity and who do not have a guardian appointed.²⁷⁹ Broadly speaking, the FHCDA gives medical decision-making authority to people with a close relationship to the patient, such as

²⁷⁴ New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (New York 1992) introduction.

²⁷⁵ *ibid* 76.

²⁷⁶ *ibid*.

²⁷⁷ Public Health Law, Articles 29-CC and 29-CCC.

²⁷⁸ John J Regan, ‘Refusing Life-Sustaining Treatment for Incompetent Patients: New York’s Response to Cruzan’ (1991) 19 NYU Rev L & Soc Ch 341, 343.

²⁷⁹ New York Mental Hygiene Law § 81.02 empowers a court to appoint a guardian to manage the affairs (personal, financial, etc.) of an incompetent person. Decision-making on behalf of such individuals is governed by SPCA § 1750-b. The Health Care Decisions Act for Persons With Mental Retardation authorises the cessation or refusal of life-sustaining treatment from an individual at the request of his guardian subject to certain conditions.

family or friends, when the patient is incompetent and should she not have another legal instrument to govern such a situation such as an advance decision, health care agent or guardian. The decision-makers are known as ‘surrogates’. For the avoidance of confusion, it sets out the order of priority according to which decision-making authority should attach; for example, an adult child ranks higher than a parent.²⁸⁰ Should a person with higher priority on the list choose not to act as decision-maker on behalf of the individual, the person with the next highest priority has the right to act. It also establishes who may not have decision-making authority for the patient, for example, an employee of the hospital from which the patient was transferred.²⁸¹ As was discussed in Chapter 3, the decision-maker must make choices based on the wishes of the individual, including their religious and moral beliefs and if these are unknown and unascertainable, decisions must be based on best interests.²⁸² Critically, it permits decisions to be made on behalf of the patient on the withdrawal or withholding of life-sustaining treatment. Such treatment can be discontinued or refused if it would constitute ‘an extraordinary burden to the patient’ and she is permanently unconscious, or likely to die within six months.²⁸³ Furthermore, treatment can be withdrawn or withheld if it would ‘involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome’ and the individual suffers from an ‘irreversible or incurable condition’.²⁸⁴ Perhaps, if this legislation had been in force when Mrs O’Connor’s daughters had attempted to refuse treatment for their mother, the outcome may have been different; on the other hand, it is possible that they would have been unable to demonstrate the ‘extraordinary burden’ of the treatment. Indeed, the same could be said for Mrs Storar had the HCDA²⁸⁵ been in place.²⁸⁶

²⁸⁰ Public Health Law §2994-d section 1(c) and (d).

²⁸¹ The exception to this is if the person in question also fulfils one of the roles laid out in Public Health Law §2994-d. section 1 i.e. they are a relative or prior close friend of the patient.

²⁸² Public Health Law §2994-d section 4. For a recent best interests assessment, see *Matter of Doe* 53 Misc 3d 829 (Sup Ct, King’s County 2016), which concerned a woman in a persistent vegetative state whose father applied to court to prevent her special guardian from withdrawing life-sustaining treatment. In her assessment of best interests, King J considered factors such as the benefits versus the pain caused by the continuation of treatment and any enhancement in the quality of life brought about by the treatment. Compare with the decision-making standard for guardians making decisions on behalf of incompetent individuals: ‘The guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the person who is intellectually disabled and, when reasonably known or ascertainable with reasonable diligence, on the person who is intellectually disabled’s wishes, including moral and religious beliefs’; (SCPA § 1750-b section 2(a)).

²⁸³ Public Health Law §2994-d section 5(a)(i) ‘Treatment would be an extraordinary burden to the patient and an attending physician or attending nurse practitioner determines, with (...) independent concurrence (...) to a reasonable degree of medical certainty and in accord with accepted medical standards, (A) the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or (B) the patient is permanently unconscious’.

²⁸⁴ Public Health Law §2994-d section 5(a)(ii).

²⁸⁵ The Health Care Decisions Act for Persons With Mental Retardation 2002. The references to this Act in the SCPA were subsequently changed to ‘persons who are intellectually disabled’.

²⁸⁶ SCPA § 1750-b; the HCDA applies to individuals with development disabilities.

The FHCDA also creates a framework for medical professionals to make decisions on behalf of incompetent patients. Where the patient does not have a family member or friend to make decisions on his behalf, then a physician or nurse practitioner may make routine decisions on behalf of the patient and major decisions on his behalf, subject to certain additional requirements.²⁸⁷ Decisions to refuse or withdraw life-sustaining treatment can be made by physicians or nurse practitioners only if they determine that the treatment offers no medical benefit to the patient because she will die imminently even with treatment and the provision of the treatment in question would violate accepted medical standards.²⁸⁸ Such a decision must have independent concurrence of a second physician or nurse practitioner chosen by the hospital.²⁸⁹

Conclusion

Prior to understanding the legal and ethical complexities associated with advance directives and indeed their history, it was necessary to understand the complexities associated with end-of-life decisions and its legal development. This should not be surprising, as it is advance refusals of life-sustaining treatment that garner the most debate and difficulty for those involved. This chapter discussed the ethical issues arising in the context of end-of-life matters and argued that where a clear decision has been made by a competent person, whether contemporaneously or in advance, that such a decision should be honoured. Giving effect to such a decision is consistent with the fundamental principles of medical ethics; respect for autonomy, beneficence, non-maleficence and justice. How such a position is affected by pregnancy, however, will be considered in Chapter 6, when compelled treatment in pregnancy is explored. The law in Ireland, England and Wales and the United States has generally developed along the same lines – sometimes through legislation and other times through common law – permitting medical treatment to be withdrawn where it is best for the individual or where it is clear that withdrawal is what the individual would have wanted, or both. Although the ways in which this general rule manifests certainly does vary between jurisdictions, as was articulated above, the fundamental underpinnings are the same. It is this acceptance that the competent person can decide for himself, contemporaneously or in advance, that underpins the idea of advance directives, as will be expanded upon in the next chapter.

²⁸⁷ For example, the physician or nurse practitioner must consult with other members of the patient's care team and the decision must have approval of another physician or nurse practitioner chosen by the hospital per Public Health Law §2994-g section 4.

²⁸⁸ Public Health Law §2994-d section 5(b).

²⁸⁹ *ibid.*

Chapter 5 Introduction

People, while still competent, care mightily whether their cherished values, including dignity, will ultimately be respected in the dying process. In recognition of the importance of this self-determination, virtually all jurisdictions provide that a person's articulated wishes contained in an advance directive should be honored post-competence, just as a person's wishes about testamentary disposition of property are respected even though the dead person cannot sense violation of those wishes.¹

In the 1960s, a lawyer and the co-founder of Amnesty International, Luis Kutner, identified a considerable legal gap in the right of a patient to refuse medical treatment.² He questioned how an individual could retain the right of privacy over his body and of self-determination, given that the law required him to be treated to preserve his life once he was in a condition that precluded consent from being given.³ This was despite the fact that the law also provided that a patient may not be subjected to treatment without his consent, namely the common law doctrine of informed consent.⁴ The requirement for the physician to presume that a patient wished to be treated to preserve his life led to situations where patients were being treated despite having no desire to be kept alive 'in a state of indefinite vegetated animation'.⁵ Furthermore, he identified the very difficult position in which the law placed the physician; any failure on his part to act fully to keep the patient alive in a particular instance may have resulted in liability for negligence.⁶ His solution was the 'Living Will':

Where a patient undergoes surgery or other radical treatment, the surgeon or the hospital will require him to sign a legal statement indicating his consent to the treatment. The patient, however, while still retaining his mental faculties and the ability to convey his thoughts, could append to such a document a clause providing that, if his condition becomes incurable and his bodily state vegetative with no possibility that he could recover his complete faculties, his consent to further treatment would be terminated. The physician would then be precluded from prescribing further surgery, radiation, drugs or the running of resuscitating and other machinery, and the patient would be permitted to die by virtue of the physician's inaction.⁷

Kutner went on to state that some patients may never have the opportunity to consent, as they may be admitted suddenly to hospital, as opposed to having prearranged treatment or surgery. In such a circumstance, his view was that the patient should be able to create a document where

¹ Norman L Cantor, 'Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying' (2001) 29 J L Med Ethics 182, 189.

² Luis Kutner, 'Due Process of Euthanasia: The Living Will, A Proposal' (1969) 44 Ind LJ 539.

³ *ibid* 550.

⁴ For example, *Schloendorff v Society of New York Hospitals* 211 NY 125 (1914). See also Chapter 3 and Ruth R Faden and Tom L Beauchamp, *A History and Theory of Informed Consent* (OUP 1986).

⁵ Luis Kutner, 'Due Process of Euthanasia: The Living Will, A Proposal' (1969) 44 Ind LJ 539, 550.

⁶ *ibid*.

⁷ *ibid* 550-551.

he could indicate the extent to which he would consent to treatment, while still in possession of his mental faculties and the ability to express himself.⁸ This document, he stated, may be referred to as ‘a living will’.⁹

Kutner went further to propose a legal model for his living will, drawing from the law of trusts. He advocated for the document to be notarised and witnessed by at least two people who would confirm the capacity of the directive maker and the voluntariness of the decision. He proposed that the individual carry a copy of the document on his person at all times, while another trusted individual such as his wife, physician or lawyer would retain the original. He considered the possibility of ambiguity, contending that ‘[s]tatements and actions subsequent to the writing of the document may indicate a contrary intent’ and proposed that ambiguity should be resolved in favour of treating the patient until clarity could be reached.¹⁰ He also proposed the possibility of revocation of the document.¹¹

Kutner proposed eligibility criteria for drafting a living will and identified features that would render it invalid or inapplicable. He stressed that a living will could only be made by individuals capable of giving consent to treatment and specifically ruled out minors and those who were adjudged incompetent.¹² He expanded further that if an individual is adjudged incompetent after drafting a living will, then that will would be invalid except if the incompetence is the result of the medical condition necessitating the declaration in the first place. He proposed that a parent should not be able to make a living will on behalf of his child, nor should a guardian be permitted to make one on behalf of his ward, ensuring that one could only make a decision for oneself, thereby protecting vulnerable persons from having treatment withheld on the basis of the convictions of another.¹³ Because much of the basis of Kutner’s article was euthanasia, he specified that whilst a patient may determine the type of medical treatment he may receive,

⁸ *ibid* 551.

⁹ *ibid*: He also included a ‘declaration determining the termination of life’, a ‘testament permitting death’, a ‘declaration for bodily autonomy’, a ‘declaration for ending treatment’ and a ‘body trust’ as other possible terms for the advance directive.

¹⁰ *ibid* 551-552: ‘If the physicians find that some doubt exists as to the patient’s intent, they would give treatment pending the resolution of the matter. The document, if carried on the patient’s person, should indicate what persons should be contacted if he reaches a comatose state. The physician would consult with them in making a determination.’

¹¹ *ibid* 551: ‘The individual could at any time, before reaching the comatose state, revoke the document’. He did warn, however, that ‘[p]ersonal possession of the document would create a strong presumption that he regards it as still binding’.

¹² He also excluded individuals who were institutionalized. It is worth bearing in mind that he does not exclude the mentally ill from holding a living will, as he argues that ‘an individual who becomes mentally ill has the same rights as any other patient’. He continues: ‘He may, by the living will, anticipate mental illness and limit his consent to treatment accordingly. If in the course of his mental illness he enters an incurable comatose state, treatment may cease. The problem, however, is that, on becoming mentally ill, the court may find him incompetent and appoint a guardian’. In ascertaining if a guardian should revoke the living will or if it is deemed to have become revoked, he argues that ‘the approach of the trust concept is suggested’. He continues: ‘The trust relationship between the doctor and the patient was created by the living will with the patient as grantor. It was the patient’s intent, in creating (...) the living will (...) to cover contingencies wherein he would be incapable of granting or withholding assent to treatment. Incompetency because of mental illness is precisely such a situation. Therefore, the living will remains in effect. The guardian may not nullify it.’ Luis Kutner, ‘Due Process of Euthanasia: The Living Will, A Proposal’ (1969) 44 *Ind LJ* 539, 552.

¹³ For example, a parent of Christian Scientist faith could not refuse medical treatment on behalf of his child or ward for religious reasons.

he could not use a living will as a mechanism for active euthanasia – ‘as means for directing a doctor or another individual to act affirmatively to terminate his life’.¹⁴ It is fascinating that over 50 years later, the mechanism proposed by Kutner is by and large the model that is used across common law countries.

Detailing and evaluating the law on the right of a pregnant woman to refuse medical intervention in advance is unachievable without first getting a clear picture of the law, which applies to advance decisions and its historical development. Thus, this chapter is of critical importance to this research as a whole and in particular to the next chapter, wherein compelled intervention in pregnancy and pregnancy exceptions to advance directive statutes will be considered. Accordingly, this chapter will explore the law on advance directives in Ireland, England and Wales and New York State with reference to the United States more generally. To thoroughly examine the legal position in New York, it is necessary to consider the United States more broadly, as the ‘historical home’ of advance decisions. Inextricably linked to the law on advance directives, are the ethical issues underpinning them; accordingly, this chapter will also consider those in some detail. There is one key point to note about advance directives – certainly the legal aspect of them – as distinct from other areas of the law, there is relatively little applicable case law. Perhaps this is because it is ‘relatively uncommon’ for lay people to prepare advance directives, as Hayden J stated in *NHS Cumbria CCG v Rushton*.¹⁵ Or perhaps, as he also suggests, the lack of jurisprudence is a testament to their effectiveness.¹⁶ To some extent, both theories are supported by literature. Studies in the United States in the early 1990s demonstrated that although the vast majority of people would want minimal, if any, treatment were they to have a condition with no hope of recovery, the vast majority of them also had no advance directive.¹⁷ For example, as part of his argument that withdrawing or withholding life support measures should be the default setting and people should have to ‘opt out’ if they wish to receive more aggressive treatment, James Lindgren uses a range of sources to demonstrate that Americans of varying ages would not want life-sustaining measures in situations, such as irreversible coma and terminal illness, yet between 76% and 87% had no advance directive to that effect.¹⁸ Some more recent studies, however, point to an increasing number of Americans

¹⁴ *ibid* 553.

¹⁵ [2018] EWCOP 41, para 19.

¹⁶ *ibid*. Given that the goal of an advance directive is to avoid unwanted medical treatment and litigation, a lack of case law could indicate their success.

¹⁷ For example, in Elizabeth Gamble’s study of elderly people living in North Carolina, 75 people were surveyed, of which 85% wished only to receive basic medical or comfort care in terminal illness, yet none of the individuals surveyed had completed an advance directive to that effect. Elizabeth R Gamble and others, ‘Knowledge, Attitudes, and Behavior of Elderly Persons Regarding Living Wills’ (1991) 151 *Arch Intern Med* 277.

¹⁸ James Lindgren, ‘Death by Default’ (1993) 56 *L Contemp Probl* 185, 197 – 199, 250 – 253. The statement ‘between 76% and 87%’ refers to the percentages contained in various studies documented in Lindgren’s article.

– 29-36% – having advance directives, perhaps suggesting that there could be some accuracy in the Honourable Mr Justice Hayden’s second point.¹⁹ It has also been suggested that this figure is higher again amongst older persons.²⁰ In any event, it is perhaps most likely that it is a combination of both their (under-) utilisation and their effectiveness that has resulted in the dearth of case law.

Ethics of Advance Directives

While much of the ethical issues surrounding advance directives have already been addressed – as they arise in the context of consent and refusal of medical treatment and of end-of-life decision-making – there are some important distinctions to make. While some end-of-life cases concerned the tension between prior wishes of the competent person and the current position of the incompetent person – or as Mary Donnelly describes it, ‘the relationship between a person’s past and present will and preferences’²¹ – all advance directives have this tension. Thus, the notion of precedent autonomy is worth specifically addressing. It is contended that advance directives maximise the autonomy of the individual; intuitively, this is an extension of the idea that one of the underpinning reasons for the legal and ethical duty to seek consent prior to administering treatment is respect for the autonomy of the person.²² It is also an extension of the idea that refraining from administering life-sustaining treatment in the face of a competent refusal maximises the autonomy of the person. It allows individuals who lose

¹⁹ Kuldeep N Yadav and others, ‘Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care’ (2017) 36 Health Aff 1244. In this study, all advance care planning documentation appears to be termed an ‘advance directive’, thus the use of the 29% figure in main text relates to the amount of people with a living will, which is what an advance directive (in the Irish and English context) is termed in some US states. Pew Research Center (2006) ‘Strong Public Support for Right to Die: More Americans Discussing — and Planning — End-of-Life Treatment.’ Telephone survey of 1,500 older adults conducted November 9th-27th, 2005 under the direction of Princeton Survey Research Associates International <<http://people-press.org/report/266/strongpublic-support-for-right-to-die>> 16 January 2020. AARP (American Association of Retired Persons) Bulletin Poll ‘Getting Ready to Go’ (January 2008) <https://assets.aarp.org/rgcenter/il/getting_ready.pdf> accessed 16 January 2020. It is worth noting that other commentators put the percentage of advance directive holders considerably lower. Robert Olick estimates the percentage to be 20% and opines that there hasn’t been a particularly ‘dramatic’ increase in the percentage over time; Robert S Olick, ‘On the Scope and Limits of Advance Directives and Prospective Autonomy’ in Peter Lack and others (eds) *Advance Directives* (Springer 2014) 69. There is considerably less data from England and Wales and Ireland, perhaps reflecting the comparative recency of both the MCA 2005 and the ADM(C)A 2015. Having said that, there is a recent study concerning the knowledge and use of advance directives amongst elderly people by John Lombard *et al*, some of the highlights of which were presented at a seminar entitled ‘Healthcare Decision-Making and the Law’. This study found that only 8% of elderly people surveyed had completed an advance directive and only 22% knew what one was. John Lombard, ‘Healthcare Decision-Making and the Older Person: Experience and Insights’ (Healthcare Decision-Making and the Law Seminar, Limerick, 5 December 2019). There are also two studies from Rebekah Schiff *et al* on the topic for England and Wales: in the first study in 2000, the data suggests that advance directives were very unpopular with 82% of respondents having never heard of ‘living wills, advance directives, or advance statements’. Arguably, this is somewhat unsurprising given that the study predates the legislation by 5 years. Rebekah Schiff and others, ‘Views of Elderly People on Living Wills: Interview Study’ (2000) 320 BMJ 1640. In a later study in 2006, Schiff and her team surveyed over 800 geriatricians, 56% of which had cared for patients with living wills. This statistic, however, gives no indication of the popularity of advance directives amongst the general population for two reasons. First, it focuses on the number of geriatricians who had encountered an advance directive, not on the percentage of patients that had one; the surveyed medical professionals could have come into contact with one or dozens of advance directives over their career. Second, by surveying only geriatricians, the study will only interact with elderly patients, thereby giving no insight into the general population. These are not criticisms of the study, the limitations articulated merely reflect what was and was not the purpose of the study; Rebekah Schiff and others, ‘Living Wills and the Mental Capacity Act: A Postal Questionnaire Survey of UK Geriatricians’ (2006) 35 Age and Ageing 116.

²⁰ In 2008, the AARP found that 53% of the 3024 respondents to their ‘Caregiving and End-of-Life Issues’ survey in Florida had a living will. Terri Guengerich, ‘Caregiving and End-of-Life Issues: A Survey of AARP Members in Florida’ 2009 <https://assets.aarp.org/rgcenter/il/fl_eol_08.pdf> accessed 16 January 2020.

²¹ Mary Donnelly, ‘Deciding in Dementia: The Possibilities and Limits of Supported Decision-making’ (2019) 66 Int’l J L & Psychiatry 101466, 3.

²² For a full discussion of the relationship between consent to medical treatment and autonomy, see Chapter 3.

capacity to have the same ability to make choices based on their wishes and preferences, as competent individuals. As Samantha Halliday argues:

The principle of patient autonomy stresses respect for the patient as an individual, rather than as an *object of concern*, and attempts to promote precedent autonomy aim to extend that respect to those no longer capable of exercising autonomy and so to prioritise the patient's wishes over her welfare.²³

Thus, if one can decide to contemporaneously refuse treatment in line with one's own priorities, perhaps objectively acting against one's interests, why should one not be allowed to do so in advance?²⁴ There are those who point out, however, that there may be conflict between one's wishes for the future and one's present interests once incompetent and that this calls into question the very justification for advance directives because they accord less respect to the interests of existing person than they do to the wishes of the 'earlier' person, who no longer exists.²⁵ Ronald Dworkin accepts the idea that we think about the rights and interests of the person in two different ways; as an incompetent person or as a person who has become incompetent.²⁶ He goes on to defend the idea of the interests of the previously competent person potentially outweighing the interests of the now incompetent person on the basis of the kinds of interests involved, namely 'critical interests' and 'experiential interests'.²⁷ The former concern critical value judgements and give meaning to our lives;²⁸ thus, if such interests are satisfied, then one's life will be more positive and if they are left unsatisfied, one's life will be worse. Wishing to shape one's death is a legitimate exercise of one's critical interests in his view.²⁹ So too is making an advance directive designed to apply when one becomes demented.³⁰ Think, for example, of the woman who was fiercely independent her whole life only to end it completely dependent on others, demented or not. Such an ending, unless desired by the woman for some reason, would be out of character when the rest of her life is considered. 'Experiential interests', by contrast, concern desirable and undesirable matters such as enjoyment or pain. He argues that there is a substantial difference between these interests and that critical interests ought to be determinative.

²³ Samantha Halliday, 'Legislating to Give Effect to Precedent Autonomy: Comparative Reflections on Legislative Incompetence' (2011) 11 *Med L Int'l* 127, 128 (emphasis added).

²⁴ *ibid* 129: 'Autonomy's central premise is that individuals should be permitted to make decisions for themselves, but the corollary to this must be that individuals must be able to make decisions contrary to their own best interests that they might later regret and that choosing to exercise autonomy in anticipation of incapacity involves accepting responsibility for that choice.' See also Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Harper Collins 1993) 224.

²⁵ Rebecca Dresser, 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law' (1986) 28 *Ariz L Rev* 373, 379-81. This conflict is affected by a number of factors including the nature of the incompetent and its permanence.

²⁶ Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Harper Collins 1993) 221. The exact phrasing he uses is 'the demented person' and 'a person who has become demented'.

²⁷ *ibid* 201-8.

²⁸ *ibid*.

²⁹ *ibid*; he gives the example of the person who can reject life-saving amputation.

³⁰ *ibid* 226.

Irrespective of whether or not one subscribes to Dworkin's particular categorisation of interests or concurs with his view on the degree to which critical interests should trump experiential ones, there is merit in his general line or argument.³¹ Where an individual has contemplated her future to the extent that she has a vision for it and critically, a vision of what she does not want it to be, then that is important and worthy of respect.³² In other words, the wishes of the now incompetent person ought not to outweigh those of the once competent individual. Thus, it is argued that advance directives can be viewed as extending the self-determination of the individual into the future.³³ This is clearly based on the previously defended assumption that the maximisation of the autonomy of the individual is a legitimate aim.

Advance directives also interact with the principles of non-maleficence and beneficence. As was articulated in the previous chapters, the treatment of a patient against her will, in the absence of a morally relevant justification, breaches the principle of non-maleficence; the corollary of this is that refraining from treating the patient and honouring her advance directive is the medical professional acting in a way consistent with the principles of non-maleficence and beneficence. Some challenges to these assertions will now be discussed in the context of criticism of advance directives.

Criticisms of Advance Directives

Advance directives are not without their criticisms.³⁴ The following criticisms are not designed to form an exhaustive list, rather a selection of the most common criticisms, which are neither mechanical in nature, nor purely ethical.³⁵ What then is meant by 'mechanical'? In short, the criticisms that will be discussed attack the concept of the advance directive and not merely their legal framework. For example, the unavailability of an advance directive at the time of treatment, thereby rendering them pointless or ineffective, is not an issue with advance directives as a concept; rather, it is an issue that could be easily remedied by the law itself by

³¹ He suggests that if a hypothetical woman with dementia made an advance directive to end her life, that her wishes should be honoured. This research would not advance that position for a variety of reasons, however, the idea that one should be able to hasten death by refusing specific intervention – in line with how the law on advance directives is generally constructed – when one has dementia is supported. For a strong criticism of Dworkin's work, see Rebecca Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy (1995) 25 Hastings Center Report 32.

³² *ibid* 24: Rebecca Dresser argues that the low number of people who engage in end-of-life planning and who draft advance directives may 'indicate that issuing explicit instructions to govern the final chapter of one's life is not a major priority for most people'. This she argues raises questions about how 'precious', 'valued' and worthy of protection this freedom really is.

³³ Jochen Vollmann, 'Advance Directives in Patients with Alzheimer's disease; Ethical and Clinical Considerations' (2001) 4 *Med Health Care & Philos* 161.

³⁴ Criticisms based on more 'practical' aspects of advance directives – such as them often being unavailable at the time of treatment, therefore rendering them pointless or ineffective – will not be considered, as often the practical issues with advance directives can easily be remedied by the law itself. For example, a central register of advance directives may limit individuals being treated against their preference where their advance directive has been stored with a family member or GP.

³⁵ That is not to say that the following criticisms will not have an ethical component to them, rather they are not solely ethical issues, as those have already been addressed.

creating a central register of advance directives.³⁶ Broadly speaking, these criticisms can be defined as:

- (i) The Failure to Maximise Autonomy
- (ii) Narrowness or Restrictiveness;
- (iii) The inability of individuals to make the correct advance decision for themselves;
and
- (iv) The susceptibility of the individual to phrasing.

Failure to Maximise Autonomy

As alluded to briefly in the previous section, there are challenges to the argument that advance directives maximise autonomy; these, it is argued, are frequently based on the relationship, or lack thereof, between our current wishes for our ‘future self’ and the wishes that we have when that future point in time is reached.³⁷ For example, George Loewenstein argues that ‘[p]atient autonomy is a wonderful thing if it means implementing choices that meet patients’ long-term preferences, but if patients change their preferences from moment to moment, then decisions are likely to have a large arbitrary component’.³⁸ Christopher Ryan argues similarly that advance directives do not promote autonomy; in support of this, he argues that individuals are prohibited from making truly autonomous choices when they create advance directives because they are unaware of the ‘distinct possibility that their choices may be inaccurate’.³⁹ If one is unaware of this, he argues, then one lacks a vital piece of information that enables an autonomous choice.⁴⁰ When one views this challenge in light of the principle of non-maleficence; if refusing treatment is not actually what the individual wants, then it is difficult to conclude that the physician is doing harm by treating her.

Although Ryan restricts his criticism to advance directives that state that the individual ‘receive only conservative or palliative care (...) where that incompetence is potentially reversible’, his argument still causes difficulty. He contends that it is not an autonomous choice to refuse life-prolonging treatment in advance, however, neither is a contemporaneous decision given that the person has lost capacity. Furthermore, his argument is based on the disparity between the attitudes of healthy people towards treatment in terminal illness and the attitudes of those with terminal illness, which he argues ‘strongly suggests that many people who, when healthy,

³⁶ Whether a centralised system of advance directives is desirable is not within the scope of this research. The example is used as a method of distinguishing ‘issues with the concept’ from ‘issues with the mechanics’.

³⁷ The argument that people are poor at predicting what they will want in the future is addressed in a later section.

³⁸ George Loewenstein, ‘Projection Bias in Medical Decision Making’ (2005) 25 *Med Decis Making* 96, 103-104.

³⁹ Christopher Ryan, ‘Betting your life: an argument against certain advance directives’ (1996) 22 *J Med Ethics* 95, 97.

⁴⁰ *ibid.*

predict they would refuse treatment in the future, will change their mind when they develop a terminal illness'.⁴¹ Assuming that this is the case, it is contended that this argument would only have validity if the ability of the individual to change or revoke her advance directive was restricted or negated altogether. As advance directives can be revoked or amended at any point in time prior to a loss of capacity, then this argument appears to have minimal merit. If an individual chooses not to amend or revoke an advance directive, why would we assume that their will is not the same, particularly in the context Ryan has given, that of the onset of terminal illness? If the onset of a terminal illness does not focus the mind on end-of-life planning, what would? Also, it is worth contrasting his view of preferences during terminal illness with the view of other commentators, such as Norman Cantor, who paints a very different picture:

The end may come hard for a chronic emphysema sufferer, unable to speak because of a tracheotomy and tortured by breathing difficulty or paroxysms of cough. For these (...) patients, the prospect of rejecting further nutrition, as well as other life-preserving measures, would seem to offer welcome relief. The principle may also be of benefit to sufferers of chronic degenerative diseases such as Alzheimer's disease, Lou Gehrig's disease, or Huntington's chorea. Death normally comes to such persons after a tortuous process of deterioration, loss of faculties, and pain.⁴²

Furthermore, even if Ryan's view is correct, often the provision of evidence that the individual acted in a way inconsistent with her advance directive renders it invalid. Accordingly, evidence that the individual spoke about her desire 'to fight on' or 'be around as long as possible' could result in the advance directive being invalid.

Rebecca Dresser goes further to argue that the reliance on past preferences is actually problematic because 'it grants prominence to values and beliefs that have no bearing on the incompetent patient's actual interests'.⁴³ She argues further:

When competent people make judgments on the conditions under which they desire to live and die, their judgments reflect their existing capacities and the activities that make their present lives worth living. Decisions about the future health care that will advance their interests are inextricably intertwined with their current conceptions of the good.⁴⁴

Furthermore, why should a patient who is now a different person be burdened by a treatment decision consistent with the former person's preferences? Compelling justification is lacking for according greater respect to the wishes of the earlier person (no longer in existence) than to the interests of the existing one.⁴⁵

⁴¹ *ibid* 96.

⁴² Norman L Cantor, 'Conroy, Best Interests, and the Handling of Dying Patients' (1985) 37 Rutgers L Rev 543, 553.

⁴³ Rebecca Dresser, 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law' (1986) 28 Ariz L Rev 373, 374.

⁴⁴ *ibid* 379.

⁴⁵ *ibid* 381.

As discussed in Chapter 4, this notion rests to a substantial extent on the premise that we are not the same person throughout our lives, but rather that we are different people along the lines of Derek Parfit's theory.⁴⁶ While there is undoubtedly merit in her arguments, one is left questioning what is the superior alternative? If the individual is not best placed to decide for herself, then who is? As will be discussed in the coming paragraphs, the answer to that question is easily reached; all decision makers are prone to letting other factors and their own experiences influence their choices on behalf of others. The question of who decides is particularly acute when we consider the position of the individual who can regain competence; how ought it be explained to her that her prior wishes were disregarded in the very circumstances in which she wanted them to have effect because they were not in her interests at the time?⁴⁷ This point has particular relevance in the context of pregnant women, as they are unlikely to suffer from degenerative conditions such as dementia, but instead are more likely to lose capacity as a result of mental illness or a trauma of some description, both of which come with the possibility of regaining capacity.

Narrowness

In essence, the description of advance directives as overly restrictive or too narrow stems from the idea that because it is challenging to foresee the myriad of situations that might arise for an individual, an advance directive may be too narrow to cover the possible situations or too broad to give clear direction to the relevant medical personnel and thus is ineffective to achieve the aims or wishes of the patient.⁴⁸ They simply do not give the individual the scope to express her wishes fully and therefore, they are not a sufficient tool to promote her autonomy. Whilst this argument is not devoid of merit, it could certainly be counterargued that this criticism relates less to advance directives themselves and more to how the relevant courts adjudicate cases involving insufficiently specific advance directives. If one considers the jurisprudence from England and Wales, then despite the advance directive being either invalid or inapplicable to the situation, the court still ordered that the treatments concerned be withdrawn.⁴⁹ For example, in *Re D*, which will be discussed in more detail later, the wishes expressed in writing in an invalid advance were still taken as evidence as part of the best interests assessment.⁵⁰ More

⁴⁶ Derek Parfit, *Reasons and Persons* (OUP 1984).

⁴⁷ It is worth noting that in both her critiques, Rebecca Dresser appears to deal with individuals with irreversible incompetence, rather than with those whose competence may return.

⁴⁸ James Lindgren, 'Death by Default' (1993) 56(3) L Contemp Probl 185, 211; See also Rebecca Dresser, 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law' (1986) 28 Ariz L Rev 373; Norman L Cantor, 'Conroy, Best Interests, and the Handling of Dying Patients' 37 Rutgers L Rev 543.

⁴⁹ [2012] EWCOP 885. See also *X Primary Care Trust v XB* [2012] EWHC 1390 (Fam) – questions regarding the validity of the advance directive as an 'end date' was on the pro forma documentation – and *NHS Cumbria CCG v Rushton* [2018] EWCOP 41.

⁵⁰ *Re D (withdrawal of treatment)* [2012] EWCOP 885 ('*Re D*').

recently, in *Barnsley Hospital NHS Foundation Trust v MSP*, Hayden J found that while the document produced was not a valid advance decision, it did represent ‘a clear and eloquent expression of MSP’s wishes and feelings’.⁵¹ In both instances, therefore, the advance decision, though invalid from a legal standpoint, was sufficient to protect individual autonomy.

Furthermore, it could be contended that a certain amount of rigidity is justified where a decision may hasten death or end a life. While there may be no circumstances in which a member of the Jehovah’s Witness faith would accept a blood transfusion, the preference for treatment of an individual without religious convictions would likely vary depending on the circumstances. It is the narrowness that protects people and serves as a defence to many of the other critiques levelled at advance directives, in other words, Ryan’s contention that people make inaccurate choices or choices based on misunderstanding. For example, the likelihood of a meaningful recovery would almost certainly be a factor in an advance decision to refuse ventilation. Were the makers of advance directives not obliged to be detailed about the circumstances in which their advance refusal is to apply, then a situation may arise where the individual would have wanted treatment but an insufficiently clear advance directive leads the physician to think that she would not.⁵²

Inability to Decide for Oneself

As described above, the third concern relates to the ability of the individual to correctly identify in advance the treatment she will not want in the future. While on the one hand, this forms part of the argument that advance directives do not promote autonomy, this argument, in its own right, also alleges that advance directives are a ‘bad thing’. To clarify the difference between the two arguments; the former argues that advance directives do not fulfil one of their core aims – protection of autonomy – and the latter alleges that they are undesirable in and of themselves. Loewenstein, for example, cautions against what he terms ‘projection bias’ – that is the projection of one’s current preferences onto points in the future when those preferences should be irrelevant – in medical decision making.⁵³ As he argues, the ‘failure to accurately predict one’s own future preferences undermines the quality of many types of decisions, but it creates special problems for medical decisions’. Citing a 1990 study conducted by Slevin *et al*,

⁵¹ *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26, para 41.

⁵² For example, an individual may not want to be placed on a ventilator in circumstances when recovery is uncertain but may be in favour of ventilation if it appears to be a short-term treatment.

⁵³ George Loewenstein, ‘Projection Bias in Medical Decision Making’ (2005) 25 *Med Decis Making* 96, 98. He explains projection bias with reference to shopping for food when one is hungry: ‘Projection bias is well illustrated by the phenomenon of shopping on an empty stomach. Normatively, how hungry one is when one enters the supermarket should not affect the amount of food one buys for the next several days, but several studies support the folkwisdom that shopping on an empty stomach leads to overshopping.’

Loewenstein emphasises the difference between the attitudes of cancer patients and the general public to chemotherapy.⁵⁴ The study found that patients with cancer were considerably more likely to consent to a hypothetical radical treatment with minimal chance of benefit than people who did not have cancer: 42% versus 10% respectively would submit to invasive treatment for their lives to be prolonged by 3 months and 53% versus 19% respectively would submit to invasive treatment on the chance that it would cure them.⁵⁵ He also suggests that the average healthy person is unable to imagine what it would be like to have this kind of sickness and therefore appreciate a situation like cancer, until they are in it, which in turn affects their decision making.⁵⁶

The argument is certainly not without strength; arguably, however, the mere potential for or existence of projection bias within advance decision making is not a justification for preventing it. Moreover, as Loewenstein himself points out in the course of his article; medical professionals and the average person are also prone to projection bias.⁵⁷ Following this logic, nobody is capable of making these kinds of decisions; the individual cannot make the decision, nor can those who would typically be called upon to act as surrogate decision makers.⁵⁸ Even Chief Justice Wachtler, who presided over the *O'Connor* case, spoke in a subsequent interview about how his personal circumstances and the illness of his own mother influenced his judgment.⁵⁹ Indeed, as Nancy Rhoden argues in relation to family members deciding on behalf of incompetent individuals:

Family members are probably at once the best and the worst decisionmakers. Ideally, they knew the patient best and loved her most. But they also have the most to gain or lose from these choices. Family members might overemphasize their own concerns and/or the patient's concern for their fiscal wellbeing, thinking she would never have wanted her fortune used up in caring for her in her dotage, and not recognizing that in the face of desperate illness, even the selfless become far more self-concerned.⁶⁰

⁵⁴ Maurice L Slevin and others, 'Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public. (1990) 300 *BMJ* 1458.

⁵⁵ *ibid* 1460.

⁵⁶ Loewenstein's exact phrase is 'people seem to have a cavalier attitude toward their own demise, until they actually face it'. George Loewenstein, 'Projection Bias in Medical Decision Making' (2005) 25 *Med Decis Making* 96, 102.

⁵⁷ *ibid* 103: Loewenstein uses the example of projection bias in physicians who are managing patients' pain; projection bias can cause physicians to underappreciate the pain that patients are in and undermedicate it as a result. To support his contention in relation to 'the average person' he cites two studies from 2 studies conducted by Fagerlin *et al*, in which surrogates predicted what treatment, if any, a close relative would want in a number of hypothetical end-of-life scenarios and answered the same question in relation to their own preferences. Often, the decision was closer to what the respondents would want if the situation arose for them, rather than what their relative would have wanted.

⁵⁸ Contrast this point with the work of Fagerlin and Schneider; when expressing support for a durable power of attorney model, they opine that surrogate decision-makers 'know more at the time of the decision than patients can know in advance'. Angela Fagerlin and Carl E Schneider, 'Enough: The Failure of the Living Will' (2004) 34(2) *Hastings Center Report* 30, 39. Contrast also with Nancy Rhoden, 'How Should We View the Incompetent?' (1989) 17 *L Med & Health Care* 264, 267; 'More objective third parties, who are better able [than family] to view the incompetent only in the present, are more likely to avoid the temptation to ascribe overly-altruistic beliefs to her'.

⁵⁹ 72 *NY 2d* 517 (1988). See Lisa Belkin, 'New York Rule Compounds Dilemma Over Life Support' *New York Times* (New York, 12 May 1992) <<https://www.nytimes.com/1992/05/12/us/new-york-rule-compounds-dilemma-over-life-support.html>> accessed 20 January 2020. The learned judge also stated that the ruling had 'been applied more widely than the court foresaw'.

⁶⁰ Nancy Rhoden, 'How Should We View the Incompetent?' (1989) 17 *L Med & Health Care* 264, 267. Again, contrast with Angela Fagerlin and Carl E Schneider, 'Enough: The Failure of the Living Will' (2004) 34(2) *Hastings Center Report* 30, 39. See also the previous chapter

Additionally, how should one discern if a current influence should not affect a future decision? Perhaps a current experience merely reinforces a previously held belief, rather than swaying the decision-maker. Conversely, perhaps it highlights something to the decision-maker that they had previously overlooked or considered unimportant. Then, rather than being an argument against advance decisions, perhaps the potential for projection bias ought to be considered a caution against making an advance directive in isolation and never returning to it to reconsider and re-evaluate its content in light of changes to one's life, thereby perhaps alleviating the concern expressed by Dresser that 'a person's interests can change radically over time, so radically that in some cases it could be said that a different person exists by the time the life and death treatment situation arises'.⁶¹ Arguably, reconsidering one's advance directive could also mitigate against the alleged failure of 'the personal preferences expressed in an advance directive [to] (...) incorporate the up-to-date information on therapy and prognosis available' at the time when the advance directive should become effective.⁶²

Other commentators attribute this inability of the individual to make the 'correct' decision to a lack of information:

The conventional—legal and ethical wisdom—insists that candidates for even a flu shot give 'informed consent'. And that wisdom has increasingly raised the standards for disclosure. If we applied those standards to the information patients have before making the astonishing catalog of momentous choices living wills can embody, the conventional wisdom would be left shivering with indignation. Not only do people regularly know too little when they sign a living will, but often (...) they analyze their choices only superficially before placing them in the time capsule.⁶³

Searing criticism, indeed; however, if one examines the interaction between the two aspects of informed consent to medical treatment, namely standard of disclosure and capacity to consent, perhaps this argument loses a little of its strength. The former is a legal standard that must be reached for a physician to discharge his duty, the other is a legal standard which must be met for an individual to have capacity to make a specific decision. Perhaps, a justification for the difference between the information that must be given and that, which must be understood, is the protection of patients and their interest in self-determination. Arguably, a 'high' standard for information disclosure combined with a 'low' or 'easily attainable' standard for understanding maximises the number of individuals enabled by the law to make a healthcare

where the contention made by Samantha Halliday and Lars Witteck that onerous standards of proof may lead family members to manufacture evidence as to the wishes of the individual was discussed. Samantha Halliday and Lars Witteck, 'Decision-Making at the End-of-Life and the Incompetent Patient: A Comparative Approach' (2003) 22 *Med & L* 533, 540.

⁶¹ Rebecca Dresser, 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law' (1986) 28 *Ariz L Rev* 373, 379.

⁶² *ibid* 376.

⁶³ Angela Fagerlin and Carl E Schneider, 'Enough: The Failure of the Living Will' (2004) 34 *Hastings Center Report* 30, 33.

decision. Patients with varying levels of understanding receive the information that they require and desire in order to choose, whether they understand the specific detail or the broad, general information. As stated previously, a ‘broad, general understanding of the kind that is expected from the population at large’ of the ‘nature, purpose and effects of the proposed treatment’ was sufficient to meet the standard for decision making competence in England and Wales.⁶⁴ Moreover, an individual is ‘not required to understand every last piece of information about her situation and her options’ in order to have capacity.⁶⁵ In Ireland, the common law standard is that the individual understands ‘the nature, purpose and effect of the proffered treatment and the consequences of accepting or rejecting it in the context of the choices available (...) at the time the decision is made’.⁶⁶ The legislative provisions define this standard similarly.⁶⁷ Therefore, in order to have capacity to make a contemporaneous decision, one must generally understand the nature of the treatment and its risks and benefits. To require a higher level of understanding than this would almost certainly make the ability to make medical decisions a privilege of the few and exclude those individuals that legislators and campaigners have sought to bring within the remit of medical decision-making.⁶⁸ Furthermore, if an advance directive is drafted by an individual who does not understand the nature of the treatment she is refusing and the consequences arising from its refusal, then the advance directive may be invalid, as it has been made by an individual with questionable capacity. The question arising from the point made by Angela Fagerlin and Carl Schneider is why a legislature would require a higher standard for advance decisions, if it is not required for contemporaneous refusal.

Perhaps their idea of an ‘astonishing catalog of momentous choices’ relates to an advance directive where the individual is laying out more than an advance refusal of specific medical treatments in specific circumstances. Perhaps they were envisaging living wills where the patient dictated the many treatments that they would and would not want in multiple situations, in which case, their argument may have more validity. That is, however, not the way advance decisions are viewed by the law in Ireland, England and Wales or New York. They are

⁶⁴ *Heart of England NHS Foundation v JB* (2014) 137 BMLR 232, 240.

⁶⁵ *ibid.*

⁶⁶ *Fitzpatrick v FK* [2009] 2 IR 7, 35.

⁶⁷ Ireland’s Assisted Decision-Making (Capacity) Act 2015 requires that an individual be able to understand information pertaining to the reasonably foreseeable consequences of each of the available choices and of failing to make a decision (section 3(7)). In New York, an individual must have the ability to understand and appreciate the nature and consequences of proposed health care, including the benefits and risks of and alternatives to proposed health care, and to reach an informed decision per Public Health Law § 2994-a section 5. Section 4.19 of the Code of Practice of the Mental Capacity Act 2005 explains relevant information as ‘the likely consequences of a decision would be (the possible effects of deciding one way or another) – and also the likely consequences of making no decision at all (section3(4))’. The same section goes on to state that ‘[i]n some cases, it may be enough to give a broad explanation using simple language. But a person might need more detailed information or access to advice, depending on the decision that needs to be made. If a decision could have serious or grave consequences, it is even more important that a person understands the information relevant to that decision’.

