“... my life is so inhibited by the fact that I am unable to drive...” A study examining the effect of epilepsy on driving

"… my life is so inhibited by the fact that I am unable to drive…" A study examining the effect of epilepsy on driving

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Abstract

Driving is a job, a hobby and a form of transport that enables occupation. It is both an occupation and an occupation enabler. This study investigated the impact of the inability to drive due to epilepsy on community mobility and occupational participation. Data was collected through an internet based survey. Quantitative data was analysed using Statistical Package for the Social Sciences (SPSS) and content analysis was used with qualitative data.

Brainwave, the Irish Epilepsy Association acted as gatekeeper. The survey received 95 eligible participants. When unable to drive, the main mode of transport was lifts from friends and relatives. Participants did also use public transport more than the general population. As a result people experienced restricted access to places, had to give up activities, had a reduced quality of life and a lowered self perception. Significantly more men than women felt that driving cessation had a negative impact on romantic relationships ($p=0.024$). Significantly more people diagnosed in adulthood than those diagnosed in childhood felt that driving cessation negatively impacted both the cost of transport ($p=0.035$) and their quality of life ($p=0.029$). The role of occupational therapy in the area of driving and community mobility was identified.

Introduction

A driving licence is held by 2.65 million people in Ireland (RSA 2009). Some people drive as an integral part of their job, others drive to get from one place to another and others drive for leisure. Driving is the most common form of transport in Ireland used to get to work (CSO 2011). Driving is an occupation (AOTA 2008) but also an occupation enabler since it facilitates access to and participation in other daily occupations and the in the community (Stav 2008). The participation in occupations is necessary for health and wellbeing (Wilcock 1993). Occupational therapists work with people to maximise independence and to ensure safety in occupations including driving (Whitehead *et al* 2006).

Some people, due to medical conditions, never have the opportunity to obtain a driving licence or are forced to stop driving for period/s of time. Epilepsy is a condition where seizures caused by abnormal brain activity can alter consciousness. It can be present from birth or can develop at any age due to various causes. Currently, there is no cure but many people manage to control their seizures through the use of anti-epilepsy drugs (Shorvon 2010). There are approximately 36,000 people in Ireland with epilepsy (Linehan *et al* 2010).

The aim of the study was to determine the impact of epilepsy on driving and community mobility. This involved addressing two main objectives.

1. Investigating the impact of the inability to drive due to epilepsy in terms of occupational disruption, community mobility, social participation and well being.
2. Identifying areas for occupational therapy involvement with people who are unable to drive due to epilepsy.

Literature Review

Driving cessation is related to increased depressive symptoms (Fonda *et al* 2001, Ragland *et al* 2005). With driving cessation comes a loss of independence and freedom (Bauer *et al* 2003, Whitehead *et al* 2006, Alder and Rottunda 2006, Scannell and Buckley 2011), decreased activity levels (Liddle and McKenna 2003) reduced out of home activities, community mobility and social interaction (Marottoli *et al* 2000). Several of these studies

involved small sample sizes meaning that the results were only relevant to specific populations (Bauer *et al* 2003, Whitehead *et al* 2006, Alder and Rottunda 2006). The inability to drive causes challenges in regard to employment, medical access, school and activities of daily living (Bautista and Wludyka 2006, Fisher *et al* 2000). Driving cessation is a life transition (Liddle *et al* 2004) which impacts on occupational identity, causes occupational disruption and restricts occupational participation (Vrkljan and Polgar 2007).

Life transitions require people to change their routines and roles and impact on peoples' health and well being (Liddle *et al* 2004). The focus of most previous