⁶⁸ For example, patients with fluid (in)capacity such as those with dementia or certain mental health conditions.

construed narrowly as time, treatment and condition specific refusals. Additionally, as Cantor argues:

While declarants may be unable to anticipate the precise scenario they will face when dying, they may have well developed and enduring notions of dignity, religion, and consideration for loved ones, which they want reflected in their future medical handling.⁶⁹

To support their point, they note that individuals can execute a living will ‘without even consulting a doctor’. While this is true, failure to consult a medical or medico-legal professional could easily result in the creation of an invalid or inapplicable advance directive; first, because the advance directive may be insufficiently clear to be applicable, in other words, she has used overly broad terms such as ‘extraordinary measures’ or ‘invasive treatment’ without clarification, thus they lack clear meaning. Second, the individual has not clearly specified the circumstances in which the advance directive should apply; namely, she used terms such as ‘no prospect of recovery’ without clarification, which would be a very high standard to achieve and difficult for a medical professional to confirm because ‘recovery’ may not mean the same thing to everyone.⁷⁰

Furthermore, while it may be considered inadvisable not to consult with a doctor when making such decisions, the law – certainly the jurisprudence from England and Wales and legislation from Ireland – suggests that a risk of an individual making an unwise decision is insufficient justification to intervene and stop her making the decision.⁷¹ Finally, it is respectfully submitted that Fagerlin and Schneider’s final point, which states that individuals analyse their choices ‘only superficially before placing them in the time capsule’, has been addressed already. That criticism is more applicable to the practice of drafting an advance directive without routine re-evaluation, than to the concept of advance directives. That statement is undermined, however, by evidence from Fagerlin and Schneider that, not only are personal preferences liable to change but that individuals ‘have trouble recognizing that their views have changed’.⁷² On that point this research must concede defeat, aside from to say that perhaps it highlights the importance of regular open conversations about end-of-life care and the necessity of a societal shift towards that aim. Operating under a misapprehension as to the effect that particular

⁶⁹ Norman L Cantor, ‘Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying’ (2001) 29 J L Med Ethics 182, 189.

⁷⁰ This is as distinct from using medical terminology such as ‘persistent vegetative state’ or ‘minimally conscious state’.

⁷¹ Via finding them incompetent. For England and Wales, see *Kings College Hospital NHS Foundation Trust v C* [2015] EWCOP 80. See also Assisted Decision-Making (Capacity) Act 2015, s 8(4).

⁷² Angela Fagerlin and Carl E Schneider, ‘Enough: The Failure of the Living Will’ (2004) 34 Hastings Center Report 30, 34.

condition would have on their lives in the long term may also affect the ability of individuals to correctly decide matters of healthcare for themselves.⁷³

Susceptibility of the individual to phrasing

It has been alleged that people can be highly reactive to the way in which information is phrased. This means that the same medical treatment may be accepted or refused by the same person depending on the way the treatment is explained. Fagerlin and Schneider state that ‘preferences about treatments are influenced by factors like whether success or failure rates are used, the level of detail employed, and whether long or short-term consequences are explained first’.⁷⁴ First, this presupposes a conversation between the individual and a medical professional, which arguably weakens their contention that people are insufficiently informed to make decisions in advance. Aside from that, they go on to cite a study which demonstrated that the percentage of people who consented to intervention increased from 12% to 18% and then to 30% depending on how the information was presented i.e. negatively, as it was phrased in the advance directive and positively.⁷⁵ Presumably, however, this would be as true for contemporaneous decision making as it is for advance directives. In other words, if people’s decisions change relative to the way that information is provided, then that would apply to all decision-making. Consequently, their argument serves more as a warning to medical professionals about the relationship between how information is presented and decision outcomes than as an argument against advance directives. However, if this is truly a criticism applicable to advance decisions, then it is as much an issue for durable power of attorney, which Fagerlin and Schneider advocate.⁷⁶ If the patient is highly susceptible to being influenced by how information is presented, then surely, so too must individuals who are making decisions on behalf of loved ones.

Perhaps what has to be taken from the above is that there is no one right method of decision-making; family deciding on behalf of the incompetent person, advance directives, decision-making on the basis of the best interests all have strengths and weaknesses. Thus, while there are legitimate ethical and conceptual arguments against advance directives, it is the position of

⁷³ See for example Daniel T Gilbert and Timothy D Wilson, ‘Miswanting: Some Problems in the Forecasting of Future Emotional States’ in Joseph Forgas (ed) *Thinking and Feeling: The Role of Affect in Social Cognition* (Cambridge University Press 2000).

⁷⁴ Angela Fagerlin and Carl E Schneider, ‘Enough: The Failure of the Living Will’ (2004) 34 *Hastings Center Report* 30, 33.

⁷⁵ *ibid* citing BB Ott, ‘Advance Directives: The Emerging Body of Research’ (1999) 8 *Am J Crit Care* 514.

⁷⁶ *ibid* 39. It is worth noting that they do not advocate for the elimination of living wills entirely; on pages 30-1, they argue for their role as narrow, existing when individuals have a clear medical situation with imminent crisis and when their preferences are ‘specific, strong, and delineable’. As with health care agents, however, surely patients with an immediate crisis will be as susceptible to reacting on the basis of how information is presented as anybody else. It is worth saying that their argument is that a cost v benefit analysis of the policy in the United States towards advance directive demonstrates that the progress made has not justified the resources spent; in doing so, they are strongly critical of advance directives. The accuracy, or not, of this cost benefit analysis is not relevant to this research, which is focussing on criticisms of advance directives themselves and not on whether or not the money spent on implementing a particular health policy is justified.

this research that none are sufficient to negate their benefits, both to the individual and to the medical professional. Arguably, this is particularly the case if the individual has taken the step of creating one on the expectation that it will be honoured.

Advance Directives: The Law

New York

The United States is considered to be the home of advance directives and with good reason; after Kutner's legal framework to empower patients to refuse treatment in advance of losing capacity and the ability to communicate, attempts were made to legislate for such a framework.⁷⁷ In the 1970s, California became the first state to legislate for advance directives; Barry Keene, a California State Assemblyman and later State Senator, sponsored a Bill that introduced advance healthcare directives. The Natural Death Act was passed in 1976 and amongst other provisions, it provided for any adult to 'execute a directive directing the withholding or withdrawal of life-sustaining procedures in a terminal condition'.⁷⁸ Seven more states followed suit in the next year including Nevada, Oregon, North Carolina and Texas.⁷⁹ The inclusion of a reference to 'terminal condition' in the California statute was and is interesting, as it appears to confine the use of advance directives to patients with a terminal condition, particularly as this type of terminology persists to this day.⁸⁰ James Hoefler, however, argues:

[S]tates typically add the disclaimer that rights expressed within the laws are cumulative. That is, rights codified by the legislature add to the rights an individual enjoys outside the statute (in common law, in the case law, or as a matter of constitutional law) (...) codification is not meant to infringe on, impair, or otherwise circumscribe the unstated rights and liberties of individuals under state jurisdiction.⁸¹

In other words, if a Jehovah's Witness has a common law right to refuse a blood transfusion in advance, then references to incurable conditions and terminal illnesses in the statutes of that

⁷⁷ For example, Dr Walter Sackett, a member of the Florida House of Representatives attempted to introduce living wills as part of his 'Death with Dignity' bills, however, the bills were unsuccessful. He also testified as to their prospective benefits at hearings on 'Death with Dignity' by the Special Senate Committee on Aging in 1972. See 'Death with Dignity: Hearings before the Special Committee on Aging' Senate, 92nd Cong. (Testimony of Walter W Sackett).

⁷⁸ California Health & Safety Code § 7188. Advance Directives are now governed by the Health Care Decisions Law § 4600 – 4701, which is contained in the Probate Code.

⁷⁹ For a comprehensive account of the development of legislation on advance directives in the United States see Chapter 8 of James M Hoefler and Brian E Kamoie, *Deathright: Culture, Medicine, Politics, and the Right to Die* (Westview Press 1994).

⁸⁰ Giving the context of the law in California, the Health Care Decisions Law states: 'Modern medical technology has made possible the artificial prolongation of human life beyond natural limits. In the interest of protecting individual autonomy, this prolongation of the process of dying for a person for whom continued health care does not improve the prognosis for recovery may violate patient dignity and cause unnecessary pain and suffering, while providing nothing (...) beneficial to the person' (§ 4650(b)). Furthermore, § 4701 which provides the form to be used *inter alia* to nominate a healthcare agent and to give specific instructions about the withholding or withdrawal of medical treatment contain specific conditions, namely 'an incurable and irreversible condition that will result in my death within a relatively short time', unconscious and a reasonable degree of medical certainty that consciousness will not be regained and 'the likely risks and burdens of treatment would outweigh the expected benefits'.

⁸¹ James M Hoefler and Brian E Kamoie, *Deathright: Culture, Medicine, Politics, and the Right to Die* (Westview Press 1994) 192.

state should not impinge on their ability to do so. As Hoefler argues, ‘State statutes should be considered a place to start when divining what rights an individual has regarding (...) life-sustaining procedures, but the statutes are no place to end such an inquiry’.⁸² The situation is not the same, however, should the state laws expressly prohibit what has been established by the courts.

New York, however, is in the minority; despite the vast majority of the states following California’s lead and passing legislation on advance directives, New York opted not to do so. Even in the wake of *Cruzan*, which is considered to be the US Supreme Court recognition of living wills, New York did not legislate in this manner.⁸³ Instead, it relies on a combination of other instruments – Do Not Resuscitate Orders, surrogate decision-making and Medical Order for Life Sustaining Treatment forms – to protect the interests of patients, perhaps with questionable efficacy. This specific change in terminology from ‘advance directives’ to ‘living wills’ is deliberate and warrants explanation. New York does have ‘advance directives’, but they do not carry the same meaning as elsewhere. An ‘advance directive’ in New York and some other US states refers to a legal document, in which provisions are made in relation to the future health care decisions of an individual.⁸⁴ Therefore, an advance directive in New York can refer to a Healthcare Proxy form, a DNR Order, a Medical Order for Life Sustaining Treatment (MOLST) Form or a Living Will – the first three are covered by legislation.⁸⁵ These mechanisms will be considered in more detail towards the end of this section.

Since 1988, New York common law has recognised living wills. The criterion is that the living will must provide ‘clear and convincing proof that the patient had made a firm and settled commitment, while competent, to decline this type of medical assistance under circumstances such as these’, established in *O’Connor*.⁸⁶ It has been argued that this standard was extremely difficult to meet and confirms ‘New York’s place as one of the most restrictive states’.⁸⁷ Mrs O’Connor had suffered a series of strokes resulting in incompetence and an inability to obtain food or drink without medical assistance. The hospital sought permission to insert a nasogastric

⁸² *ibid.*

⁸³ 497 US 261 (1990); *Cruzan* was discussed in detail in Chapter 4 in the context of end-of-life decision-making.

⁸⁴ New York State Office of the Attorney General (2017) ‘Advance Directives: Making Your Wishes Known And Honored’ <<https://ag.ny.gov/sites/default/files/advancedirectives.pdf>> accessed 6 December 2019.

⁸⁵ DNRs are currently governed by Public Health Law § 2964. The appointment of a health care agent (proxy form) is governed by Public Health Law § 2981 section 2. MOLSTs are not governed by law *per se*, but instead have been issued by the New York Department of Health to complement traditional advance directives.

⁸⁶ *Re Westchester County Medical Center [O’Connor]* 72 NY 2d 517 (1988). See also *Grace Plaza v Elbaum* 82 NY 2d 10 (1993); 16: ‘[W]e have required the families of hopelessly ill patients who are unable to express their wishes with respect to continuing care to establish by clear and convincing evidence that the patient when sentient expressed a clear and settled wish that care should not be continued under the circumstances’. See also *Fosmire v Nicoleau* 75 NY 2d 218 (1990); 225: Where ‘the patient is not presently competent the court must determine whether there is clear and convincing evidence that the patient, when competent, made a firm resolve to decline treatment’.

⁸⁷ James N Zartman, ‘The Legacy of *Cruzan*’ (1991) 5 Prob & Prop 13, 14.

tube. Her daughters, who were both nurses, objected on the grounds that the tube would be contrary to her ‘expressed wishes’.⁸⁸ Although Mrs O’Connor’s daughters accepted that that they did not know if their mother would have specifically wanted to decline a feeding tube under the circumstances, particularly if it would result in a painful death, they had submitted a signed document for inclusion in her medical file at the care facility. It stated that Mrs O’Connor had expressed the wish in many conversations that ‘no artificial life support be started or maintained in order to continue to sustain her life’.⁸⁹ She had, while competent, made several statements that indicated that she would not want to be kept alive by artificial means if she were unable to care for herself. These statements were corroborated by numerous witnesses and it was accepted that her views were likely to have been the result of witnessing family members at the end of life, including her husband and two brothers.

Citing the judgments in *Storar* and *Eichner*, Wachtler CJ opined that the requirement for ‘clear and convincing evidence (...) forbids relief whenever the evidence is loose, equivocal or contradictory’.⁹⁰ The learned judge found that the patient in *Eichner*, a member of a religious order, had ‘conscientiously discussed his moral and personal views concerning the use of a respirator on persons in a vegetative state’ leading the court to find ‘clear and convincing’ evidence as to his wishes.⁹¹ Regarding Mrs O’Connor, however, Wachtler J stated:

Every person has a right to life, and no one should be denied essential medical care unless the evidence clearly and convincingly shows that the patient intended to decline the treatment under some particular circumstances (...) This is a demanding standard, the most rigorous burden of proof in civil cases (...) It is appropriate here because if an error occurs it should be made on the side of life.⁹²

Despite the acknowledgement that the court must ‘always remain open to applications (...) which are based upon the repeated oral expressions of the patient’ the learned judge found in favour of the hospital and approved treatment, stating:

Although Mrs O’Connor’s statements about her desire to decline life-saving treatments were repeated over a number of years, there is nothing, other than speculation, to persuade the fact finder that her expressions were more than immediate reactions to the unsettling experience of seeing or hearing of another’s unnecessarily prolonged death.⁹³

How this statement tallies with the stated intention of the court not to suggest that ‘to be effective, a patient’s expressed desire to decline treatment must specify a precise condition and

⁸⁸ 72 NY 2d 517 (1988); 522.

⁸⁹ *ibid* 523.

⁹⁰ *ibid* 529.

⁹¹ *ibid*.

⁹² *ibid* 530-1.

⁹³ *ibid* 532.

a particular treatment' is unclear.⁹⁴ It may be reasonable to ask what more Mrs O'Connor needed to do to give effect to her wishes and to satisfy the clear and convincing standard given that it was neither a requirement to put her wishes in writing, nor was it one to specify particular treatments in the course of such conversations.⁹⁵ It appears that at least some of the justification given by the court for viewing her statements as insufficiently clear and convincing was that Mrs O'Connor's statements 'were generally prompted by her experience with persons suffering terminal illnesses', which was not her situation; instead the court categorised her as 'simply an elderly person who as a result of several strokes suffers certain disabilities'.⁹⁶

The challenge for New Yorkers is clear: on the one hand, oral statements regarding how they would wish to be cared for in certain situations are sufficient to create an advance directive. On the other, despite evidence of countless statements by Mrs O'Connor to family and friends to the effect that she would not want to be kept alive artificially, her expressions were not considered to be sufficient to withdraw treatment in her particular situation. Given that there is no legislation on living wills, any case where the patient expressed prior desires to have treatment withdrawn or withheld in certain circumstances can be considered to be an attempt at an advance directive, albeit an oral one. The effect given to such statements will be a matter of opinion and uncertainty.

During the course of the *O'Connor* judgment, Wachtler CJ appeared to endorse written advance directives:

The ideal situation is one in which the patient's wishes were expressed in some form of a writing, perhaps a 'living will', while (...) still competent. The existence of a writing suggests the author's seriousness of purpose and ensures that the court is not being asked to make a life-or-death decision based upon casual remarks.⁹⁷

Furthermore, he opined that where the individual expresses her preference in writing, she is more likely to also put any subsequent changes of heart in writing or at a minimum, express them to relevant parties. This was not the case for people who expressed their wishes orally, in the opinion of the learned Chief Justice.

Thus, despite the cues to legislate for living wills, written or oral, the New York legislature opted not to; instead as discussed earlier, New York relies on a system of healthcare agents, surrogate decision-making, DNR Orders and MOLST Forms. Accordingly, there are points

⁹⁴ *ibid.*

⁹⁵ *ibid* 532-3: The learned judge stated that 'we recognize that human beings are not capable of foreseeing either their own medical condition or advances in medical technology'. At 531-2, he also stated that 'a requirement of a written expression in every case would be unrealistic'.

⁹⁶ *ibid* 533.

⁹⁷ *ibid* 531.

worth making in relation to the law in New York, or more accurately, gaps in that law identified by this research. DNRs enable a competent person to refuse resuscitation during or before hospital admission once certain conditions are met;⁹⁸ in hospital, the decision may be expressed orally in the presence of at least two adult witnesses, one of whom is a physician or nurse practitioner affiliated with that hospital.⁹⁹ Prior to hospitalisation, the decision must be expressed in writing, dated and signed in the presence of at least two adult witnesses.¹⁰⁰ DNRs, however, only apply to cardiopulmonary resuscitation, thus they are of limited value in the context of this research. Naturally, healthcare agents and surrogate decision-making require others to make decisions on behalf of the patient, which is equally separate to the focus of this research, which is concerned with the specific decision of the individual herself. Finally, MOLST forms, although relevant to intervention other than CPR – such as intubation, artificially administered fluids and nutrition and antibiotics – are drafted by the medical professional after consultation with the patient, as opposed to being drafted by the patient herself.¹⁰¹ Thus, somewhat ironically, they fail to alleviate the very problem with the law identified by Kutner in the 1960s; if an individual is rushed to hospital with cardiac arrest, stroke or head trauma from which they may not regain consciousness, they have no opportunity to discuss their wishes and complete these forms. Furthermore, the MOLST form is ‘generally for patients with serious health conditions’, thus it is not clear how, if at all, this would be applicable to a woman wishing to refuse a Caesarean section, for example. The form itself identifies those patients who want ‘to avoid or receive any or all life-sustaining treatment’, who reside in a long-term care facility or require long-term care services and who ‘might die within the next year’ as those who should work with the relevant medical professionals in this regard.¹⁰² It is unclear from the form if it is an ‘and’ or an ‘or’ situation; in other words, it is unclear if the patient should satisfy all of these criteria, or some. In any event, a pregnant woman who wishes to refuse treatment that is being advised for the benefit of the foetus will meet none of these criteria. In this regard, the fundamental flaws in New York law, which apply to both pregnant and non-pregnant patients, are abundantly clear.

⁹⁸ Public Health Law § 2964 section 2.

⁹⁹ Public Health Law § 2964 section 2(a).

¹⁰⁰ Public Health Law § 2964 section 2(b).

¹⁰¹ New York State Department of Health, *Medical Orders for Life-Sustaining Treatment (MOLST) Form* <<https://www.health.ny.gov/forms/doh-5003.pdf>>.

¹⁰² *ibid.*

There was one curious addition to the law in New York by the Family Health Care Decision Act. Public Health Law § 2994-d(3) provides that a health care provider need not seek consent to treat from a surrogate decision-maker if the patient has:

[A]lready made a decision about the proposed health care, expressed orally or in writing or, with respect to a decision to withdraw or withhold life-sustaining treatment expressed either orally during hospitalization in the presence of two witnesses eighteen years of age or older (...) or in writing.

This is noteworthy for several reasons; first, in contrast to a DNR, life-sustaining treatment is ‘any medical treatment or procedure without which the patient will die within a relatively short time, as determined by an attending physician to a reasonable degree of medical certainty’.¹⁰³ Second, ‘proposed health care’ applies to any treatment, not just those that are life-sustaining. Therefore, this has the potential to apply to treatment that is not necessary to sustain the life of a pregnant patient, but instead necessary to benefit the foetus. Arguably, this is, in all but name, an advance directive as understood in Irish and English law. It is limited, however, in that it only functions to absolve the medical professional of the responsibility to seek consent from the surrogate decision-maker for the same treatment. Furthermore, the same requirement is absent *via-à-vis* medical professionals who are acting as decision-maker on behalf of the patient, which is the case when they have no surrogate. With that said, it is submitted that such an advance decision would serve as a clear indication to the medical professional of the wishes of the patient, in line with which decisions should be made on their behalf. Still, however, how the decisiveness of the wishes of the individual would play out in pregnancy is unclear.¹⁰⁴

Ireland

In Ireland, advance healthcare directives will be governed by Part 8 of the Assisted Decision-Making (Capacity) Act, 2015, once commenced.¹⁰⁵ Prior to the Act, however, there was a recognition of advance directives at common law. In *Governor of X Prison v PMcD* the validity of a written refusal of treatment in anticipation of the patient losing capacity as a result of lapsing into a coma was considered.¹⁰⁶ Mr McD was a hunger striker refusing food contemporaneously and artificial nutrition in advance should he lapse into a coma. In the course of his written statement, Mr McD stated his understanding that refusing food would likely lead

¹⁰³ Public Health Law § 2980 section 9(a).

¹⁰⁴ As was argued in the context of England and Wales in Chapter 4, unless such wishes and beliefs specifically referred to pregnancy, they may be deemed not to be ascertainable in the circumstances.

¹⁰⁵ The current status of Part 8 (sections 82 – 92) of the ADM(C)A 2015 is that it is not commenced. Section 1(3) of the Act states that Part 8 and the provisions relating to an advance healthcare directive or designated healthcare representative ‘shall come into operation on such day or days as the Minister for Health, after consultation with the Minister, may appoint by order or orders either generally or with reference to any particular purpose or provision, and different days may be so appointed for different purposes and different provisions’.

¹⁰⁶ *Governor of X Prison v PMcD* [2016] 1 ILRM 116.

to organ failure and death but wished to persist in his refusal nonetheless.¹⁰⁷ He stated his awareness that his health was in decline as a result of the hunger strike; still, he was emphatic in his refusal of food in any form.¹⁰⁸ In assessing the lawfulness of such an advance statement, Baker J was clear:

I consider that as a matter of law, and finding the above statements persuasive, that a person may make a freely stated wish in regard to their future care and that this ought to be, and can in an appropriate case be, respected by those with care of that person.¹⁰⁹

Accordingly, the learned judge made a declaration that the direction given by Mr McD should remain operative should he lose capacity to make the decision to accept such treatment and a declaration that the prison was entitled to give effect to those wishes of Mr McD to refuse nutrition and medical assistance.¹¹⁰ At the time of the judgment, the Assisted Decision-Making Capacity Bill had not yet been passed by the Oireachtas, therefore it was referred to only in the context of what it was likely to do in the future.¹¹¹

It may be somewhat unsurprising that the Assisted Decision Making (Capacity) Act 2015 has its roots as far back as the mid-2000s; in 2003, Inclusion Ireland published a paper entitled ‘*Who Decides & How? People with Intellectual Disabilities - Legal Capacity & Decision Making*’, which called for the abolition of the wardship system.¹¹² Within the same timeframe, the Law Reform Commission published a consultation paper making the same call.¹¹³ In 2006, the Law Reform Commission published the *Report on Vulnerable Adults and the Law*, which had two primary recommendations; first, the enactment of a new law to establish clear rules on when a person has the legal capacity to make decisions, including commercial and healthcare decisions and second, the replacement of wardship with a guardianship system.¹¹⁴ In 2007, the Mental Capacity and Guardianship Bill was introduced to the Seanad by Senators Dr Mary Henry and Joe O’Toole via a private members motion.¹¹⁵ The Bill was based entirely on the Law Reform Commission recommendations and its draft scheme for a Bill.¹¹⁶ Although, the

¹⁰⁷ *ibid* 149.

¹⁰⁸ *ibid*.

¹⁰⁹ *ibid* 151.

¹¹⁰ It is interesting to contrast the rights afforded to patients in Ireland with the situation in the United States. Some courts have upheld the right of a prisoner to embark on hunger strike, for example, *Zant v Prevatte* 286 SE 2d 715 (Ga 1982) and *Singletary v Costello* 665 So 2d 1099 (Fla 1996) and others have rejected the existence of such a right or overruled it, for example *Laurie v Senecal* 666 A 2d 806 (RI 1995) and *Van Holden v Chapman* 450 NYS 2d 623 (1982).

¹¹¹ ‘Professor Kelly helpfully described the decision-making process as complex, and not binary (...) He said that in truth the capacity to make decisions may fall in different parts of the spectrum, or “that there are shades of grey”.’ He took the view that the Assisted Decision-Making Bill now before the Oireachtas attempts to reflect the reality of the tiered process.’ [2016] 1 ILRM 116, 142.

¹¹² Inclusion Ireland, ‘Who Decides & How? People with Intellectual Disabilities - Legal Capacity & Decision Making’ <<http://www.inclusionireland.ie/content/publications-who-decides-how-people-intellectual-disabilities-legal-capacity-decision>> accessed on 21 November 2019.

¹¹³ Law Reform Commission, *Consultation Paper on Law and the Elderly* (LRC CP 23–2003).

¹¹⁴ Law Reform Commission, *Report on Vulnerable Adults and the Law* (LRC 83-2006).

¹¹⁵ Seanad Deb 21 February 2007 <<https://www.oireachtas.ie/en/debates/debate/seanad/2007-02-21/9/>> accessed on 21 November 2019.

¹¹⁶ Seanad Deb 21 February 2007 <<https://www.oireachtas.ie/en/debates/debate/seanad/2007-02-21/9/>> accessed on 21 November 2019.

Bill garnered considerable praise and support within the Seanad, it lapsed with the dissolution of the Seanad and Dáil in 2007.¹¹⁷

In 2008, the Government issued the Scheme of the Mental Capacity Bill 2008; although the 2008 Bill formed the basis of the Assisted Decision-Making (Capacity) Bill 2013, it contained no reference to advance directives. Nor, for that matter, did the 2007 Bill presented to the Seanad. Also in 2008, the Law Reform Commission published a consultation paper *Bioethics: Advance Care Directives* and in 2009 published a Report by the same name.¹¹⁸ Consequently in 2012, the Advance Healthcare Decisions Bill 2012 was proposed and debated in the Dáil; it was subsequently withdrawn when it became apparent that advance directives would form part of the ADM(C) Bill.¹¹⁹ In 2015, the Bill was presented to both houses, having undergone significant changes including, critically, a rejection of ‘best interests’ in favour of ‘will’ and ‘preference’.¹²⁰ As outlined in Chapter 3, the former was the common law position in Ireland; where an individual lacked capacity, decisions to administer or withhold treatment were to be made in line with her ‘best interests’.¹²¹ The latter has come from the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which Ireland signed in 2007 and ratified in 2018:

State parties have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity. (...) Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making.¹²²

‘Legal capacity’ is defined by the CRPD as ‘indispensable for the exercise of civil, political, economic, social and cultural rights’ and as acquiring ‘a special significance for persons with disabilities when they have to make fundamental decisions regarding their health, education and work’.¹²³ In the absence of a court determination to the contrary, ‘will’ in Ireland is understood to mean ‘a person’s longterm [sic] vision of what constitutes a “good life” and fulfilling life for them’.¹²⁴ ‘Preference’ is understood to mean the ‘greater liking for one

¹¹⁷ In 2008, the Mental Capacity and Guardianship Bill (2008), sponsored by Senators Feargal Quinn, Joe O’Toole, David Norris, Ivana Bacik and Shane Ross was introduced to the Seanad, however, it too lapsed due to the dissolution of the Seanad and Dáil.

¹¹⁸ Law Reform Commission, *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51 - 2008); Law Reform Commission, *Report on Bioethics: Advance Care Directives* (LRC 94 – 2009).

¹¹⁹ Dáil Deb 8 June 2012 <<https://www.oireachtas.ie/en/debates/debate/dail/2012-06-08/2/>> accessed on 21 November 2019.

¹²⁰ Head 3 of the Scheme of Mental Capacity Bill 2008 dealt with ‘best interests’. See also the comments made by Kathleen Lynch T.D. in the Dáil regarding the shift from ‘best interests’ to ‘will’ and ‘preference’; Dáil Deb 17 December 2015 <<https://www.oireachtas.ie/en/debates/debate/dail/2015-12-17/16/>> accessed on 21 November 2019.

¹²¹ *Re a Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 IR 79 (*‘Re a Ward of Court’*).

¹²² Committee on the Rights of Persons with Disabilities, General Comment No. 1 on Article 12: Equal recognition before the law. CRPD/C/GC/1. 2014, paras 16-17. For discussion on the CRPD and the Mental Capacity Act 2005, see Mary Donnelly, ‘Best Interests in the Mental Capacity Act: Time to Say Goodbye?’ (2016) 24 Med L Rev 318–332.

¹²³ Committee on the Rights of Persons with Disabilities, General Comment No. 1 on Article 12: Equal recognition before the law. CRPD/C/GC/1. 2014, para 8.

¹²⁴ HSE National Programme Lead for Assisted Decision Making, Caoimhe Gleeson, defined it as such when presenting to HSE staff in May 2019. As the purpose of the team is to prepare staff and services for the commencement of the Assisted Decision Making (Capacity) Act 2015

alternative or another over others which can be, or has been, demonstrated by words or behaviour or both'.¹²⁵

An advance directive is defined by section 82(a) of the ADM(C)A 2015 as 'an advance expression made by the person (...) of his or her will and preferences concerning treatment decisions that may arise (...) if he or she subsequently lacks capacity'.¹²⁶ As illustrated above, Ireland provides for advance directives to be made by the adult patient him or herself, but also provides for a designated healthcare representative to do so.¹²⁷ Albeit in relation to the Mental Capacity Act 2005, Rob Heywood is somewhat critical of the legal requirement that the patient have capacity at the time when the advance directive is drafted without a corresponding requirement that a capacity assessment be conducted at the same time:

Amid the range of formalities that were included in the (...) [Act], what mechanisms are in place within the legislation to ensure that a patient is competent at the time they actually draft their advance decision? The answer is, quite simply, none. A case can be made that the legislation should have included more robust requirements in terms of the assessment of capacity at this crucial point.¹²⁸

While he recognises that this lack of regulation may have its reasons and uses, it can be problematic if 'the law allows a judge to override the presumption in favour of capacity too easily, based on an ill-defined measure of doubt'.¹²⁹ He explains this as the law undoing a lot of the work it has done in seeking to ensure accessibility of advance directives to all competent individuals, including those with a 'history of mental illness (...) [or] suicidal tendencies'.¹³⁰

He suggests that one of the reasons for the lack of requirement to assess capacity at the time of giving the advance decision is the presumption of capacity, which is central to the MCA 2005, so too the Irish Act. He argues that requiring a capacity assessment reverses the presumption of capacity and instead 'works from the starting position that patients are incapable of exercising their right of choice before someone else confirms they are capable of doing so'.¹³¹ While perhaps an honourable intention on the part of the legislature not to undermine the presumption of capacity, if the effect is that those with fluctuating capacity may have their advance directives disregarded, then perhaps it does more to jeopardise than vindicate the

and to prepare the Code of Practice for the Act, one can reasonably assume that the Code will reflect this definition <<https://www.hse.ie/eng/about/who/qid/resourcespublications/qitalktime-presentation-adm-may-19.pdf>> accessed 22 November 2019.

¹²⁵ As above.

¹²⁶ Section 82(a) pertains to 'a person who has capacity'. Section 84, referred to in section 82(a), lays out the steps to be taken in order to create an advance directive.

¹²⁷ Assisted Decision-Making (Capacity) Act 2015, s 82(b).

¹²⁸ Rob Heywood, 'Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages' (2015) 23 Med L Rev 81, 92.

¹²⁹ *ibid.*

¹³⁰ *ibid.*

¹³¹ *ibid.*

individual autonomy.¹³² Heywood argues that adding a requirement to assess capacity at the time of creating an advance directive may be justified given the rarity of advance directives:

[T]hose patients who do take the time and make the effort to create an advance decision would be unlikely to object to the additional requirement of an assessment of capacity at the time it is made (...) because, having taken the conscious decision to make an advance decision in the first place, the aim of most patients will be to make it as difficult as possible to overturn.¹³³

In order to mitigate against the possibility of an advance directive being overturned for suspected incompetence, Emily Jackson suggests that those suffering from a condition which affects capacity ‘would therefore be well advised not to rely upon the presumption of capacity, but instead to ensure that a doctor specifically certifies that they have capacity when they make their AD’;¹³⁴ an effective solution, if not simultaneously an onerous responsibility to put on the decision-maker.

Section 83 of the ADM(C)A 2015 articulates the two purposes of Part 8, namely to enable patients to be ‘treated according to their will and preferences’ and to provide healthcare professionals with information relevant to patient treatment choices.¹³⁵ Critically, it embeds in statute what has been established by jurisprudence, that is, the right of a competent person to refuse life-saving treatment irrespective of the reasons.¹³⁶ Section 84 is the most detailed section in Part 8 and lays out the conditions which need to be fulfilled by the adult advance directive-maker in order to create a valid directive, namely, that the treatment and the circumstances in which it should be refused must be clearly specified in writing and that the directive-maker lacks capacity at the time when the treatment is required.¹³⁷ Revocation of or amendments to an advance directive can be made in writing by the directive-maker once she has capacity and in the case of amendments, fulfils the conditions laid out for drafting a valid advance directive. An interesting aspect of the Irish legislation is that while a request for

¹³² *ibid* 92-3: Heywood argues that requirements to assess capacity may ‘severely undermine the notion of autonomy by placing a barrier in the way of patient choice’. He goes on to argue, however, that ‘capacity is issue specific, and requiring a formal assessment of capacity only in relation to validating an advance decision would not cause harm to the general proposition that a patient is still presumed to be able to make autonomous choices about other aspects of their life’.

¹³³ Rob Heywood, ‘Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages’ (2015) 23 *Med L Rev* 81, 93.

¹³⁴ Emily Jackson, *Medical Law: Texts, Cases and Materials* (4th edn, Oxford University Press 2016) 271.

¹³⁵ Assisted Decision-Making Capacity Act 2015, s 83(1).

¹³⁶ Assisted Decision-Making Capacity Act 2015, s 83(2): ‘A relevant person who has attained the age of 18 years and who has capacity is entitled to refuse treatment for any reason (including a reason based on his or her religious beliefs) notwithstanding that the refusal— (a) appears to be an unwise decision, (b) appears not to be based on sound medical principles, or (c) may result in his or her death.’ For further discussion, see Chapters 3 and 4.

¹³⁷ Assisted Decision-Making (Capacity) Act 2015, s 84(2) and (4). Section 85(2) specifies that if the conditions in section 84(2) are not present, then the advance directive is not applicable. Section 84(5) lays out the information which needs to be contained in the advance directive in order to ensure validity. It must contain the name, date of birth and contact details of the directive-maker; the date and his or her signature or the signature of an individual directed to do so by the directive-maker and the signatures of two witnesses, at least one of whom is not a family member (section 84(6)(a)). Per section 84(5), the advance directive should also contain, if relevant, the name, date of birth and contact details of the designated healthcare representative, his or her signature and the date that the representative signed the directive.

treatment contained in an advance directive is not legally binding, the healthcare professional is required to take it into consideration in the decision-making process and required to make a note of why the request was refused, if applicable.¹³⁸ It could certainly be suggested that this section demonstrates considerable respect for self-determination and autonomy. Furthermore, it could be argued that the requirement for a healthcare professional to explain why he has not acquiesced to the request of the patient creates an extra layer of responsibility; while the medical professional will have his reasons for the decision, arguably the requirement to justify, and not merely make, the decision forces that professional to give more thought to the matter.

Over and above failing to adhere to the criteria for creating a valid advance directive, section 85 establishes specific situations or actions that invalidate an advance directive, including where the directive-maker does anything ‘clearly inconsistent’ with the directive while she has capacity.¹³⁹ For example, as was the situation in the pre-MCA English case of *HE v A Hospital NHS Trust*, a female Jehovah’s Witness getting engaged to a person of Muslim faith was sufficient to amount to a change in circumstances for the purposes of making an order to administer treatment.¹⁴⁰ The inclusion of the requirement that the patient have capacity while acting inconsistently with the directive is noteworthy. The MCA 2005 lacks this requirement, so too does the Code of Practice; interestingly, the Code of Practice states that a withdrawal of the advance decision by the person ‘while they still had capacity to do so’ would render the advance decision invalid, however, competence is not a requirement for the other ground, namely that ‘the person has done something that clearly goes against the advance decision which suggests that they have changed their mind’.¹⁴¹ This omission has been criticised on the grounds that it may be possible for a patient to invalidate his own advance decision by acting inconsistently with it at a time when he lacks capacity.¹⁴² Furthermore, the Court of Protection has yet to rule on this matter, at least exclusively. Charles J in *Briggs v Briggs* merely stated that the section ‘does not specify whether to qualify the inconsistent act must take place when the person has capacity’.¹⁴³ The learned judge did, however, go on to state:

An interpretation of these safety nets [25(2)(c) and s. 25(3)] based on the sanctity of life or anything else (...) that sets a low threshold to rendering an advance decision invalid or inapplicable would run counter to the enabling intention of ss. 24 to 26 of the MCA.¹⁴⁴

¹³⁸ Assisted Decision-Making (Capacity) Act 2015 s 84(3)(a)(b).

¹³⁹ Assisted Decision-Making (Capacity) Act, 2015, s 85(1).

¹⁴⁰ [2003] EWHC 1017 (Fam).

¹⁴¹ Code of Practice accompanying the Mental Capacity Act 2005 (‘Code of Practice’), para 9.4.

¹⁴² Samantha Halliday, ‘Advance Decisions and the Mental Capacity Act’ (2009) 18 BJN 697, 698.

¹⁴³ [2016] EWCOP 53, para 22.

¹⁴⁴ *ibid.*

In *A Local Authority v E*, Jackson J opined that an instruction contained in the advance decision to disregard any behaviour seeming to be inconsistent with it could not be binding in light of the relevant section of the Act.¹⁴⁵ As the learned judge determined that Ms E did not have capacity when she drafted the advance decision containing the proviso – ‘If I exhibit behaviour seemingly contrary to this advanced directive this should not be viewed as a change of decision’ – it was not necessary to determine if she had actually behaved inconsistently.¹⁴⁶

It is possible, therefore, that the court would view the actions of an incompetent person, which appear to be contrary to his advance decision, to be insufficient to justify a declaration of invalidity or inapplicability. In practice, however, the circumstances of the individual case may dictate the ease with which (in)competence at the time of the inconsistency can be established. For example, where the person suffers periods of lucidity and incompetence as part of a particular condition, it may be difficult to retrospectively establish if they had capacity at particular points in time. It is almost certain that the court would err on the side of the preservation of life in such situations.

In order to be valid in the case of life-saving treatment, the refusal must be ‘substantiated by a statement (...) by the directive-maker (...) that the directive is to apply to that treatment even if his or her life is at risk’.¹⁴⁷ This is a key difference between contemporaneous and advance refusals. While it may be the case that a patient must understand that her life is risked by her decision to refuse treatment – as a failure to do so may be an indication of incompetence – a patient is not required to sign any document stating that she understands the risk to life.¹⁴⁸ In the case of ambiguity, the healthcare professional should consult with the designated healthcare representative, if relevant, or the directive-maker’s family and friends and seek a second medical opinion.¹⁴⁹ If the ambiguity persists, then the healthcare professional shall ‘resolve the ambiguity in favour of the preservation of the directive-maker’s life’.¹⁵⁰ According to section 85(4), an advance directive cannot apply to basic care including warmth, shelter and oral hydration and nutrition. In line with the jurisprudence, artificial hydration and nutrition is not

¹⁴⁵ *A Local Authority v E* [2012] All ER (D) 96, para 63.

¹⁴⁶ *ibid*, para 69.

¹⁴⁷ Assisted Decision-Making (Capacity) Act 2015, s 85(3).

¹⁴⁸ Perhaps, however, this requirement to put refer to the risk to life in writing could be explained as a combination of first, the requirement to have all advance decisions in writing in Ireland and second, the definition of capacity given by the Act as *inter alia* the ability ‘to understand (...) the nature and consequences of the decision to be made by him’ [emphasis added] (s 3(1)). If everything else must be in writing under the Irish legislation, the requirement to state understanding of the risk to life seems logical.

¹⁴⁹ Assisted Decision-Making (Capacity) Act, 2015, s 85(5)(a).

¹⁵⁰ Assisted Decision-Making (Capacity) Act 2015, s 85(5)(b).

considered ‘basic care’, so can be refused.¹⁵¹ Although the inclusion of AHN is hardly surprising given the jurisprudence that predates the legislation, it is interesting to briefly return to the United States and to contrast this choice with some state legislation. As the common law largely dictates the legal position of advance refusals of AHN in New York, information regarding the legislation in other states is beneficial from a comparative perspective.¹⁵²

In Wisconsin, it is expressly prohibited to withhold or withdraw AHN in an advance directive.¹⁵³ Missouri has a similar prohibition; in light of the fact that it was the home of the *Cruzan* case, which centred around whether AHN should be withdrawn from Ms Cruzan – which it eventually was after further evidence was presented to the Missouri officials subsequent to the Supreme Court judgment – this irony has not been lost on commentators.¹⁵⁴ The Illinois Living Will Act, prohibits the inclusion of AHN in an advance directive, if it would be the cause of death.¹⁵⁵ The conservative approach taken by some states seems patently inconsistent with the general approach of the courts in the so-called ‘right to die’ cases in the US, which were discussed in the previous chapter. Perhaps, however, such hesitance to permit death to be the result of the withdrawal of AHN reflects an unease about the idea of allowing somebody to ‘starve to death’ or ‘die from thirst’, even if the mechanism for delivering hydration and nutrition is mechanical. In any event, it is contended that Ireland has adopted the appropriate approach with the 2015 Act in making a clear distinction between oral and mechanically delivered hydration and nutrition and in not excluding the latter from being specified in an advance directive.

Section 86 of the ADM(C)A lays out exemptions from criminal and civil liability enjoyed by healthcare professionals in particular situations, for example, a healthcare professional will be exempt from liability where (s)he complies with an advance healthcare directive on the reasonable belief that it was valid and applicable.¹⁵⁶ In section 89, the role of the courts in cases involving advance directives is explained; the Circuit Court has jurisdiction to decide the validity and applicability of an advance directive, where the directive does not apply to life-

¹⁵¹ Assisted Decision-Making (Capacity) Act 2015, s 85(4)(b). See also *Re a Ward of Court* [1996] 2 IR 79. This is also in line with the guidance given by the Medical Council, see Medical Council, ‘Guide to Professional Conduct and Ethics for Registered Medical Professionals’ (2019), s 46.2.

¹⁵² It is worth noting that it appears that MOLST forms can contain information regarding refusal of AHN.

¹⁵³ WI Stat § 154.01 (2018): “‘Life-sustaining procedure’ means any medical procedure or intervention that (...) would serve only to prolong the dying process but not avert death when applied to a qualified patient (...) but does not include: (...) The provision of nutrition or hydration.’

¹⁵⁴ 497 US 261 (1990); MO Rev Stat § 459.010(3) (2018): ‘Death-prolonging procedure shall not include the administration of medication or the performance of medical procedure deemed necessary to provide comfort, care or to alleviate pain nor the performance of any procedure to provide nutrition or hydration’. See commentary from James M Hoefler, Brian E Kamoie, *Deathright: Culture, Medicine, Politics, and the Right to Die* (Westview Press 1994) 202.

¹⁵⁵ 755 ILCS 35/2(d); ‘Nutrition and hydration shall not be withdrawn or withheld from a qualified patient if the withdrawal or withholding would result in death solely from dehydration or starvation rather than from the existing terminal condition.’

¹⁵⁶ Assisted Decision-Making (Capacity) Act 2015, s 86(2)(a). Other exemptions include failure to comply with an advance directive on the grounds of a reasonable belief that it was invalid (s 86(2)(b)).

sustaining treatment.¹⁵⁷ The High Court has jurisdiction to decide the validity and applicability of advance directives specifying a refusal of life-sustaining treatment.¹⁵⁸ While the matter is being adjudicated by the High Court, the healthcare professionals should provide life-sustaining treatment and/or act in such a way as to prevent ‘a serious deterioration in the health of the directive-maker’.¹⁵⁹

A noteworthy feature of the Irish legislation is the provisions relating to criminal sanctions contained in section 90. Section 90(1) criminalises the use of fraud, coercion or undue influence to force the directive-maker to make, alter or revoke his advance directive.¹⁶⁰ Coercion or undue influence in this case includes ‘where a person’s access to, or continued stay in, a designated centre or mental health facility is contingent (...) on the person having to, or being led to believe that he or she has to, make, alter or revoke an advance healthcare directive’.¹⁶¹ Section 90 also criminalises the creation or alteration, without consent, of an advance healthcare directive on behalf of an individual; falsification of or purporting to revoke an advance directive is also an offence.¹⁶² It could be suggested that such an approach stemmed from general concerns that legislating for advance directives could expose elderly or vulnerable people to abuse or exploitation.

One aspect which has not been addressed in any detail in the preceding paragraphs and which is clearly the focus of this research is the content of section 85(6) of the ADM(C)A; that is, the validity of advance directives during pregnancy. This section will be discussed in the requisite detail in the next chapter. For now, it should suffice to say that no other group of adults within Irish society has been singled out for ‘special treatment’ by the legislation aside from pregnant women. Indeed, if we look back to the guiding principles that were discussed in Chapter 1, interventions¹⁶³ are to be made in a way that minimises ‘the restriction of the relevant person’s rights, and the restriction of the relevant person’s freedom of action’.¹⁶⁴ Critically, they must be made with ‘due regard to the need to respect the right of the relevant person to dignity,

¹⁵⁷ Assisted Decision-Making (Capacity) Act 2015, s 89(1)(a)(b). The Circuit Court also has jurisdiction to decide if a designated healthcare representative is acting in accordance with the relevant powers per s 89(1)(c).

¹⁵⁸ Assisted Decision-Making (Capacity) Act 2015, s 89(2)(a)(b). Similarly, the High Court has jurisdiction to decide if a designated healthcare representative is acting in accordance with the relevant powers per s 89(2)(c).

¹⁵⁹ Assisted Decision-Making (Capacity) Act 2015, s 89(3)(a) and (b)(i). Section 89(3)(b)(ii) states that, while the High Court is determining the validity and applicability of the advance directive of a pregnant woman, treatment should be provided to her to prevent a ‘deleterious effect on the unborn’. See Chapter 6 for a full discussion of this provision.

¹⁶⁰ Per sections 90(1)(a)(b), the penalty upon conviction for such an act is a class A fine or imprisonment for a term not exceeding 12 months, or both (summary conviction) or a fine not exceeding €50,000 or imprisonment for a term not exceeding 5 years, or both (indictment).

¹⁶¹ Assisted Decision-Making (Capacity) Act 2015, s 90(3).

¹⁶² Assisted Decision-Making (Capacity) Act 2015, s 90(2). The penalties under section 90(2) are the same as under section 90(1).

¹⁶³ As defined by s 2(1) means: ‘an action taken under this Act, orders made under this Act or directions given under this Act in respect of the relevant person by (a) the court or High Court... (e) a healthcare professional’.

¹⁶⁴ Assisted Decision-Making (Capacity) Act 2015, s 8(6)(a).

bodily integrity, privacy [and] autonomy'.¹⁶⁵ The next chapter will discuss the degree to which this aim will likely be achieved where pregnant patients are concerned.

England and Wales

In contrast to Ireland, the law on advance directives in England and Wales has been settled for some time. Prior to the introduction of the relevant legislation, there was a common law recognition of advance directives, evidenced by the judgment in *Bland*:

[T]he right to reject treatment extends to deciding not to accept treatment in the future by way of advance directive or 'living will'. A well-known example of advance directive is provided by those subscribing to the tenets of the Jehovah's Witnesses, who make it clear that they will not accept blood transfusions.¹⁶⁶

In the majority of cases where the American courts have sanctioned the withdrawal of life-supporting medical care they have done so by developing the rule that informed consent can release the doctor from his duty to treat (...). It is perhaps sufficient to say that it takes two forms. In the first, the court looks for the making of an antecedent choice by a patient who can no longer make one, or communicate one, by the time that the question of termination has arisen. What is often called a 'living will' has been held sufficient for this purpose.¹⁶⁷

Re AK concerned a 19-year old man suffering from advanced Motor Neurone Disease.¹⁶⁸ He wished to have ventilation withdrawn once he lost the ability to communicate, which was limited to eye movements at the time that he drafted the advance directive. Hughes J held:

It is (...) clearly the law that the doctors are not entitled (...) [to administer treatment in an emergency where the person cannot communicate] if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advance indication of the wishes of a patient of full capacity and sound mind are effective.¹⁶⁹

During the 1990s, the Law Commission published a series of consultation papers on decision making, incapacity and vulnerable adults.¹⁷⁰ In its consultation paper entitled 'Mentally Incapacitated Adults and Decision-Making: An Overview', the Law Commission described an advance directive along the lines of the American definition, as:

The purpose of an advance directive is to enable a competent person to give instructions about what he wishes to be done, or who he wishes to make decisions for him, if he should subsequently lose the capacity to decide for himself (...) It can give the person

¹⁶⁵ Assisted Decision-Making (Capacity) Act 2015, s 8(6)(b).

¹⁶⁶ *Airedale NHS Trust v Bland* [1993] 1 All ER 821, 843.

¹⁶⁷ [1993] 1 All ER 821, 891-2

¹⁶⁸ *Re AK (Medical Treatment: Consent)* (2001) 58 BMLR 151.

¹⁶⁹ *ibid* 156.

¹⁷⁰ Law Commission, *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction* (Law Com No 128, 1993); Law Commission, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research* (Law Com No 129, 1993); Law Commission, *Mentally Incapacitated and Other Vulnerable Adults: Public Law Protection* (Law Com No 130, 1993); Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview* (Law Com No 119, 1991).

concerned the assurance that his expressed wishes will be followed and his autonomy respected to the highest possible degree.¹⁷¹

The 'living will' was described in the same consultation paper as:

[E]ssentially a formal declaration by a competent adult expressing the wish that if he becomes so (...) ill that there is no prospect of recovery, any procedures designed to prolong life should be withheld. The object is to rebut any presumption that the patient has consented to treatment which may be administered under the doctrine of necessity, and to give the patient power to direct in advance the treatment, or lack of treatment, that he wishes to receive at the end of his life should he lose the ability to do so at the time.¹⁷²

In its subsequent consultation paper entitled 'Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research', the Law Commission proposed a type of framework for advance decision. In short, the Law Commission proposed legislation that provided for the scope, legal effect and conditions necessary to create a valid anticipatory decision, including specifying that a clearly established anticipatory decision should be as effective as a contemporaneous decision would be in the same circumstances,¹⁷³ that a signed and witnessed anticipatory decision in writing should be presumed to be an established advance decision and that revocation of an anticipatory decision orally or in writing by a competent individual should be possible at any time.¹⁷⁴ The Commission further suggested that anticipatory decisions should not be effective where pertaining to pain relief or 'basic care', including nursing care and spoon-feeding. Furthermore, it was proposed that medical professional should have no criminal or civil liability for abiding by an apparently valid advance unless there was bad faith or lack of reasonable care and that criminal liability should attach to any person who falsifies or forges an advance directive or revocation, or who conceals, alters or destroys a directive or revocation without the authority of the decision-maker. Finally, the Commission suggested that the relevant statutory authority should not permit treatment contrary to an advance decision before the court makes a determination unless that treatment is essential to prevent death or irreversible damage to the health of the individual.

The Law Commission subsequently made recommendations in the form of a Report and Draft Bill, which became the basis for the Mental Capacity Act 2005.¹⁷⁵ Accordingly, advance

¹⁷¹ Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview* (Law Com No 119, 1991) 137-8.

¹⁷² *ibid* 139-40.

¹⁷³ This was subject to certain the other proposals contained in the paper.

¹⁷⁴ Law Commission, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research* (Law Com No 129, 1993).

¹⁷⁵ Law Commission, *Mental Incapacity* (Law Com No 231, 1995) and Draft Mental Incapacity Bill 1995.

directives, or advance decisions, as they are termed, are governed by sections 24 – 26.¹⁷⁶ Under section 24 an advance decision is defined as:

[A] decision made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if —

- (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued (...) and
- (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.¹⁷⁷

The specific reference to continuation of treatment contained in the MCA 2005 has obvious importance in that it appears to make it explicit that even if a treatment has commenced, it should be withdrawn if the circumstances, which the individual specifies, occur. For example, it is common practice for an individual, who is unresponsive following a head injury, to be ventilated quickly while medical professionals determine the level of brain damage, a process which can take quite some time. Thus, for example, ventilation can be withdrawn if it becomes apparent that the individual is suffering from a disorder of consciousness, provided the diagnosis and treatment were both specified in an advance directive.¹⁷⁸ Irish legislation, by contrast, is less specific in that it refers to ‘treatment decisions that may arise’. It is submitted, however, that ‘treatment decisions’ should logically encompass both a refusal of treatment prior to commencement and a withdrawal of treatment.¹⁷⁹ Frankly, it would be bizarre for the Irish legislature to deliberately exclude withdrawal of treatment in view of the case law.¹⁸⁰

It is submitted that the first critical difference between the situation in England and Wales and in Ireland is the requirement to have the advance directive in writing. As briefly stated earlier, all advance directives in Ireland must be in writing in order to be valid.¹⁸¹ By contrast, only advance decisions pertaining to life-sustaining treatment must be in writing in England and

¹⁷⁶ Although slightly different terms are used by the two jurisdictions – advance decision versus advance healthcare directive – they will be used interchangeably in this chapter in order to facilitate a comparison between the two systems.

¹⁷⁷ Mental Capacity Act 2005 (MCA 2005), s 24(1). As was discussed in Chapter 4, the *Re C* capacity test was codified by the MCA 2005 and is defined as the ability to understand and retain the information relevant to the decision, use or weigh that information in order to make a choice and communicate that decision (s 3).

¹⁷⁸ Such a situation can be contrasted sharply with the case of Vincent Lambert, a Frenchman, who has been in a vegetative state since 2008 with irreversible brain damage. His family have been embroiled in court cases for a number of years over the withdrawal of life-sustaining treatment; his wife, the majority of his siblings and his nephew with the support of his doctors have petitioned to stop artificial hydration and nutrition, however, his parents and some of his (half) siblings have objected. The case is still ongoing, as the UN Committee on the Rights of Persons with Disabilities requested that it be permitted to investigate the case – to which a Paris court acquiesced – after the French Council of State, France’s highest court, had ruled that treatment could be ceased. See Aurelien Breeden, ‘Hours After French Patient Is Taken Off Life Support, a Court Orders It Be Restored’ *The New York Times* (New York, 20 May 2019) <<https://www.nytimes.com/2019/05/20/world/europe/france-vincent-lambert-life-support.html>> accessed 22 November 2019.

¹⁷⁹ Furthermore, given that the circumstance, in which a treatment, should be refused must be specified, it is likely that the hypothetical situation laid out in the previous footnote would have a similar outcome in Ireland. Once it becomes apparent that the individual is in the circumstances, in which they have specified that the treatment should be refused, then the refusal should stand, once it is otherwise validly drafted.

¹⁸⁰ *Re a Ward of Court* [1996] 2 IR 79. See also *HSE v JM* [2017] IEHC 399.

¹⁸¹ Assisted Decision-Making (Capacity) Act 2015 s 84(4).

Wales; advance decisions expressed verbally are valid for all other treatments.¹⁸² Accordingly, withdrawals and amendments expressed verbally are valid, unless the amendment falls within the scope of section 25(5), in other words, life-sustaining treatment. The requirements for valid refusal of life-sustaining treatment in advance in England and Wales are broadly similar to the requirements in Ireland, as articulated above. The refusal must be signed by the directive-maker, in the presence of a witness, who in turn must sign the directive in the presence of the directive-maker.¹⁸³ Finally, it must also be stated that the directive-maker intends the refusal to have effect in the event that it poses a risk to life.¹⁸⁴

The MCA 2005 contains similar exemptions for medical professionals who treat, or withhold treatment, based on the reasonable belief that there was, respectively, an invalid or valid advance decision.¹⁸⁵ The phrasing of the exemptions for individuals complying with an advance directive that they reasonably believe is valid and applicable is slightly different in the two jurisdictions. In England and Wales, the ‘person’ – as distinct from ‘healthcare professional’ in the Irish legislation – will not incur liability for providing treatment unless ‘he is satisfied that an advance decision exists which is valid and applicable to the treatment’.¹⁸⁶ In Ireland, the healthcare professional will not be liable for failure to comply with an advance healthcare directive if, at the time in question, he had reasonable grounds to believe that the advance healthcare directive was invalid or inapplicable.¹⁸⁷ It can be suggested, however, that the effect of the two statutes would be quite similar and the difference lies merely in the detail provided in the Acts; Ireland has a later section that exempts healthcare professionals from liability if they have no grounds for believing that the directive exists or if they know it exists but they have no access to its contents and there is an urgency associated with the provision of treatment.¹⁸⁸ Arguably, section 26(3) of the MCA 2005 would encompass both of these situations as the professional would not be ‘satisfied that an advance decision exists which is valid and applicable to the treatment’ under the circumstances.

There is no specific direction in the legislation as to how healthcare professionals should handle ambiguity, however, the Code of Practice for the MCA gives guidance as to how disagreements, as opposed to ambiguity, should be approached. Section 9.64 states that

¹⁸² MCA 2005, s 25(6).

¹⁸³ MCA 2005, s 25(6)(b)(c)(d); where the directive-maker can’t sign herself, she may nominate somebody to sign on her behalf. In that case, the nominee must sign the directive in the presence of the directive-maker, who then acknowledges the signature in the presence of the witness, who in turn signs the directive in the presence of the directive-maker.

¹⁸⁴ MCA 2005, s 25(5)(a).

¹⁸⁵ MCA 2005, s 26(2)(3).

¹⁸⁶ MCA 2005, s 26(2).

¹⁸⁷ Assisted Decision-Making (Capacity) Act 2015, s 86(2)(b).

¹⁸⁸ Assisted Decision-Making (Capacity) Act 2015, s 86(3)(a)(b).

responsibility for deciding if there is a valid and applicable advance decision rests with the healthcare professional responsible for the care of the person at the time when treatment is required. In the event of disagreement about an advance decision between healthcare professionals, or between healthcare professionals and family members or others close to the person, the senior clinician must consider all the available evidence and should garner the views of staff involved in the care of the person.¹⁸⁹ Section 9.66 of the COP states that where the senior clinician has a ‘reasonable belief’ that the advance decision is valid and applicable, then it should be adhered to. Should the doubt as to the advance directive persist, then section 26(4) of the MCA 2005, which states that the court may make a declaration as to whether an advance decision exists, is valid and is applicable to a treatment, should apply. As discussed previously, there is a provision in the Irish legislation which permits a healthcare professional to resolve ambiguity in favour of the preservation of life, if all other attempts at resolution have been unsuccessful.¹⁹⁰ This appears to give medical professionals in Ireland more discretion than their counterparts in England and Wales, or more accurately, more discretion to favour the preservation of life in ambiguous cases. One could opine, however, that it is unlikely that a situation involving ambiguity would not be referred to the court for adjudication, given the novelty of the legislation.

Section 26(5) of the MCA 2005 provides that, while the validity and/or applicability of an advance decision is being considered by the court, the directive-maker should be provided with life-sustaining treatment and/or treated in order to prevent ‘a serious deterioration’ in her condition. This section likely provided inspiration for the Irish legislature, as it is almost identical to section 89(3) of the ADM(C)A 2015.¹⁹¹ The interpretation of the advance decision provisions in the MCA 2005 is restrictive and – in the opinion of Jackson J in *Re D* – understandably so.¹⁹² *Re D* concerned a man who had put his wishes regarding treatment in writing, however, his letter that specifically refused a feeding tube did not comply with the requirements in the MCA 2005.¹⁹³ Accordingly, it was not a valid advance decision, however, the letter was taken as an indication of his wishes and the case was decided on the basis of his best interests. A similar conclusion was reached more recently in *Barnsley Hospital NHS Foundation Trust v MSP*;¹⁹⁴ Mr MSP’s advance decision did not comply with the statutory

¹⁸⁹ Code of Practice, paras 9.64 and 9.65. The ‘senior clinician’ is ‘likely to be a hospital consultant or the GP where the person is being treated in the community’.

¹⁹⁰ Assisted Decision-Making (Capacity) Act 2015, s 85(5).

¹⁹¹ Aside from the reference to pregnant women and the unborn in the Irish Act.

¹⁹² *Re D* [2012] EWCOP 885, para 16.

¹⁹³ *ibid.*

¹⁹⁴ *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26.

requirements, however, when taken together with the ‘choate and consistent evidence’ given by his family and the evidence of three consultants who had treated him previously, the document was treated as clearly indicating his wishes and feelings, which in turn informed his best interests assessment.¹⁹⁵

In *X Primary Care Trust v XB*, the matter before Theis LJ was whether a valid advance decision had been drafted by an individual with the necessary capacity to do so and if so, whether that decision was valid and applicable at the time of the judgment.¹⁹⁶ XB had been unable to communicate verbally for some time prior to allegedly executing the advance directive. Accordingly, he communicated his comprehension of conversation and (dis)agreement to statements through eye movement. One such conversation was alleged to be the one when the advance decision was drafted, however, there was evidence to suggest that he had discussed declining treatment with his family and GP on a number of prior occasions.¹⁹⁷ The question as to XB’s competent agreement with the advance decision arose because a member of staff responsible for his care expressed doubt that he had agreed to the advance decision. The judge, however, found on the evidence that the advance decision had been competently made by XB and that, while the staff member may have been present on other occasions, she was not present on the date when it was drafted. The second issue – the validity and applicability of the advance decision at the time of the hearing – arose because a ‘ready-made’ advance directive form was used, as opposed to one specifically drafted with XB in mind. Consequently, it contained a specific ‘end date’, something which is not required in an advance directive under the law in England and Wales. The learned judge took the opportunity to highlight the difficulty caused by internet forms and to caution their use:

One of the difficulties in this case was the inclusion in the pro forma of a ‘valid until’ date. Those organisations that have such terms in their pro formas may want to look again at the necessity for that being in the pro forma form. It is clearly in the interests of the person who has made the advance decision, his or her family, and those who have responsibility for providing or withholding treatment that there is clarity in relation to what the terms of the advance decision are.¹⁹⁸

She was, however, satisfied on the evidence that XB did not intend his advance decision to expire and that he was unaware of the inclusion of an ‘end date’ on the form. Accordingly, she made the requested declaration of validity under the MCA.

¹⁹⁵ *ibid*, para 41.

¹⁹⁶ [2012] EWHC 1390 (Fam), para 2.

¹⁹⁷ The advance directive being considered by the court was one dated November 2011 and the judgment was on 1st May 2012.

¹⁹⁸ [2012] EWHC 1390 (Fam).

In *Nottinghamshire Healthcare NHS Trust v RC*, the court was faced with two questions in relation to an advance refusal of treatment by a man suffering from a severe personality disorder.¹⁹⁹ First, it was asked to decide if the written advance decision of RC was valid and applicable to the treatment in question in line with the MCA 2005. Second, because the patient was compulsorily detained under the Mental Health Act 1983 ('MHA 1983'), the question arose as to whether section 63 of that Act permitted RC to be treated despite his advance decision.²⁰⁰ On the first question, the Court found that the advance decision satisfied the requirements of the MCA 2005 and it was valid.²⁰¹ The second question was considerably more difficult to decide. Although the Court engaged in some analysis of the issue, Holman J declined to make the order requested and instead ordered a further hearing on the matter to take place in the days that followed. Interestingly, the learned judge stated the following regarding the role of the court in ethical matters:

I must stress at once that it is never the business of a court in these sorts of situations to make any kind of ethical decision. That is a matter for doctors alone, applying such guidance, if any, as they can obtain from their professional medical bodies.²⁰²

It is argued by some that it is unsatisfactory for the important ethical issues to be merely sidestepped.²⁰³ It is interesting to contrast the hesitance to consider ethical issues with the view of some US courts that the consideration of moral matters is not only within the remit of the court, but its responsibility:

Such notions as to the distribution of responsibility [to physicians], heretofore generally entertained, should however neither impede this Court in deciding matters clearly justiciable nor preclude a re-examination by the Court as to underlying human values and rights. Determinations as to these must, in the ultimate, be responsive not only to

¹⁹⁹ [2014] EWCOP 1136.

²⁰⁰ MHA 1983, s 63: 'The consent of a patient shall not be required for any medical treatment given to him for the mental disorder from which he is suffering (...) if the treatment is given by or under the direction of the approved clinician in charge of the treatment.'

²⁰¹ [2014] EWCOP 1136, para 9: The primary consideration of the court was if the patient and witness had actually signed the document in each other's presence. Although both dated the document with the same date, the document does not specify that it was signed by the maker and the witness in the presence of each other. The judge found, however, that on the balance of probability the two parties signed in the presence of the other; 'I will, for the purposes of the present hearing and interim order, make an assumption on the balance of probability that the maker did indeed sign it in the presence of the witness and the witness signed it in the presence of the maker himself.'

²⁰² *ibid.* This perceived reluctance on the part of some of the judiciary to engage with ethical issues is a theme that will be picked up in Chapter 6 in the context of the ethical status of the foetus.

²⁰³ For example, see Rosamund Scott, 'The Pregnant Woman and the Good Samaritan: Can a Woman Have a Duty to Undergo a Caesarean Section?' (2000) 20 *Oxford J Legal Stud* 407, 410. See also the quote from Ward LJ in *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] EWCA Civ 254, para 4; '[t]his is a court of law, not of morals'. Contrast with John Coggon, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 *Health Care Anal* 235, 236: 'It is rare for a judge to provide an explicit, philosophical investigation of autonomy. This is both unsurprising and understandable. Perhaps it is even desirable (...) were judges to follow too assiduously a specific doctrinal approach [created by bioethicists], they may well be open to the sort of criticism that they are employed to judge the law and not questions of ethics.' See also Bernardette J Richards who argues in relation to autonomy: 'The judiciary is not equipped to engage with the complex considerations that should underpin any discussion of autonomy and, therefore, would be better served to cease adopting it as a touchstone. Judicial process should, instead, rest of clearly defined and well understood legal terms.' Bernardette J Richards, 'Autonomy and the Law: Widely Used, Poorly Defined' in David G Kirchoff and Bernardette J Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019) 20.

the concepts of medicine but also to the common moral judgment of the community at large. In the latter respect the Court has a non-delegable judicial responsibility.²⁰⁴

It is also interesting to contrast that statement with the judgment Mostyn J, who refers to the work of John Stuart Mill in exploring the right to refuse medical treatment and to harm oneself, in the subsequent hearing of *Nottinghamshire Healthcare NHS Trust v RC*, which took place less than a week after the first.²⁰⁵ While the court did consider if RC had capacity to make an advance decision and the validity of that advance decision, these aspects garnered significantly less scrutiny than the primary issue of whether a blood transfusion amounted to treatment, which prevented the worsening of a symptom or manifestation of the patient's mental disorder or one which treated a consequence of the disorder. This distinction is critical to establish if section 63 applies to the particular case and consequently, if the consent of the patient is necessary or if the physician can dispense with consent and where relevant, circumvent an advance decision. On the matter of capacity, the independent psychiatrist considered it difficult to describe that the ability of RC to weigh the risks of refusing blood against his religious beliefs because those beliefs effectively created 'an absolute prohibition on blood products'. Mostyn J was unequivocal in accepting RC's capacity to refuse blood products, however, stating that 'it would be an extreme example of the application of the law of unintended consequences were an iron tenet of an accepted religion to give rise to questions of capacity under the MCA'.²⁰⁶ As had been found in the previous hearing, the advance decision was ruled to be valid and applicable, as further evidence was provided that supported that the document was signed by the maker in the presence of the witness and vice versa.²⁰⁷

The distinction between a symptom or manifestation of the patient's mental disorder, or a consequence of the disorder, was key as treatment of the latter does not come within section 63 of the MHA 1983, whereas the former does.²⁰⁸ The already challenging matter for the court was made more difficult by a difference of opinion amongst the psychiatrists as to whether the treatment was of a symptom or manifestation of, or a consequence of the disorder.²⁰⁹ Mostyn J, however, found that the cutting of the brachial artery by the patient was a symptom or manifestation of the underlying personality disorder and therefore treatment of that wound,

²⁰⁴ *Re Quinlan* 70 NJ 44 (1976).

²⁰⁵ [2014] EWCOP 1317, paras 8-13.

²⁰⁶ *ibid* 34; using an example provided by John Stuart Mill, Mostyn J compares the prohibition on blood transfusions within the Jehovah's Witness faith to the prohibition on the eating of pork in Islam. He states: 'There can be no circumstances where a Muslim could "weigh" the merit of eating pork. It is simply beyond the pale. So too, it would appear, when it comes to Jehovah's Witnesses and blood transfusions.'

²⁰⁷ [2014] EWCOP 1317, para 40.

²⁰⁸ MHA 1983, s 145(4): 'Any reference (...) to medical treatment, in relation to mental disorder, shall be construed as a reference to medical treatment the purpose of which is to alleviate, or prevent a worsening of, the disorder or one or more of its symptoms or manifestations'.

²⁰⁹ [2014] EWCOP 1317, para 24: Mostyn J stated that he found the distinction between a symptom or manifestation and a consequence 'intellectually challenging', further noting that a 'wide (but not always consistent) interpretation has been given to section 145(4)'.

such as suturing or the administration of antibiotics, would be to treat the manifestation or symptom of the underlying disorder. If the bleeding led to lowered haemoglobin levels, then treatment of this with a blood transfusion would also equate to treatment of a symptom or manifestation of the disorder. Accordingly, the blood transfusion came within the scope of section 63 of the MHA 1983. Somewhat unusually, the court was actually being asked to declare that the treating physician (Dr S) could lawfully withhold treatment from RC, rather than choose to treat under section 63. She expressed serious ethical concern about treating RC against his competent wishes, when he would have a valid refusal in other circumstances.²¹⁰

Speaking about these kinds of case, Mostyn J stated:

[W]here the approved clinician makes a decision not to impose treatment under section 63, and where the consequences of that decision may prove to be life-threatening, then the NHS trust in question would be well advised, as it has here, to apply to the High Court for declaratory relief. The hearing will necessarily involve a ‘full merits review’ of the initial decision. It would be truly bizarre if such a full merits review were held where a positive decision was made under section 63, but not where there was a negative one, especially where one considers that the negative decision may have far more momentous consequences (i.e. death) than the positive one.

Notwithstanding the power under section 63, Mostyn J held that Dr S was correct in her decision not to treat and instead to respect the advance decision.

In *NHS Cumbria CCG v Rushton*, the matter before the court was the withdrawal of clinically assisted hydration and nutrition.²¹¹ Judgments concerning the withdrawal of AHN are generally made on the grounds of best interests and futility, as a court hearing almost always presupposes that a valid advance decision does not exist. The facts of *Rushton*, however, were that Mrs Rushton did have an advance decision, which she lodged with her GP. The hospital, unaware of the advance decision, inserted a nasogastric tube, an act referred to by Hayden J as one ‘done instinctively by conscientious medical staff, whose every instinct would have been to promote her welfare’.²¹² When her condition improved the hospital staff replaced the NG tube with a percutaneous endoscopic gastrostomy (PEG). The insertion of the PEG, however, was carried out subsequent to a conversation between Mrs Rushton’s GP and hospital staff, where the GP was recorded as stating that ‘the only ADR (Advance Directive) in place is in regards to do not resuscitate’.²¹³ Consequently, it appears that the contents of Mrs Rushton’s advance decision

²¹⁰ [2014] EWCOP 1317, para 41. She stated: ‘I have some ethical difficulty in using the MHA to override a capacitous patient’s wishes based on religious wishes and I would not choose to use my MHA powers to override his advanced [sic] decision’.

²¹¹ [2018] EWCOP 41.

²¹² *ibid* para 12.

²¹³ *ibid* para 24.

were incorrectly interpreted or communicated.²¹⁴ In deciding whether to approve the withdrawal of AHN, Hayden J stated:

I must say, I have heard sufficient [evidence] to be clear, that Mrs Rushton would have hoped that her wishes in her advance decision would have applied to her present situation. I cannot easily contemplate circumstances in which the views of an adult with this degree of disorder of consciousness could be communicated more volubly or unambiguously.²¹⁵

As Mrs Rushton's advance decision had already been contravened, however inadvertently, Hayden J reverted to best interests to make his decision and as was the case with *Re D*, the written wishes of Mrs Rushton were viewed as clear guidance as to what she would have wanted in the circumstances.²¹⁶ One could opine, however, that making the decision to withdraw treatment on the basis of best interests was curious; as articulated earlier, the MCA 2005 provides for advance decisions to apply to both the refusal of treatment before it begins and the refusal of continued treatment.²¹⁷ One could argue, therefore, that Hayden J ought to have made a determination on the validity and applicability of the advance decision to the refusal of the continued administration of AHN before progressing to assess Mrs Rushton's best interests. After all, when commenting on her advance decision in the course of the judgment, he stated that the 'document (...) complied with the [legal] provisions fastidiously'.²¹⁸

As her advance decision stated that she was 'refusing all treatment' if certain events were to transpire – which they did – and if Mrs Rushton's advance decision complied 'fastidiously' with the law, then why was there a need to utilise the best interests test? Ought 'on collapse, I do not wish to be resuscitated by any means (...) I am refusing all treatment' not be understood as a directive to cease all treatment once the directive was discovered? If not, it seems to render any advance directive that has been inadvertently contravened void, even if the treatment in question can be ceased after the directive is discovered. Moreover, if the advance decision was invalid or inapplicable for some reason and a best interests test was required, then the reason for this ought to have been explained. Furthermore, this decision may disproportionately affect pregnant women; as pregnancy is clearly a finite state, there may be scope for an advance decision to be inadvertently contravened but for that position to be maintained until a hearing

²¹⁴ Mrs Rushton's document actually stated the following: 'on collapse, I do not wish to be resuscitated by any means (...) I am refusing all treatment. Even if my life is at risk as a result (...) in all circumstances of collapse that put my life at risk, this direction is to be applied.' Hayden J remarked: 'Having heard from Mrs Rushton's family I have not the slightest doubt that she intended that her directive would have applied to the insertion of the PEG' – [2018] EWCOP 41, paras 20-22.

²¹⁵ *ibid* 34.

²¹⁶ [2012] EWCOP 885.

²¹⁷ MCA 2005, s 24(1).

²¹⁸ [2018] EWCOP 41, para 20.

on best interests can be undertaken. This in turn may have the effect of delaying the withdrawal of medical treatment until a more desirable stage of foetal development, despite the administration of treatment being clearly against the previously expressed wishes of the woman.

Conclusion

Initially, advance directives were seen as a method of filling a gap that had appeared in medical decision-making. It was viewed as a method of ensuring that people who had no opportunity to discuss their consent to or refusal of treatment with their physicians in advance had a method of making their wishes known. Kutner, however, was not armed with the various studies, which purport to demonstrate that individuals can seldom be trusted with making decisions in advance. Rather, he arguably viewed his legal framework as a means of solving what he saw as a large inconsistency within the law. It is the position of this paper that, despite the criticisms levelled at advance directives, they are still a valuable tool to indicate the treatment preferences of patients and a necessary and effective mechanism to maximise the autonomy of those who choose to use them. It is also the position of this paper that they are the best mechanism of achieving that aim as it is the individual and not family nor friends nor strangers, with whom there has been no consultation, that are best placed to make these important decisions. This does not preclude a situation where an individual chooses to appoint somebody to make these decisions on their behalf, nor does it undermine their decision to do so. Rather, it is the opposite; if the individual chooses to put their trust and faith into another person to make medical decisions on their behalf, having discussed their beliefs and values with them, then they too are exercising their autonomy. What is most important is that the individual has a choice in this regard and not that one or other decision-making framework is foisted upon her.

It is almost impossible to evaluate the law regarding the right of a pregnant woman to refuse medical treatment in advance without first establishing the law applicable to advance decisions and how that law came to be. Thus, this chapter fulfils a very necessary role within this thesis as a whole, however, as suggested in Chapter 1, it is best to consider the issues of compelled treatment in pregnancy and 'pregnancy exceptions' to advance directive laws together, separately to this chapter, in the interest of clarity and coherence. It appears to this research that the law in New York is deficient, as it fails to provide a suitable legal framework for an individual to create an advance refusal of treatment and consequently leaves those with written advance refusals in a state of uncertainty. Until recently, Ireland was in a similar situation in

that there was a common law recognition of advance directives, but no corresponding legislation. This has been changed for the better by the ADM(C)A 2015; indeed, until its commencement, one can reasonably presume that its provisions would serve as clear guidance to the High Court as to what constitutes a valid advance directive, should a case on the matter arise. England and Wales clearly has the most advanced framework by far from a legislative and common law perspective, however, that is not to say that there are no issues with its law. Of particular concern to this research was the judgment in *Rushton* and the consequences for future individuals whose advance decisions are accidentally contravened, particularly pregnant patients. This research now turns to a specific discussion of advance directives in pregnancy, while simultaneously considering compelled obstetric interventions.

Chapter 6

Introduction

Arguably, few areas within healthcare garner as much publicity, discussion and often vitriolic debate than pregnancy. Even leaving aside the issue of termination of pregnancy, what was at some point in time a private matter between woman, partner and physician, namely pregnancy, is now ‘a political matter’.¹ It is important to say that not all of this politicisation has been negative for women or their infants. Rather, some of it has resulted in campaigning on behalf of women, to further or protect their rights and has led to the drafting and signing of transnational conventions² and government commitments to improve maternal, foetal and infant outcomes in pregnancy and to some extent, thereafter.³ Some has resulted in improvements in maternity and paternity leave.⁴ Still, it remains that this area of healthcare has been opened up as a public matter and often, legislative proposals pertaining to pregnancy and those cases involving it, garner a special kind of interest.

Thus far, discussions of medical treatment in pregnancy have focused on the patient herself, without referring to the foetus. This has been deliberate so that this conversation could take place in this chapter alongside the legal analysis of compelled interventions in pregnancy. Both the ‘abortion debate’ and the ‘compelled treatment debate’ are often framed in terms of the rights of the woman versus the rights of the foetus, or as ‘maternal-foetal conflict’. It is argued, however, that this framing is unhelpful if the end goal is to resolve very complex ethical issues arising in practice. As will become apparent, the vision of a woman and foetus ‘battling it out’ is hardly reflective of the situation occurring when a woman wishes to refuse a Caesarean section or blood transfusion. Indeed, as Samantha Halliday argues, a woman refusing intervention in pregnancy is not doing so in order to harm the foetus;⁵ rather, she is doing so because she disagrees with medical opinion as to the best course of action for her, just as any other patient might. Jane Mair has described the term ‘maternal-foetal conflict’ as ‘a violent image which disrupts the coexistence of mother and foetus’ and ‘an emotive phrase which

¹ For a discussion on the politicisation of pregnancy, see Vivienne Harpwood, *Legal Issues in Obstetrics* (Dartmouth 1996) Chapter 2.

² For example, the United Nations Convention on the Elimination of All Forms of Discrimination against Women of 18 December 1979, which has been signed by Ireland, the United Kingdom and the United States.

³ Department of Health, *National Maternity Strategy – Creating a Better Future Together 2016-2026* (2016) <<https://www.gov.ie/en/publication/0ac5a8-national-maternity-strategy-creating-a-better-future-together-2016-2/>> accessed 6 April 2020. See also Chapter 3 of the National Health Service, *Long Term Plan* (2018) <<https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/>> accessed 6 April 2020. For a global example, see the WHO Millennium Development Goals, which included ‘to reduce child mortality’ and ‘to improve maternal health’ and were signed by all 191 UN member states: World Health Organization, ‘Millennium Development Goals’ (2000) <https://www.who.int/topics/millennium_development_goals/about/en/> accessed 6 April 2020.

⁴ For example, paid maternity leave in Ireland started at 12 weeks and increased to 18 weeks in 2001, 22 weeks in 2006 and 26 weeks in 2007 respectively. Increases of a similar nature were also seen in the United Kingdom.

⁵ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 176.

suggests unmotherly feelings and a grotesque perception of the struggling foetus'.⁶ It is argued that these should not be the descriptions that come to mind when a woman is refusing medical treatment in pregnancy.

In relation to the idea of competing rights, Emily Jackson astutely argues that a 'debate' framed in this manner can never be conclusively 'won' because neither side 'accepts the other's foundational moral premises'.⁷ Furthermore, such debates are of limited value in reality; it is argued that they almost never grapple with or acknowledge the very real challenges faced by the women and physicians involved. Rather, they can one-dimensionally portray the woman as an uncaring or selfish individual, unconcerned with the welfare of her child, simultaneously thinking she knows 'better' than her medical team. The physician can be portrayed as viewing his patient as little more than a 'foetal container', an object whose aims and values are irrelevant provided she maintains this 'other patient'. In reality, situations involving the refusal of medical treatment in pregnancy are multi-faceted and reducing them to a basic hero versus villain situation, as these debates often do, does a disservice to all parties. Consequently, it is essential to devise another way of analysing situations in which the medically indicated treatment is being refused in pregnancy.

The previous chapter outlined the law pertaining to advance healthcare directives in Ireland, England and Wales, New York State and the greater United States. Chapter 4 explored the ethical justification and legal basis for the right to refuse life-sustaining medical treatment in those jurisdictions. How this right is limited, or is likely to be limited, if the patient is pregnant varies from jurisdiction to jurisdiction and indeed from state from state within the United States; those limits will be discussed in considerable detail in this chapter. As such, this chapter considers the right of pregnant women to contemporaneously refuse medical treatment in Ireland, England and Wales and New York (including the greater US) in order to discern the legal position regarding refusals expressed in advance, where there is no 'pregnancy exception' to the advance directive legislation. It also discusses legislation that prevents the advance directives of pregnant women from being honoured.

Analytical Framework

⁶ Jane Mair, 'Maternal/Foetal Conflict: Defined or Defused?' in Sheila McClean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996) 79.

⁷ She notes this in relation to some of the work of undertaken by Sheila McClean; Emily Jackson, 'DIY Abortion and Harm Reduction' in Pamela R Ferguson and Graeme T Laurie (eds) *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean* (2015 Ashgate) 25.

As argued previously, an alternative to the *woman versus foetus* framework is necessary to attempt to resolve the issues arising from the refusal of medical treatment in pregnancy. Though more nuanced and sophisticated arguments are neither unavailable nor remain *unmade* by either side of this debate, it is contended that many of the arguments – perhaps, regrettably the most widespread ones – are simplified down to the point of being completely unhelpful. Often the ‘pro-life’⁸ side of the debate advance foetal rights and interests in the context of a separate ‘person’. Such arguments are often supported by examples of this *separateness*, such as the foetus’ unique DNA and fingerprints and its sometimes-different blood type. Images from ultrasound technology are used to further bolster this argument.⁹ Furthermore, as Rosamund Scott argues, the potential to treat the foetus *in utero* can have the effect of conferring upon it ‘the status of a patient with rights’.¹⁰ However, as she also argues, law and ethics, not science, ought to determine if the foetus has the status of patient and any accompanying rights that it should have.¹¹ Arguments of separate entities refer to the foetus as ‘the (unborn) baby’ or the ‘child not yet born’. Sometimes, these arguments draw on the similarities between a foetus and a neonate with the line of argument that it is not permissible to kill a newly born baby, so why is it permissible to kill a foetus? What is so significant about birth that it allows one to be killed but not the other? Reduced to its most basic form, on the pro-choice side, arguments that ‘it’s the woman’s body, the end(!)’ or that the foetus is akin to a body part, are advanced.

As should be apparent, these two viewpoints are so divergent that a meaningful debate is almost impossible. Their starting points are simply too far apart. It is also advanced that neither of these positions properly reflect the nature of the foetus or the pregnant woman, nor their relationship. The foetus is neither a body part nor a separate person, at least not entirely. The body part comparison, while clearly accurate in the sense that the foetus is ‘contained’ within the body of the woman, is problematic because it denies the distinctiveness of the foetus and indeed, runs contrary to physiology.¹² A foetus is not functional like a kidney and the woman

⁸ In line with common parlance, this research will utilise the term ‘pro-life’; in this context, it is intended to apply to both those who are anti-abortion and those who would be in favour of compelling treatment in pregnancy.

⁹ Catherine MacKinnon argues that technology may also be contributing to the idea that the foetus is a separate person because ultrasound technology has made it possible to view it as a ‘free-floating independent entity rather than as connected with the pregnant woman’. Catherine A MacKinnon, ‘Reflections on Sex Equality under Law’ (1991) 100 Yale L J 1281, 1310. Samantha Halliday argues similarly that ultrasound technology shows ‘the separateness of the foetus and the pregnant woman’ and is used to suggest that the foetus is a baby, or at the very least, ought to be treated as one; Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 173. See also American College of Obstetricians and Gynecologists Committee on Ethics, *Refusal of Medically Recommended Treatment During Pregnancy* (Number 664, 2016) 3.

¹⁰ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 26. Samantha Halliday argues that terms such as ‘foetal medicine unit’ and foetal surgery’ ‘explicitly recognise the patient status of the foetus’ with no reference to the impact of surgery on the pregnant woman; Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 175.

¹¹ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 26.

¹² John Seymour, *Childbirth and the Law* (OUP 2000) 189-90. See also, Catherine A MacKinnon, ‘Reflections on Sex Equality under Law’ (1991) 100 Yale L J 1281, 1314: ‘The body part analogy derives some of its credibility from the intricate and intimate connection between the fetus and woman (...) From before viability until fully completed live birth, the fetus is within the person of the woman and at one with

is not dependent on it for survival like she is with many organs.¹³ No body part or organ has the potential to be independent or live its own life one day.¹⁴ Furthermore, the ‘body part’ understanding can preclude or severely limit action being taken on behalf of a harmed foetus;¹⁵ this should not be the case where the foetus is harmed by the conduct of another, such as when a pregnant woman is attacked, where the negligence of another person has caused a car accident or where there is lack of informed consent arising from insufficient disclosure of risks pertinent to the foetus and said risk has materialised.¹⁶ As John Seymour argues, ‘it is unsatisfactory to answer all questions relating to the appropriateness of legal intervention to protect a fetus by denying that it exists and has intrinsic value’.¹⁷

It has been posited that in recognising the distinctiveness of the foetus, a legal system can sometimes benefit women;¹⁸ it does not follow, however, that the separate foetal person construct is preferable to the ‘body part’ one. Rather, it is also problematic. Irrespective of biological differences between the woman and the foetus, it is not independent of her body during pregnancy. Until birth, it is part of her and decreasingly dependent on her for its survival as time passes. The foetus cannot be reached except through the woman and the separate entity argument ignores this. The foetus cannot leave the pregnant woman to return at a later date. Just as the body part analysis fails to recognise the difference and uniqueness of the foetus, so too does the separate entities model fail to recognise the unique state of, and role being played by, the pregnant woman. The foetus is carried inside her and cared for and nourished exclusively by her body; nobody else has this role aside from the woman. The American College of Obstetricians and Gynecologists (ACOG) also expresses concern about this model:

When the pregnant woman and fetus are conceptualized as separate patients, the pregnant woman and her medical interests, health needs, and rights can become secondary to those of the fetus. At the extreme, construing the fetus as a patient sometimes can lead to the pregnant woman being seen as a ‘fetal container’ rather than as an autonomous agent.¹⁹

Furthermore, as Halliday argues, this model fails to reflect the view of pregnancy held by many pregnant women themselves, thereby ‘neglecting (...) the social relational context of

her bodily systems’. Eike-Henner Kluge, ‘When Caesarian Section Operations Imposed by a Court Are Justified’ (1988) 14 J Med Ethics 206, 208.

¹³ See Catherine A MacKinnon, ‘Reflections on Sex Equality under Law’ (1991) 100 Yale L J 1281, 1314.

¹⁴ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 180.

¹⁵ John Seymour, *Childbirth and the Law* (OUP 2000) 194.

¹⁶ See for example, the New York cases of *Hughson v St. Francis Hospital* 92 AD 2d 131 (NY 1983). See clarification to the position regarding general medical negligence in *Albala v City of New York* 54 NY 2d 269 (1981) wherein the Court of Appeals of the State of New York found that a defendant could not be liable for harm to the foetus, which was caused prior to conception.

¹⁷ *ibid* 189.

¹⁸ *ibid* 194.

¹⁹ ACOG Committee on Ethics, *Refusal of Medically Recommended Treatment During Pregnancy* (Number 664, 2016) 3.

pregnancy'.²⁰ Plainly, while it is distinguishable from her in a variety of ways, the foetus is not separate. As Catherine MacKinnon summarises:

Sometimes there are no adequate analogies. As it is, the fetus has no concept of its own, but must be like something men have or are: a body part to the Left, a person to the Right. Nowhere in law is the fetus a fetus.²¹

Thus, instead of adopting one or other extreme, the response of the law to the foetus can be determined by the context in which it is being invoked, thereby negating the need for it to (artificially) characterise the foetus.²² This research, therefore, advocates for the 'Not-One-But-Two' model when considering the refusal of medical treatment during pregnancy. It is argued that this model neither reduces the woman to a maternal environment nor 'inanimate machine to be tinkered with to produce the best product'.²³ It does not ignore or disregard the uniqueness and distinctiveness of the foetus for fear of causing a corresponding decline in the rights of the pregnant woman. Its strength, as identified by Halliday, is that 'it recognises the organic value of the woman and the foetus, circumventing the potential for "maternal"/foetal conflict, while still enabling the state to protect the foetus from third parties'.²⁴

Ethics and Compelled Treatment in Pregnancy

The ethical issues connected to advance directives and end-of-life decision-making were considered in the previous chapters enabling this chapter to specifically focus on advance refusal of and compelled treatment in pregnancy. The role of autonomy in healthcare decision-making has already been discussed, however as Halliday summarises:

The principle of patient autonomy stresses respect for the patient as an individual rather than as an object of concern, and attempts to promote precedent autonomy aim to extend that respect to those no longer capable of exercising autonomy and thereby to prioritise the patient's wishes over her welfare.²⁵

Yet, when we turn to advance directives in pregnancy, we often see a hesitance or refusal to honour the wishes of the woman. What is shared between the chosen jurisdictions is the underpinning ethical issues connected to medical treatment in pregnancy. What is not shared, as will become apparent, is how relevant courts and legislatures – and indeed physicians – resolve these ethical dilemmas. To understand the variances at a domestic level and on occasion, inconsistencies within the same jurisdictions, it is key to explore both legal and

²⁰ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 181.

²¹ Catherine A MacKinnon, 'Reflections on Sex Equality under Law' (1991) 100 Yale L J 1281, 1314.

²² John Seymour, *Childbirth and the Law* (OUP 2000) 193.

²³ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 174.

²⁴ *ibid* 184.

²⁵ *ibid* 30.

ethical issues. It is simply impossible to look at the law in this area in a vacuum, as though it is independent of medical ethics – rather, ethics must fill in the blanks left by what have been described, in varying degrees, as the failure of the law in this area.²⁶ MacKinnon, for example, argues:

The legal system has not adequately conceptualized pregnancy, hence the relationship between the fetus and the pregnant woman. This may be because the interests, perceptions, and experiences that have shaped the law have not included those of women. The social conception of pregnancy that has formed the basis for its legal treatment has not been from the point of view of the pregnant woman, but rather from the point of view of the observing outsider (...)²⁷

Some commentators attribute much of the development of the discipline of bioethics itself to reproductive matters or ‘fertility control’, as Warren Reich has termed it.²⁸ Thus, there is one inescapable reality when treatment is being sought against the will of the pregnant woman and that is that the pregnancy has complicated the matter, ethically and in many jurisdictions, legally. Even if one takes the view that medical treatment ought never to be compelled in pregnancy, that does not result in pregnancy not being a consideration for the medical professionals, the hospital, the legal representatives and the courts. Were this research simply examining the law on a competent refusal of treatment by a non-pregnant person, then there would be very little to discuss. The matter is, for all intents and purposes, settled from a legal perspective with competent individuals having ‘a broad legal prerogative to decide how to respond to fatal afflictions – how much to struggle, how much to suffer, how much bodily invasion to tolerate, and how much helplessness and indignity to endure’.²⁹ They can refuse even if ‘the personal values underlying the choice seem idiosyncratic or foolish’.³⁰

There may be situations where the morally right decision is to submit to treatment, either to preserve one’s own life or the life of another. But this duty will rarely, if ever, translate to a legal one. The morally right decision may be to donate a kidney or bone marrow for the benefit of another, but the law will almost certainly decline to compel it.³¹ The morally right decision

²⁶ For example, John Seymour, *Childbirth and the Law* (OUP 2000) Chapters 8 and 9; Rosamund Scott argues: ‘[B]oth legally and morally, reliance upon the fetus’ lack of personhood (...) is unsatisfactory: the question of fetal harm or death needs, so far as possible, to be *justified*, not just *excused*’. Rosamund Scott, ‘The Pregnant Woman and the Good Samaritan: Can a Woman Have a Duty to Undergo a Caesarean Section?’ (2000) 20 Oxford J Legal Stud 407, 410.

²⁷ Catherine A MacKinnon, ‘Reflections on Sex Equality under Law’ (1991) 100 Yale Law Journal 1281, 1309.

²⁸ Warren Reich, ‘The Wider View: André Hellenger’s Passionate, Integrating Intellect and the Creation of Bioethics’ (1999) Kennedy Institute of Ethics Journal 25, 37; Kenneth Boyd, ‘Medical Ethics: Hippocratic and Democratic Ideals’ in Law’ in Sheila McClean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 29-30.

²⁹ Norman L Cantor, ‘Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying’ (2001) 29 J L Med Ethics 182.

³⁰ *ibid*.

³¹ See *McFall v Shimp* 10 Pa D & C 3d 90 (1978) 91: The court declined to compel David Shimp to donate bone marrow to save the life of his cousin, who was suffering from aplastic anaemia. While the court viewed Shimp’s refusal to donate as ‘morally indefensible’, it noted that the ‘decision rest[ed] with the defendant’ and that to ‘compel defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded’ and ‘defeat the sanctity of the individual’. In this context, it is interesting to look at the case of *Re Y (Adult Patient: Transplant: Bone Marrow)* [1997] 2 FCR 172 from England and Wales as discussed in Chapter 4. In this case, an order

for a parent may be to consent to life-saving treatment, perhaps because being a parent demands some level of sacrifice.³² Yet, the courts are loathe to compel treatment on this basis, at least in more recent times.³³ Instead, ‘a woman does not forfeit her fundamental rights to liberty and privacy by becoming a mother’.³⁴ The question of whether she forfeits these rights on becoming an expectant ‘mother’ and whether she ought to, will be examined.

The ethical analysis in this chapter will be split into two parts; first, this section will consider the idea of the pregnant woman having a duty to submit to medical treatment in the interest of her foetus, while simultaneously looking at how her interests – self-determination, bodily integrity – are directly affected by the intervention, just as the interests of any patient would be.³⁵ Although the duty that a non-pregnant patient may have to submit to treatment only received scant attention in the previous chapters, it is submitted that in order to fully engage with the ethics of refusal of treatment in pregnancy, this research must venture outside Principlism and explore the idea of the pregnant woman owing a duty to accept treatment. Second, this section will consider the role and duties of the physician in respect of the pregnant patient and suggest the conduct that most fulfils his ethical obligations to her.

As the refusal of medical treatment has already been explored from a Principlist perspective, it serves little purpose to tread over that ground once more, as, all things being equal, the autonomy of the competent person should be respected. Pregnancy, however, appears not to be an ‘all things being equal’ situation. While we may arrive at the same outcome – that all competently expressed valid advance decisions ought to be respected, pregnancy aside – the ethical analysis cannot ignore the difference between a pregnant and non-pregnant person. To do so, ignores the ethical challenges faced by lawmakers, physicians and the patient herself.

was made authorising a bone marrow donation from an incompetent woman with considerable mental and physical disabilities utilising an arguably roundabout interpretation of best interests.

³² Draper discusses the idea of parental duties towards children and the expectation of sacrifice; Heather Draper, ‘Women, Forced Caesareans and Antenatal Responsibilities’ (1996) 22 J Med Ethics 327, 330.

³³ See *Fosmire v Nicoleau*, which will be discussed in more detail later in the chapter and *Re Dubreil* 629 So 2d 819 (Fla 1993). In Patricia Dubreil’s case, the court of first instance compelled treatment. This was subsequently overruled by the Supreme Court of Florida. Seymour argues, however, that the Supreme Court in this case did not completely reject the interests of the children as a reason for ordering treatment. Ms Dubreil was married and her husband would be there to parent the children if she were to die, therefore the issue of abandonment was not really relevant. In the *ex tempore* hearing in the K case, Abbot J ordered the blood transfusion to be administered in the interest of the newborn child, whom it was believed would be abandoned if Ms K were to die. It was subsequently discovered that Ms K had lied about the whereabouts of her husband and the baby would not have been abandoned. In relation to the ‘balancing of rights question’, Laffoy J found that the matter should not be addressed, nor should it have been an issue before Abbott J because it had no foundation in fact. Although she did not specifically overrule this aspect of the ruling of Abbot J, she did state that, in view of previous jurisprudence, ‘it could not be argued that a competent adult is not free to decline medical treatment’; *Fitzpatrick v FK* [2009] 2 IR 7, 14; *Re K* (HC, 22 September 2006).

³⁴ Lacey Stutz, ‘Myth of Protection: Florida Courts Permitting Involuntary Medical Treatment of Pregnant Women’ (2013) 67 U Miami L Rev 1039, 1045. See also the judgment in *Re Dubreil* 629 So 2d 819 (Fla 1993).

³⁵ For cogently made arguments against the idea that a mother who fails to act to benefit her child must be able to provide sufficient countervailing reasons to justify her decision or face moral criticism, see Fiona Woollard, ‘Motherhood and Mistakes about Defeasible Duties to Benefit’ (2018) 97 PPR 126.

Accordingly, the analysis focuses on moral issues specific to pregnancy, with inclusions of and some expansion past discussions of the four principles.³⁶

Before progressing to the discussion of duties in respect of the foetus, it is useful to briefly outline its moral status as understood by this research. Extensive literature exists on foetal moral status, however, it is beyond the scope of this research to engage in any more than a cursory fashion with this debate.³⁷ Rather, this research largely looks at the matter of intervention in pregnancy from the perspective of the patient, as it did with informed consent and end-of-life decisions. This enables an enquiry into the sometimes strong moral duties that may be held by the woman in respect of the foetus – neither body part nor separate – and advocates the position, once again, that discussion of pitting maternal and foetal *rights* against one another is both unhelpful and inaccurate.³⁸ It is felt that the ‘gradualist approach’ to the foetus most reflects its true nature. This approach identifies that neither the idea that a right³⁹ to life exists immediately from conception, nor the idea that a nearly born foetus has no right to life, are satisfactory; in other words, that it is difficult to accept that a foetus has no rights at one moment, but suddenly gains them at another.⁴⁰ As John Harris put it:

What do people think has happened in the passage down the birth canal to make it okay to kill the foetus at one end of the birth canal but not the other.⁴¹

Though a little blunt, he has captured some of what is wrong with the idea that a foetus acquires claims or rights solely upon birth. It is an equally unsatisfactory view for the foetus to have full ‘rights’ from conception:

We are asked to notice that the development of a human being from conception through birth into childhood is continuous; then it is said that (...) to choose a point in this development and say ‘before this point the thing is not a person, after this point it is a person’ is to make an arbitrary choice, a choice for which in the nature of things no good reason can be given. It is concluded that the fetus is, or anyway that we had better say it is, a person from the moment of conception. But this conclusion does not follow

³⁶ Respect for autonomy, beneficence, non-maleficence and justice.

³⁷ For various accounts of the moral status of the foetus, see Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 27-57.

³⁸ See for example, Judith Jarvis Thomson on the casual use of the word ‘rights’ in this manner: Judith Jarvis Thomson, ‘A Defense of Abortion’ in D Kelly Weisberg (ed) *Applications Of Feminist Legal Theory* (Temple University Press 1996) 971. First published, Judith Jarvis Thomson, ‘A Defense of Abortion’ (1971) 1 Phil & Pub Aff 47.

³⁹ Rights in this sense do not refer to legal rights, rather they refer to ‘claim-rights’ that is that another person has a corresponding duty. The right to life in this sense refers to the duty – positive or negative – held by another to let the foetus live. Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 43.

⁴⁰ *ibid.*

⁴¹ Margot Brazier and John Harris, ‘Fetal Infants’: At the Edge of Life’ in Pamela R Ferguson and Graeme T Laurie (eds) *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean* (2015 Ashgate) 55 discussing an interview that he undertook with Sarah-Kate Templeton in the Sunday Times in 2006.

(...) A newly fertilized ovum, a newly implanted clump of cells, is no more a person than an acorn is an oak tree.⁴²

Instead, the gradualist approach recognises that as the foetus develops, the reasons against destroying it gain strength. If there are persuasive countervailing reasons for not recognising the claims of the foetus, then they may be disregarded. Thus, the woman may be 'justified in refusing medical treatment where she has a serious reason proportionate to the fetus' stage of development'.⁴³ Accordingly, the morality of the decision in question – abortion, refusal of treatment, drug use – is not dependent on foetal 'rights', rather the potential personhood of the foetus, or respect for the value of foetal life, acts as a reason against destroying it, or a responsibility not to.⁴⁴ Therefore, a stronger reason or justification on the part of the woman for the harmful choice is required.⁴⁵

It is also argued that the gradualist approach most accurately reflects the foetus within the maternal-foetal relationship as something 'on a distinctively finite journey of development within the womb which comes ever closer to its end as it nears parturition (...) anything but a static being'.⁴⁶ In that way:

[T]he strength of the fetus's (...) interests, at least so far as they are in conflict with its mother's, are always tempered to some degree by its location inside her body, given that through its medical needs it is likely to call upon her interests in bodily integrity or self-determination or both.⁴⁷

The Pregnant Woman's Duty

The provision of unwanted medical treatment to any patient is a violation of her interest in bodily integrity, or self-determination, or both. The severity or nature of this infringement may vary with the type of intervention and with the nature of her beliefs or reasons, if any, that precipitate the refusal. As outlined in Chapter 1, bodily integrity can be understood as the ability to decide what happens to and with one's body, thus a violation of bodily integrity is an interference with this ability. Self-determination, by contrast, extends past the body to personal choices and the process by which one shapes her life. When the 'duty' to the foetus is discussed in jurisprudence, it is rarely in the context of it being a legally enforceable duty.⁴⁸ Indeed, as

⁴² Judith Jarvis Thomson, 'A Defense of Abortion' in D Kelly Weisberg (ed) *Applications Of Feminist Legal Theory* (Temple University Press 1996) 971.

⁴³ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 52.

⁴⁴ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 44, 52.

⁴⁵ *ibid* 44.

⁴⁶ *ibid* 45.

⁴⁷ *ibid* 59.

⁴⁸ See the references to the moral duty of the woman in *St. George's Healthcare NHS Trust v S, R v Collins and ors, ex parte S* [1999] Fam 26, 47 ('*St. George's Healthcare NHS Trust v S*'); '[W]hile pregnancy increases the personal responsibilities of a woman it does not diminish her entitlement to decide whether or not to undergo medical treatment (...) Her right is not reduced or diminished merely because her decision

Heather Draper argues, ‘it is one thing to show what a woman ought do in relation to her unborn child and quite another to say that this obligation ought to be enforced’.⁴⁹ The duties of the pregnant woman in respect of the foetus have been described in a variety of ways; some accounts view the duty to be of a special nature, generated by the pregnancy itself. For example, it has been opined that the woman may owe a duty to the foetus in view of her choice to continue the pregnancy.⁵⁰ Thus, by opting not to terminate pregnancy, she has accepted a ‘special set of responsibilities’ to the foetus that go hand in hand with that choice.⁵¹ Or as Eike-Henner Kluge has argued:

[B]y voluntarily allowing the fetus to become a person (...) the mother has *de facto* accepted the conditions accompanying that action – (...) since she was aware of the dependent nature of fetuses (...) (or ought to have been thus aware) she has, through her action, voluntarily accepted the responsibilities attendant on the fact of such dependence and thereby has *de facto* subordinated her right to otherwise unhindered autonomy to the right to life of the fetus and to the conditions that follow from it.⁵²

Though this research would not accept the categorisation of the foetus as ‘a person’ for a variety of other reasons, the general thrust of the argument is worth stating: through her choice to be pregnant, the woman has knowingly accepted the responsibilities that accompany that choice, one of which is that her interests and rights may need to submit to the interests of the foetus. This argument will be challenged in subsequent paragraphs, as it is not accepted that the woman always has a duty to give primacy to the interests of the foetus. Equally, it is not necessarily accepted that she may never have such a duty.

The duty of the woman to the foetus may not be exclusive to pregnancy, but instead may be a version of the general duty to rescue; namely, the moral duty on an individual to prevent serious harm to another, if there is minimal cost to herself in doing so.⁵³ Whether medical or surgical intervention could be considered a ‘minimal cost’ is certainly a matter to be debated. In any event, as Scott argues: although rescue attempts regularly involve a degree of physical exertion

to exercise it may appear morally repugnant’. In the section entitled ‘The Law: Compelled Treatment in Pregnancy’, legal enforcement of the ethical duty the foetus will be considered in more detail.

⁴⁹ Heather Draper, ‘Women, Forced Caesareans and Antenatal Responsibilities’ (1996) 22 J Med Ethics 327, 331.

⁵⁰ *ibid* 328; naturally, this argument rests on the availability of legal termination, in other words the continuation of the pregnancy being a choice and not unavoidable. It is worth bearing in mind that her argument focuses on both whether a woman ought to consent to a Caesarean section and whether she ought to be compelled to do so. While she finds that there may be a duty in respect of the former, she finds the latter to be unjust.

⁵¹ Rosamund Scott, ‘The Pregnant Woman and the Good Samaritan: Can a Woman Have a Duty to Undergo a Caesarean Section?’ (2000) 20 Oxford J Legal Stud 407, 413: ‘[W]here pregnancy is the result of a voluntary act undertaken in full knowledge of the possible consequences then, having been partly responsible for bringing this dependent fetus into existence, a woman has “a special kind of responsibility for it, a responsibility that gives it rights against her which are not possessed by any independent person (...)”’. It is worth bearing in mind that this quote is commentary on Judith Jarvis Thomson’s analysis of abortion, but is taken to highlight the line of thinking.

⁵² Eike-Henner Kluge, ‘When Caesarian Section Operations Imposed by a Court Are Justified’ (1988) 14 J Med Ethics 206, 209-10.

⁵³ For example, Peter Singer’s hypothetical of a child drowning in a pond and the obligation on the passer-by to assist that child, even if it means some inconvenience for the rescuer. He uses this to argue that affluent people have an obligation to assist poorer people around the globe but it could be formulated to apply to a pregnant woman and foetus. Peter Singer, *Famine, Affluence and Morality* (OUP 2016) 6 (first published as ‘Famine, Affluence and Morality’ (1972) 1 Phil & Pub Aff 229).

or risk, they do not ‘seriously invade the body in the special sense of a duty that is (...) to be realised through the body’.⁵⁴ Thus, while the theory of the pregnant woman having the role of general rescuer has some appeal, it does not really reflect the reality of the situation.

Some argue that the responsibility to have particular medical treatment, such as a Caesarean section, for the benefit of the foetus may arise from it being the ‘minimally decent’ thing to do:⁵⁵

Whilst the cost to a woman of saving a life by having a caesarean section is not insignificant, it is not sufficiently high to justify a refusal of consent because the gain to the fetus – the saving of his life – is so great.⁵⁶

Or to combine this proposition and Kluge’s view; by virtue of her choice to continue the pregnancy and as Caesarean sections are not an exceptional or even uncommon method of giving birth, the woman is aware that her role in bringing her child into the world may extend to this procedure. It is not as if there are a multitude of ways in which birth can occur, not currently at any rate; rather, there are two.⁵⁷ Two points arise in relation to this; first, it is obvious that the ‘cost’ of undergoing a Caesarean section is not the same for every woman, just as the ‘cost’ of undergoing a particular medical procedure is not universal for every non-pregnant person. If it were, we would all choose the same options in the same circumstances and have the same reactions following the same events. Therefore, in-keeping with the gradualist account of the foetus, the reason why the woman wishes to refuse is relevant to the morality of the decision. Second, such a contention rests on the Caesarean section being medically necessary, whether by virtue of the risk to the woman or the foetus or both.⁵⁸

On the first point, where a decision to refuse is for religious reasons, it may be argued by some, particularly those who do not subscribe to a religious faith, that a belief of this nature ‘cannot be so important that it would justify or excuse the fetus’s death (...)’.⁵⁹ It may be questioned

⁵⁴ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 103: she contends this as a response to John Finnis’ categorisation of continuing a pregnancy as part of the ‘ordinary neighbourly’ duties of a woman.

⁵⁵ This is adapted from Judith Jarvis Thomson’s ‘Minimally Decent Samaritanism’ argument in relation to abortion: ‘There may well be cases in which carrying the child to term requires only Minimally Decent Samaritanism of the mother, and this is a standard we must not fall below’. Judith Jarvis Thomson, ‘A Defense of Abortion’ in D Kelly Weisberg *Applications Of Feminist Legal Theory* (Temple University Press 1996) 983.

⁵⁶ Heather Draper, ‘Women, Forced Caesareans and Antenatal Responsibilities’ (1996) 22 J Med Ethics 327, 328. She does subsequently go on to exempt two groups of women from this obligation: ‘[T]hose who have either not willingly become pregnant or who have not willingly continued with their pregnancy; and those who have willingly continued their pregnancy, but have done so only to preserve the life of a baby which they have no intention of parenting’ [330].

⁵⁷ For these purposes, assisted vaginal births are considered the same as unassisted. Contrast with later in Draper’s argument later in the same paper: ‘If pregnant women are unsure about which therapies it is unacceptable to refuse on religious grounds, we should not be surprised. But if such confusion exists, we cannot also argue that women who continue with their pregnancies understand what they are letting themselves in for by so doing’ [ibid, 332]. Contrast also Rosamund Scott’s discussion of the social context of pregnancy and the difference between risks being inherent in pregnancy and being part of a woman’s duty. Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 96-103.

⁵⁸ Heather Draper also makes this point herself; Heather Draper, ‘Women, Forced Caesareans and Antenatal Responsibilities’ (1996) 22 J Med Ethics 327, 331.

⁵⁹ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 67.

why a woman should have “the right to sacrifice” the fetus in the interests of her religious faith’.⁶⁰ The practice of religion is, however, an exercise in self-determination; it is one of the many processes by which an individual shapes her existence. Self-determination has been clearly identified as valuable and an interest therein has been identified as worthy of protection. Religion often focuses on consequences and the idea that if one behaves the ‘right’ way throughout her lifetime, then she will enjoy the rewards of afterlife. As Scott argues:

[W]here a pregnant woman for whom religious faith has a valid purpose wishes to refuse caesarean delivery with the likely consequence that the fetus will die (...) her religious faith is clearly a fundamental, indeed central, aspect of her life and its meaning. So, by recognising the important *role* religion plays in her deliberations about how to live, we can accord significant weight to the question of religion in moral argument.⁶¹

Thus, even with similar physical outcomes, the ‘cost’ to a Christian Scientist of submitting to a Caesarean section can hardly be considered the *same* as a person of a different or no religious faith, even if that person has a strong non-religious reason for refusing. Though she may have strong justification for refusing, the non-religious person will not fear that her opportunity at an afterlife has disintegrated nor fear negation of all of her prior ‘good deeds’, whatever logic one may see as lacking in that fear.

Not only can compelled medical treatment in pregnancy be viewed as compromising the autonomy, bodily integrity and interests that a woman has in self-determination, it has also been viewed by the courts as an affront to her dignity.⁶² During the course of the legal analysis, it will become apparent that dignity is referred to in case law and its protection has been considered to come within the remit of the court.⁶³ For example, the performance of a Caesarean section despite competent refusal was viewed to be a violation of the dignity of the woman.⁶⁴ Arguably, the concept of dignity being protected in such situations is dignity in the empowerment or aspirational sense. Given that it was a competent refusal, one could argue that dignity as a basis for the recognition of a right, in other words the right to refuse unwanted medical treatment, is being protected. The dignity being protected could also be interpreted as aspirational in that it enables the woman to live in accordance with her own standards. It may be remembered, however, that in her discussion of *Compartment Dignity*, Doris Schroeder specifically referred to behaviour that adhered to social norms and expectations and not one’s

⁶⁰ *ibid.*

⁶¹ *ibid* 70.

⁶² See for example, *HSE v B* [2017] 1 ILRM 54, 61.

⁶³ See *PP v Health Service Executive* [2015] 1 ILRM 324; *HSE v B* [2017] 1 ILRM 54.

⁶⁴ *HSE v B* [2017] 1 ILRM 54.

one norms and expectations. With that in mind, such refusal could be seen as going against norms and expectations and therefore, as failing to uphold dignity. Indeed, as has already been argued in this research, there are expectations amongst much of society that pregnant women will make sacrifices for their future children and that harming or failing to prevent the foetus from being harmed is morally impermissible conduct.

On the second point raised, namely medical necessity, a specific point somewhat outside of moral theory needs to be made: there is some evidence to suggest that Caesarean sections are being performed despite not being medically necessary. The WHO states ‘the ideal rate for caesarean sections to be between 10% and 15%’ and furthermore, that there is evidence to suggest that rates of over 20% do not improve perinatal or neonatal outcomes.⁶⁵ Yet, the jurisdictions that will be discussed in the context of this research have a higher rate than both the WHO optimal rate and the upper level of demonstrable benefit. It is estimated that 13% of Caesarean sections performed in the United States are not medically necessary.⁶⁶ In Ireland, the figures for Caesarean section births reported by the Health Service Executive are similarly high – 32.1% and 33.8% in 2017 and 2018 respectively – thereby indicating that in excess of 12% may not have been medically necessary.⁶⁷ The situation is similar in England, Caesarean sections accounted for 28% of the total births in 2017-18.⁶⁸ It is absolutely the case that the performance of a Caesarean section is the medically necessary and appropriate method of delivery in certain circumstances – hence the optimal percentage of between 10% and 15% set by the international medical community – however, the potential for in excess of 10% of Caesarean sections to be performed unnecessarily presents considerable ethical issues.⁶⁹

First, it is questionable if the women undergoing Caesarean sections are aware that the surgery may not be medically necessary but may instead be desirable. If not, a legitimate question as to whether the consent was informed arises. In Chapter 3, the essential criteria for informed consent were discussed; informed consent must be given freely by someone with the requisite

⁶⁵ See Ties Boerma and others, ‘Global epidemiology of use of and disparities in caesarean sections’ (2018) 392 *The Lancet* 1341. See also World Health Organization, *Statement on Caesarean Section Rates* (2015) <https://apps.who.int/iris/bitstream/handle/10665/161442/WHO_RHR_15.02_eng.pdf;jsessionid=25C9CB8E680887F5C8D83BBF2CB52221?sequence=1> accessed 12 February 2020. It is worth bearing in mind that some authors disagree that consensus has been reached regarding the optimum level of Caesarean sections; Ana Pilar Betrán and others, ‘Interventions to Reduce Unnecessary Caesarean Sections in Healthy Women and Babies’ (2018) 392 *The Lancet* 1358.

⁶⁶ Thaddeus Mason Pope, ‘Legal Briefing: Unwanted Caesareans and Obstetric Violence’ (2017) 28 *The Journal of Clinical Ethics* 163. This is based on Caesarean sections amounting to approximately 32% of births in the United States and the level of demonstrable benefit, per the WHO, sitting at 20%.

⁶⁷ Health Service Executive, *Irish Maternity Indicator System National Report 2018* (2019) <<https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/national-reports-on-womens-health/imis-national-report-2018.pdf>> accessed 12 February 2020.

⁶⁸ National Health Service, *NHS Maternity Statistics, England 2017-18* (2018) <<https://files.digital.nhs.uk/C3/47466E/hosp-epis-stat-mat-summary-report%202017-18.pdf>> accessed 12 February 2020.

⁶⁹ The following paragraphs are not intended to relate to elective Caesarean sections at the request of the woman. In such cases, the woman is aware that the Caesarean is not necessarily required on medical grounds but is requesting its performance for other reasons.

capacity to do so, after attaining the necessary information. If the woman is under the mistaken impression that the Caesarean section is medically necessary then her consent may not be valid, primarily because she may not receive information about the risks associated with Caesarean sections, or alternatives. There may also be questions as to her ability to weigh the information as part of the decision-making process given her mistaken belief that the procedure is medically necessary. The relationship between informed consent and autonomy, which was also discussed in Chapter 3, therefore arises in this context; it is legitimate to question if the autonomy of the woman is being respected if she is being misinformed about the intervention.

The Role of the Physician

A further question arises in the context of medically (un)necessary Caesarean sections, that is whether the obstetrician has breached his ethical duties of beneficence and non-maleficence, first, in terms of his reasons for recommending a Caesarean section in the circumstances. There is a considerable body of research in the area of what has been termed ‘defensive Caesarean sections’, in other words, performance in order to minimise the risk of litigation against the physician.⁷⁰ It is questionable, to put it mildly, if such conduct fulfils the duties of beneficence and non-maleficence if the intention is to protect the physician from liability and not to confer the most benefit on his patient. Though these two things are certainly not mutually exclusive, the maximisation of the welfare of the patient must take primacy if the doctor is to fulfil his ethical obligations. Furthermore, as outlined above, the autonomy of the woman is unlikely to receive the respect it deserves with such a practice. The possibility that some physicians are utilising Caesarean sections ‘for convenience’ or in order to allow ‘for private work to be reconciled with public duties’ has also been suggested.⁷¹ It goes without saying that such motivation is contrary to the ethical obligations of the physician.

Second, it is accepted that Caesarean sections can lead to an increased risk of complications, both post-birth and in future births. There is a higher rate of maternal morbidity associated with Caesarean section than vaginal birth and they carry an increased risk of ectopic pregnancy, stillbirth, and preterm births.⁷² They typically carry a longer or more difficult recovery than

⁷⁰ Dale A Tussing and Martha Wojtowycz, ‘Malpractice, Defensive Medicine, and Obstetric Behavior’ (1997) 35 *Med Care* 172; Ana Pilar Betrán and others, ‘Interventions to Reduce Unnecessary Caesarean Sections in Healthy Women and Babies’ (2018) 392 *The Lancet* 1358; Cringu Antoniu Ionescu and others, ‘Defensive Caesarean Section: A Reality and a Recommended Health Care Improvement for Romanian Obstetrics’ (2019) 25 *J Eval Clin Pract* 111. Ana Pilar Betrán *et al* in particular note that ‘practitioners are more likely to be sued for complications during vaginal delivery than for unnecessary CS, even if there is no evidence of error’; accordingly, they may push for a Caesarean section ‘for professional protection, rather than to benefit the mother and the baby’ [1360].

⁷¹ Ana Pilar Betrán and others, ‘Interventions to Reduce Unnecessary Caesarean Sections in Healthy Women and Babies’ (2018) 392 *The Lancet* 1358, 1360. The authors cite a number of sources in support of this contention; sources are from Chile, Brazil, Hungary, Cambodia and Tanzania.

⁷² Jane Sandall and others, ‘Short-term and Long-term Effects of Caesarean Section on the Health of Women and Children’ (2018) 392 *The Lancet* 1349.

vaginal birth, or both. Thus, the woman who undergoes an unnecessary Caesarean section may be exposed to these negative consequences unnecessarily and unjustifiably. Given that the duty to prevent avoidable harm is subsumed within the duty of beneficence, a physician who recommends a Caesarean section should only do so where he is satisfied that it is medically indicated.⁷³

Furthermore, there is a tendency to conflate a ‘good outcome’ with the physician fulfilling his duties of beneficence and non-maleficence, however, this idea that the survival of woman and child equates to a ‘good outcome’ is highly problematic and goes against what has been argued previously in relation to beneficence.⁷⁴ Halliday argues:

It may well be that both [the woman] and her baby can be reported to be doing well after the intervention, but that does not negate the harm she suffered at the hands of the state. By treating her in a way that a non-pregnant person would not be treated, the woman is reduced to a uterine environment, a patient who must follow medical advice.⁷⁵

It may be recalled that it was argued that ‘doing good’ for patients extends beyond preserving their physical health, instead it relates to maximising their overall welfare. This kind of ‘good outcome’ conclusion likely fails to accord sufficient importance to the effect that a traumatic birth can have on the physical and mental health of a woman⁷⁶ and fails to appreciate the link between Post Traumatic Stress Disorder and a traumatic birth experience.⁷⁷ Furthermore, as was argued more generally in relation to non-consensual medical treatment, not only does such conduct breach trust within the individual patient-physician relationship, but potentially damages the reputation of that physician, that hospital or birth centre and the medical

⁷³ This comment is not intended to apply to a Caesarean section that is not medically indicated but is carried out at the request and preference of the woman.

⁷⁴ This has been recognised by the English courts in *Re MB (Medical Treatment)* [1997] 2 FLR 426, 438:

A feature of some of the cases to which we have referred [in the context of compelled intervention] has been the favourable reaction of the patient who refused treatment to the subsequent medical intervention and the successful outcome. Having noted that, we are none the less sure that however desirable it may be for the mother to be delivered of a live and healthy baby, on this aspect of the appeal it is not a strictly relevant consideration (...) The mother may indeed later regret the outcome [if treatment is not compelled], but the alternative would be an unwarranted invasion of the right of the woman to make the decision.

⁷⁵ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 213.

⁷⁶ Rakime Elmir and others, ‘Women’s Perceptions and Experiences of a Traumatic Birth: A Meta-ethnography’ (2010) 66 *J Adv Nurs* 2142, 2143: ‘A traumatic birth experience (...) is associated with negative outcomes, such psychological distress and ongoing physical pain (...) There is increasing recognition that, for some women, traumatic birth can lead to post-traumatic stress disorder (...) Women experiencing PTSD related to childbirth report that they feared for their lives or the lives of their babies, or that they would experience physical damage during the birth’. See also Hans Skari and others, ‘Comparative Levels of Psychological Distress, Stress Symptoms, Depression and Anxiety after Childbirth — A Prospective Population-based Study of Mothers and Fathers’ (2002) 109 *BJOG* 1154, 1159-60: ‘Women who had a previous history of a subjective a traumatic birth were at significantly increased risk of developing clinically important psychological distress (...) The consequences of negative birth experiences have been further investigated in a recent Swedish study, which showed that a negative birth experience is related to a reduced probability of having a subsequent child’.

⁷⁷ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 92. See also Debra K Creedy and others, ‘Childbirth and the Development of Acute Trauma Symptoms: Incidence and Contributing Factors’ (2000) 27 *Birth* 104; Jo Czarnocka and Pauline Slade, ‘Prevalence and Predictors of Posttraumatic Stress Symptoms following Childbirth’ (2000) 39 *Br J Clin Psychol* 35. More generally, for the link between ‘medical trauma’ and mental and physical health with some coverage of obstetric trauma, see Michelle Flaum Hall and Scott E Hall, *Managing the Psychological Impact of Medical Trauma: A Guide for Mental Health and Health Care Professionals* (Springer 2017).

profession as a whole in the eyes of some pregnant women. After all, if they seek prenatal care and a hospital birth, they may be forced to undergo unwanted treatment. An argument put forward by Draper, albeit in relation to reluctant consent, ties the ‘good outcome’ and medical necessity points together:

If a woman does reluctantly consent to a caesarean section, there is no way of discovering whether it was actually necessary. Who, in any case, is likely to complain or be taken seriously if the baby is born safe and well?⁷⁸

Indeed, should the woman not just be content with her healthy baby? Surely the coerced or questionable consent to a procedure that may or may not have been necessary should have now disappeared from her mind because the child has been born. This research would argue not.

It is unsurprising that if one views the obstetrician as having two patients and not one, as Scott argues is not uncommon amongst obstetricians, then fulfilling the duty of beneficence is complex.⁷⁹

In obstetrics the problem of caring for two patients, mother and baby, creates the concern that to do what the mother desires might harm her baby, and to do what a doctor considered to be in the best interests of the baby might harm the mother.⁸⁰

The primary purpose of adopting the ‘Not-One-But-Two’ framework was to appreciate the difficulty encountered, not just by courts, but by physicians who experience the challenge of treatment refusal in pregnancy. In proposing what is essentially this model, the ACOG states:

This ethical approach recognizes that the obstetrician–gynecologist’s primary duty is to the pregnant woman. This duty most often also benefits the fetus. However, circumstances may arise during pregnancy in which the interests of the pregnant woman and those of the fetus diverge. These circumstances demonstrate the primacy of the obstetrician–gynecologist’s duties to the pregnant woman.⁸¹

The College goes on to opine that the *obligation* of beneficence is owed by the physician to the woman, whereas the physician should be thought of as having ‘beneficence-based *motivations* toward the fetus’.⁸²

Perhaps then Ranaan Gillon best summarises the duty of the medical professional:

The central moral objective of medicine (...) is to produce net medical benefit for the patient with as little harm as possible. Today we may add to that Hippocratic objective the moral qualifications that we should pursue it in a way

⁷⁸ See Heather Draper, ‘Women, Forced Caesareans and Antenatal Responsibilities’ (1996) 22 J Med Ethics 327; Kristina Stern, ‘Court-Ordered Caesarian Sections: In Whose Interests?’ (1993) 56 MLR 238, 332.

⁷⁹ Rosamund Scott, *Rights, Duties and the Body: Law and Ethics of Maternal-Fetal Conflict* (Hart Publishing 2002) 26.

⁸⁰ Vivienne Harpwood, *Legal Issues in Obstetrics* (Dartmouth 1996) 16.

⁸¹ ACOG Committee on Ethics, *Refusal of Medically Recommended Treatment During Pregnancy* (Number 664, 2016) 3.

⁸² *ibid* (emphasis added).

that respects people's deliberated choices for themselves and that is just or fair to others (whether in the context of distribution of scarce resources, respect for people's rights, or respect for morally acceptable laws).⁸³

It is argued that anything short of that represents a failure by the physician to discharge his ethical duties.

The Law: Compelled Treatment in Pregnancy

While discussing the ethical issues that arise when a pregnant woman wishes to refuse medical treatment, the idea of the woman owing an ethical duty to her foetus in various contexts was considered. As was outlined, however, this ethical duty does not necessarily translate to a legal one. While a woman may have a moral duty to refrain from engaging in risky behaviour, there is scant law under which to prosecute her, provided such behaviour is not unlawful in and of itself.⁸⁴ Even where that conduct is unlawful, the legal precedent for prosecuting the woman where there is a negative outcome for the foetus is uncertain.⁸⁵ In New York, where the pregnant woman has acted unlawfully, the law has been interpreted as holding her criminally responsible for conduct that is undertaken with the intention of harming the foetus.⁸⁶ The Court of Appeal has been quite clear that any broader interpretation was outside of its purview:

The imposition of criminal liability [for such acts] (...) should be clearly defined by the legislature, not the courts. It should also not be left to the whim of the prosecutor. Conceivably, one could find it 'reckless' for a pregnant woman to disregard her obstetrician's specific orders concerning bed rest; take prescription and/or illicit drugs; shovel a walkway; engage in a contact sport; carry groceries; or disregard dietary restrictions. Such conduct, if it resulted in premature birth and subsequent death of the child, could result in criminal liability for the mother. At present, such conduct (...) would not result in criminal prosecution of the mother if the fetus died in utero.⁸⁷

Legal enforceability of the moral duty owed by a pregnant woman to her foetus is most commonly seen in two ways; first, unsurprisingly in the enforced medical treatment of the woman in the interests of the foetus. As will become apparent, '[d]espite common law and (...) constitutional law principles recognizing and protecting the right to refuse medical treatment,

⁸³ Ranaan Gillon, 'Patients in The Persistent Vegetative State: A Response to Dr. Andrews' (1993) 306 BMJ 1602.

⁸⁴ This does not preclude the possibility that certain prosecutors in the United States may attempt to bring charges for child endangerment or abuse for engaging in such activities, as will be evident from the wide interpretation of these statutes in situations of maternal drug use.

⁸⁵ For example, although subsequently dropped, a District Attorney in Alabama filed manslaughter charges against a woman who was shot in the stomach during an altercation. The shooting led to the death of the foetus, however, she was charged with manslaughter (and not the shooter) because she had initiated the fight. See Farah Stockman, 'Manslaughter Charge Dropped Against Alabama Woman Who Was Shot While Pregnant' *The New York Times* (New York, 3 July 2019) <<https://www.nytimes.com/2019/07/03/us/charges-dropped-alabama-woman-pregnant.html>> accessed 23 July 2020.

⁸⁶ *People v Jorgensen* 26 NY 3d 85 (2015): Ms Jorgensen was initially convicted of the manslaughter of her daughter, who was born alive following a car accident involving Ms Jorgensen and another vehicle. At the time of the accident, Ms Jorgensen had been driving over the speed limit, without a seatbelt and while under the influence of prescription drugs and alcohol. It was noted that the prosecution accepted that had Ms Jorgensen's child died in utero, as opposed to 6 days after birth, she would not have been prosecuted [91].

⁸⁷ *ibid* 92.

pregnancy is often viewed as a special case by courts'.⁸⁸ The second manifestation is seen most commonly in so-called 'cocaine mom' laws; in other words, when the use of drugs or alcohol during pregnancy can result in the compulsory administration of treatment (civil confinement) or the woman being taken into custody.⁸⁹ While there are no US states that specifically criminalise drug use in pregnancy,⁹⁰ there have been several instances where pregnant women have been prosecuted using a generous interpretation of existing statutes such as child abuse,⁹¹ child endangerment⁹² and naturally, drug offences. In South Carolina, for example, pregnant women admitted to the Medical University of South Carolina who met one of nine criteria – which included abruptio placentae and quite routine occurrences such as late or incomplete prenatal care – were tested for cocaine use. Upon a positive test, the hospital contacted the Charleston Police Department exposing the women to being charged with drug possession, drug possession and distribution to a person under 18 (the foetus) or unlawful neglect of a child, once born.⁹³ Such laws have been described as setting 'the outer limits of what the community regards as morally tolerable'.⁹⁴ These laws are also, quite evidently, an example of the state exercising its interest in protecting the foetus, with questionable legitimacy.⁹⁵ While drug-use may pose a risk in pregnancy, so too do other factors such as poor nutrition and exposure to environmental toxins;⁹⁶ if it is a legitimate use of state power to pursue pregnant women for drug use during pregnancy, then ought it not also be a corresponding responsibility of the state

⁸⁸ Margo Kaplan, "'A Special Class of Persons': Pregnant Women's Right to Refuse Medical Treatment After *Gonzales v Carhart*' (2010) 13 U Pa J Const L 145, 162.

⁸⁹ For example, Wisconsin law through WI Stat § 48.193 (2019) states that an order can be made to take a pregnant woman into custody: [U]pon a showing satisfactory to the judge that due to the adult expectant mother's habitual lack of self-control in the use of alcohol beverages, controlled substances or controlled substance analogs, exhibited to a severe degree, there is a substantial risk that the physical health of the unborn child, and of the child when born, will be seriously affected or endangered unless the adult expectant mother is taken into custody and that the adult expectant mother is refusing or has refused to accept any alcohol or other drug abuse services offered to her or is not making or has not made a good faith effort to participate in any alcohol or other drug abuse services offered to her.

⁹⁰ Tennessee introduced a law in 2014, which criminalised drug-use in pregnancy if the woman experienced a bad pregnancy outcome, for example, if the baby is born addicted or is harmed in some way or dies because of the drug use. This law lapsed in 2016, as according to the ACLU and others, it appeared to deter women from seeking prenatal care and impeded their access to medical treatment <https://www.aclu-tn.org/wp-content/uploads/2016/09/Fetal-Assault-Direct-Impact.pdf>.

⁹¹ *Johnson v Florida* 602 So 2d 1288 (Fla 1992): After Jennifer Johnson's two children were born testing positive for illegal drugs, she was convicted using child abuse statutes in Florida. Her conviction was overturned by the Florida Supreme Court, which concluded that the legislative history of the child abuse statutes made it clear 'that the Legislature considered and rejected a specific statutory provision authorizing criminal penalties against mothers for delivering drug-affected children who received transfer of an illegal drug derivative metabolized by the mother's body, in utero' [1294].

⁹² For example, Alabama's Chemical Endangerment laws were introduced to protect children, whose parents were making methamphetamines, from exposure to the drug (AL Code § 26-15-3.2 (2019)). Depending on the outcome for the child, it ranges from a Class C to a Class A felony. Nowhere in the text is there a reference to fetuses, however, that law has been used to prosecute women whose babies are born with illegal drugs in their system. The Supreme Court of Alabama has upheld such convictions; see *Ankrom v Alabama* 152 So 3d 373 (Ala 2013) and *Hicks v Alabama* 153 So 3d 53 (Ala 2014). The interpretation of the Chemical Endangerment laws in this fashion were considered by the Alabama Supreme Court to further 'Alabama's policy of protecting life from the earliest stages of development' (*Hicks*).

⁹³ *Ferguson v City of Charleston* 532 US 67 (2001); the Supreme Court of the United States subsequently ruled that the non-consensual nature of the drug testing was unconstitutional, as it violated the 4th Amendment.

⁹⁴ Sue Mahan, *Crack Cocaine, Crime and Women: Legal, Social, and Treatment Issues* (Sage Publications 1996) 48; it should be noted that Mahan is not supportive of these laws, this is merely the description she uses. See also Chapter 2, where the argument that the function of the law is to uphold 'the ethical minimum' was introduced.

⁹⁵ This is an argument advanced in a number of cases where a court order authorising the treatment of the competent pregnant woman is being sought. Many of these cases will be discussed in more detail later in this chapter.

⁹⁶ Barbara M Newman and Philip R Newman, *Development Through Life: A Psychosocial Approach* (10th edn, Wadsworth 2009) 116-7.

to ensure that poverty does not deny pregnant women adequate nutrition and a safe environment?⁹⁷

Ireland: Advance Directives in Pregnancy

The core question in this research is whether the likely effect of Irish law is that an otherwise valid advance directive will be overridden if the decision-maker is pregnant when the directive should have effect. Plainly, the second question is if pregnancy does nullify or invalidate an advance directive, ought this to be the case from a legal and ethical standpoint? These questions arise as a result of the specific provisions within the Assisted Decision-Making Capacity Act 2015 pertaining to advance decisions and pregnancy. Operating prior to the repeal of the 8th Amendment, the legislature inserted specific exceptions for pregnant directive holders to the general rules on the validity of advance directives.⁹⁸ Section 85(6)(a) of the ACM(C)A 2015 makes it possible to override the otherwise valid advance directive of a pregnant woman if the failure to treat would have a ‘deleterious effect on the unborn’, provided she has not specified that the directive should apply in pregnancy.⁹⁹ Bearing in mind the former role of Article 40.3.3 as a ‘protector of the unborn’ and not merely as a ‘preventer of abortion’, one could see the logic behind section 85(6)(a) and the attempt to strike a fair balance between protecting the bodily integrity of the pregnant woman and her autonomy and the right to life of the unborn. Leaving aside the ethical issues with such an approach,¹⁰⁰ even with the repeal of the 8th Amendment, one could see how it may be reasonable to have a rebuttable presumption that treatment should be administered where an advance directive does not specify that the refusal should apply in pregnancy. Pregnancy can be an entirely unforeseen situation for a variety of reasons, such as a mistaken diagnosis of infertility or a failed sterilisation attempt.¹⁰¹ Because of this unforeseen change in circumstances, her attitude towards that particular treatment may also have changed, even if only for the duration of her pregnancy. Furthermore, the refusal of

⁹⁷ To continue this line of questioning would be beyond the scope of this research, however, it is viewed by the author as an important point to raise, albeit briefly. See Heather Draper, ‘Women, Forced Caesareans and Antenatal Responsibilities’ (1996) 22 J Med Ethics 327; Kristina Stern, ‘Court-Ordered Caesarian Sections: In Whose Interests?’ (1993) 56 MLR 238, 331: ‘The threat which women pose to fetuses by refusing to have caesarean sections is dwarfed by the threat which social inequalities and environmental factors such as pollution pose. If a fetus does have a right to be protected from harm, then this should extend to all harm and not just that posed by his mother’.

⁹⁸ As outlined in the introduction, the 8th Amendment was the insertion of Article 40.3.3 into the Irish Constitution. This article enshrined the right to life of the unborn in Bunreacht na hÉireann.

⁹⁹ Assisted Decision-Making (Capacity) Act 2015, s 85(6)(a).

¹⁰⁰ From an ethical perspective, however, there is an argument that any exception for pregnant women epitomises an attitude in healthcare that the decisions of women cannot be completely trusted; Rebecca Cook and Bernard Dickens, for example, have made similar arguments regarding mandatory waiting periods or ‘reflection delay laws’ attached to the termination of pregnancy. Such laws, they have often argued presuppose that women have not already given thought to their decision and paint them as impulsive or capricious. Amongst others, see Bernard M Dickens, ‘The Right to Conscience’ in Rebecca J Cook and others (eds) *Abortion Law in Transnational Perspective* (University of Pennsylvania Press, 2014) 222; Rebecca J Cook and Bernard M Dickens, ‘Human Rights Dynamics of Abortion Law Reform’ (2003) 25 Hum Rts Q 1, 49. See also Mary Donnelly, ‘Developing a Legal Framework for Advance Healthcare Planning: Comparing England & Wales and Ireland’ (2017) 24 EJHL 67, 76; she argues that such measures ‘second-guesses the decisions of women of child-bearing age, and accords too little respect to their moral agency’.

¹⁰¹ The rate of failure of female sterilisation is generally considered to be one pregnancy in every 200 women per year.

treatment may depend on the stage of gestation and the likelihood of her child surviving. Even if it were possible for these factors to be accurately documented in an advance directive, they will not be if a pregnancy is completely unexpected. Furthermore, if an individual has gone to the trouble of drafting a valid advance directive and is steadfast in her opposition to particular treatment, pregnant or not, then one could question why she would not state that it should apply in all circumstances ‘including pregnancy’?

Either way, it can be argued that a significant amount of the legal rationale for the exceptional treatment of pregnant women is no longer that law in Ireland. Yet, there appears to have been no move made to remove this section from the Act, not so far at any rate. Thus, on the one hand Article 40.3.3 of the Constitution now states that provision may be made for the termination of pregnancy and the National Consent Policy states that the consent of the pregnant woman ‘is required for all health and social care interventions in pregnancy’ in accordance with the rules that apply to non-pregnant people.¹⁰² On the other hand, the right to life of the unborn was not protected exclusively by the 8th Amendment prior to repeal. Rather, as Hamilton P stated in *AG (SPUC) v Open Door Counselling*, Irish law recognises the right to life of the unborn through ‘common law; by statute law; as one of the unenumerated personal rights which the State guaranteed by its laws to respect, and, as far as practicable, to defend and vindicate’.¹⁰³ Indeed, as Andrea Mulligan argues, ‘[t]he original right to life of the unborn, if it existed, was an unenumerated right’.¹⁰⁴ Therefore, it bears a certain similarity in origin to other unenumerated rights, which still exist under the Irish Constitution such as bodily integrity and the right to work. As Mairead Enright and others argued prior to its repeal, it is conceivable that the right to life of the unborn, albeit a weaker right than that guaranteed by Article 40.3.3, may still exist.¹⁰⁵

It is the position of this research that the Act becomes highly problematic at section 85(6)(b), which provides that an advance directive with the stated intention to apply in pregnancy should be referred to the High Court for adjudication. The only criterion for referral is that the healthcare professional considers the failure to treat harmful to the unborn.¹⁰⁶ Furthermore, the legislation specifies that the matter ‘shall’ be referred to the High Court, thereby seeming to prevent the medical professional from exercising his own judgment on the matter and obliging

¹⁰² National Consent Advisory Group of the Health Service Executive ‘National Consent Policy’ (2019) <<https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf>> accessed on 6 August 2020, s 7.10.

¹⁰³ *Attorney General (SPUC) v Open Door Counselling Limited and the Wellwoman Centre Ltd* [1988] 1 IR 593, 597.

¹⁰⁴ Andrea Mulligan, ‘Maternal Brain Death and Legal Protection of the Foetus in Ireland Case Review’ (2015) 15 *Med L Int* 182, 185.

¹⁰⁵ Mairead Enright and others, ‘Abortion Law Reform in Ireland: A Model for Change’ (2015) 5 *Feminists@Law* 12.

¹⁰⁶ Assisted Decision-Making (Capacity) Act 2015, s 85(6)(b).

him not to honour the refusal. When making a determination on the matter, the High Court must consider the impact of failing to treat on the unborn and ‘the invasiveness and duration of the treatment and the risk of harm to the directive-maker’, should the advance directive be overridden.¹⁰⁷ Essentially, the Court appears to be required to enter into a kind of balancing exercise; the interests of the pregnant woman and the interests of the foetus. Accordingly, the effect of advance directive on the foetus may be grounds for the High Court to overturn it. From a legal perspective, the subsection is particularly problematic for three reasons; first, much, if not all, of the constitutional basis for such a power is no longer the law, as was discussed above. Consequently, the basis for the continued existence of this section is questionable, to say the least. Furthermore, a concern of considerable magnitude in relation to the 8th Amendment pertained to its pervasiveness in issues separate to abortion. This presence will be abundantly clear when the relevant Irish jurisprudence is discussed in the next section. Despite being repealed, advance directives appear to be one area of Irish law in which the spectre of the 8th Amendment is still present. With that said, it is necessary to reflect on the wording of Article 40.3.3, which is that ‘[p]rovision may be made by law for the regulation of termination of pregnancy’. Plainly, it does not read that the unborn *must not* be protected by law or constitute a consideration in legislation pertaining to other areas of healthcare. This, combined with the 12-week time limit applicable to most terminations in Ireland¹⁰⁸ could suggest that an advance directive may be invalidated in pregnancy; if not in all cases, then particularly in more advanced pregnancies. As will be demonstrated, however, Ireland is not alone in providing for different rules for advance directives during pregnancy despite a questionable basis for doing so.

Second, there appears to be scant guidance or precedent as to how this balancing of the predicted impact on the unborn with the invasiveness and predicted risk of the treatment to the woman should be done. All relevant jurisprudence is pre-repeal, thus the constitutional right to life of the unborn is the main focus. One could imagine that likely factual scenarios for referrals under the Act would be blood transfusions, life-sustaining treatment and Caesarean sections; judgments pertaining to the latter two interventions were handed down in 2014 and 2016 respectively, though not in relation to advance directives.¹⁰⁹

¹⁰⁷ Assisted Decision-Making (Capacity) Act 2015, s 85(6)(c).

¹⁰⁸ This research does not utilise the terminology ‘social’ abortion. The 12-week time limit applies to an abortion, unless it is necessary to protect the health or life of the woman or if there is a diagnosis of fatal foetal abnormality; Health (Regulation of Termination of Pregnancy) Act 2018, ss 9-12.

¹⁰⁹ There have also been instances where the High Court has ordered a Caesarean section to be performed on a patient who lacked capacity, for example; Mary Carolan, ‘Mentally Ill Woman Can be Given Caesarean, Court Rules’ *Irish Times* (Dublin, 13 March 2017) <<https://www.irishtimes.com/news/crime-and-law/courts/high-court/mentally-ill-woman-can-be-given-caesarean-court-rules-1.3008603>>

Third, Deirdre Madden argues:

[I]t might be the case that if the refusal by a pregnant woman is contemporaneous rather than contained in an advance directive, the spirit of s 85(6)(b) would be considered to be an appropriate mechanism by which to deal with the maternal-foetal conflict issue.¹¹⁰

In other words, despite the position of the National Consent Policy on treatment in pregnancy, the pregnancy exception contained in the Act may have wider ramifications than the legislature intended. Now, this research turns to examining the jurisprudence on compelled obstetric interventions in Ireland to theorise how this *balancing of interests* may play out in future cases.

Ireland: Medical Treatment in Pregnancy

Natasha Perie was 15 weeks pregnant when she died on December 3rd 2014, having sustained a head injury some days previously.¹¹¹ Prior to establishing that Ms Perie had suffered brain stem death, she was put on a life support system. During the period between December 8th and 17th, she received somatic care, in that her body was being maintained with the aid of multiple interventions and medications.¹¹² It was the stated intention of the hospital to continue treatment for the duration of the pregnancy. There is consensus within the international medical community as to when somatic support in pregnancy should be continued, however, as Mulligan notes, these are very limited circumstances that were absent in the case of Ms Perie.¹¹³ After a tracheostomy was performed on December 17th, Ms Perie's father applied to the High Court for an order to cease all further treatment. It was the view of the Court that Article 40.3.3 was engaged as it was viewed to extend beyond the sphere of abortion.¹¹⁴ The Court, however, was satisfied in the circumstances of the case – namely the unanimous agreement of all of the medical experts that the foetus had no prospect of survival – that cessation of treatment was appropriate.

What is noteworthy about the judgment and completely at odds with other cases involving the withdrawal of treatment was that Ms Perie's best interests were not discussed. Although Kearns P refers to dignity and autonomy in the course of his judgment, his ruling appears to be based solely on the prospect of survival of the unborn:

accessed 17 October 2019. Such cases, however, do not involve a balancing of competing interests or rights, as the treatment is considered to be in the best interests of both the woman and foetus.

¹¹⁰ Deirdre Madden, *Medicine, Ethics and the Law* (3rd edn, Bloomsbury 2016) 489.

¹¹¹ *PP v Health Service Executive* [2015] 1 ILRM 324.

¹¹² Interventions included ventilation, a nasogastric tube and daily physiotherapy. The medications were to prevent pneumonia, infection, fluid build-up and high blood pressure, amongst others.

¹¹³ Andrea Mulligan notes that generally these circumstances are 'where [somatic support] is in accordance with the wishes of the family and where the deceased woman was not known to object'; Andrea Mulligan, 'Maternal Brain Death and Legal Protection of the Foetus in Ireland Case Review' (2015) 15 *Med L Int* 1182, 183.

¹¹⁴ [2015] 1 ILRM 324, 337-339.

This does not mean that the court discounts or disregards the mother's right to retain in death her dignity with proper respect for her autonomy (...) Such an approach has been the hallmark of civilised societies from the dawn of time. It is a deeply ingrained part of our humanity and may be seen as necessary both for those who have died and also for the sake of those who remain living and who must go on. The court therefore is unimpressed with any suggestion that considerations of the dignity of the mother are not engaged once she has passed away.

However, when the mother who dies is bearing an unborn child at the time of her death, the rights of that child, who is living, and whose interests are not necessarily inimical to those just expressed, must prevail over the feelings of grief and respect for a mother who is no longer living.¹¹⁵

As Mulligan opines: 'it seems that because NP was dead, and because the rights of the foetus were not necessarily inimical to those of NP, no such balance [of rights] was necessary'.¹¹⁶ In this regard, the judgment presents a very confusing picture; on the one hand, the learned judge talks of rights or interests in respect of dignity and autonomy, but does not mention best interests. On the other hand, there is no further discussion of how these rights or interests are to be protected or vindicated or why they should give way to those of the foetus. The issue, it is contended, is that either Ms Perie had no rights or interests because she was already dead, or she had rights and interests that ought to have been balanced against those of the foetus to arrive at the decision.

Furthermore, the accuracy of the description of foetus' rights as 'not necessarily inimical' is worth questioning. Given that it was accepted by the court that Ms Perie had a right to retain her dignity with proper respect for her autonomy, then surely the interests of the foetus could be considered inimical to these. Merely stating that the rights of the foetus *must* prevail over respect for the mother without analysis of why this ought to be the case or without identifying the conflict being resolved seems to leave a chasm where analysis should be. Fiona de Londras argues 'what mattered in coming to the conclusion that the care could be withdrawn in PP was the Court's determination of what was in the best interests of the fetus in order to achieve its live birth'.¹¹⁷ Arguably, there is something at odds about a case failing to really focus on the person to whom the treatment was being administered; it was as though Ms Perie was virtually irrelevant to the situation. One could certainly argue that the best interests of Ms Perie should

¹¹⁵ *ibid* 339.

¹¹⁶ Andrea Mulligan, 'Maternal Brain Death and Legal Protection of the Foetus in Ireland Case Review' (2015) 15 *Med L Int'l* 182, 191.

¹¹⁷ Fiona de Londras, 'Constitutionalizing Fetal Rights: A Salutory Tale from Ireland' (2015) 22 *Mich J Gender & L* 243, 270.

have formed an integral part of the decision and that consequently the matter ought to have been assessed in line with previous case law.¹¹⁸

Mulligan, however, opines:

Because NP was deceased and the ‘treatment’ of the foetus was futile, the Court approached the decision as a withdrawal of treatment case. The test established in the withdrawal of treatment cases is based on best interests. The decision does not involve a balancing of the rights of the woman and the rights of the foetus as would apply in the usual circumstances of pregnancy.¹¹⁹

Arguably, however, this contention does not explain why the best interests of the foetus were the only consideration. This failure to discuss Ms Perie’s best interests is also particularly strange given the cases cited in the judgment, all of which focused on the best interests of the individual when deciding if withdrawal of treatment was appropriate.¹²⁰ For example, the learned judge quotes a passage from the English judgment in *Re A (A Minor)*;¹²¹

It would be wholly contrary to the interests of A., as they may now be, for his body to be subjected to the continuing indignity to which it was currently subject. Moreover it would be quite unfair to the nursing and medical staff of the hospital, who are finding it increasingly distressing to be caring for a dead child.¹²²

In this decision, Johnson J considers the interests of the child to be the paramount concern, clearly expressing that to continue life-sustaining treatment would be to subject him to ‘continuing indignity’.¹²³ Yet in applying this judgment, Kearns P states:

At present the artificial measures which maintain the bodily functions of the mother in this case also maintain the unborn child. However, the question which must be addressed is whether even if such measures are continued there is a realistic prospect that the child will be born alive.¹²⁴

Perhaps this failure to consider what was in the best interests of Ms Perie partly stems from the position adopted by her counsel. He argued that the court ‘should infer what NP’s wishes were in relation to this pregnancy and strive to have the unborn delivered as a testament to her and as a sibling to her other children’.¹²⁵ Critically, he acknowledged that ‘she had an interest in dying with dignity and minimal suffering’, however because of ‘what had occurred, a death without indignity was not possible and thus greater weight should be given to the continuance

¹¹⁸ *Re a Ward of Court (Withholding medical treatment) (No. 2)* [1996] 2 IR 79.

¹¹⁹ Andrea Mulligan, ‘Maternal Brain Death and Legal Protection of the Foetus in Ireland Case Review’ (2015) 15 *Med L Int* 182, 191-2.

¹²⁰ In the course of his judgment, Kearns P referred to *Re SR (A Ward of Court)* [2012] 1 IR 305, *Airedale NHS Trust v Bland* [1993] A.C. 789; [1993] 2 WLR 316; [1993] 1 All ER 821 and *Re a Ward of Court* [1996] 2 IR 79.

¹²¹ [1993] 1 *Med L Rev* 98.

¹²² *ibid.*

¹²³ It is worth noting that Johnson J did not order the ventilator be removed; instead, the court made a declaration that it was not contrary to the law for the consultant(s) to disconnect the ventilator, if they considered to appropriate. This was because A was already deceased, thereby meaning the court could neither exercise inherent jurisdiction over him nor make him a ward of court.

¹²⁴ *PP v Health Service Executive* [2015] 1 *ILRM* 324, 340.

¹²⁵ *ibid* 337

of the pregnancy than striving to achieve the lost opportunity of a dignified death'.¹²⁶ One must question why counsel for Ms Perie, as distinct from counsel for the foetus, would opine that the chance for a dignified death was lost but would then go on to propose continuing the treatment acknowledged to be the cause of the indignity. One could certainly contend that although the past indignity may have been unavoidable,¹²⁷ that gives scant reason to prolong and indeed intensify the indignity into the future. Furthermore, the position adopted by her counsel is at odds with the position of her family, in other words, those who knew her best while she was alive, which also raises questions.

In the aftermath of *PP*, it seemed entirely plausible to suggest that women could be compelled to undergo treatment against their wishes in order to protect the right to life of the foetus. As de Londras argued, the combination of Article 40.3.3 – the right to life of the foetus takes precedence over a woman's health, autonomy, and bodily integrity – and the judgment in *PP* that a foetus also has a 'best interest' in being born alive 'may pervade medical decision-making throughout a pregnancy'.¹²⁸ Accordingly, it was possible that *PP* had opened the door to the best interests of the unborn in being born alive demanding that the woman be treated to vindicate that right. This contention, however, is not without its opponents.¹²⁹

With that in mind, the decision in *HSE v B* some two years later may be a little surprising.¹³⁰ Twomey J considered an application to compel a pregnant woman to undergo an 'elective' Caesarean section.¹³¹ Ms B was pregnant with her fourth child and sought a vaginal delivery (VBAC), despite having delivered her other children via Caesarean. She was advised of the considerably elevated risks associated with VBAC – uterine rupture, death and increased risk of harm to the foetus – given her circumstances. Fully aware, Ms B still wished to proceed with a VBAC on the understanding that an emergency Caesarean section would likely be needed after VBAC had been attempted. She expressed willingness to consent to the emergency Caesarean section when the need arose, however, Ms B's obstetrician was unwilling to facilitate a VBAC and the consensus appeared to be that no other hospital in Ireland was

¹²⁶ *ibid.*

¹²⁷ By unavoidable, it is meant that the event had already occurred, not that her injury and subsequent death were not preventable. The HSE has accepted liability for her death, which was caused by failure to diagnose the cyst.

¹²⁸ Fiona de Londras, 'Constitutionalizing Fetal Rights: A Salutory Tale from Ireland' (2015) 22 *Mich J Gender & L* 243, 271; using, amongst others, the example of the management of pregnancies with fatal foetal abnormalities, she argues that there is a 'practice of fetocentric medical' in Ireland, something which she argued *PP* would crystallize in a legal form. Her article, however, was published prior to Ireland's only decision on compelling a Caesarean in 2016.

¹²⁹ In relation to points similar to this, Andrea Mulligan argues that they may 'overstate the likely impact of *PP*' and while '[t]he court certainly subordinated the interests of NP to those of the foetus (...) one must acknowledge the context in which it did so'. Andrea Mulligan, 'Maternal Brain Death and Legal Protection of the Foetus in Ireland Case Review' (2015) 15 *Med L Int'l* 182, 191.

¹³⁰ [2017] 1 *ILRM* 54.

¹³¹ *ibid.*

available or willing to facilitate her labour either. This view of vaginal birth as a kind of ‘procedure of choice’ is hugely problematic and must be addressed, albeit it more briefly than would be liked. Irrespective of the view of this obstetrician or any other towards *facilitating* Ms B’s labour, it was going to occur anyway, assuming there was no intervention to prevent it starting. This is markedly different to a consensual procedure that is *performed* on a woman at her request.

The Court was of the view that it was a step too far to order Ms B to undergo a Caesarean section in the interest of the foetus. Citing ‘the PKU case’, Twomey J stated that ‘the right of the Courts to intervene in a parent’s decision in relation to an unborn child could not be any greater than the Court’s right to intervene in relation to born children’.¹³² The learned judge then applied the test articulated in the PKU case, namely was the case at hand of a sufficiently exceptional nature so as to permit the Court to intervene on behalf of the child?¹³³ In this instance, the Court found that the case was not of an exceptional nature and the authorisation of a procedure, which if done without consent, would ordinarily be ‘a gross violation of [Ms B’s] right to bodily integrity, her right to self-determination, her right to privacy and her right to dignity’ was unjustified.¹³⁴ It was the opinion of Twomey J, that the increased risk of harm or death at which the foetus would be placed, did not warrant the Court to effectively authorise Ms B ‘to have her uterus opened against her will, something which would constitute a grievous assault’.¹³⁵

There are several points to be made in relation to this judgment. First, there is virtually no guidance on how future cases of this nature should be approached. In this instance, the legal position is simply that the increased risk of harm or death to the foetus is not so ‘exceptional’ to warrant intervention. While this may well be an unavoidable feature of the nature of the case – an *ex tempore* hearing at the time, as opposed to a subsequent review – it still leaves uncertainty as to the circumstances in which state intervention in private healthcare decisions is justified. Consequently, it leaves pregnant women in doubt as to the strength of their refusal. Second, there may be scope for the HSE to apply for permission to perform emergency Caesarean sections without the consent of the patient; *B* dealt with an elective Caesarean

¹³² *ibid* 60, citing *North Western Health Board v HW and CW* [2001] 3 IR 622. It is interesting to consider this judgment in light of the *ex tempore* judgment of Abbott J in *Re K* (HC, 22 September 2006) where the woman was compelled to undergo a blood transfusion in the interest of her newborn child, as to refuse would have deprived him of his only parent. It subsequently emerged that K’s husband was in Ireland, but she had led hospital staff to believe she was alone as he was in the country illegally. When the 2006 decision was reviewed in *Fitzpatrick v FK* [2008] IEHC 104, Laffoy J sidestepped the balancing of rights, considering it to be a moot point in light of the change to what would have been the child’s circumstances, had Ms K died.

¹³³ [2017] 1 ILRM 54, 61.

¹³⁴ *ibid*.

¹³⁵ *ibid*.

section, where the woman was willing to consent to an emergency Caesarean section if the attempted VBAC warranted intervention. Arguably, this provided a substantial safety net for the Court when vindicating her right to refuse, as the risk of death to the foetus, though not quantified in the case, does appear to have been quite low. Perhaps, this situation is likely to be viewed vastly differently to an instance of a woman refusing an emergency Caesarean section, where the risk to the life of the foetus is considerably higher. Third, the characterisation of a Caesarean section as highly invasive and an action which would amount to ‘grievous assault’ in other circumstances by Twomey J, though not inaccurate, may leave the door open for pregnant women to be compelled to undergo other less physically invasive procedures, for example blood transfusions, hormonal induction or augmentation of labour.¹³⁶

Fourth, *PP* was neither referred to, nor distinguished. This seems strange given that it was one of the most recent preceding cases to consider medical treatment in the interests of the foetus. It is interesting to note the discordance between this judgment and *PP*; this case approached the matter from the perspective of the interests and rights of the pregnant woman and parent, whereas as outlined, the earlier case almost completely ignored Ms Perie’s interests and determined that treatment ought not to be continued on the basis of its effectiveness at facilitating a live birth. While the factual scenarios in these two cases are vastly different, one cannot but be confused as to what the criteria are for assessing if the pregnant woman ought to be treated against her wishes, whether contemporaneously expressed or stated in advance. Instead of anything akin to certainty, we now have ‘two parallel lines of authority rather than a coherent body of precedent’.¹³⁷ It is unclear which risks to the foetus, and consequently which refusals, constitute an ‘exceptional’ case, thereby permitting State intervention in private medical decision-making. It is unclear which ones do not. Perhaps the key difference was that Ms B expressed her refusal, whereas Ms Perie did not. Though the law of consent does not condone a position of ‘well you didn’t say no, therefore you mean yes’, the absence of a decision on Ms Perie’s part may have provided room for the court to infer a lack of opposition to being treated.

It remains uncertain what grounds, if any, the Court will consider sufficient to overturn an otherwise valid advance directive, where the refusal of treatment will have a deleterious effect

¹³⁶ See the arguments put forward in *Re Fetus Brown* 689 NE 2d 397 (Ill 1997) seeking to distinguish Caesarean sections from blood transfusions on a similar basis.

¹³⁷ Conor O’Mahony, ‘Squaring Circles: Recent Case Law on Medical Decision-Making and the Unborn’ (*Constitution Project @ UCC*, 3 November 2016) <<http://constitutionproject.ie/?p=593>> accessed 14 May 2019.

on the foetus. Perhaps, as Mulligan argues, it will depend on whether the woman is alive or deceased at the time that the advance directive is intended to have effect:

The decision in *PP* suggests that the analysis is quite different where she is deceased. Rather than apply a balancing test, the High Court would likely follow *PP* in subordinating the interests of the deceased woman to those of the foetus. That said, it should be noted that the Court in *PP* specifically found that it was possible to prefer the interests of the foetus where those interests were 'not necessarily inimical' to the interests of NP. This could be used to support the argument that where an advance directive refuses the maintenance of somatic support, the decision in *PP* is not binding.¹³⁸

Were she alive, perhaps intervention of a similar nature with the goal of continuing her life would be seen as too great an invasion for too long a time. Perhaps not. As a result, it is argued that this ambiguity is far from ideal and urgent clarification is required in order for medical professionals to be clear on their responsibilities and women to be confident that their advance refusals will be honoured, ensuring that they have the same rights as any other person in respect of their bodies and bodily integrity by the law.

England and Wales

England and Wales has quite soundly rejected any idea that competent pregnant women do not enjoy the same right to refuse medical treatment as any other competent patient, however, it took some time for this view to be reached and the position was not always as clear as it is now. The case of *Re T* was discussed in Chapter 4 in the context of Lord Donaldson's robust vindication of the right of the competent adult to refuse treatment.¹³⁹ Speaking *obiter*, however, the learned judge identified a possible exception to that right:

An adult patient who (...) suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment (...) The only possible qualification is a case in which the choice may lead to the death of a viable foetus. That is not this case and, if and when it arises, the courts will be faced with a novel problem of considerable legal and ethical complexity.¹⁴⁰

A mere matter of months later, such a question of 'considerable legal and ethical complexity' arose; *Re S* concerned a woman refusing a Caesarean section against medical advice.¹⁴¹ Ms S, with the support of her husband, persisted with the refusal, which was motivated by her 'quite

¹³⁸ Andrea Mulligan, 'Maternal Brain Death and Legal Protection of the Foetus in Ireland Case Review' (2015) 15 *Med L Int'l* 182, 193.

¹³⁹ *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, 115: 'Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death. Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent (...)'

¹⁴⁰ *ibid* 102.

¹⁴¹ *Re S (Adult: Refusal of Treatment)* [1992] 4 All ER 671.

sincere' religious beliefs.¹⁴² The surgeon responsible for her care stated that the Caesarean section was the only means of preventing both her death and the death of the foetus. Citing the American case of Angela Carder, the learned judge ordered that the '[Caesarean] section and any necessary consequential treatment (...) in the vital interests of the patient and her unborn child' were lawful despite the patient's competent refusal.¹⁴³ His reliance on *Re AC* is questionable in view of the critical difference between the two cases; in *Re AC* it was unclear if Angela Carder had capacity to refuse treatment, as the matter was never adjudicated at trial.¹⁴⁴ It was, however, clear that an order was being sought to override a competent refusal in *Re S*.¹⁴⁵ The decision of Sir Stephen Brown P was roundly criticised from a legal and ethical standpoint in both academic literature and subsequent case law.¹⁴⁶ As Butler-Sloss LJ stated in relation to *Re S* and other cases where attempts were made to protect the rights of a foetus:

It is a decision the correctness of which we must now call in doubt. That is not to say that the ethical dilemma does not remain. None the less, as has so often been said, this is not a court of morals.¹⁴⁷

The learned judge was unequivocal in relation to the right to refuse:

A competent woman who has the capacity to decide may, for religious reasons, other reasons, for rational or irrational reasons or for no reason at all, choose not to have medical intervention, even though the consequence may be the death or serious handicap of the child she bears, or her own death. In that event the courts do not have the jurisdiction to declare medical intervention lawful and the question of her own best interests objectively considered, does not arise.¹⁴⁸

The capacity dimension of *Re MB* was discussed in Chapter 3, however, it is interesting to note the specific reference made to 'irrational reasons' in view of the facts of the case. One could certainly question what characterises a phobia, if not irrationality. As discussed, however, it did appear that MB wanted the procedure and had consented to it, she just could not consent to

¹⁴² *ibid* 672.

¹⁴³ *ibid*; *Re AC* 573 A 2d 1235 (DC 1990).

¹⁴⁴ *Re AC* 573 A 2d 1235 (DC 1990); 1247. Perhaps more critically, upon review of the case, the Court ruled that it had erred in compelling Angela Carder to undergo a Caesarean section.

¹⁴⁵ The passages referred to by Sir Stephen Brown P in his judgment could be interpreted to support an order compelling a pregnant woman to undergo treatment for the benefit of the foetus, however, it was the view of the Court of Appeal in *Re MB* [1997] 2 FLR 426, 444 that 'Sir Stephen Brown P in *Re S* (above) was invited to rely upon an incomplete reference to *Re AC* 573 A 2d 1235 (DC 1990) to support a contrary and incorrect conclusion [to the most recent trend in US appellate decisions to a move towards the approach of the English courts]'

¹⁴⁶ See Michael Thomson, 'After re S' (1994) 2 Medical Law Review 127; Heather Draper, 'Women, Forced Caesareans and Antenatal Responsibilities' (1996) 22 J Med Ethics 327; Kristina Stern 'Court-Ordered Caesarian Sections: In Whose Interests?' (1993) 56 MLR 238.

¹⁴⁷ *Re MB* [1997] 2 FLR 426, 440; the cases referenced by the court were typically partners attempting to prevent abortions in the interest of the foetus. In those cases, it was found that the foetus did not have rights in English law. See *Paton v British Pregnancy Advisory Service Trustees* [1979] QB 276.

¹⁴⁸ *Re MB* [1997] 2 FLR 426, 436-7.

the insertion of a needle or the administration of gas to facilitate its insertion.¹⁴⁹ Thus, the court viewed the irrationality of the decision as an indication of incompetence.¹⁵⁰

The learned judge was also clear on the duties of the medical professionals in respect of the pregnant woman:

If therefore the competent mother refuses to have the medical intervention, the doctors may not lawfully do more than attempt to persuade her. If that persuasion is unsuccessful, there are no further steps towards medical intervention to be taken (...) The mother may indeed later regret the outcome, but the alternative would be an unwarranted invasion of the right of the woman to make the decision (...) The only situation in which it is lawful for the doctors to intervene is if it is believed that the adult patient lacks the capacity to decide.¹⁵¹

Not only was it found that a competent pregnant woman has the right to refuse, but it was stated that the court does not have ‘the jurisdiction to take into account the interests of the unborn child at risk from the refusal of a competent mother to consent to medical intervention’ and critically that ‘the foetus up to the moment of birth does not have any separate interests capable of being taken into account’ when the court is considering compelling the performance of a procedure without consent.¹⁵² Although *Re MB* can be distinguished from *Re S* for the same reason that *Re AC* can, namely that Ms MB was found to lack capacity, the court made a clear statement as to the lack of relevance of *Re S*.

St. George’s NHS Trust v S appeared to clarify, in no uncertain terms, any outstanding uncertainty regarding the right of a competent pregnant woman to refuse medical intervention.¹⁵³ Judge LJ questioned how a forced invasion of a competent adult’s body against her will for even ‘the most laudable of motives’ be permitted without ‘irremediably damaging the principle of self-determination’.¹⁵⁴ He went on:

¹⁴⁹ This is evidenced by the facts of the case; MB consented to, the refused the Caesarean section a number of times but each time the refusal hinged on the use of a needle as part of the procedure i.e. taking bloods, administering anaesthesia.

¹⁵⁰ During the course of the judgment the learned judge expanded on the word ‘irrationality’ as follows; ‘Irrationality (...) connote[s] a decision which is so outrageous in its defiance of logic or of accepted moral standards that no sensible person (...) could have arrived at it (...) Although it might be thought that irrationality sits uneasily with competence to decide, panic, indecisiveness and irrationality in themselves do not as such amount to incompetence, but they may be symptoms or evidence of incompetence’. See also the judgment in *Re L (patient: non-consensual treatment)* [1997] 2 FLR 837 at 839 where Kirkwood J held that a needle phobia ‘amounted to an involuntary compulsion that disabled L from weighing treatment information in the balance to make a choice’ in line with the *Re C* test. He described it as ‘an affliction of a psychological nature’ held that she was ‘incapable of weighing relevant treatment information in the balance and (...) lacked the relevant mental competence to make the treatment decision’.

¹⁵¹ *Re MB* [1997] 2 FLR 426, 438.

¹⁵² *ibid* 426 and 444. Rosamund Scott is quite critical the notion that the court simply does not have jurisdiction – in other words the reliance on the foetus’ ‘lack of personhood’; Rosamund Scott, ‘The Pregnant Woman and the Good Samaritan: Can a Woman Have a Duty to Undergo a Caesarean Section?’ (2000) 20 Oxford J Legal Stud 407, 410.

¹⁵³ *St. George’s Healthcare NHS Trust v S* [1999] Fam 26; Ms S was suffering from pre-eclampsia, the recommended management of which is bedrest and induced delivery. Ms S had a preference for a natural delivery, so refused consent to intervention, including a Caesarean section. An application was made under the Mental Health Act and she briefly transferred to a mental health facility for assessment against her will, then she was transferred back to St. George’s for the performance of a court ordered Caesarean section. During her time at the mental health facility, she was received no specific treatment for mental disorder nor mental illness.

¹⁵⁴ *ibid* 47.

When human life is at stake the pressure to provide an affirmative answer authorising unwanted medical intervention is very powerful. Nevertheless, the autonomy of each individual requires continuing protection even, perhaps particularly, when the motive for interfering with it is readily understandable (...) ¹⁵⁵

In stark contrast to *Re S*, Judge LJ stated the robust right to refuse medical treatment that is enjoyed by a competent pregnant woman:

[W]hile pregnancy increases the personal responsibilities of a woman it does not diminish her entitlement to decide whether or not to undergo medical treatment. Although human, and protected by the law in a number of different ways (...) an unborn child is not a separate person from its mother. Its need for medical assistance does not prevail over her rights. She is entitled not to be forced to submit to an invasion of her body against her will, whether her own life or that of her unborn child depends on it. Her right is not reduced or diminished merely because her decision to exercise it may appear morally repugnant. The declaration in this case involved the removal of the baby from within the body of her mother under physical compulsion. Unless lawfully justified this constituted an infringement of the mother's autonomy. Of themselves the perceived needs of the foetus did not provide the necessary justification. ¹⁵⁶

Therefore, the position in England and Wales can be summarised as where the woman is competent, her decision will stand and where she is incompetent, treatment may be administered in *her* best interests, but not in the interests of the foetus. As we know from the previous chapters that best interests extend beyond mere health, the likely positive outcome for the foetus would be viewed as forming part of the best interests of the woman. ¹⁵⁷ Many of the earlier Caesarean section cases feature late-in-the-day and emergency hearings, which arguably had the effect of disadvantaging already vulnerable women. ¹⁵⁸ This aspect of compelled treatment cases was tackled by the Court of Protection and guidance has been given to NHS Trusts regarding women suffering from a psychiatric condition who lack or may lack capacity; ¹⁵⁹ this includes an obligation on the Trust to bring court applications 'at the earliest opportunity' and 'no later than 4 weeks before the expected date of delivery' except in genuine emergency situations. ¹⁶⁰

In the absence of case law or an amendment to the MCA 2005 to the contrary, the jurisprudence indicates that once an advance directive is lawfully drafted and valid and applicable at the

¹⁵⁵ *ibid.*

¹⁵⁶ *ibid* 50.

¹⁵⁷ *Royal Free NHS Foundation Trust v AB* [2014] EWCOP 50; *Re AA* [2012] EWHC 4378.

¹⁵⁸ Samantha Halliday gives an account of the timings involved in some of the earlier hearings: '[I]n *Re S* the application was made at 1.30pm, the hearing started just before 2.00pm and the declaration was granted at 2.18pm (...) In *Re L* the declaration was granted within 25 minutes of the application being made, and in *Rochdale* the declaration was granted after a two-minute hearing.' Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 55.

¹⁵⁹ *NHS Trust 1 v G: Practice Note* [2014] EWCOP 30; 142 BMLR 209, 236: 'This Guidance applies in cases where a pregnant woman who lacks, or may lack, the capacity to make decisions about her obstetric care (...) resulting from a diagnosed psychiatric illness, falls within one of the four categories of cases set out in paragraph 3 below.'

¹⁶⁰ *ibid* 238. See *University Hospitals NHS Trust v CA* [2016] EWCOP 51 para 4, where Baker J was extremely critical of the Trust for failing to start proceedings at an early stage.

relevant point in time, then it should stand irrespective of whether the woman is pregnant and irrespective of the risk posed to the foetus by the refusal. Indeed, as far back as 1993, the Law Commission was of the opinion that no ‘greater restriction should be imposed upon any anticipatory decision of a pregnant woman’.¹⁶¹ Arguably, the only potential caveat to this is contained in the Code of Practice accompanying the MCA 2005; when deciding the applicability of advance directives, ‘healthcare professionals must consider (...) whether there have been changes in the patient’s personal life (for example, the person is *pregnant*, and this was not anticipated when they made the advance decision) that might affect the validity of the advance decision’.¹⁶² It remains to be seen if this section may result in an otherwise valid advance decision being considered inapplicable.

New York

As discussed in the previous chapters, a competent adult in the United States has a constitutional right to refuse medical treatment.¹⁶³ Furthermore, there was an assertion in Chapter 3 that New York has one of the longest traditions of supporting the right of a competent adult to make decisions regarding her medical care, albeit tempered by its use of the professional standard to information disclosure. In view of that, the jurisprudence pertaining to the competent refusal of medical treatment by pregnant women may seem surprising.¹⁶⁴ Despite its size, there is a dearth of case law in the United States, certainly at state appellate level, pertaining to pregnant women seeking to refuse medical treatment. Rather, much of the case law is at county court level or equivalent, leading to significant discrepancies in how the law treats such women, even within states.¹⁶⁵ One could attribute this lack of case law in the US to a number of things; practically, it could be because of the cost of appealing a county court or mid-level appellate decision or because the women in question find it difficult to find

¹⁶¹ Law Commission, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research* (Law Com No 129, 1993) 43-4.

¹⁶² Code of Practice accompanying the Mental Capacity Act 2005 (‘Code of Practice’), para 9.43 (emphasis added).

¹⁶³ The constitutional right stems from the due process clause in the Fourteenth Amendment; see *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990); 271. Where the decision is for religious reasons, then a constitutional right to refuse may stem from the First Amendment, see *Cantwell v Connecticut* 310 US 296 (1940); 303, which held that the First Amendment, as extended to the individual States by the Fourteenth Amendment, protects the right of individuals to exercise their religious beliefs provided that such exercise does not endanger public health, welfare or morals. It has also been held that the unwritten right to privacy protects ‘the freedom of a woman to terminate pregnancy under certain conditions (...) so it encompasses the right of a patient to preserve his or her right to privacy against unwanted infringements of bodily integrity in appropriate circumstances’; *Superintendent of Belchertown State School v Saikewicz* 373 Mass 728 (1977). State interests, however, may prevail over this right.

¹⁶⁴ *Dray v Staten Island University Hospital* No. 500510/14 (Sup Ct, King’s County 2015); *Dray v Staten Island University Hospital* 160 AD 3d 614 (NY 2018).

¹⁶⁵ See for example Lacey Stutz’s analysis of how Florida law is being applied by county and intermediate appellate courts. She argues: ‘Lower courts use incorrect legal tests despite explicit precedent. Reviewing courts misapply doctrinal tests, ignore merits of individual cases, and attempt to use mootness to avoid addressing these cases.’ Lacey Stutz, ‘Myth of Protection: Florida Courts Permitting Involuntary Medical Treatment of Pregnant Women’ (2013) 67 U Miami L Rev 1039, 1041, 1049-1053.

legal representation.¹⁶⁶ If a woman has lost at county and appellate court, she may not have the resources to mount another legal challenge at state level. It could also be attributed to hospitals utilising methods other than court applications to attain the required consent to medical procedures, such as threatening women with (unrelated) criminal charges or with Child Protective Services, which could result in them losing custody of their children in addition to the foetus, once born.¹⁶⁷

In 2018, a mid-level appellate court in New York heard the case of Rinat Dray. It found in favour of a hospital, in which she had been subjected to a Caesarean section without her consent and critically, in the absence of a court order. Perhaps even more surprising was that her capacity to refuse treatment was never in doubt.¹⁶⁸ The facts of the case were as follows; Ms Dray was pregnant with her third child and wanted to attempt VBAC after two previous Caesarean sections. She had found an obstetrician willing to facilitate this, however, when she presented at the hospital in labour, this doctor was unavailable.¹⁶⁹ The doctor treating her, Dr Gorelik, advised her immediately to have a Caesarean section and when she declined, he accepted that surgery might not yet be necessary and allowed labour to continue.¹⁷⁰ After a consultation with the Head of Obstetrics – Dr Ducey – and the hospital’s General Counsel, it was decided that the hospital would not apply for a court order in view of the time that it would take to get one and that Dr Ducey would dispense with Ms Dray’s consent and perform the Caesarean section.¹⁷¹

In the Supreme Court of King’s County, Ms Dray alleged *inter alia* negligence, medical malpractice, lack of informed consent and violations of New York Public Health Law and the New York Codes, Rules and Regulations. Specifically, in relation to pregnant women and medical treatment, Jacobson J held:

New York Appellate Courts have not specifically held that medical providers can never override a pregnant woman’s refusal to proceed with a C-section. New York court’s [sic] have held that the state cannot intervene to require life saving medical care over a competent adult’s refusal of care (...) In doing so, however, the Court of Appeals noted

¹⁶⁶ Rinat Dray and Kimberly Turbin, who both took cases for ‘obstetric violence’ cited difficulty in getting legal representation. For example, Ms ‘Turbin and her supporters couldn’t find anyone to take the case. They talked to 80 different lawyers over the course of 18 months, and were repeatedly turned down’. See Rebecca Grant, ‘Ethics of the delivery room: Who’s in control when you’re giving birth?’ *The Independent* (London, 18 December 2017) <https://www.independent.co.uk/news/long_reads/childbirth-delivery-room-ethics-doctor-patient-healthcare-a8085346.html> accessed 23 January 2020. For Ms Dray, see Wendy Chavkin and Farah Diaz-Tello, ‘When Courts Fail: Physicians’ Legal and Ethical Duty to Uphold Informed Consent’ (2017) 1(2) *Col Med Rev* 6, 7.

¹⁶⁷ See Lynne Paltrow and Jeanne Flavin, ‘Arrests of and Forced Interventions on Pregnant Women in the United States, 1973-2005: Implications for Women’s Legal Status and Public Health’ (2013) 38 *J Health Pol, Pol’y & L* 299. See also the discussion of ‘cocaine mom’ laws earlier in this Chapter.

¹⁶⁸ *Dray v Staten Island University Hospital* No. 500510/14 (Sup Ct, King’s County 2015); 10. One of Ms Dray’s treating physicians noted on her chart that she had ‘decisional capacity’, however, he had ‘decided to override her refusal to have a c-section’.

¹⁶⁹ *ibid* 3.

¹⁷⁰ *ibid*.

¹⁷¹ *ibid*.

that when an ‘individual’s conduct threatens injury to others, the State’s interest is manifest and the State can generally be expected to intervene’...While a fetus is not a legally recognized person until there is a live birth (...) the State recognizes an interest in the protection of a viable fetus by retaining the crimes of abortion (...) The court thus finds that the state interest in the well being of a viable fetus is sufficient to override a mother’s object to medical treatment, at least where this is a viable full term fetus and the intervention itself presents no serious risk to the mother’s well being (...) This court thus rejects the plaintiff’s assertion that she has an absolute right to reject medical care necessary to protect her viable fetus.¹⁷²

Two matters of concern emerged from this judgment; first, the passage from Jacobson J is unambivalent regarding the right of a pregnant woman to refuse medical treatment where the foetus is ‘full term’. There is quite a stark contrast with jurisprudence from Ireland – *HSE v B* – and England and Wales – *St. George’s Healthcare v S* – where forced Caesarean sections were described in much more serious terms than procedures merely posing ‘no serious risk to the mother’s well being’.¹⁷³ On the first count, it is argued that New York has ‘gotten it wrong’. Second, in relation to the disagreement between Ms Dray’s medical expert and the hospital staff, the learned judge stated that although Dr Lyerly’s findings demonstrated factual issues as to whether the foetus was at risk, they ‘fail[ed] to show, as a matter of law, that the plaintiff was not placing the fetus at risk’ by refusing. It is difficult to see how this is anything but an onerous burden to put on the pregnant woman; the basis for the performance of the Caesarean section without consent was the risk to the foetus, this fact is in doubt owing to the evidence from the plaintiff’s medical expert, however, the court has ruled that the plaintiff must prove, as a matter of law, that she is not endangering the foetus with her conduct. Critically, if the danger to the foetus is in doubt, then the basis for dispensing with consent is also in doubt. Furthermore, it is highly unusual for the individual to have to prove the absence of a negative where there is no law requiring positive action; the onus is on the state to prove that an individual was driving dangerously, not on the individual to prove that they were not. Once again, New York has ‘gotten it wrong’.

From a technical perspective, it is understandable that Ms Dray’s case failed; all of the informed consent cause of action and much of the negligence and malpractice causes of action were grounded battery, however Ms Dray could not pursue a case for battery, as she was outside of

¹⁷² *ibid* 11-13. Arguably, the manner in which this portion of the judgment arose is unusual. Its context was the plaintiff seeking a summary judgment on the matter of the violations of Public Health Law § 2803-c and 10 NYCRR 405.7. During the course of this adjudication, Jacobson J referred to a portion of Ms Dray’s medical records in which Dr Ducey stated the risk to foetus and the lack of alternative options for a safe delivery, with which Ms Dray’s medical expert disagreed. Ms Dray argued that ‘the issue of the risk to the fetus should not matter because a pregnant woman [sic] has the right to refuse a C-section regardless of the risk faced by the fetus’.

¹⁷³ *ibid* 13; *HSE v B* [2017] 1 ILRM 54; *St. George’s Healthcare NHS Trust v S* [1999] Fam 26.

the one-year statute of limitations in New York State.¹⁷⁴ On the matter of alleged violations of patients' rights contained in Public Health Law § 2803-c and 10 NYCRR 405.7, the Appellate Court overruled the judgment in the court of first instance and found:¹⁷⁵

- (i) '[N]o private right of action arising from an alleged violation of [10 NYCRR 405.7] has been recognized'.¹⁷⁶
- (ii) Public Health Law § 2803-c was not intended to apply to hospitals.

One critical point needs to be made in relation to the *Dray* case; in *Fosmire v Nicoleau*, which will be discussed in more detail in the following paragraphs, Mollen J of the Appellate Court stated:

[G]iven the important and serious nature of the rights involved in cases such as this [ordering a blood transfusion], the court should forego taking any action on applications to administer medical treatment against the will of the patient until the patient and/or his or her legal representatives have been notified thereof and given an opportunity to be heard.¹⁷⁷

It seems counterintuitive that the courts should be obliged to meet this high standard, but not a hospital. Furthermore, it is submitted that it is contrary to the general purpose of the law that a hospital would be capable of circumventing the kind of rigour and scrutiny – and perhaps, due process – required where a patient is to be treated without consent, by simply not applying for a court order and relying on 'hospital policy'.¹⁷⁸ This failure on the part of the hospital in *Dray* was not addressed by the appellate court and excused in the first hearing, with Jacobsen J describing getting a court order as merely 'preferable'.¹⁷⁹

¹⁷⁴ The Appellate Court noted that the 'plaintiff could not avoid the running of the limitations period by attempting to couch the claim as one sounding in negligence, medical malpractice, or lack of informed consent'. *Dray v Staten Island University Hospital* 160 AD 3d 614 (NY 2018); 618.

¹⁷⁵ *ibid*; *Dray v Staten Island University Hospital*, No. 500510/14 (Sup Ct, King's County 2015); 8. Jacobson J ruled in the court of first instance that 'reflect the long held public policy of [the] state that a competent adult has the right to determine the course of his or her medical care and to refuse treatment even when the treatment may be necessary to preserve the patient's life'; while she noted that neither that section expressly 'creates a private right of action for hospital patients', she found that Ms Dray met the criteria for establishing that she may seek relief, namely (i) the plaintiff is one of a class for whose particular benefit the statute was enacted, (ii) recognition of a private right of action would promote the legislative purpose and (iii) the creation of such a right would be consistent with the legislative scheme.

¹⁷⁶ *Dray v Staten Island University Hospital* 160 AD 3d 614 (NY 2018); 620: 'Although a violation of that regulation may be cited in support of a medical malpractice cause of action based upon a violation of a standard of care, a violation of that regulation does not give rise to an independent private right of action'.

¹⁷⁷ 144 AD 2d 8 (NY 1989); 12.

¹⁷⁸ In relation to the 'due process' argument, the Court of Appeals in *Fosmire v Nicoleau* 75 NY 2d 218 (1990); 224 acknowledged that 'there may be cases in which the patient's condition is so grave that there is no opportunity for prior notice and a hearing', however given the contradictory evidence in *Dray* regarding the risk to her and the foetus, this exception may well have been absent. Also 'hearing' in this context appears to refer to a hearing with both parties present, as the original order to transfuse Ms Nicoleau was granted *ex parte*. Furthermore, the court also recognised that 'it is not always necessary for a doctor or a hospital to obtain a court order before providing treatment to a patient in an emergency', however, this statement was clarified as applying to patients 'in need of immediate medical attention' who are 'unconscious or otherwise unable to consent', in other words the so-called 'emergency doctrine'. Ms Dray's situation can be distinguished as, similar to Ms Nicoleau she clearly stated her opposition to the Caesarean and her capacity was intact.

¹⁷⁹ *Dray v Staten Island University Hospital*, No. 500510/14 (Sup Ct, King's County 2015); 13.

Pre-*Dray*, case law in New York suggested no more of an inclination to vindicate the right of pregnant women to refuse medical treatment. In a series of County Supreme Court decisions, medical treatment was ordered despite the competent refusal of the woman. In the 1985 case of *Crouse-Irving Memorial Hosp. v Paddock*, Hayes J ordered that a competent pregnant Jehovah's Witness be transfused against her wishes.¹⁸⁰ Quite controversially, the learned judge ordered the transfusion as he considered Ms Paddock to have 'put the hospital and her doctors in an untenable position' as she was willing to undergo surgery but not corrective action (a blood transfusion) should a likely complication arise.¹⁸¹ He opined that once 'a patient puts her doctor in charge of a surgical procedure, she necessarily makes him responsible for the conduct of the operation' and he extended that to stabilising her with a blood transfusion, if necessary.¹⁸² Accordingly, the autonomy and religious beliefs of the pregnant woman were 'subordinated not only to the welfare of the foetus but also to the ethical integrity of the medical profession', which was found 'to continue to justify transfusion even after the foetus had been delivered'.¹⁸³

In effect, the learned judge appeared to view that the transfusion as part of the Caesarean section, the latter could not be performed without the ability to perform the former. Two points can be made in relation to this judgment; first, a complete lack of justification was given for why the blood transfusions ordered should be administered for as long as was 'medically indicated to stabilize her condition', including in the post-operative period.¹⁸⁴ As the surgery was a Caesarean section, there would be no danger to the life or health of the foetus in the post-operative period; the only risk would be to Ms Paddock. It is difficult to see any grounds for the intervention if the baby were to be born at this point. If one looks at the wording of the judgment, it can be argued that the reasoning did not appear to actually focus on the patient, despite the inclusion of a heading entitled 'Blood Transfusions to Safeguard the Mother's Welfare'.¹⁸⁵ Instead, the primary focus of this portion of the judgment appeared to be on the position in which the medical staff were being put. Second, there is scant detail on the wellbeing of the foetus and the detriment to health, if any, that would be caused by a failure to transfuse. Instead the opening of the judgment refers to doctor having applied to the court for 'authorization to administer blood transfusions as necessary to safeguard Ms Paddock's life';¹⁸⁶

¹⁸⁰ 127 Misc 2d 101 (NY 1985).

¹⁸¹ *ibid* 103; Ms Paddock was at a higher than normal risk of complications from the Caesarean due to a series of other factors.

¹⁸² *ibid*.

¹⁸³ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 11-12.

¹⁸⁴ 127 Misc 2d 101 (NY 1985).

¹⁸⁵ *ibid* 103.

¹⁸⁶ *ibid*.

furthermore the portion of the judgment entitled ‘Blood Transfusions to Safeguard the Baby’s Life and Health’ appears to approach the decision as though Mr and Ms Paddock are refusing a blood transfusion on behalf of their (born) child.¹⁸⁷ One could argue that this judgment is of limited value for several reasons; the first is the level of the court, which heard the case. Second, as Halliday points out, the American Medical Association issued guidance in 1990 stating that judicial intervention in medical decision-making in pregnancy will almost always be inappropriate.¹⁸⁸ As such, the ethical integrity of the medical profession would be a questionable ground upon which to override the right of a competent woman to refuse treatment.

Some three months later, the Queen’s County Supreme Court ordered that a Jehovah’s Witness who was 18 weeks pregnant be transfused against her wishes.¹⁸⁹ The learned judge expressed the State’s ‘highly significant interest in protecting the life of a mid-term fetus, which outweighs the patient’s right to refuse a blood transfusion on religious grounds’.¹⁹⁰ This view on the protection that should be conferred on a ‘mid-term’ foetus can be sharply contrasted with *Klein*, which was decided by Appellate Division of the Supreme Court of the State of New York some 4 years later.¹⁹¹ Ms Klein had been involved in a car accident, which resulted in brain damage. She had been in a coma since the accident and was, at the time of the case, 17 weeks pregnant. Her husband sought to be appointed her guardian, as did a man named John Short, who was a stranger to the family. A second man, John Broderick, sought to be appointed guardian of the foetus. As was stated in the judgment, the ‘ultimate purpose of these applications is to either authorize or enjoin the termination of Ms Klein’s pregnancy’, as both Mr Short and Mr Broderick were pro-life activists.¹⁹² Justices Mollen, Mangano, Thompson, Bracken and Brown all concurred:

The State has no compelling interest in the protection of the fetus prior to viability, since the mother’s constitutional right to privacy, which includes the right to terminate her pregnancy, is paramount at that stage. Accordingly, Broderick’s application is totally without merit.¹⁹³

¹⁸⁷ *ibid*: ‘The highest court of this State has made it clear that the State has a vital interest in the welfare of children, an interest that will override even the parents’ most fervently held religious beliefs: “A parent or guardian has a right to consent to medical treatment on behalf of an infant” (Public Health Law, § 2504, subd 2). The parent, however, may not deprive a child of lifesaving treatment, however well intentioned (...)’

¹⁸⁸ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 12.

¹⁸⁹ *Re Jamaica Hospital* 128 Misc 2d 1006 (NY 1985).

¹⁹⁰ *ibid* 1008: He noted the consistency of this position with that of other States such as New Jersey (*Raleigh Fitkin-Paul Morgan Mem. Hosp. v Anderson* 42 NJ 421) and Georgia (*Jefferson v Griffin Spalding County Hospital Authority* 247 Ga 86).

¹⁹¹ *Re Klein* 145 AD 2d 145 (NY 1989).

¹⁹² *ibid*: Though they are not referred to as ‘pro-life activists’ in the judgment, they are identified as such in newspaper articles; see ‘Court Won’t Halt Abortion on N.Y. Woman in Coma’ *Los Angeles Times* (Los Angeles, 11 Feb 1989) <<https://www.latimes.com/archives/la-xpm-1989-02-11-mn-1772-story.html>> accessed 23 January 2020. See also Eric Schmitt, ‘Two Men Who Fought L.I. Abortion’ *The New York Times* <<https://www.nytimes.com/1989/02/13/nyregion/two-men-who-fought-li-abortion.html>> accessed 23 January 2020.

¹⁹³ 145 AD 2d 145 (NY 1989); 147.

It is important to note the inclusion of the phrase ‘prior to viability’ in the judgment, which may invite a logical inference to be drawn; prior to 24 weeks, intervention by the New York courts may be seen as inappropriate but from 24 weeks it may be seen as justified.¹⁹⁴ The importance placed on viability, which largely stems from the approach of the Supreme Court of the United States in *Roe v Wade*, will be discussed in more detail later in this section when compelled intervention in other states is being considered and again in the context of advance directives in pregnancy.¹⁹⁵ It is questionable whether the Court of Appeals of New York would have the same or a markedly different view on the matter; first, it is worth remembering that *Klein* was the decision of an intermediate appellate court and concerned abortion, as distinct from refusal of medical treatment. With that said, it is worth also noting the origin of the reference to viability and the connection to the interest of the state, namely the interpretation of a US Supreme Court decision.¹⁹⁶ Finally, as will be demonstrated in the coming paragraphs, there is also lack of clarity in other states, thus New York may have persuasive authority coming from both sides.

In *Fosmire v Nicoleau*, the Supreme Court of Suffolk County ordered Ms Nicoleau be transfused against her competent wishes, an order, which the Appellate Court vacated. Although *Fosmire* concerned a post-partum woman, it is relevant as one of the few appellate decisions in New York, which considers the balancing of rights question. In his judgment, Mollen J upheld the right of a competent adult to refuse medical treatment on religious grounds, which is qualified by compelling State interests, namely the preservation of life, the prevention of suicide, the protection of innocent third parties and the maintenance of the ethical integrity of the medical profession.¹⁹⁷ As *Fosmire* concerned a post-partum woman, there were no competing foetal interests to consider; instead, the argument advanced by the hospital in the Court of Appeals case was that Ms Nicoleau should be transfused in the interest of her minor child. Wachtler CJ affirmed the right of an individual to refuse medical treatment, despite having children:

[T]he patient’s right to decide the course of his or her own medical treatment was not conditioned on the patient being without minor children or dependents (...) Similarly, when the Legislature codified the common-law rule it imposed no such restriction (...) And the hospital can point to no law or regulation which requires a parent to submit to medical treatment to preserve the parent’s life for the benefit of a minor child or other

¹⁹⁴ Again, contrast with *Re Jamaica Hospital* 128 Misc 2d 1006 (NY 1985) where viability was not considered determinative.

¹⁹⁵ *Roe v Wade* 410 US 113 (1973).

¹⁹⁶ It is worth noting that this judgment was post-*Roe* but prior to *Casey*, the importance of which will be discussed later in this chapter.

¹⁹⁷ *Fosmire v Nicoleau* 144 AD 2d 8 (NY 1989); 14.

dependent. If, as the hospital urges, the State has an interest in intervening under these circumstances, it has never expressed it.¹⁹⁸

He expanded further to note that the State does not prohibit parents from engaging in dangerous activities in light of the risk to their lives and the related risk that it could leave their children without parents. Indeed, were this the case, there would have to be regulations preventing single parents and both parents in a couple from holding hazardous jobs for example police, army, fire brigade. The learned judge stated that the policy of New York ‘is to permit *all* competent adults to make their own personal health care decisions without interference from the State’;¹⁹⁹ this is certainly worth bearing in mind should a case involving a pregnant woman arise in the future.

What is key to take away from *Fosmire* is that the highest court in New York State has not yet had to adjudicate a case ‘solely by balancing the common-law right against opposing State interests’, which would likely be the case were a woman to refuse a blood transfusion or Caesarean section.²⁰⁰ Speaking *obiter*, Mollen J in the Appellate Court in *Fosmire*, opined that where a pregnant woman refuses medical treatment and risks the life of the foetus, the interest of the state in protecting the health and welfare of the child would take precedence.²⁰¹ The Court of Appeals declined to specifically address the remark, instead generally upholding the right of competent adults to refuse.

Were the justices of the Court of Appeals of the State of New York to look to other states within the US for guidance, they encounter a complete lack of coherence countrywide and even within states. The only common thread appears to be the primary arguments advanced by those seeking a court order to treat; the *state* has an interest in protecting a foetus and the foetus itself has interests or rights.²⁰² The learned justices would find some judgments of equivalent courts that compel treatment and others that uphold the right to refuse. Cases such as *Jefferson* in Georgia and *Anderson* in New Jersey mandated treatment.²⁰³ In *Jefferson*, although Hill J stated that the ‘power of a court to order a competent adult to submit to surgery is exceedingly limited’ and furthermore that ‘until this unique case arose, [he] would have thought such power to be

¹⁹⁸ *Fosmire v Nicoleau* 75 NY 2d 218 (1990); 230.

¹⁹⁹ *ibid* 231 (emphasis added).

²⁰⁰ *ibid* 232.

²⁰¹ *Fosmire v Nicoleau* 144 AD 2d 8 (NY 1989); 15.

²⁰² See for example, the argument in *Re Fetus Brown* 689 NE 2d 397 (Ill 1997) 402 versus the one in *Re Baby Boy Doe* 632 NE 2d 326 (Ill 1994).

²⁰³ *Jefferson v Griffin Spalding County Hospital Authority* 247 Ga 86 (1981); *Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson* 42 NJ 421 (1964). See also decisions of mid-level courts such as *Pemberton v Tallahassee Memorial Regional Medical Center* 66 F Supp 2d 1247 (Fla 1999) in Florida, but contrast with *Burton v Florida* 49 So 3d 263 (Fla 2010).

nonexistent’, the court weighed the right of the mother to practice her religion and to refuse surgery, against the right of the foetus to live and found the latter to be paramount.²⁰⁴ Smith J opined that although such an intrusion into the private life and medical decision-making of an individual was extraordinary, the ‘state’s compelling interest in preserving the life of this fetus is beyond dispute’.²⁰⁵ Scott argues that these cases are ‘dubious precedents’ in view of their age and the general advancements in the rights of patients in the intervening years.²⁰⁶ Furthermore, specifically in relation to *Anderson*, Halliday argues that as the case was pre-*Roe*, its reasoning is no longer sound.²⁰⁷ Be that as it may, however, they are decisions of the highest courts in those states, which have yet to be overturned, but perhaps their persuasiveness as authorities may no longer be as strong.

Conversely, cases such as *AC* in the District of Columbia Court of Appeals and *Baby Boy Doe* in the Appellate Court of Illinois – applying a ruling of the Supreme Court of Illinois – ruled against compelling pregnant women to undergo Caesarean sections.²⁰⁸ Angela Carder had terminal cancer and uncertain capacity. There was evidence that, while conscious, she had stated that she did not want a Caesarean section, however, the court granted an order permitting the hospital to perform the procedure in the interest of the foetus. The surgery was only likely to benefit the foetus and posed a danger to Ms Carder as a result of her condition. The Court of Appeal hearing the matter *en banc* found that the role of the court of first instance in such cases was to determine if a competent decision had been made, and if so, the wishes of the decision maker would ‘control in virtually all cases’.²⁰⁹ Critically, Terry J stated that the court did not exclude ‘the possibility that a conflicting state interest may be so compelling that the patient’s wishes must yield’ but anticipated such cases as ‘extremely rare and truly exceptional’.²¹⁰ He then went further to clarify that Angela Carder’s case, was not such a case.²¹¹ The learned judge also emphasised that ‘it would be an extraordinary case indeed in

²⁰⁴ 247 Ga 86 (1981); 89.

²⁰⁵ *ibid* 91.

²⁰⁶ Rosamund Scott, *Rights, Duties and the Body: Legal and Philosophical Reflections on Refusing Medical Treatment during Pregnancy* (Hart, 2002) xxviii. Furthermore, as will be discussed later, it is worth noting that New Jersey does not invalidate advance directives in pregnancy, likely lending more credence to the idea that a contemporaneous decision may be respected, as least as far as a Caesarean section is concerned.

²⁰⁷ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 10.

²⁰⁸ *Re AC* 573 A 2d 1235 (DC 1990) (*en banc*); *Re Baby Boy Doe* 632 NE 2d 326 (Ill 1994). For cases involving pregnant women and blood transfusions, see *Re Fetus Brown* 689 NE 2d 397 (Ill 1997) from Illinois and *Mercy Hospital v Jackson* 306 Md 556 (1986) from Court of Appeals of Maryland. Two points are worth bearing in mind in relation to *Jackson*, however; first, the Court declined to ‘express its views concerning the merits of a moot controversy’ and ruled that the Court of Special Appeals of Maryland should not have ruled on the matter either in view of the mootness. Second, the Court of Special Appeals judgment specifically refers to the fact that there was no risk to the foetus from Ms Jackson refusing the blood transfusion, accordingly, future cases could be distinguished on that ground; *Mercy Hospital v Jackson* 62 Md App 409 (1985).

²⁰⁹ 573 A 2d 1235 (DC 1990) 1252. Terry J went on to state that ‘in virtually all cases the decision of the patient, albeit discerned through the mechanism of substituted judgment, will control’.

²¹⁰ *ibid*.

²¹¹ *ibid*.

which a court might ever be justified in overriding the patient's wishes and authorizing a major surgical procedure such as a caesarean section' and expanded further to state that 'some may doubt that there could ever be a situation extraordinary or compelling enough to justify a massive intrusion into a person's body, such as a caesarean section, against that person's will'.²¹²

In *Baby Boy Doe*, DiVito J opens with a clear statement on the rights of the competent pregnant woman:

This case asks whether an Illinois court can balance whatever rights a fetus may have against the rights of a competent woman to refuse medical advice to obtain a cesarean section (...) Following the lead of the Illinois Supreme Court in *Stallman* (...) we hold that no such balancing should be employed, and that a woman's competent choice to refuse medical treatment as invasive as a cesarean section during pregnancy must be honored, even in circumstances where the choice may be harmful to her fetus.²¹³

Furthermore, he states:

Appreciating the fact that the circumstances in which each individual woman brings forth life are as varied as the circumstances of each woman's life, the court strongly suggested that there can be no consistent and objective legal standard by which to judge a woman's actions during pregnancy (...) a woman's right to refuse invasive medical treatment, derived from her rights to privacy, bodily integrity, and religious liberty, is not diminished during pregnancy.²¹⁴

Accordingly, the court upheld the right of the woman to refuse the intervention. It is worth bearing in mind that DiVito J did distinguish blood transfusions from Caesarean sections, describing the former as 'a relatively non-invasive and risk-free procedure' and the latter as a 'massively invasive, risky, and painful' procedure.²¹⁵ This did leave the door open to courts and hospitals treating the two interventions differently in the future, however, the matter was settled by *Fetus Brown*, wherein it was held:

[I]n this case balancing the mother's right to refuse medical treatment against the State's substantial interest in the viable fetus, we hold that the State may not override a pregnant woman's competent treatment decision, including refusal of recommended invasive medical procedures, to potentially save the life of the viable fetus.²¹⁶

The path that the highest court in New York will take when it is confronted with a pregnant woman refusing medical treatment remains uncertain. On the one hand, its highest court has stated the intent of New York law as permitting *all* competent adults to refuse treatment and

²¹² *ibid.* See the dissenting opinion of Belson J, which provides an alternative to the 'extremely rare and truly exceptional' test advocated by the majority [1254-9].

²¹³ 632 NE 2d 326 (Ill 1994).

²¹⁴ *ibid* 332.

²¹⁵ *ibid* 333.

²¹⁶ 689 NE 2d 397 (Ill 1997); 405.

made no attempt to exclude pregnant women. It also stated, however, that this right was not absolute and ‘in some circumstances may have to yield to superior interests of the State’.²¹⁷ As is evident, one of the compelling state interests which justifies state intervention in healthcare decisions, is the protection of innocent third parties. While, as Margo Kaplan argues ‘the protection of third parties has only been applied in very limited circumstances’ by the United States courts, as a viable foetus could be considered a ‘third party’, the court may conclude that intervention is justified.²¹⁸ Particularly, given that jurisprudence from outside New York is conflicting. Thus, there are two issues; first, if a foetus – either viable or pre-viability – can be considered a ‘third party’ and second if the viability of the foetus is relevant to it being considered a third party. There appears to be divergence across the United States on both points. As DiVito J stated in *Baby Boy Doe*:

[T]he third interest—the protection of third parties—is also irrelevant here. The ‘third parties’ referred to in this context are the family members, particularly the children, of the person refusing treatment.²¹⁹

This kind of distinction between children and foetuses has been seen in some cases concerning the prosecution of women for harm to the foetus through drug use or other behaviour.²²⁰ Sometimes, however, the distinction is blurred by the law as is evidenced by some mid-level appellate court decisions in New York. In *Hughson*, the court acknowledged that as a child is not legally competent to give consent to treatment, the parent must give consent on her behalf.²²¹ Weinstein J then extended that to the foetus, commenting that ‘[p]erforce, a fetus or infant *in utero* is also unable to give legal consent, much less (...) any consent at all’, therefore consent is sought from the pregnant woman on its behalf. Such reasoning may open the door for treatment to be compelled in the interest of the foetus, given that the state can override a decision of a parent to refuse medical treatment on behalf of a minor.²²² Erin Davenport, however, argues that the woman’s right to refuse stems from her right to privacy through informed consent, as well as bodily integrity; thus, it outweighs the state’s four countervailing interests, including protection of third parties – potentially the viable foetus – and negates the need for a balancing exercise.²²³ As should be evident from the cases discussed in this section,

²¹⁷ *Fosmire v Nicoleau* 75 NY 2d 218 (1990); 225.

²¹⁸ Margo Kaplan, “A Special Class of Persons”: Pregnant Women’s Right to Refuse Medical Treatment After *Gonzales v Carhart*’ (2010) 13 U Pa J Const L 145, 164.

²¹⁹ 632 NE 2d 326 (Ill 1994); 334.

²²⁰ For example, *Johnson v Florida* 602 So 2d 1288 (Fla 1992). As discussed earlier, however, some states successfully prosecute women for acts undertaken in pregnancy under statutes designed to protect children.

²²¹ *Hughson v St Francis Hospital* 92 AD 2d 131 (NY 1983); 135.

²²² *Santos v Goldstein* 16 AD 2d 755 (NY 1962).

²²³ Erin P Davenport, ‘Court Ordered Cesarean Sections: Why Courts Should Not Be Allowed to Use a Balancing Test’ (2010) 18 Duke J Gender L & Pol’y 79, 90.

however, the courts do not necessarily agree with this assertion and balancing exercises are often conducted. Furthermore, in a decision of the Family Court in *Re Unborn Child* it was held that a definitively recognised legitimate state interest is the protection of the foetus, as well as protection of the woman's health.²²⁴ Furthermore, it was held that '[s]ince the common law (...) protects the fetus from negligent acts of a third party, then surely it may be found to encompass protection of the fetus from intentional acts by its mother, which acts could cause the child to begin life in an impaired condition'.²²⁵ Freudlich J clarified that this was not a case where the constitutional right to privacy of the woman was engaged, as it concerned the use of illegal drugs;²²⁶ however, as may be recalled from Chapter 4, the refusal of medical treatment in New York is not grounded in a privacy right as far as the Court of Appeal is concerned.²²⁷ Moreover, as outlined in Chapter 3, the statutory right of a pregnant woman to consent to treatment is limited to prenatal care.²²⁸

In cases including *Klein* and the King's County judgment in *Dray*, it appears that the viability of the foetus was considered decisive in whether the state could intervene on its behalf.²²⁹ In fact, Kaplan argues that 'every post-*Roe* reported opinion compelling the medical treatment of a pregnant woman for the benefit of the fetus has relied on *Roe* in its argument that the state's interest in fetal life outweighs the mother's right to refuse treatment', even extending to situations involving pre-viability fetuses.²³⁰ The reliance on *Roe* in this context has been criticised; Davenport, for example, argues that such applications misinterpret the judgment as *Roe* 'allows states to prohibit abortions after viability, but (...) does not mention anything about compelling treatment "to promote fetal health"'.²³¹

²²⁴ 179 Misc 2d 1 (NY 1998); 7.

²²⁵ *ibid.*

²²⁶ *ibid.*

²²⁷ *Re Storar* 52 NY 2d 363 (1981); 376-7: 'Father Eichner urges that this right is also guaranteed by the Constitution, as an aspect of the right to privacy. Although several courts have so held (...) this is a disputed question (...), which the Supreme Court has repeatedly declined to consider (...) Neither do we reach that question in this case because the relief granted to the petitioner, Eichner, is adequately supported by common-law principles.' See also *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990).

²²⁸ Public Health Law § 2504 section 3.

²²⁹ See also *Pemberton v Tallahassee Memorial Regional Medical Center* 66F Supp 2d 1247 (Fla 1999); 1251: 'Whatever the scope of Ms Pemberton's personal constitutional rights in this situation, they clearly did not outweigh the interests of the State of Florida in preserving the life of the unborn child (...) This is confirmed by *Roe v. Wade* (...) There the Court recognized the state's increasing interest in preserving a fetus as it progresses toward viability'.

²³⁰ Margo Kaplan, "'A Special Class of Persons": Pregnant Women's Right to Refuse Medical Treatment After *Gonzales v Carhart*' (2010) 13 U Pa J Const L 145, 169. For a reference to *Roe* in the context of a pre-viability foetus, see *Re Jamaica Hospital* 128 Misc 2d 1006 (NY 1985); 1007-8: 'The Supreme Court has held, in the context of abortion, that the State has a significant interest in protecting the potential of human life represented by an unborn fetus, which increases throughout the course of pregnancy, becoming "compelling" when the fetus reaches viability [applying *Roe*] (...) While I recognize that the fetus in this case is not yet viable, and that the State's interest in protecting its life would be less than "compelling" in the context of the abortion cases, this is not such a case. In this case, the State has a highly significant interest in protecting the life of a mid-term fetus, which outweighs the patient's right to refuse a blood transfusion on religious grounds'.

²³¹ Erin P Davenport, 'Court Ordered Cesarean Sections: Why Courts Should Not Be Allowed to Use a Balancing Test' (2010) 18 Duke J Gender L & Pol'y 79, 89.

A further dynamic that may affect the judgment of the Court of Appeals of New York is best practice within the medical community. It is worth noting that both the American Medical Association (AMA) and the ACOG advise against physicians seeking legal remedies where a competent pregnant woman refuses intervention. The AMA Policy states:

Judicial intervention is inappropriate when a woman has made an informed refusal of a medical treatment designed to benefit her fetus. If an exceptional circumstance could be found in which a medical treatment poses an insignificant or no health risk to the woman, entails a minimal invasion of her bodily integrity, and would clearly prevent substantial and irreversible harm to her fetus, it might be appropriate for a physician to seek judicial intervention. However, the fundamental principle against compelled medical procedures should control in all cases which do not present such exceptional circumstances.²³²

Clearly, a Caesarean section would not fulfil the criteria of ‘insignificant or no health risk’ or ‘minimal invasion of her bodily integrity’. Arguably, nor would a blood transfusion. Furthermore, the burden of proof of clearly preventing substantial and irreversible harm to the foetus is very high. The ACOG Policy states:

Pregnancy is not an exception to the principle that a decisionally capable patient has the right to refuse treatment, even treatment needed to maintain life. Therefore, a decisionally capable pregnant woman’s decision to refuse recommended (...) interventions should be respected.²³³

On the matter of court ordered intervention, the ACOG is quite clear:

The College opposes the use of coerced medical interventions for pregnant women, including the use of the courts to mandate medical interventions for unwilling patients (...) [and] strongly discourages medical institutions from pursuing court-ordered interventions or taking action against obstetrician–gynecologists who refuse to perform them.²³⁴

Thus, the strong message from both the AMA and the ACOG is that in pregnancy, physicians should be guided by the general principle that competent adults have the right to refuse intervention.²³⁵ Only the AMA discusses an exception for a minor intervention that will yield significant benefit to the foetus. In any event, it remains to be seen what the Court of Appeals in New York will do when faced with a decision of this nature but can be said with conviction that the lower courts have dismally failed to protect the right of pregnant women to refuse medical treatment.

²³² American Medical Association, *Legal Interventions During Pregnancy* (Policy H-420.969, 2018) s 1.

²³³ AGOC Committee on Ethics, *Refusal of Medically Recommended Treatment During Pregnancy* (Number 664, 2016) 1-2.

²³⁴ *ibid* 2.

²³⁵ *ibid* 3; The ACOG specifically notes that ‘[p]regnancy is not an exception to the principle that a decisionally capable patient has the right to refuse treatment, even treatment needed to maintain life. Therefore, a decisionally capable pregnant woman’s decision to refuse recommended medical or surgical interventions should be respected’.

United States: Advance Directives in Pregnancy

As discussed in Chapter 5, New York statute does not provide for advance directives, rather there is a legislative preference for other mechanisms. Accordingly, there can be no statutory exclusion on the basis of pregnancy, because there is no advance directive statute. Whether a pregnancy exclusion would exist at common law is largely subsumed within the discussion of contemporaneous refusal in pregnancy. At present, there appears to be no legislative prohibition on a hospital honouring the contents of a MOLST or DNR order if the patient is pregnant, however, to consider the relationship between advance directives and pregnancy, it is beneficial to look to other states for insight into how the law manages this matter. As outlined previously, Ireland is not alone in legislating to limit the effect of an advance directive in pregnancy. In fact, the majority of US states limit or expressly nullify advance directives in pregnancy. In states such as Alabama,²³⁶ Missouri,²³⁷ Texas,²³⁸ Washington²³⁹ and Wisconsin,²⁴⁰ any advance directive refusing life-sustaining treatment is rendered invalid once the directive-maker is pregnant. Colorado invalidates the advance directives only if the foetus has reached viability.²⁴¹ States such as Arkansas²⁴² and Iowa²⁴³ permit the advance directive to be overridden if it is *possible* that the foetus could be born alive with continued administration of treatment; Delaware²⁴⁴ and Rhode Island²⁴⁵, if live birth is *probable*. No explanation of the meaning of probable is given;²⁴⁶ thus one can legitimately question if probable refers to ‘on the balance of probabilities’ or if it would require ‘clear and convincing evidence’. States such as North Dakota,²⁴⁷ Pennsylvania²⁴⁸ and South Dakota²⁴⁹ will continue treatment unless there is a reasonable degree of medical certainty that it will not result in a live birth. Interestingly, they also balance this against the health and wellbeing of the woman, in that they do not require that medical professionals persist with treatment if the required professionals conclude that prolongation of life would cause physical harm or severe pain to the woman, or prolong severe pain that could not be alleviated by medication.²⁵⁰ The slim

²³⁶ AL Code § 22-8A-4 (2018).

²³⁷ MO Rev Stat § 459.025 (2018).

²³⁸ Tex. Health & Safety Code § 166.049 and 166.098.

²³⁹ WA Rev Code § 70.122.030(1)(d) (2018).

²⁴⁰ WI Stat § 154.07(2)(2) (2018)

²⁴¹ CO Rev Stat § 15-18-104 (2018).

²⁴² AR Code § 20-17-206(c) (2018).

²⁴³ IA Code § 144A.6(2) (2018). Iowa also adds the following caveat: ‘[T]he provisions of this subsection do not impair any existing rights or responsibilities that any person may have in regard to the withholding or withdrawal of life-sustaining procedures’.

²⁴⁴ 16 DE Code § 2503(5)(j) (2018).

²⁴⁵ RI Gen L § 23-4.11-6(c) (2018).

²⁴⁶ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 34.

²⁴⁷ North Dakota Century Code 23-06.5-09(5) (2018).

²⁴⁸ 20 PA Cons Stat § 5429(a) (2018).

²⁴⁹ SD Codified L § 34-12D-10 (2018).

²⁵⁰ SD Codified L § 34-12D-10 (2018); 20 PA Cons Stat § 5429(a) (2018); North Dakota Century Code 23-06.5-09(5) (2018).

progressiveness demonstrated by at least considering the woman in all of this is somewhat tempered by the fact that the legislation only focuses on her health and not on her clearly-expressed prior wishes.²⁵¹ Several states such as California, North Carolina, Maine and the District of Columbia do not reference pregnancy in their advance directive legislation and states such as New Jersey²⁵² and Vermont²⁵³ allow the directive-maker to indicate what effect, if any, she would want the advance decision to have in pregnancy.

Minnesota approaches the matter in a similar fashion to New Jersey and Vermont, however goes further to provide that it is assumed that treatment should be continued if the patient is pregnant and there is ‘in reasonable medical judgment (...) a real possibility’ that the foetus could be born alive, subject to two exceptions:²⁵⁴ first, where the woman has indicated the effect that her pregnancy should have health care decisions made on her behalf.²⁵⁵ Second, where there is ‘clear and convincing evidence that the patient’s wishes, while competent, were to the contrary’.²⁵⁶ Thus, Minnesota law leaves room for the patient to specify how pregnancy should affect her advance directive, as New Jersey and Vermont do, but also leaves room for the advance directive to be honoured if ‘clear and convincing evidence’ can be presented that the patient would not want treatment to be continued. Arguably, if a state legislator is going to insist on addressing pregnancy in its advance directive legislation, this is one of the better ways to go about it. In summary, if one were looking for an example of consistent legal approach across the United States, it certainly would not be found in the laws relating to advance decisions and pregnancy.

At this juncture, the appropriateness of such exceptions for pregnant women must be called into question and indeed, so too, must their constitutionality. First, issues of constitutionality are raised when one considers that certain states mandate physicians to determine that a female patient of childbearing age is not pregnant before withholding or terminating life-sustaining treatment.²⁵⁷ Were this obligation to make such a determination to require the physician to administer a pregnancy test to the (presumably incompetent) woman, as some commentators contend it does,²⁵⁸ then arguably such an obligation would seem to run contrary to the right to

²⁵¹ Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 34: ‘Whilst this form of exception takes account of the woman health and life, it does so by treating her as an object of concern, rather than as an individual with critical interests that outstrip her claim to be free of pain’.

²⁵² NJ Rev Stat § 26:2H-56 (2018).

²⁵³ 18 V.S.A. § 9702(a)(8).

²⁵⁴ MN Stat § 145C.10(g) (2018)

²⁵⁵ Applying MN Stat § 145C.05(2)(a) (2018).

²⁵⁶ MN Stat § 145C.10(g) (2018).

²⁵⁷ For example, Alaska (AK Stat § 13.52.055a (2019)) and Georgia (GA Code § 31-32-9 (2018)).

²⁵⁸ Erin S DeMartino and others, ‘US State Regulation of Decisions for Pregnant Women Without Decisional Capacity’ (2019) 321 JAMA 1629, 1630.

privacy, which has been established in a variety of US Supreme Court decisions.²⁵⁹ Assuming consent to a pregnancy test is sought from another individual on behalf of the pregnant woman, then the ability of that person to refuse is virtually non-existent as the law obliges that a determination that there is no pregnancy be made.²⁶⁰

It also seems inconsistent that in many US states, incompetent pregnant women have fewer constitutional – and perhaps common law – rights than if they were competent and pregnant or competent and opt to terminate the pregnancy.²⁶¹ First, assuming that it is a legitimate aim of the law to prevent harm to a third party and to view a foetus as correctly coming within that protection (or within another basis for state protection), if legislation then invalidates all advance directives in pregnancy – irrespective of the stage of development of the foetus or its likelihood of being born alive – then such legislation will not necessarily achieve this aim. If the foetus cannot be born alive, then the question that must be asked is what, if anything, are such laws protecting? Moreover, one must question precisely what ‘harm’ is being prevented. Thus, as Halliday argues:

In seeking to protect its interest in potential life, the state fails to seek a balance between that interest and its interest in recognising and respecting the woman’s precedent autonomy.²⁶²

Second, guaranteed by the 14th amendment to the United States Constitution, an individual has constitutional rights to privacy and liberty, although qualified, which extend to the right to make medical decisions; this is in addition to a common law right to refuse, which stems from the doctrine of informed consent.²⁶³ The right to privacy has been extended to the right of a woman to choose to have an abortion.²⁶⁴ In *Roe v Wade*, the right to privacy outweighed legitimate state interest in protecting the foetus, an interest which became ‘compelling’ at viability.²⁶⁵ Accordingly, post-*Roe*, it was questionable if states that disregarded all advance

²⁵⁹ *Griswold v Connecticut* 381 US 479 (1965) (Connecticut’s prohibition against the use of contraceptives was struck down as an unconstitutional infringement of the right of marital privacy). See *Ferguson v City of Charleston* 532 US 67 (2001), which was mentioned earlier in the context of drug testing; the Supreme Court ruled the non-consensual drug testing of pregnant women was unconstitutional.

²⁶⁰ Georgia (GA Code § 31-32-9(a) (2018)): ‘Prior to effecting a withholding or withdrawal of life-sustaining procedures or the withholding or withdrawal of the provision of nourishment or hydration from a declarant pursuant to a declarant’s directions in an advance directive for health care, the attending physician: (1) Shall determine that, to the best of that attending physician’s knowledge, the declarant is not pregnant (...)’

²⁶¹ Timothy Burch makes a similar point more strongly; he argues that the current variety of statutes make it ‘unclear exactly what the rights of an incompetent pregnant woman are and whether she would be better off not having a prior directive and relying upon the common law and the Constitution to protect her right to bodily integrity and autonomy’. Timothy J Burch, ‘Incubator or Individual: The Legal and Policy Deficiencies of Pregnancy Clauses in Living Will and Advance Health Care Directive Statutes’ (1995) 54 Md L Rev 528, 537-8.

²⁶² Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 36.

²⁶³ See United States Supreme Court decisions in *Washington v Harper* 494 US 210 (1990) and *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990) for ‘liberty interests’ being found as the basis for the right to refuse medical treatment. At state level, *Re Quinlan* 70 NJ 10 (1976) and *Conservatorship of Drabick* 200 Cal App 3d 185 (1988) both considered ‘privacy’ as a basis for the right to refuse medical treatment. Cases such as *Re Storar* 52 NY 2d 363 (1981) and *Re Estate of Longeway* 133 Ill 2d 33 (1989) the court preferred to find basis for the right to refuse medical treatment solely in the common law doctrine of informed consent.

²⁶⁴ *Roe v Wade* 410 US 113 (1973).

²⁶⁵ *ibid* 163.

directives in pregnancy were not breaching the constitutional right to privacy of the individuals. Commentators such as Elizabeth Benton also argued that statutes – such as in Arkansas and Rhode Island – ‘that suspend[ed] the will if the fetus could develop to the point of live birth with continued maintenance of the woman’s body also violate[d] Roe’s viability rule because cases obviously will arise in which a nonviable fetus could develop to the point of live birth with enough time’.²⁶⁶ Whether or not one agrees that the state should have an interest in protecting foetal life after viability has been attained is somewhat irrelevant in the context of the logic of her argument.

Roe was subsequently clarified by the two further Supreme Court decisions, namely *Webster*²⁶⁷ and *Casey*.²⁶⁸ In *Webster*, the court held that state interest in protecting the foetus was broader than the judgment in *Roe* had indicated and accordingly, held that it was not confined to viability:

[W]e do not see why the State’s interest in protecting potential human life should come into existence only at the point of viability, and that there should therefore be a rigid line allowing state regulation after viability but prohibiting it before viability.²⁶⁹

In *Casey*, it was held:

Before viability, *Roe* and subsequent cases treat all governmental attempts to influence a woman’s decision on behalf of the potential life within her as unwarranted. This treatment is, in our judgment, incompatible with the recognition that there is a substantial state interest in potential life throughout pregnancy (...)

The very notion that the State has a substantial interest in potential life leads to the conclusion that not all regulations must be deemed unwarranted. Not all burdens on the right to decide whether to terminate a pregnancy will be undue. In our view, the undue burden standard is the appropriate means of reconciling the State’s interest with the woman’s constitutionally protected liberty.²⁷⁰

Thus, *Casey* can be summarised as holding that a woman has the right to obtain an abortion without state interference before viability and that the state has the right to restrict abortions after viability unless the woman’s health was in danger. Critically, for the purpose of compelled medical treatment and advance directives, that the state has legitimate interests in protecting both the life of the foetus and the health of the woman. Thus, there is certainly an argument

²⁶⁶ Elizabeth Carlin Benton, ‘The Constitutionality of Pregnancy Clauses in Living Will Statutes’ (1990) 43 Vand L Rev 1821, 1826.

²⁶⁷ 492 US 490 (1989).

²⁶⁸ 505 US 833 (1992).

²⁶⁹ 492 US 490 (1989); 519: The Court ruled that the facts of *Webster* differed from *Roe* in that the former concerned a determination by the State of Missouri that ‘viability is the point at which its interest in potential human life must be safeguarded’. *Roe* concerned a Texas statute that ‘criminalized the performance of all abortions, except when the mother’s life was at stake’ As a result, the Court ruled that *Webster* ‘affords us no occasion to revisit the holding of *Roe*, which was that the Texas statute unconstitutionally infringed the right to an abortion derived from the Due Process Clause, (...) and we leave it undisturbed. To the extent indicated in our opinion, we would modify and narrow *Roe* and succeeding cases’.

²⁷⁰ 505 US 833 (1992); 876.

that restrictions or complete nullification of advance directives in pregnancy are incompatible with the Constitution, however, attempts to attain judicial determinations of unconstitutionality in state courts have generally been frustrated.²⁷¹ Timothy Burch, referring to the *Casey* standard of ‘undue burden’ asserts:

There can be no doubt that, just as a prior directive statute with a pregnancy clause denying enforcement of a directive in the case of an incompetent woman with a pre-viable fetus is an ‘undue burden’ on her right to abortion, it is an ‘undue burden’ on her right to forego medical treatment.²⁷²

This seems intuitive; if a woman separately has the right to terminate pregnancy and the right to refuse medical treatment, then why not the right to refuse treatment, which results in ending a pregnancy? Benton, however, argues that pregnancy clauses could be upheld by the Supreme Court ‘based on broad state interests in fetal life’ in view of the judgment in *Webster* ‘abandon[ing] the trimester approach and expand[ing] the scope of the state’s interest in fetal life’.²⁷³ In her view, by permitting state intervention during the second trimester, *Webster* enabled ‘[c]ourt approval of increased state-mandated medical intervention at earlier stages during pregnancy’.²⁷⁴ Perhaps, then, what will dictate the response of the Supreme Court is whether or not withholding or withdrawing treatment is considered to fall within the same scope as abortion and private reproductive decision-making. Or as Benton argues, perhaps it will rest on how broadly the Supreme Court construes the state’s compelling interest in the life of the foetus.²⁷⁵

Conclusion

There is no doubt that pregnancy adds an additional layer of complexity – legal and ethical – to the refusal of medical treatment. What is evident from the jurisprudence is that, irrespective of the legal status of the foetus and the abortion laws in the relevant jurisdictions, judges have approached similar fact patterns in very different ways. It is submitted that if a jurisdiction has not upheld the general right of a competent pregnant woman to refuse medical treatment, then it is unlikely that an advance refusal will be upheld. It is proffered that the opposite may not be true.

²⁷¹ See *DiNino v Gorton* 684 P 2d 1297 (Wash 1984); *Gabrynowicz v Heitkamp* 904 F Supp 1061 (ND 1995); in both cases, the courts found that the actions non-judicial as neither woman was pregnant nor terminally ill at the time of the case.

²⁷² Timothy J Burch, ‘Incubator or Individual: The Legal and Policy Deficiencies of Pregnancy Clauses in Living Will and Advance Health Care Directive Statutes’ (1995) 54 Md L Rev 528, 546.

²⁷³ Elizabeth Carlin Benton, ‘The Constitutionality of Pregnancy Clauses in Living Will Statutes’ (1990) 43 Vand L Rev 1821, 1829.

²⁷⁴ *ibid.*

²⁷⁵ *ibid.*

The challenge with Ireland and New York is that it is unclear how the relevant courts regard the right of a pregnant woman to refuse treatment. As discussed, two parallel lines of Irish authority exist without interaction within the High Court. Accordingly, the situation of the pregnant holder of an advance directive in Ireland is unclear. The legislation mandates that the High Court take into account the interests of the foetus, presumably to enter into some kind of balancing exercise – the rights and interests of the woman versus the rights and interests of the foetus – but without any guidance on how the issue should be resolved and with questionable precedent to guide. Despite the repeal of the 8th amendment, this provision remains in the legislation raising significant questions as to how it will operate, once commenced. This research must be clear: this situation is both inexcusably flawed and untenable. It leaves the courts to decide matters on the basis of precedent, which interprets a now-repealed constitutional amendment. Given that there are over 6000 Jehovah's Witnesses in Ireland, one could suggest that it is only a matter of time before a case involving a pregnant member of the faith arises. This research argues that what the law ought to do is ensure that the valid advance directive of a pregnant woman is not overturned on the basis of its effect on the foetus unless there is clear evidence that the woman did not want the decision to apply in pregnancy – perhaps through omitting pregnancy or specifying that pregnancy is an exception – or that she would not have wanted it to, had she considered the refusal in light of pregnancy. Anything less than that accords too little respect to the autonomy of the woman, her will and preferences and her valid interests in self-determination and bodily integrity.

In New York, it is questionable whether an advance refusal expressed on behalf of or by the pregnant woman would be sufficient to prevent her from being treated against her wishes. As is argued in relation to Ireland, this position is patently defective and needs to be addressed so that women, physicians and service providers are clear as to the law. The combination of the jurisprudence across the United States, the legal lacuna in New York where living wills are concerned and the fact that other states restrict the healthcare decisions of pregnant women suggests that a refusal could be overridden in the interest of the viable foetus. With that said, jurisprudence from other states such as Illinois²⁷⁶ demonstrate a different approach, as does the legislation from states such as New Jersey and Vermont; perhaps an interesting choice for New Jersey, if one considers it in light of the *Anderson* case, which was also discussed earlier.²⁷⁷ As articulated, the law in Minnesota goes further to consider if, in the absence of a reference to

²⁷⁶ *Re Baby Boy Doe* 632 NE 2d 326 (Ill 1994).

²⁷⁷ NJ Rev Stat § 26:2H-56 (2018). Compare with the judgment in *Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson* 42 NJ 421 (1964).

pregnancy in the advance directive, there is clear and convincing proof that the individual would want the treatment withheld or discontinued. Where the case concerns a foetus prior to viability, as was the situation in *Klein*, the approach that would likely be taken by the Court of Appeal is still unclear;²⁷⁸ arguably, the grounds for state intervention would be considerably weaker where the foetus is pre-viability given the judgment in *Roe*, however, the effect that the subsequent Supreme Court judgments in *Webster* and *Casey* would have is still a matter of opinion.

In stark contrast to the preceding paragraphs, when one considers the relevant jurisprudence from England and Wales pertaining to pregnant women, there appears to be little indication that an otherwise valid advance directive could be disregarded in the interests of the foetus.²⁷⁹ Arguably, in fact, having a validly executed advance directive in pregnancy may be the best way of ensuring that the right of the pregnant woman to refuse a Caesarean section is respected, in view of the cases discussed in Chapter 3 and given Graeme Laurie's contention that there is 'precious little evidence of cases in which a pregnant woman's refusal has been accepted' in practice, irrespective of what should happen in principle.²⁸⁰ In *St. George's Trust v S*, Ms S expressed her wishes regarding intervention in writing, as well as verbally, in that she documented her 'extreme objection to any medical or surgical intervention', that such intervention was against her clearly articulated wishes and that she would consider such intervention to be 'an assault on [her] person'.²⁸¹ There was no suggestion at trial that she had attempted to draft an advance decision when she wrote down her wishes, however, if the same situation arose today and the woman complied with the MCA formalities, then it is questionable if the NHS would have any lawful grounds to intervene. If the woman is considered competent to refuse at the time – as was the case with *Re S* and *St. George's Trust v S* – then her contemporaneous refusal is valid; if she is considered incompetent, then her advance directive should be given effect.

The situation in England and Wales, however, may be different when the treatment being refused is a blood transfusion or other less or non-invasive treatment. As established previously, though the recent jurisprudence has upheld the right of a competent pregnant woman to refuse any medical treatment – thereby including blood transfusions – the Code of

²⁷⁸ 145 AD 2d 145 (NY 1989).

²⁷⁹ See for example guidance from the RCOG: 'In the case of a woman losing mental capacity after refusing consent to a treatment following previous discussion during pregnancy, even if this is at the expense of the fetus, her wishes should be respected in the same way as if she were competent'. Royal College of Obstetricians and Gynaecologists, *Obtaining Valid Consent* (Clinical Governance Advice No. 6, 2015) 7.

²⁸⁰ Graeme Laurie, 'The Autonomy of Others: Reflections on the Rise and Rise of Patient Choice in Contemporary Medical Law' in Sheila McClean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006) 143.

²⁸¹ [1999] Fam 26, 37.

Practice specifically states pregnancy as an example of an (unanticipated) change to the circumstances of the patient, which may result in the advance decision not being applicable.²⁸² As a Caesarean section is exclusively an obstetric surgery, it would be obvious to all parties that the advance decision was intended to apply in pregnancy. By contrast, blood transfusions are not exclusive to pregnancy, though not uncommon given the blood loss involved in labour, the likelihood of anaemia in pregnancy and complications such as post-partum haemorrhage. Therefore, the applicability of the advance decision to the treatment could be questioned unless it was clear that the pregnancy was not an unanticipated change in circumstances. Perhaps the best course of action for women in England and Wales who may become pregnant is to specify that they intend the advance decision to apply in pregnancy to ensure its applicability, even though they are not specifically required to do so by law. Many less invasive or non-invasive treatments may be similar to blood transfusions in that the condition that necessitates their provision is not exclusive to pregnancy. Furthermore, where the non-invasive or less invasive treatment is exclusive (or heavily connected) to pregnancy, the fact that it is non-invasive or less invasive may mean that it is unlikely to be included in an advance refusal. For example, one could reasonably question how many women would think to write an advance directive specifically refusing a membrane sweep or augmentation of labour though many women may not want either.

This strength and importance of a valid advance directive in pregnancy in England and Wales is particularly evident when one briefly revisits some of cases from Chapter 3 in which the woman was judged incompetent. If one returns to *Rochdale NHS v C*, the ‘throes of labour with all that is involved in terms of pain and emotional stress’ was sufficient to render the woman incompetent when combined with her acceptance of ‘the inevitability of her own death’.²⁸³ *Re T* and *Re MB* leave doubt where the competence of a pregnant woman is concerned in light of the reference made by Lord Donaldson MR to the ‘effects of shock, severe fatigue, pain or drugs being used in their treatment’ as factors that deprive or reduce capacity.²⁸⁴ Women have been known to encounter some, if not all, of these in the ordinary course of labour but there is no evidence that their competence to consent to the medically advised treatment is routinely

²⁸² Code of Practice, para. 9.43, Healthcare professionals must also consider ‘how long ago the advance decision was made’. See also Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 30 regarding the ‘temporal and psychological distance’ separating the advance decision from the time that it should be given effect and ‘the asymmetries between such decisions will be particularly important where there has been a *significant change in circumstances* since the drafting of the advance directive’ (emphasis added).

²⁸³ *Rochdale Healthcare (NHS) Trust v C* [1997] 1 FCR 274, 275.

²⁸⁴ *Re T* [1993] Fam 95, 113. In *Re MB* [1997] 2 FLR 426, 437: Butler-Sloss LJ stated that “‘the ‘temporary factors’” mentioned by Lord Donaldson MR in *Re T* (confusion, shock, fatigue, pain or drugs) may completely erode capacity but those concerned must be satisfied that such factors are *operating to such a degree that the ability to decide is absent*’ (emphasis added). Arguably, this gives a little more protection to the autonomy of the pregnant woman in that the bar is that the ability to decide must be absent, not a merely reduced or compromised.

called into question.²⁸⁵ The same cannot be said, however, where they seek to go against medical advice.²⁸⁶ On this point, Vivienne Harpwood has argued:

[I]n light of (...) *Re T* (...) it might be difficult to establish as a fact that a woman who had been in labour for many hours and who had received powerful analgesic drugs, was capable of giving or refusing consent to a surgical procedure which had not been explained to her beforehand.²⁸⁷

The significant challenge presented by this is that medical advice is opinion, undoubtedly highly educated opinion, but still opinion as to the likely outcome in a given situation. Not only may it be affected by external factors, but critically, the alleged *serious risk* to the foetus or woman may not materialise, as has occurred in several cases such as that of Laura Pemberton in Florida and Amber Marlowe in Pennsylvania.²⁸⁸ This often leads to the (perhaps) mistaken conclusion that the doctor was ‘wrong’.²⁸⁹

²⁸⁵ In contrast to the opinion of Butler-Sloss LJ, commentators such as Paul Burcher contend that women in active labour have ‘a very limited ability to participate in decision making according to the classical parameters of informed consent’, something which is routinely ‘overlooked’ or ‘ignored’ by medical professionals. He does, however, acknowledge that further empirical studies would be helpful, as existing ones are scarce. Paul Burcher, ‘The Ulysses Contract in Obstetrics: A Woman’s Choices Before and During Labour’ (2013) 39 *J Med Ethics* 27.

²⁸⁶ See *Rochdale NHS v C* [1997] 1 FCR 274; during the hearing Johnson J noted that Ms C had changed her mind and agreed to the Caesarean section, despite him finding her incompetent to refuse it. For criticism of this aspect of the judgment, see Samantha Halliday *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 51.

²⁸⁷ Vivienne Harpwood, *Legal Issues in Obstetrics* (Dartmouth 1996) 76.

²⁸⁸ Taking the case of Laura Pemberton, for example, she successfully gave birth to subsequent children via VBAC after being compelled to have a Caesarean section in the interests of the foetus, while she was in labour and attempting a VBAC. See *State v Pemberton* No. 96-759 (Cir Ct, Leon County 1996) and *Pemberton v Tallahassee Memorial Regional Medical Center* 66F Supp 2d 1247 (Fla. 1999). In *Re S (Adult: Refusal of Treatment)* [1992] 4 All ER 671, Ms S had been advised and refused to have a Caesarean section during labour on a previous pregnancy; that child was delivered vaginally. Another example is the case of Amber Marlowe; unbeknownst to her, the hospital had been granted a court order by a court in Pennsylvania to perform a Caesarean section without her consent. As she was unaware of the court order, she went to another hospital and delivered the baby vaginally. *Wyoming Valley Health Care Systems, Inc. & Baby Doe v Jane Doe & John Doe* No. 3-E-2004 (Pa Ct Com Pl 2004). In the *Jefferson* case, after the court order was granted, Ms Jefferson was rescanned and found not to be suffering from the condition that had precipitated the recommendation of a Caesarean section; Samantha Halliday, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016) 18. See also Heather Draper discussing a case of a woman who successfully delivered vaginally in the time it took to get the court order to compel her to undergo a Caesarean section. Heather Draper, ‘Women, Forced Caesareans and Antenatal Responsibilities’ (1996) 22 *J Med Ethics* 327, 332.

²⁸⁹ As John Seymour notes: ‘In the field of obstetrics, it is not uncommon for a woman to decline to follow medical advice and to deliver a healthy child. Such an outcome is sometimes incorrectly relied on as evidence that the doctor was “wrong” and the patient was “right”. This is to misinterpret the outcome. When harm does not eventuate, it is fallacious to assert that no risks existed.’ He argues further: ‘All that a competent doctor can do is to identify and explain the risks presented in a particular situation, a properly informed woman may elect to accept those risks.’ John Seymour, *Childbirth and the Law* (Oxford University Press 2000) 208. It is argued that this can be distinguished from a situation where a medical professional assures the patient or the court of a negative outcome unless the recommended course of treatment is followed.

Chapter 7

Conclusion

For the most part, the Irish legislature introduced a forward-thinking piece of legislation with the individual at its heart. That individual is not, however, the pregnant woman assuming that the Assisted Decision-Making Capacity Act 2015 remains in its current form. Pregnant women will likely be excluded from holding applicable advance directives refusing life-sustaining medical treatment purely by virtue of being pregnant women. Indeed, the validity of any advance refusal, life-sustaining or otherwise, that would result in harm to the unborn is questionable. At a minimum, the advance directives of pregnant women will be the subject of a High Court inquiry once the treating professional ‘considers’ it to be harmful to the foetus to honour the refusal. While the foetus is certainly worthy of forms of legal protection and entitled to remedy where it is damaged by the conduct of another, this research does not support the impingement on the interests of the woman in self-determination and bodily integrity that will, in all likelihood, occur if this provision remains. Furthermore, as explained in the various chapters up to now, to invalidate one’s decision – in this case an advance directive – because it is not agreeable or represents the ‘wrong choice’ is to permit no choice at all. The likelihood of an otherwise valid advance decision being disregarded in the interests of the foetus, may also undermine the general trust of pregnant women with particular beliefs, whether religious or otherwise, in the healthcare system. Even if general confidence in maternity services is not undermined by such a policy, then the message it gives is still, to some extent, that the value of the previously competent woman is tied to her ability to safely deliver this child. In any event, those with particularly strong (religious) convictions, such as members of the Jehovah’s Witness faith or those opposed to Caesarean sections for various reasons, need to have as much confidence seeking help at Irish hospitals as those open to any medical intervention.

Accordingly, this research has advanced two complimentary points; first, irrespective of any ethical duty that we may feel is owed by the woman to her foetus to submit to intervention in its interests, this should not translate to a legal duty. The reasons for this were laid out in in this research, however, to summarise: ethically, it breaches the most important of principles to force treatment upon a (previously) competent woman in the interests of her foetus and reduces her to a mere object, the value of which hinges on its ability to birth a child. Legally, it creates an unjust exception for pregnant women that no other group within society must tolerate. The second point is that respect for an advance directive in pregnancy is actually critical to protect the autonomy of pregnant women and their interests in self-determination and bodily integrity.

As was discussed at length in Chapter 6, pregnant women, particularly those in labour, are especially vulnerable to unwanted intervention because of some of the ordinary features of labour and the significant power imbalance inherent in the process of childbirth. Together, these points can be summarised as: in view of the importance of advance directives in pregnancy to protecting the autonomy of the woman, created by the increased likelihood of intervention therein, any attempt to limit their effect is not only unjust, but particularly so given the increased tendency to intervene during labour.

The Irish legislature could learn much from the jurisdictions that were considered in the course of this research and yet, it is claimed that those jurisdictions, in turn, could learn much from Ireland. What this research has discovered is that no framework is without its issues. While England and Wales has the most jurisprudence demonstrating respect for and vindication of the right of the competent pregnant woman to refuse treatment, advance directives in pregnancy are not specifically legislated. Indeed, as discussed previously, pregnancy is one of the potential unanticipated circumstances that may result in the validity of the advance decision being questioned according to the Code of Practice.¹ Furthermore, that statement relates to competent pregnant women and the approach of the courts towards the capacity of women in labour may be viewed as questionable. Consequently, it is still argued that the best course of action for a woman wishing to refuse specific intervention, particularly in labour or following labour, is to draft an advance decision to that effect. A specific reference to pregnancy, though not obliged by the law, would certainly be desirable. Arguably, a court would find it very difficult not to respect the (precedent) autonomy of the woman when faced with the combination of a contemporaneous, though potential incompetent decision and an advance decision that has not been left open to interpretation. That assumes that such a situation would be sufficiently unclear to the hospital and treating physician to even make it to the Court of Protection for a determination. Though a very developed system, it can still be asserted that the English legislature could learn from the approach taken in Ireland, particularly where best interests assessments and effective protection of autonomy are concerned. Ireland has already, very clearly, learned from its nearest neighbour given the inspiration provided to the Irish legislation by the Mental Capacity Act 2005 and the jurisprudence preceding and succeeding it.

New York – and indeed the greater United States – has presented a confusing picture. On one hand, New York has vindicated and upheld the personal rights of the individual in various

¹ Code of Practice accompanying the Mental Capacity Act 2005, para. 9.43.

ways. On the other hand, despite having quite liberal abortion laws, it has become apparent during the course of this research that it has failed to uphold the right of a pregnant woman to refuse medical treatment. Furthermore, it has failed to legislate to protect the right to refuse specifically in relation to pregnant women. Having evaluated the jurisprudence in New York and in light of the courts in which healthcare matters are routinely heard, it can be asserted that the decision of the court may very well depend on the presiding judge and his interpretation of the statute; does the lack of legislation pertaining to pregnant women mean that they should be treated the same as everybody else, or that they are not in receipt of specific protection when their foetuses may be in danger? Does omission mean they are treated the same, or differently? The benefit of New York is that it highlights, to some extent, what could happen in Ireland if the entirety of Part 8 of the Assisted Decision-Making Capacity Act 2015 remains uncommenced. After all, despite the vast differences between the jurisdictions, there are some similarities in how the issue of medical treatment in pregnancy has been treated and its current legal position. For example, there is uncertainty as to the right of a pregnant woman to refuse, there is a largely untested common law right to decide in advance, the issue of an advance directive in pregnancy has not yet been adjudicated and there are constitutional issues at play that are very much a matter of interpretation. In that way, New York serves as a sort of cautionary tale to Ireland and should offer all of the necessary evidence that legislating clearly on such matters is desirable for all parties – women, physicians, courts and facilities. Furthermore, the problem is only being pushed out by the refusal of various courts to hear cases challenging the constitutionality of pregnancy exceptions contained in state advance directive legislation, as occurred in *DiNino*² and *Gabrynowicz*.³ The issue needs to be tackled somewhere, whether at a legislative or court level; the former is most desirable, the latter may be necessary as long as the former fails to act.

Throughout this research, a number of key themes were explored. Chapter 2 served as an introduction to ethical issues in healthcare and culminated with an explanation of Principlism, in addition to an explanation as to why it would be used as the primary ethical framework. Then, in each chapter, the ethical analysis was built upon a Principlist framework, with the addition of some more detailed analysis on related concepts where necessary, such as the degree to which advance directives are a valid and real exercise of autonomy. Chapter 3 examined the doctrine of informed consent, providing the necessary theoretical basis for the

² See *DiNino v Gorton* 684 P 2d 1297 (Wash 1984).

³ *Gabrynowicz v Heitkamp* 904 F Supp 1061 (ND 1995).

right to refuse treatment in advance. It highlighted the considerable differences between how the issue of capacity is treated in New York versus England and Wales and Ireland and how the law – and the relevant ethical or professional guidelines – in the three jurisdictions views information disclosure. It also criticised how the law operates in this area given that its purpose, from an ethical perspective, is to protect autonomy. Thus, given that the purpose of the doctrine is to protect autonomy, it questioned why the duty to provide information exists within negligence and not battery or another more suitable, perhaps human rights based area, wherein the interests of the individual in bodily integrity could be more adequately protected. As was argued in Chapter 3, though this question is not a primary focus of this research, it was worth bearing in mind when intervention in pregnancy and labour was discussed in Chapter 6 in view of the intimate nature of the process of childbirth and the significant power imbalance associated with it.

Chapter 4 extended the discussion to an analysis of the right to refuse life-sustaining medical intervention. Though certainly not always a clear-cut distinction, the chapter considered the position of competent and incompetent individuals to refuse treatment. Where incompetent individuals were concerned, the analysis was split further between those who had capacity at some point – and where the wishes of the previously competent person may have been determinative or persuasive – and those who never did. The tension between protecting and respecting the autonomy of the individual on one hand and the focus of English law on ‘best interests’ and the application of the ‘clear and convincing’ evidentiary standard to decisions in New York on the other, was highlighted to a significant extent. Arguably, there were situations in both jurisdictions where the wishes of the individual regarding the continuation of life-sustaining treatment were not honoured.⁴ With that said, England and Wales has demonstrated growing respect for the wishes and feelings of the individual, albeit in the course of the best interests assessment.

Chapter 5 discussed the development of the advance directive from its root in Luis Kutner’s work to its common law recognition in the three jurisdictions to its statutory footing in England and Wales and Ireland, once the ADM(C)A 2015 is commenced. This research met challenges to the idea of advance directives – and to a lesser extent their operation in practice – head on and argued that though undeniably flawed in some ways, advance directives are an effective tool for the individual to exercise her autonomy. Perhaps, they may even be the best tool to do

⁴ For example, *Re Westchester County Medical Center [O'Connor]* 72 NY 2d 517 (1988) and *Re M (Adult Patient)(Minimally Conscious State: Withdrawal of Treatment)* [2012] 1 All ER 1313.

so when the other options are considered. This chapter highlighted some key differences between Irish and English legislation, including the Irish requirement that any behaviour inconsistent to the advance directive be while the individual has capacity in order to be determinative, something which is not present in the MCA 2005. The research also compared the clarity of the position in England and Wales and Ireland, with the equivocation in New York and highlighted the gaps present in its law.

Finally, Chapter 6 built upon the discussions in the previous chapters to deal with the primary research questions. By considering the heavily related issues of compelled intervention in pregnancy and ‘pregnancy exclusions’ to advance directive legislation, it proffered a theory as to the legal position of a pregnant advance directive holder in each jurisdiction. It was highlighted that, although insufficiently clear to some extent, England and Wales appears to have the framework most likely to protect the interests in bodily integrity and self-determination of the pregnant woman. Both New York’s silence and Ireland’s express singling out of pregnant women represent a failure to respect the autonomy of the pregnant woman, albeit it in different ways. It is essentially left to the courts to decide if the advance directive of the pregnant woman ought to be honoured, arguably an undertaking that no judge nor court would relish. Still, as highlighted in the course of the chapter, England and Wales does not have an unblemished record where compelled intervention in pregnancy is concerned. Though largely overruled by more recent jurisprudence, cases were discussed in which treatment was compelled irrespective of the capacity of the woman. Furthermore, as discussed previously, it could be argued that courts have been a little too willing to make findings of incapacity on occasion.

It appeared to many that the presence of the 8th Amendment in matters outside of abortion had recently receded with its repeal. Its reach, which can be seen in the drafting of section 85(6) and its continued presence therein may well serve as an indication that merely repealing the 8th Amendment has not changed everything in the way people may have expected. As discussed during the course of Chapter 6, section 85(6)(a) may provide an important safeguard against a woman being bound by an advance decision in a pregnancy that she had neither anticipated, nor factored into her healthcare decision-making. It can be asserted that this provision has struck the appropriate balance between a legitimate state interest in protecting a foetus and the interests of the woman that arise in the context of healthcare decisions. What can be argued is the presence of an imbalance between the relevant interests is section 85(6)(b); this research contends that it is incumbent upon the legislature to honour the will of the majority of the

people of Ireland that pregnant women be free from illegitimate interference with their healthcare decisions in the reproductive context. Accordingly, it is argued that it is preferable for the legislature to remove section 85(6)(b) from the ADM(C)A 2015.



Report of the **Irish Maternity Support Network** to the UN Special Rapporteur on Women on

Mistreatment and violence against women during reproductive health care with a focus on childbirth

17 May 2019

<https://www.ohchr.org/EN/Issues/Women/SRWomen/Pages/Mistreatment.aspx>

Introduction

Reproductive healthcare has been the subject of considerable public commentary in Ireland in recent years. From the controversial handling of the symphysiotomy redress scheme; to the publicisation of the appalling abuses perpetrated against women and children in mother and baby homes; and the long awaited and hard won process of liberalisation of the laws on termination of pregnancy – the mistreatment of women in the context of reproductive health care has been very much to the fore of public discourse. As recently as April 2019 a national radio talk show devoted two full weeks of programming to women who called in to describe their experiences in Irish maternity hospitals, and the national health service, the Health Service Executive, issued a public apology stating “The HSE apologises to those women where our service has failed to meet their expectations.”ⁱ The recurring thread throughout all of these controversies has been a fundamental failure to listen to and to believe women: to hear and believe their wishes; their preferences; and their accounts of what happened to them.

Snapshot of Reproductive Healthcare Services in Ireland

Ireland is a stable modern democracy considered to have a high standard of living and a young and well educated population. There is a system of universal healthcare through which all citizens are entitled to access care. However, problems with waiting lists for non-emergency treatments and with waiting times to access acute treatment, as well as with access to certain treatments and to choice of place, provider, and type of treatment have led to the growth of a significant private healthcare industry and a significant proportion of the population purchase private health insurance products.

Reproductive health care and care during pregnancy and childbirth is provided to all pregnant people free of charge under the Maternity and Infant Child Scheme.ⁱⁱ For the majority of pregnant people what this provides is ante natal care shared between their General Practitioner (GP) and an obstetric unit either in a standalone maternity facility or within a larger hospital setting; and labour and delivery and post-partum care in the obstetric unit. In some areas of the country pregnant people can access midwifery led care either through a midwife-led unit attached to an obstetric unit; or via community midwifery services either through a domiciliary midwife service run from an obstetric unit or by engaging a self-employed community midwife. There are also private midwifery services available through independent enterprises to access homebirth care where the State supported homebirth service is unavailable by reason of geography, scarcity, or the strict exclusion criteria applied.

The Maternity and Infant Child Scheme provides care to all pregnant people at all stages of pregnancy. Gynaecological care is provided under the free public health care system run by the Health Service Executive (HSE). Fertility treatments are not provided on the public health care system and can only be accessed privately. Until 2018 termination of pregnancy services were strictly curtailed and available only in extremely limited circumstances. Following a referendum vote to change the Constitution of Ireland, a termination of pregnancy service was introduced in January 2019. This is a GP-led service up to 12 weeks' gestation and a hospital-led service thereafter. The service is available on the public health care system.

There are approximately 67,000 births every year in Ireland. This includes figures for stillbirths and ectopic pregnancies. It does not include the figures for miscarriage. The rate of miscarriage is internationally accepted to be above 25% of all pregnancies. This indicates the total number of pregnancies in Ireland is approximately 95,000 each year. (The Irish Maternity Indicator System 2015)

There are 19 maternity units in Ireland. Three of these are dedicated tertiary maternity hospitals based in Dublin. A further 14 maternity units are located within general hospitals throughout the country. There are two midwifery led units, one of which is co-located alongside an obstetric unit in a general hospital. Almost all maternity care is obstetric led although usually delivered by midwives. There are no independent midwives in Ireland and home birth is provided by self-employed community midwives (SECMs) under contract to the Health Service Executive. Many areas of the country have no state provided or private home birth service. A limited homebirth service is also provided by Domino clinics

There are two full time perinatal psychiatrists one in Dublin and one in Cork.

While all maternity care is provided free of charge on the public health system, certain medications for pregnancy related conditions are not universally freely available.

The National Maternity Strategy was launched in 2017 and sets out a ten-year vision for maternity care in Ireland. Funding for this project has been re-allocated to other related areas, which has implications for its development and implementation.

High levels of understaffing, particularly of midwives has a detrimental impact on the quality of care that women receive throughout the maternity services. In comparison with internationally accepted standards there also a lack of consultants throughout the service.

Midwifery received professional recognition in Ireland in 2011. All midwives practising in Ireland must have completed a four year BSc in Midwifery or a Higher diploma in Midwifery post BSc Nursing and are registered by the Nurses and Midwives Board of Ireland (NMBI). The National Perinatal Epidemiology Centre audits clinical data from the maternity services for review.

1. Cases of mistreatment and violence against women during childbirth

Please indicate whether in your country there are cases of mistreatment and violence against women during reproductive health care, particularly facility-based childbirth. If so, please specify what kind of cases and describe your country's response and any good practices, including protection of human rights;

Women's Experiences of Mistreatment and Violence in the Irish Maternity System.

The incidence of reports of disrespectful and abusive treatment in the Irish maternity system during labour and childbirth has become increasingly persistent in the last few years. The advent of social media has contributed to women sharing and documenting their experiences and led to women feeling less isolated and alone and able to speak out and feel understood and supported. There is very little recorded data in relation to these reports, partly due to the intangible nature of the experiences and partly due to the isolation experienced by women who believed they were alone in their experiences and that no-one would believe them. Having not being listened to and their concerns dismissed, they were discouraged from complaining or articulating their distress. Following the death of a woman and her baby in a maternity unit in January 2019, as recently as April 2019, a woman phoned a national radio station to describe her own experience of mistreatment and neglect and unsafe conditions during her own recent labour and birth. This programme aired on national radio for 75 minutes each day from the 2nd to the 10th of April and for these almost 2 weeks it was exclusively dedicated to women describing their own experiences of unsafe care, disrespect, abuse and mistreatment in the Irish maternity system. Following the initial phone call more than 1000 women contacted the programme of which only a small number could be accommodated to tell their stories on the national airwaves. The experiences and testimonies of these women are now on record but as yet need to be documented and analysed. They cover instances of abuse ranging from verbal abuse, humiliation, shaming, neglect, coercion, lack of consent, to intimidation, aggressive and threatening behaviour, the withholding of pain medication, practice of unsafe, outdated, non-evidence-based procedures, dismissal of their concerns, restraint and emotionally abusive behaviours such as emotional blackmail and 'gaslighting'. In addition, they reported vindictive remarks and abuse, being treated with lack of dignity and respect, being exposed in public, not being informed of what was happening and not being asked or consulted about decisions which

directly affected their labours and births. Most seriously, they were frequently not listened to, - their concerns and experiential knowledge of when something was wrong was ignored and dismissed, often resulting in adverse outcomes for themselves or their babies which they felt could have been avoided. Their input and experience in their own labour and birth experiences was dismissed and ignored and their valuable information about their own and their babies' health was not listened to, in some cases leading to tragic outcomes. They frequently reported feeling silenced. When they followed up with complaints, it was almost universally the case that crucial aspects of the events which had occurred were not documented. Many women reported being frightened and in shock and describe their labours and birth as extremely traumatic experiences. Many continue to experience post-traumatic stress disorder which they attribute to the events surrounding labour and birth and the mistreatment they received in childbirth. Women also consider that experiences of fear, isolation and helplessness they felt during labour contributed in no small measure to the high levels of postnatal depression and anxiety they subsequently have experienced. Women have been left with life-changing injuries as a result of not being listened to and further silenced when records are lost and incomplete and events denied.

Silence can act as a tool of oppression. Women felt unable to speak of their experiences for fear of judgement, manipulated out of guilt to feel they have no right to complain when they should be grateful that they have a healthy baby, even though their mental, physical and emotional health may have been so badly damaged that they are barely able to function and yet they continue to put a brave face on it and look after their babies and families. Furthermore, psychological supports for perinatal mental health are almost non-existent and state counselling services very limited and difficult to access in many parts of the country. This may be slowly improving but voluntary and charitable organisations often attempt to fill the gap, which is a far from satisfactory situation.

The innumerable instances of obstetric violence which women describe are systemic and often deeply embedded as part of the institutionalised culture which historically has demonstrated a misogyny which has manifested in many scandals of gender-based cruelty and violence since the foundation of the State. These include, among others, the practice of Symphysiotomy which continued until the early 1990s and for which many victims have still not received redress and the Neary scandal, where hysterectomies were performed on women, many after their first child, for no medically indicated reason and without their knowledge or consent.

The experiences of obstetric violence women have reported go back as far as sixty years. They cover the entire spectrum of disrespect, abuse and violence which goes unacknowledged and for which no individual or institution can be held accountable for. The experiences women describe demonstrate a consistent attitude of disrespect emanating through all areas of maternity care. This disrespect manifests as verbal abuse, cruelty, lack of awareness and an absence of motivation to change on many levels. The lack of understanding of the process of consent and how it should be applied in maternity situations is also very evident.

Women describe the lack of compassionate care and disrespect as being a major contributing factor in these traumatic experiences. Very often, they state that it is not the actual events of the birth which cause them distress and trauma but, rather, how they are treated. What might

appear to be a traumatic birth to a professional – one which is complicated or suddenly changes, may not be experienced or perceived as excessively traumatic or difficult for the women if she receives supportive care. Whereas, what might seem to be a relatively straightforward birth may be a cause of severe distress with consequent implications for her physical or mental health if she has experienced disrespectful, neglectful and abusive care. Health professionals should be aware of the impact their presence and care has, not only on the immediate welfare of the woman and her baby, but also of the far reaching consequences it can have on her well-being and that of her family and in effect on the wider community. In the midst of the most traumatic experience, a woman will often speak of one specific person who showed her even a moment of kindness and care. A maternity system needs to be developed where disrespect will not be tolerated, where there are robust mechanisms for ensuring respect and communication are respectful and compassionate at all times, and where feedback both positive and negative is used to improve the system for all. A culture that supports everyone involved in maternity care should be developed and nurtured, recognising the more intangible outcomes as well as the measurable outcomes – putting the woman at the centre of her care and supporting the health professionals in providing such care.

While obstetric violence is generally considered to be abuse and violence towards women during labour and childbirth, it also pervades the maternity system in other ways. There are very many caring compassionate and conscientious professionals within the maternity system in Ireland striving to provide woman-centred, safe, evidence-based, respectful maternity care. However, the environment in which they seek to provide this care is often itself the cause of trauma and distress to these caring professionals. They are overworked, working in an understaffed, highly stressful environment. It was recently reported that three midwives were caring for thirty one women and their babies at a major maternity unit (Irish Times 29 March 2019), and similar instances have been reported elsewhere, often with recently qualified midwives feeling overwhelmed. They often in turn experience distress and trauma when they continually witness the treatment that women are subjected to on such a frequent basis and feel powerless to provide the care they entered the profession intending to provide. They feel guilty and overwhelmed and unsupported. Bullying at all levels within the maternity system has been reported. The effects of all this neglect on the maternity system and the lack of funding and resourcing and management issues can be seen in the large numbers of midwives that are leaving due to burnout and stress. Student midwives, in particular, leave either before completing their studies or as soon they have completed their studies, reporting the working conditions and unsafe environment as being a major factor in their decision. In the face of such inhospitable and difficult working conditions, such professionals still manage to provide care with kindness and respect, clearly demonstrating that there is no excuse for disrespectful or abusive care under any circumstances – either towards the women and babies they care for, or towards colleagues.

2. Consent

Please specify if full and informed consent is administered for any type of reproductive health care and if these include childbirth care;

Irish law provides that full and informed consent must be provided for any medical procedure it is proposed to perform on a competent patient. This is provided for both in case law precedent in the civil law of tortsⁱⁱⁱ and also at statute in the Non-Fatal Offences Against the Person Act 1997.^{iv} Ireland has also ratified the European Convention on Human Rights and Fundamental Freedoms and adopted its provisions into domestic law in the ECHR Act 2003, thereby also adopting the European Court of Human Rights jurisprudence on the rights to dignity and privacy and their consequential applications to the right to give and to withhold consent to a medical procedure.

All of the professional bodies of the medical professions in Ireland provide in their codes of professional conduct that consent must be sought and received for medical procedures.^v The HSE's National Consent Policy 2017^{vi} reiterates this position. In relation to reproductive healthcare specifically, the National Consent Policy in § 7.7.1 'Refusal of treatment in pregnancy' still retains on paper a provision that significantly limits the scope of pregnant people to refuse consent to treatment that may impact on the unborn child. The provision in question^{vii} curtailed a pregnant woman's ability to refuse a proposed medical treatment if a health care practitioner believed that not accepting the treatment would pose a risk to the life of her unborn foetus, and provided that the appropriate forum for mediating any disputes that might arise between a woman and her health care providers in this context would be the High Court. This provision was necessary in the National Consent Policy because of the constitutional protection of the right to life of the unborn child provided for in Article 40.3.3 of the Constitution of Ireland 1937. In the wake of the referendum decision in May 2018 to repeal Article 40.3.3, § 7.7.1 of the National Consent Policy is no longer necessary and is considered defunct. However, certain pieces of legislation remain on the statute books that were drafted prior to repeal and necessarily made similar provision for the curtailment of the maternal right to give or to refuse consent to medical treatment during pregnancy. The Assisted Decision Making (Capacity) Act 2015 is one such example. This legislation, which has been enacted but not fully commenced, deals with the introduction of advance healthcare directives to Irish law. In its treatment of the right to make advance care directives regarding medical treatment in the event of a possible future loss of capacity, the 2015 Act in section 85 (6) provides that any treatment specified in an advance healthcare directive can only be administered to an incapacitated pregnant person if it does not negatively affect the right to life of the unborn, and that an application must be made to the High Court in the event of any uncertainty. It will be necessary for the Irish government now to reconsider the provisions of section 85 (6) in the light of repeal of Art. 40.3.3, as to commence this provision unamended now would breach the legislature's obligation not to knowingly enact unconstitutional legislation.

Women's Experiences of Consent

Women frequently report procedures which have been carried out without their consent. Some examples are described below.

The practice of Membrane Sweeps (also known as Stretch and Sweep) is often performed without women's knowledge or consent, often under the guise of vaginal exams. There is no evidence that this procedure is effective in inducing labour. A membrane sweep is frequently presented to women as an alternative to other forms of induction which may be avoided if they accept it, leaving them feeling they are in a position where they must accept it to avoid the alternative. This does not satisfy the criteria for informed consent.

Artificial rupture of membranes (ARM/AROM) is routinely performed as standard procedure during Active Management of Labour (AML), usually without explanation or consent being sought and presented as an inevitable part of inducing or moving on labour (see Hamilton v HSE).

Use of Admission CTG: This is routinely insisted on at admission and women are intimidated into accepting it as refusal can often lead to further pressure or fear of further consequences or lack of support as labour progresses. The Institute of Obstetricians and Gynaecologists' recommendations for admission CTG state 'The current evidence base does not support the use of the admission CTG in low risk pregnancies and is, therefore, not recommended as a routine.' (Institute of Obstetricians and Gynaecologists, Intrapartum Fetal Heart Rate Monitoring, June 2012:9). These guidelines are frequently not adhered to.

For continuous CTG monitoring in labour, the Institute of Obstetricians and Gynaecologists' recommendations for low-risk women are: 'For a woman who is healthy and has an uncomplicated pregnancy (low risk), intermittent auscultation should be offered and recommended in labour using either a Doppler ultrasound or a Pinard Stethoscope.' (Institute of Obstetricians and Gynaecologists, Intrapartum Fetal Heart Rate Monitoring, June 2012:9).

There are many other examples during labour and childbirth care in the Irish Maternity system where consent is not considered or sought for procedures. An example of this is the routine use of syntocinon to induce or augment a labour which is not progressing according to the standardised timeframe used in the Active Management of Labour model - which originated in Ireland and is used throughout the maternity units.

Women have a natural expectation that the healthcare professionals that attend them in labour and childbirth are fully cognisant of the most up-to-date guidelines and best international practice standards and will therefore generally comply with what is suggested. Women want the best for themselves and their families at such an important time. That this is always uppermost for women during pregnancy and birth is illustrated by the fact that antenatal care never needs to be incentivised. Globally, women will endure hardship, discomfort, lengthy queues and other obstacles to avail of antenatal care. They have a right to expect that

comprehensive and accurate information is given to them by their health professional in order to make the informed decisions that are right for themselves and their family. Withholding this information is denying women this right to fully informed decision making.

The factors that are necessary for fully Informed consent are frequently not present in the interactions and attitudes of many within the system when caring for women. These include ensuring that full Information is provided, in a way that is clear and understandable for the pregnant person; that both the benefits and the risks of a procedure are clearly explained; that the option for declining or refusing is given without intimidation, and that the power dynamic is recognized and accounted for. Additional training should be provided to healthcare professionals on a regular basis in order to ensure that best practice with regard to facilitating informed consent at every stage of labour and childbirth for the pregnant person and to effect change within the culture at the institutional as well as at the individual level.

3. Accountability mechanism

Please specify whether there are accountability mechanisms in place within the health facilities to ensure redress for victims of mistreatment and violence, including filing complaints, financial compensation, acknowledgement of wrongdoing and guarantees of non-repetition. Please indicate whether the ombudsperson is mandated to address such human rights violations;

The accountability systems within the health facilities and the National Health Service Executive are experienced as being inadequate in addressing the complaints of those who experience mistreatment in any form.

Under the Data Protection Act (2018) and The Freedom of Information Amendment Act (2003), medical records must be provided to service users of a public body. Under Section 9 of the Data Protection Act, there is also a facility to have these notes amended where the service user disputes them and this must be recorded, even in the event of the provider disputing the fact. In reality, there are often delays in providing the notes, notes are often incomplete and/or inaccurate and it can be a lengthy and obstructive process to acquire them. In cases which go to court, it often takes many months and high costs in legal fees to secure them through the courts.

Many hospitals have a complaints procedure, which generally consists of a written complaint which must be responded to within a specified timeframe. This can be followed up with a meeting if the service user wishes. However, there is no mechanism in place to ensure guarantees of non-repetition. Frequently, service users report that the meeting appears to have been held in an attempt to prevent the complainant taking further legal action. More recently, as a result of awareness and advocacy, these meetings appear to be

a more genuine attempt to recognise the woman's distress and concerns, although fall far short of acknowledge the failings in care or ensuring change in practices. There is currently no mechanism in place to monitor or implement changes.

People may also complain to the Health Service Executive, although once again, there are no mechanisms for further action to be taken in implementing changes.

The only facility for redress or financial compensation is through the judicial system. As this is a lengthy and costly process, people generally only take this option when financial support is necessary to support and care for a child gravely injured at birth due to failings in care.

It is proposed that a Mandatory Open Disclosure Policy for the Health Service will be in place by legislation by the end of 2019, although this is not certain. However, it will provide for a statutory duty of candour on individual healthcare professionals and organisations. It does not directly address implementation of changes.

At present, when all other avenues of complaint have been followed, complaints can be made to the Ombudsman's Office where they will be investigated. Women are advised of this option but it seems to be seldom utilised.

In the case of professional fitness to practice, complaints may be made to the professional bodies. In the case of doctors, this is the Irish Medical Board, who will address the complaint and apply sanctions. The Nursing and Midwifery Board of Ireland address complaints and professional standards regarding midwives and nurses.

Excepting in the case where a complaint goes to court, when women make a complaint about the standards of care they receive, they are generally attempting to achieve two objectives – 1. An acknowledgement, recognition, and where possible an apology for the mistreatment and lack of care; and 2. An assurance that changes will be put in place to ensure that it is not repeated and that other women and families do not have to go through a similar experience.

4. National policies v WHO guidelines and standards

Does your health systems have policies that guide health responses to VAW and are these in line with WHO guidelines and standards on this issue, see: [1](#) | [2](#)

Active Management of Labour is still practised widely in Ireland, where it originated. Policies to change this in line with the latest WHO guidelines are not in evidence. Continuity of carer, in line with the WHO guidelines is not available to women in maternity units throughout Ireland and due to the structure of the maternity system and the current staff shortages is unlikely to be implemented in the near future.

There are very many issues which need to be addressed to bring the policies of the Irish Maternity system in line with the WHO guidelines and standards.

Aspects such as clear communication by maternity staff, mobility in labour and position of choice, respect and dignity and the avoidance of unnecessary medical intervention if mother and baby are in good condition, along with the forced hastening of labour are issues which need to be addressed.

Other issues such as respectful communication and provision of evidence-based care are also of great importance.

Liz Kelly Edel Quirke
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ⁱ <https://www.thejournal.ie/childbirth-joe-duffy-4585612-Apr2019/>

ⁱⁱ <https://www.hse.ie/eng/services/list/3/maternity/combinedcare.html>

ⁱⁱⁱ *In Re a Ward of Court* (withholding medical treatment) (No. 2) [1996] 2 IR 79

^{iv} <http://www.irishstatutebook.ie/eli/1997/act/26/enacted/en/html>

^v In the context of reproductive healthcare, see the *Guide to Professional Conduct and Ethics for Registered Medical Practitioners* (Medical Council, 2018) available at <https://medicalcouncil.ie/News-and-Publications/Reports/Guide-to-Professional-Conduct-and-Ethics-8th-Edition-2016-.pdf>; *Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives* (An Bord Altranais, December 2014) available at https://www.nmbi.ie/NMBI/media/NMBI/Code-of-professional-Conduct-and-EthicsAd_2.pdf?ext=.pdf

^{vi} <https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-august-2017.pdf>

^{vii} The full text of § 7.7.1 reads as follows: “The consent of a pregnant woman is required for all health and social care interventions. However, because of the constitutional provisions on the right to life of the “unborn”, there is significant legal uncertainty regarding the extent of a pregnant woman’s right to refuse treatment in circumstances in which the refusal would put the life of a viable foetus at serious risk. In such circumstances, legal advice should be sought as to whether an application to the High Court is necessary.”

Bibliography

Books

Beauchamp T and Childress J, *Principles of Biomedical Ethics* (1st, OUP 1979)

Beauchamp T and Childress J, *Principles of Biomedical Ethics* (8th edn, OUP 2019)

Bentham J, *Introduction to the Principles of Morals and Legislation* (1789)

Berg JW and others, *Informed Consent: Legal Theory and Clinical Practice* (2nd edn, OUP 2001)

Beyleveld D and Brownsword R, *Human Dignity in Bioethics and Biolaw* (OUP 2001)

Brandt R, *Ethical Theory: The Problems of Normative and Critical Ethics* (Prentice-Hall 1959)

Donnelly M, *Consent: Bridging the Gap between Doctor and Patient* (Cork University Press 2002)

Dworkin G, *The Theory and Practice of Autonomy* (Cambridge University Press, 1988)

Dworkin R, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Harper Collins 1993)

Faden R and Beauchamp T, *A History and Theory of Informed Consent* (Oxford University Press 1986)

Feinberg J, *Harm to Self* (OUP 1986)

Finnis J, *Fundamentals of Ethics* (Georgetown University Press 1983)

Foot P, *Vices and Virtues: And Other Essays in Moral Philosophy* (Oxford 2002)

Foster C, *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics* (Hart Publishing 2009)

Frankena W, *Ethics* (2nd edn, Prentice-Hall 1973)

Flaum Hall M and Hall SE, *Managing the Psychological Impact of Medical Trauma: A Guide for Mental Health and Health Care Professionals* (Springer 2017)

Gillon R, *Philosophical Medical Ethics* (John Wiley & Sons 1986)

Grubb A, *Principles of Medical Law* (3rd edn, OUP 2010)

Halliday S, *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention* (Routledge 2016)

Harpwood V, *Legal Issues in Obstetrics* (Dartmouth 1996)

Herring J, *Medical Law and Ethics* (7th edn, OUP 2018)

Hoefler JM and Kamoie BE, *Deathright: Culture, Medicine, Politics, and the Right to Die* (Westview Press 1994)

Hoppe N and Miola J, *Medical Law and Medical Ethics* (Cambridge University Press 2014)

Jackson E, *Medical Law: Text, Cases and Materials* (3rd edn OUP 2013)

-- *Medical Law: Text, Cases and Materials* (4th edn, OUP 2016)

Kant I, *Groundwork of the Metaphysics of Morals* (1785)

-- *Lectures on Ethics* (Louis Infield tr, Harper & Row 1963)

Keown J, *Euthanasia, Ethics and Public Policy* (Cambridge University Press 2002)

MacIntyre A, *After Virtue: A Study in Moral Theory* (3rd edn, University of Notre Dame Press 2007)

Maclean A, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press 2009)

McLean S, *A Patient's Right to Know* (Dartmouth 1989)

Madden D, *Medicine, Ethics and the Law* (3rd edn, Bloomsbury Professional 2016)

Mahan S, *Crack Cocaine, Crime and Women: Legal, Social, and Treatment Issues* (Sage Publications 1996)

Meisel A and Cerminara KL, *The Right to Die: The Law of End-of-life Decision Making* (3rd edn, Aspen 2004)

Newman BM and Newman PR, *Development Through Life: A Psychosocial Approach* (10th edn, Wadsworth 2009)

O'Neill O, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002)

Parfit D, *Reasons and Persons* (OUP 1984)

-- *On What Matters: Volume One* (OUP 2011)

Pattinson SD, *Revisiting Landmark Cases in Medical Law* (Routledge 2019)

Ross WD, *The Right and the Good* (1930)

Quill E, *Torts in Ireland* (4th edn, Gill & Macmillan 2014)

Scott R, *Rights, Duties and the Body: Legal and Philosophical Reflections on Refusing Medical Treatment during Pregnancy* (Hart 2002)

Seymour J, *Childbirth and the Law* (OUP 2000)

Singer P, *Famine, Affluence and Morality* (OUP 2016)

Book Chapters

Boyd K, 'Medical Ethics: Hippocratic and Democratic Ideals' in Law' in S McClean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006)

Braun SS, 'Compromised Autonomy: Social Inequality and Issues of Status and Control' in DG Kirchhoffer and BJ Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019)

Brazier M and Harris J, "Fetal Infants': At the Edge of Life' in PR Ferguson and GT Laurie (eds) *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean* (2015 Ashgate)

Cook RJ and Dickens BM 'Reproductive Health and the Law' in PR Ferguson PR and GT Laurie (eds) *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean* (2015 Ashgate)

Devereux J, 'Continuing Conundrums in Competency' in S McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006)

Dickens BM, 'The Right to Conscience' in Rebecca J Cook and others (eds) *Abortion Law in Transnational Perspective* (University of Pennsylvania Press, 2014)

Docker C, 'Advance Directives / Living Wills' in S McLean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996)

Feinberg J, 'The Rights of Animals and Unborn Generations' in Blackstone WT (ed) *Philosophy and Environmental Crisis* (University of Georgia Press 1974)

Gilbert DT and Wilson TD, 'Miswanting: Some Problems in the Forecasting of Future Emotional States' in J Forgas (ed) *Thinking and Feeling: The Role of Affect in Social Cognition* (Cambridge University Press 2000)

Harris J, 'Euthanasia and the Value of Life' in J Keown (ed) *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 1995)

Jackson E, 'Informed consent' to Medical Treatment and the Impotence of Tort' in S McLean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006)

--'DIY Abortion and Harm Reduction' in in PR Ferguson and GT Laurie (eds) *Inspiring a Medico-Legal Revolution: Essays in Honour of Sheila McLean* (2015 Ashgate)

Jarvis Thomson J, 'A Defense of Abortion' in D Kelly Weisberg (ed) *Applications Of Feminist Legal Theory* (Temple University Press 1996)

Kennedy I, 'Consent to Treatment: The Capable Person' in C Dyer (ed) *Doctors Patients and the Law* (Blackwell Science 1992)

Kilcommins S, 'Doctrinal Legal Method (Black-Letterism): assumptions, commitments and shortcomings' in L Cahillane and J Schweppe (eds) *Legal Research Methods: Principles and Practicalities* (Clarus Press 2016)

Laurie G, 'The Autonomy of Others: reflections on the Rise and Rise of Patient Choice in Contemporary Medical Law' in S McClean (ed) *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006)

Mair J, 'Maternal/Foetal Conflict: Defined or Defused?' in S McClean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996)

Matthews S and Kennett J, 'Diminished Autonomy: Consent and Chronic Addiction' Defined' in DG Kirchhoffer and BJ Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019)

McLean SA, 'Decisions at the End of Life; An Attempt at Rationalisation' in C Stanton and others (eds) *Pioneering Healthcare Law; Essays in Honour of Margaret Brazier* (Routledge 2016) 58.

Mill JS, 'Utilitarianism' in JE White (ed) *Contemporary Moral Problems* (9th edn, Thomson 2009)

Murray C, 'Troubling Consent: Pain and Pressure in Labour and Childbirth' in C Pickles and J Herring (eds) *Childbirth, Vulnerability and Law: Exploring Issues of Violence and Control* (Routledge 2019)

Olick RS, 'On the Scope and Limits of Advance Directives and Prospective Autonomy' in P Lack, N Biller-Andorno and S Brauer (eds) *Advance Directives* (Springer 2014)

Quill E, 'Ireland', in H Koziol and BC Steininger (eds) *European Tort Law 2007* (Springer 2008)

Richards BJ, 'Autonomy and the Law: Widely Used, Poorly Defined' in DG Kirchhoffer and BJ Richards (eds) *Beyond Autonomy: Limited and Alternatives to Informed Consent in Research Ethics and Law* (Cambridge University Press 2019)

Sheikh AA, 'Patient autonomy and responsibilities within the patient-doctor partnership: two sides of the same unequal coin?' in M Donnelly and C Murray (eds) *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester University Press 2016)

Walker T, 'If they can consent, why can't they refuse?' in M Donnelly and C Murray (eds) *Ethical and Legal Debates in Irish Healthcare: Confronting Complexities* (Manchester University Press 2016)

Journal Articles

Anscombe E, 'Modern Moral Philosophy' (1958) 33 *Philosophy* 1

Beauchamp T, 'Methods and principles in biomedical ethics' (2003) 29 *Journal of Medical Ethics* 269

Betrán AP and others, 'Interventions to Reduce Unnecessary Caesarean Sections in Healthy Women and Babies' (2018) 392 *The Lancet* 1358

Beecher H, 'Ethics and Clinical Research' (1966) 274 *New England Journal of Medicine* 1354

Brazier M, 'Patient autonomy and consent to treatment: the role of the law?' (1987) 7 *Legal Studies* 169

Boerma T and others, 'Global epidemiology of use of and disparities in caesarean sections' (2018) 392 *The Lancet* 1341

Burch TJ, 'Incubator or Individual: The Legal and Policy Deficiencies of Pregnancy Clauses in Living Will and Advance Health Care Directive Statutes' (1995) 54 *Maryland Law Review* 528

Burcher P, 'The Ulysses Contract in Obstetrics: A Woman's Choices Before and During Labour' (2013) 39 *Journal of Medical Ethics* 27

Campbell M, 'Case Note: *Montgomery v Lanarkshire Health Board*' (2015) 44 *Common Law World Review* 222

Cantor NL, 'Conroy, Best Interests, and the Handling of Dying Patients' (1985) 37 *Rutgers Law Review* 543

-- 'The Permanently Unconscious Patient, Non-Feeding and Euthanasia' (1989) 15 *American Journal of Law & Medicine* 381

-- 'Twenty-Five Years After *Quinlan*: A Review of the Jurisprudence of Death and Dying' (2001) 29 *The Journal of Law, Medicine & Ethics* 182

Capron A, 'Informed Consent in Catastrophic Disease Research and Treatment' (1974) 123 *University of Pennsylvania Law Review* 340

Carlin Benton E, 'The Constitutionality of Pregnancy Clauses in Living Will Statutes' (1990) 43 Vanderbilt Law Review 1821

Cave E, 'The Ill-Informed: Consent to Medical Treatment and the Therapeutic Exception' (2017) 46 Common Law World Review 104

Chadwick R and Wilson D, 'The Emergence and Development of Bioethics in the UK' (2018) Medical Law Review 183

Chavkin W and Diaz-Tello F, 'When Courts Fail: Physicians' Legal and Ethical Duty to Uphold Informed Consent' (2017) 1(2) Columbia Medical Review 6

Christmas J, 'Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves' (2004) 117 Philosophical Studies 143

Clouser KD and Gert B, 'A Critique of Principlism' (1990) 15 The Journal of Medicine and Philosophy 219

Cody WK, 'Paternalism in Nursing and Healthcare: Central Issues and their Relation to Theory' (2003) 16 Nursing Science Quarterly 288

Coe CA, 'Beyond Being Mortal: Safeguarding the Rights of People with Developmental Disabilities to Efficacious Treatment and Dignity at the End of Life' (2016) 88 New York State Bar Association Journal 9

Coggon J, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15 Health Care Analysis 235

-- 'Mental Capacity Law, Autonomy, and Best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection' (2016) 24 Medical Law Review 396

Copelton DA, "'You Are What You Eat': Nutritional Norms, Maternal Deviance, and Neutralization of Women's Prenatal Diets' (2007) 28 Deviant Behavior 467

Cook RJ and Dickens BM, 'Human Rights Dynamics of Abortion Law Reform' (2003) 25 Human Rights Quarterly 1

Creedy DK and others, 'Childbirth and the Development of Acute Trauma Symptoms: Incidence and Contributing Factors' (2000) 27 Birth 104

Czarnocka J and Slade P, 'Prevalence and Predictors of Posttraumatic Stress Symptoms following Childbirth' (2000) 39 *British Journal of Clinical Psychology* 35

Davenport EP, 'Court Ordered Cesarean Sections: Why Courts Should Not Be Allowed to Use a Balancing Test' (2010) 18 *Duke Journal of Gender Law & Policy* 79

DeMartino ES and others, 'US State Regulation of Decisions for Pregnant Women Without Decisional Capacity' (2019) 321 *JAMA* 1629

De Londras F, 'Constitutionalizing Fetal Rights: A Salutary Tale from Ireland' (2015) 22 *Michigan Journal Gender & Law* 243

Dixon M, 'A Doctrinal Approach to Property Law Scholarship: Who Cares and Why?' (2014) 3 *Property Law Review* 160

Donley G, 'Encouraging Maternal Sacrifice: How Regulations Governing the Consumption of Pharmaceuticals during pregnancy Prioritize Fetal Safety over Maternal Health and Autonomy' (2015) 39 *New York University Review of Law & Social Change* 45

Donnelly M, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 *Medical Law Review* 1

-- 'Best Interests in the Mental Capacity Act: Time to Say Goodbye' (2016) 24 *Medical Law Review* 318

-- 'Decisions at the End of Life: "The Inimitable Hallmark of the Lawyer"?' (2017) 26 *Medical Law Review* 531

-- 'Developing a Legal Framework for Advance Healthcare Planning: Comparing England & Wales and Ireland' (2017) 24 *European Journal of Health Law* 67

-- 'Deciding in Dementia: The Possibilities and Limits of Supported Decision-making' (2019) 66 *International Journal of Law and Psychiatry* 101466

Doukas DJ, 'Where is the virtue in professionalism?' (2003) 12 *Cambridge Quarterly of Healthcare Ethics* 147

-- 'Promoting Professionalism Through Virtue Ethics' (2019) 19 *The American Journal of Bioethics* 37

Downie RS and Telfer E, 'Autonomy' (1971) 46 *Philosophy* 293

Draper H, 'Women, Forced Caesareans and Antenatal Responsibilities' (1996) 22 *Journal of Medical Ethics* 327

Draper H and Sorrell T, 'Patients' Responsibilities in Medical Ethics' (2002) 16 *Bioethics* 335

Dresser R, 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law' (1986) 28 *Arizona Law Review* 373

-- 'Dworkin on Dementia: Elegant Theory, Questionable Policy' (1995) 25 *Hastings Center Report* 32

Elmir R and others, 'Women's Perceptions and Experiences of a Traumatic Birth: A Meta-ethnography' (2010) 66 *Journal of Advanced Nursing* 2142

English DM, 'Defining the Right to Die' (1993) 56 *Law and Contemporary Problems* 255

Enright M, and others 'Abortion Law Reform in Ireland: A Model for Change' (2015) 5 *Feminists@Law* 12

Evans HM, 'Should Patients be Allowed to Veto Their Participation in Clinical Research?' (2004) 30 *Journal of Medical Ethics* 198

Fagerlin A and Schneider CE, 'Enough: The Failure of the Living Will' (2004) 34 *Hastings Center Report* 30

Feagels PE and others, 'An Analysis of State Legislative Responses to the Medical Malpractice Crisis' (1975) 24 *Duke Law Journal* 1417

Foot P, 'The Problem of Abortion and the Doctrine of Double Effect' (1967) 5 *Oxford Review* 5

Freedman L and others, 'When There's a Heartbeat: Miscarriage Management in Catholic-owned Hospitals' (2008) 98 *American Journal of Public Health* 1774

Gamble ER and others, 'Knowledge, Attitudes, and Behavior of Elderly Persons Regarding Living Wills' (1991) 151 *Archives of Internal Medicine* 277

Gardiner P, 'A Virtue Ethics Approach to Moral Dilemmas in Medicine' (2003) 29 *Journal of Medical Ethics* 297

Gaudin AM, '*Cruzan v. Director, Missouri Department of Health: To Die or Not to Die: That is the Question - But Who Decides?*' (1991) 51 *Louisiana Law Review* 1307

Giacino J and others, 'The Minimally Conscious State: Definition and Diagnostic Criteria' (2002) 58 *Neurology* 349

Giacino J and others, 'Practice Guideline Update Recommendations Summary: Disorders of Consciousness' (2018) 91 *Neurology* 450

Gillon R, 'Justice and Medical Ethics' (1985) 291 *British Medical Journal* 201

-- 'Patients in The Persistent Vegetative State: A Response to Dr. Andrews' (1993) 306 *British Medical Journal* 1602

-- 'Medical Ethics: Four Principles Plus Attention to Scope' (1994) 309 *British Medical Journal* 184

-- 'Persistent Vegetative State, Withdrawal of Artificial Nutrition and Hydration, and the Patient's "Best Interests"' (1998) 24 *Journal of Medical Ethics* 75

-- 'Four Scenarios' (2003) 29 *Journal of Medical Ethics* 267

Glick S, 'The Morality of Coercion' (2000) 26 *Journal of Medical Ethics* 393

Halliday S, 'Advance Decisions and the Mental Capacity Act' (2009) 18 *British Journal of Nursing* 697

-- 'Legislating to Give Effect to Precedent Autonomy: Comparative Reflections on Legislative Incompetence' (2011) 11 *Medical Law International* 127

-- and Witteck L, 'Decision - Making At The End Of Life and The Incompetent Patient: A Comparative Approach' (2003) 22 *Medicine and Law* 533

Harris J, 'In Praise of Unprincipled Ethics' (2003) 29 *Journal of Medical Ethics* 303

Harrod RF, 'Utilitarianism Revised' (1936) 45 *Mind* 137

Harsanyi J, 'Morality and the Theory of Rational Behavior' (1977) 44 *Social Research* 623

Heywood R, 'Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages' (2015) 23 *Medical Law Review* 81

Holm S, 'Not Just Autonomy – The Principles of American Biomedical Ethics' (1995) 21 *Journal of Medical Ethics* 332

-- and Edgar A, 'Best Interest: A Philosophical Critique' (2008) 16 *Health Care Analysis* 197

Huxtable R, 'Autonomy, Best Interests and the Public Interest: Treatment, Non-Treatment and the Values of Medical Law' (2014) 22 *Medical Law Review* 459

Ionescu CA and others, 'Defensive Caesarean Section: A Reality and a Recommended Health Care Improvement for Romanian Obstetrics' (2019) 25 *Journal of Evaluation in Clinical Practice* 111

Jackson E, 'From 'Doctor Knows Best' to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment' (2018) 81 *Modern Law Review* 247

Jarvis Thomson J, 'A Defense of Abortion' (1971) 1 *Philosophy and Public Affairs* 47

Jennett B and Plum F, 'Persistent Vegetative State after Brain Damage: A Syndrome in Search of a Name' (1972) 299 *The Lancet* 734

Kaplan M, "'A Special Class of Persons": Pregnant Women's Right to Refuse Medical Treatment After *Gonzales v Carhart*' (2010) 13 *University of Pennsylvania Journal of Constitutional Law* 145

Kluge EH, 'When Caesarian Section Operations Imposed by a Court Are Justified' (1988) 14 *Journal of Medical Ethics* 206

Kutner L, 'Due Process of Euthanasia: The Living Will, A Proposal' (1969) 44 *Indiana Law Journal* 539

Killmister S, 'Dignity: Not Such A Useless Concept' (2010) 36 *Journal of Medical Ethics* 160

Kirby MD, 'Informed Consent: What Does It Mean?' (1983) 9 *Journal of Medical Ethics* 69

Levin P and Sprung C, 'Withdrawing and Withholding Life-sustaining Therapies are Not The Same' (2005) 9 Critical Care 230

Lewis P, 'Procedures that are Against the Medical Interests of Incompetent Adults' (2002) 22 Oxford Journal of Legal Studies 575

-- 'Withdrawal of treatment from a Patient in a Permanent Vegetative State: Judicial Involvement and Innovative "Treatment"' (2007) 15 Medical Law Review 392

Lindgren J, 'Death by Default' (1993) 56 Law and Contemporary Problems 185

Loewenstein G, 'Projection Bias in Medical Decision Making' (2005) 25 Medical Decision Making 96

Lyerly A and others, 'Risk and the Pregnant Body' (2009) 39 The Hastings Center Report 34

Lyons B, 'The Irish Council for Bioethics: An Unaffordable Luxury?' (2012) 21 Cambridge Quarterly of Healthcare Ethics 375

Macklin R, 'Applying the four principles' (2003) 29 Journal of Medical Ethics 275

MacKinnon CA, 'Reflections on Sex Equality under Law' (1991) 100 Yale Law Journal 1281

McCall Smith A, 'Beyond Autonomy' (1997) 14 J Journal of Contemporary Health Law and Policy 23

Melltorp G and Nilstun T, 'The Difference Between Withholding and Withdrawing Life-sustaining Treatment' (1997) 23 Intensive Care Medicine 1264

Meyer M, 'Patients' Duties' (1992) 17 The Journal of Medicine and Philosophy 541

Misselbrook D, 'Virtue Ethics – An Old Answer to a New Dilemma? Part 1. Problems with Contemporary Medical Ethics' (2015) 108 Journal of the Royal Society of Medicine 53

-- 'Virtue Ethics – An Old Answer to a New Dilemma? Part 2. The case for inclusive virtue ethics' (2015) 108 Journal of the Royal Society of Medicine 89

Mulheron R, 'Has Montgomery Administered the Last Rites to Therapeutic Privilege? A Diagnosis and a Prognosis' (2017) 70 Current Legal Problems 149

Mulligan A, 'Maternal Brain Death and Legal Protection of the Foetus in Ireland Case Review' (2015) 15 *Medical Law International* 182

Ott BB, 'Advance Directives: The Emerging Body of Research' (1999) 8 *American Journal of Critical Care* 514

Paltrow L and Flavin J, 'Arrests of and Forced Interventions on Pregnant Women in the United States, 1973-2005: Implications for Women's Legal Status and Public Health' (2013) 38 *Journal of Health Politics, Policy and Law* 299

Pope TM, 'Legal Briefing: Unwanted Caesareans and Obstetric Violence' (2017) 28 *The Journal of Clinical Ethics* 163

Regan JJ, 'Refusing Life-Sustaining Treatment for Incompetent Patients: New York's Response to Cruzan' (1991) 19 *New York University Review of Law & Social Change* 341

Reich W, 'The Wider View: André Hellenger's Passionate, Integrating Intellect and the Creation of Bioethics' (1999) *Kennedy Institute of Ethics Journal* 25

Rhoden N, 'How Should We View the Incompetent?' (1989) 17 *Law, Medicine and Health Care* 264

Ruck Keene A and Auckland C, 'More Presumptions Please? Wishes, Feelings and Best Interests Decision-Making' (2015) 5 *Elder Law Journal* 293

-- and Lee A, 'Withdrawing Life-Sustaining Treatment: A Stock-Take of the Legal and Ethical Position' (2019) 45 *Journal of Medical Ethics* 794

Ryan C, 'Betting your life: an argument against certain advance directives' (1996) 22 *Journal of Medical Ethics* 95

Sandall J and others, 'Short-term and Long-term Effects of Caesarean Section on the Health of Women and Children' (2018) 392 *The Lancet* 1349

Savulescu J, 'Two Worlds Apart: Religion and Ethics' (1998) 24 *Journal of Medical Ethics* 382

-- and others, 'Philosophical Medical Ethics: More Necessary Than Ever' (2018) 44 *Journal of Medical Ethics* 434

Schiff R and others, 'Views of Elderly People on Living Wills: Interview Study' (2000) 320 British Medical Journal 1640

-- and others, 'Living Wills and the Mental Capacity Act: A Postal Questionnaire Survey of UK Geriatricians' (2006) 35 Age and Ageing 116

Schroeder D, 'Dignity: Two Riddles and Four Concepts' (2008) 17 Cambridge Quarterly of Healthcare Ethics 230

Scott R, 'The Pregnant Woman and the Good Samaritan: Can a Woman Have a Duty to Undergo a Caesarean Section?' (2000) 20 Oxford Journal of Legal Studies 407

Sepper E, 'Taking Conscience Seriously' (2012) 98 Virginia Law Review 1501

Singer P, 'Famine, Affluence and Morality' (1972) 1 Philosophy and Public Affairs 229

-- 'Voluntary Euthanasia: A Utilitarian Perspective' (2003) 17 Bioethics 526

Skari H and others, 'Comparative Levels of Psychological Distress, Stress Symptoms, Depression and Anxiety after Childbirth — A Prospective Population-based Study of Mothers and Fathers' (2002) 109 British Journal of Obstetrics and Gynaecology 1154

Skowron P, 'Giving Substance to 'the Best Interpretation of Will and Preferences' (2019) 62 International Journal of Law and Psychiatry 125

Slevin ML and others, 'Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public. (1990) 300 British Medical Journal 1458

Smith C, 'Origin and Uses of *Primum Non Nocere*— Above All, Do No Harm!' 45 Journal of Clinical Pharmacology 371

Sokol DK, 'First Do No Harm Revisited' (2013) 347 British Medical Journal 23

Stern K, 'Court-Ordered Caesarian Sections: In Whose Interests?' (1993) 56 Modern Law Review 238

Stutz L, 'Myth of Protection: Florida Courts Permitting Involuntary Medical Treatment of Pregnant Women' (2013) 67 University of Miami Law Review 1039

Takala T, 'What Is Wrong with Global Bioethics? On the Limitations of the Four Principles Approach' (2001) 10 Cambridge Quarterly of Healthcare Ethics 72

Taylor HJ, 'What are 'Best Interests'? A Critical evaluation of 'Best Interests' Decision-Making in Clinical Practice' (2016) 24 Medical Law Review 176

The Multi-Society Task Force on PVS, 'Medical Aspects of the Persistent Vegetative State' (1994) 330 New England Journal of Medicine 1499

Tussing DA and Wojtowycz M, 'Malpractice, Defensive Medicine, and Obstetric Behavior' (1997) 35 Medical Care 172

Vollmann J, 'Advance Directives in Patients with Alzheimer's disease; Ethical and Clinical Considerations' (2001) 4 Medicine, Health Care and Philosophy 161

Woollard F, 'Motherhood and Mistakes about Defeasible Duties to Benefit' (2018) 97 Philosophy and Phenomenological Research 126

Yadav KN and others, 'Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care' (2017) 36 Health Affairs 1244

Zartman JN, 'The Legacy of Cruzan' (1991) 5 Journal of Probate & Property 13

Zuckerman S and others, 'Information on Malpractice: A Review of Empirical Research on Major Policy Issues' (1986) 49 Law and Contemporary Problems 85

Research Papers and Research Reports

Hill EL and others 'Reproductive Health Care in Catholic-Owned Hospitals' (2017) National Bureau of Economic Research Research Paper 23768 <<https://www.nber.org/papers/w23768.pdf>> accessed 9 September 2020.

Irish Maternity Support Network 'Report of the Irish Maternity Support Network to the UN Special Rapporteur on Women on Mistreatment and Violence against Women during Reproductive Health Care with a Focus on Childbirth' (17 May 2019)

Pew Research Center (2006) 'Strong Public Support for Right to Die: More Americans Discussing — and Planning — End-of-Life Treatment.' Telephone survey of 1,500 older adults conducted November 9th-27th, 2005 under the direction of Princeton Survey Research

Associates International <<http://people-press.org/report/266/strongpublic-support-for-right-to-die>>

Parliamentary Reports

Ireland

Dáil Deb 8 June 2012 <<https://www.oireachtas.ie/en/debates/debate/dail/2012-06-08/2/>>

Dáil Deb 17 December 2015 <<https://www.oireachtas.ie/en/debates/debate/dail/2015-12-17/16/>>

Dáil Deb 28 March 2019, [14560/19] <<https://www.oireachtas.ie/en/debates/question/2019-03-28/107/>>

Seanad Deb 21 February 2007 <<https://www.oireachtas.ie/en/debates/debate/seanad/2007-02-21/9/>>

Official / Government Documents

International

World Health Organization (Department of Reproductive Health and Research) ‘Statement on Caesarean Section Rates’ (April 2015) RHR/15.02 <https://apps.who.int/iris/bitstream/handle/10665/161442/WHO_RHR_15.02_eng.pdf;jsessionid=25C9CB8E680887F5C8D83BBF2CB52221?sequence=1>

England and Wales

Department of Constitutional Affairs, *Government Response to the Scrutiny Committee's Report on the Draft Mental Incapacity Bill* (Cm 6121, 2004)

National Health Service, *Long Term Plan* (2018) <<https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/>>

National Health Service, *NHS Maternity Statistics, England 2017-18* (2018) <<https://files.digital.nhs.uk/C3/47466E/hosp-epis-stat-mat-summary-report%202017-18.pdf>>

National Health Service, *Drinking Alcohol While Pregnant* (2020) <<https://www.nhs.uk/conditions/pregnancy-and-baby/alcohol-medicines-drugs-pregnant/>>

The Rt Hon Lord Archer, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products* (2009) <https://archercbbp.files.wordpress.com/2017/01/76_lord-archer-report.pdf>

Ireland

Department of Health *National Maternity Strategy – Creating a Better Future Together 2016-2026* (2016) <<https://www.gov.ie/en/publication/0ac5a8-national-maternity-strategy-creating-a-better-future-together-2016-2/>>

Department of Health *Tribunal of Inquiry into the Infection with HIV and Hepatitis C of Persons with Haemophilia and Related Matters* (2002) <<https://health.gov.ie/wp-content/uploads/2014/04/Tribunal-of-Inquiry-into-the-Infection-with-HIV-and-Hep-C-of-persons-with-Haemophilia-and-Related-Matters.pdf>>

Health Service Executive ‘Alcohol during pregnancy’ (2018) <<https://www2.hse.ie/wellbeing/child-health/alcohol-during-pregnancy.html>>

Health Service Executive *Irish Maternity Indicator System National Report 2018* (2019) <<https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/national-reports-on-womens-health/imis-national-report-2018.pdf>>

National Consent Advisory Group of the Health Service Executive ‘National Consent Policy’ (2019) <<https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national-consent-policy-hse-v1-3-june-2019.pdf>>

United States

New York State Office of the Attorney General, (2017) ‘Advance Directives: Making Your Wishes Known And Honored’ <<https://ag.ny.gov/sites/default/files/advancedirectives.pdf>>

New York State Department of Health, *Medical Orders for Life-Sustaining Treatment (MOLST) Form* <<https://www.health.ny.gov/forms/doh-5003.pdf>>

New York State Task Force on Life and the Law, *When Others Must Choose: Deciding for Patients Without Capacity* (New York 1992)

President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, *Summing Up: Final Report on Studies of Ethical Problems in Medicine and Behavioral Research* (1983)

https://repository.library.georgetown.edu/bitstream/handle/10822/559377/summing_up.pdf?sequence=4&isAllowed=y

Dondero TJ and others 'Human Immunodeficiency Virus Infection in the United States: A Review of Current Knowledge' (1987) 36 CDC Morbidity and Mortality Weekly Report 1

United States Senate, 'Death with Dignity: Hearings before the Special Committee on Aging', 92nd Cong. (Testimony of Walter W Sackett)

Law (Reform) Commission Papers

England and Wales

Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview* (Law Com No 119, 1991)

Law Commission, *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction* (Law Com No 128, 1993)

Law Commission, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research* (Law Com No 129, 1993)

Law Commission, *Mentally Incapacitated and Other Vulnerable Adults: Public Law Protection* (Law Com No 130, 1993)

Law Commission, *Mental Incapacity* (Law Com No 231, 1995) and Draft Mental Incapacity Bill 1995

Ireland

Law Reform Commission, *Consultation Paper on Law and the Elderly* (LRC CP 23–2003)

Law Reform Commission, *Report on Vulnerable Adults and the Law* (LRC 83-2006)

Law Reform Commission, Consultation Paper on Bioethics: Advance Care Directives (LRC CP 51 - 2008)

Law Reform Commission, Report on Bioethics: Advance Care Directives (LRC 94 – 2009)

Professional Guidelines / Codes of Practice

International

World Medical Association (1949) ‘International Code of Medical Ethics’ <<https://www.wma.net/wp-content/uploads/2018/07/International-Code-of-Medical-Ethics-1949.pdf>>

World Medical Association (1964) ‘Declaration of Helsinki: Ethical principles for Medical Research Involving Human Subjects’ <<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>>

World Medical Association (1991) ‘Declaration of Malta on Hunger Strikers’ <<https://www.wma.net/policies-post/wma-declaration-of-malta-on-hunger-strikers/>>

World Medical Association (2006) ‘International Code of Medical Ethics’ <<file:///C:/Users/afinnerty/Downloads/wma-international-code-of-medical-ethics.pdf>>

England and Wales

British Medical Association, *Medical Ethics Today: Its practice and philosophy* (BMJ Publishing 1998)

Code of Practice accompanying the Mental Capacity Act 2005

Royal College of Physicians Prolonged Disorders of Consciousness: National Clinical Guidelines (London 2013)

Royal College of Physicians Prolonged Disorders of Consciousness following Sudden Onset Brain Injury: National Clinical Guidelines (London 2020)

Royal College of Obstetricians and Gynaecologists *Obtaining Valid Consent* (Clinical Governance Advice No. 6, 2015)

Ireland

Medical Council ‘Guide to Professional Conduct and Ethics for Registered Medical Practitioners (Amended)’ (2019) <<https://www.medicalcouncil.ie/news-and-publications/reports/guide-to-professional-conduct-and-ethics-8th-edition-2016-.pdf>>

United States

American College of Obstetricians and Gynecologists Committee on Ethics, *Refusal of Medically Recommended Treatment During Pregnancy* (Number 664, 2016)

American Medical Association, ‘Code of Ethics Opinion 2.1.3: ‘Withholding Information from Patients’’ <<https://www.ama-assn.org/delivering-care/ethics/withholding-information-patients>>

American Medical Association, ‘Code of Ethics Opinion 2.1.1: ‘Informed Consent’’ <<https://www.ama-assn.org/delivering-care/ethics/informed-consent>>

American Medical Association, *Legal Interventions During Pregnancy* (Policy H-420.969, 2018)

Conferences / Seminars

Lombard J, ‘Healthcare Decision-Making and the Older Person: Experience and Insights’ (Healthcare Decision-Making and the Law Seminar, Limerick, 5 December 2019)

Websites and Blogs

American Association of Retired Persons Bulletin Poll ‘Getting Ready to Go’ (January 2008) <https://assets.aarp.org/rgcenter/il/getting_ready.pdf>

American Civil Liberties Union ‘Drug Use and Pregnancy in Tennessee’ <<https://www.aclu-tn.org/wp-content/uploads/2016/09/Fetal-Assault-Direct-Impact.pdf>>

Beauchamp T, ‘The Principle of Beneficence in Applied Ethics’ *The Stanford Encyclopedia of Philosophy* (Spring edn, 2019) <<https://plato.stanford.edu/entries/principle-beneficence/>>

Birthrights and Birth Companions, ‘Holding It All Together: Understanding How Far the Human Rights of Women Facing Disadvantage are Respected during Pregnancy, Birth and

Postnatal Care' (2019) <<https://www.birthrights.org.uk/wp-content/uploads/2019/09/Holding-it-all-together-Full-report-FINAL-Action-Plan.pdf>>

Catholic Health Association of the United States <<https://www.chausa.org/about/about>>

Center for Disease Control 'The Tuskegee Timeline' <www.cdc.gov/tuskegee/timeline.htm>

Freidlin DL and Mobilia TA, 'Informed Consent Considerations for Mammography in Women with Breast Implants' (2019) <https://www.martindale.com/legal-news/article_martin-clearwater-bell-llp_2522638.htm>

Guengerich T, 'Caregiving and End-of-Life Issues: A Survey of AARP Members in Florida' 2009 <https://assets.aarp.org/rgcenter/il/fl_eol_08.pdf>

Hastings Center <<https://www.thehastingscenter.org/>>

Inclusion Ireland, 'Who Decides & How? People with Intellectual Disabilities - Legal Capacity & Decision Making' <<http://www.inclusionireland.ie/content/page/publications-who-decides-how-people-intellectual-disabilities-legal-capacity-decision>>

Kennedy Institute of Ethics <<https://kennedyinstitute.georgetown.edu/about/mission/>>

Kitzinger C, 'Advance Requests for Restraint and Compulsory Treatment' (*Open Justice: Court of Protection Project*, 28 September 2020) <<https://openjusticecourtofprotection.org/2020/09/28/advance-requests-for-restraint-and-compulsory-treatment/#comments>>

Nuffield Council on Bioethics <<http://nuffieldbioethics.org/about>>

O'Mahony C, 'Squaring Circles: Recent Case Law on Medical Decision-Making and the Unborn' (*Constitution Project @ UCC*, 3 November 2016) <<http://constitutionproject.ie/?p=593>>

Patients Association of the United Kingdom <www.patients-association.org.uk/background>

Scottish Council on Human Bioethics <<http://www.schb.org.uk/about/>>

UNESCO Chair in Bioethics (Irish Unit) <<https://unescobioethicsireland.eu/home/aims-objectives/>>

World Health Organization, 'Millennium Development Goals' (2000) <https://www.who.int/topics/millennium_development_goals/about/en/>

Newspaper Articles

— 'Clinical trial of cancer drug deferred' *Irish Times* (Dublin, 3 October 2005) <<https://www.irishtimes.com/news/clinical-trial-of-cancer-drug-deferred-1.500245>>

— 'Court won't halt abortion on N.Y. Woman in Coma' *Los Angeles Times* (Los Angeles, 11 Feb 1989) <<https://www.latimes.com/archives/la-xpm-1989-02-11-mn-1772-story.html>>

Baker N, 'Clinic Insists Couples Must be Married to Get Fertility Treatment' *Irish Examiner* (Cork, 15 April 2010) <<https://www.irishtimes.com/news/arid-20117246.html>>

Belkin L, 'New York Rule Compounds Dilemma Over Life Support' *New York Times* (New York, 12 May 1992) <<https://www.nytimes.com/1992/05/12/us/new-york-rule-compounds-dilemma-over-life-support.html>>

Boylan P, 'National Maternity Hospital Concerns' (Letters to the Editor) *Irish Times* (Dublin, 22 May 2020) <<https://www.irishtimes.com/opinion/letters/national-maternity-hospital-concerns-1.4259557>>

Breeden A, 'Hours After French Patient Is Taken Off Life Support, a Court Orders It Be Restored' *The New York Times* (New York, 20 May 2019) <<https://www.nytimes.com/2019/05/20/world/europe/france-vincent-lambert-life-support.html>>

Campbell K, 'I needed surgery but because I was pregnant, I was left to rot' *Irish Times* (Dublin, 19 May 2018) <<https://www.irishtimes.com/life-and-style/health-family/i-needed-surgery-but-because-i-was-pregnant-i-was-left-to-rot-1.3500349>>

Carolan M, 'Mentally Ill Woman Can be Given Caesarean, Court Rules' *Irish Times* (Dublin, 13 March 2017) <<https://www.irishtimes.com/news/crime-and-law/courts/high-court/mentally-ill-woman-can-be-given-caesarean-court-rules-1.3008603>>

Chini M, 'Belgian Woman (90) Dies after Refusing Ventilator' *The Brussels Times* (Brussels, 1 April 2020) <<https://www.brusselstimes.com/belgium/104108/coronavirus-belgian-woman-90-dies-after-refusing-ventilator/>>

Hogan C, 'Catholic Church's Influence over Irish Hospital Medicine Persists' *Irish Times* (Dublin, 28 April 2016) <<https://www.irishtimes.com/opinion/catholic-church-s-influence-over-irish-hospital-medicine-persists-1.2626856>>

Holland K, 'Reasons For Women Not To Be Cheerful' *Irish Times* (Dublin, 29 December 2012) <<https://www.irishtimes.com/news/reasons-for-women-not-to-be-cheerful-1.5496>>

Higgin S and others 'The National Maternity Hospital Project' (Letters to the Editor) *Irish Times* (Dublin, 21 May 2020) <<https://www.irishtimes.com/opinion/letters/the-national-maternity-hospital-project-1.4258455>>

Grant R, 'Ethics of the delivery room: Who's in control when you're giving birth?' *The Independent* (London, 18 December 2017) <https://www.independent.co.uk/news/long_reads/childbirth-delivery-room-ethics-doctor-patient-healthcare-a8085346.html>

Nessman R, 'Karen Ann Quinlan's Parents Reflect on Painful Decision 20 Years Later' *Los Angeles Times* (Los Angeles, 7 April 1996) <<https://www.latimes.com/archives/la-xpm-1996-04-07-mn-55744-story.html>>

O'Doherty C, 'Anti-D scandal was a bloody disgrace' *Irish Examiner* (Cork, 21 February 2014) <www.irishexaminer.com/viewpoints/analysis/anti-d-scandal-was-a-bloody-disgrace-259488.html>

Riding A, 'Scandal Over Tainted Blood Widens in France' *The New York Times* (New York, 13 February 1994) <www.nytimes.com/1994/02/13/world/scandal-over-tainted-blood-widens-in-france.html>

Russell C, 'Religion and health care: What role does the Catholic Church play in Irish hospitals?' *The Journal* 30 April 2017 <<https://www.thejournal.ie/religion-health-care-catholic-church-3360849-Apr2017/>>

Schmitt E, 'Two Men Who Fought L.I. Abortion' *The New York Times* <<https://www.nytimes.com/1989/02/13/nyregion/two-men-who-fought-li-abortion.html>>

Stockman F, 'Manslaughter Charge Dropped Against Alabama Woman Who Was Shot While Pregnant' *The New York Times* (New York, 3 July 2019) <<https://www.nytimes.com/2019/07/03/us/charges-dropped-alabama-woman-pregnant.html>>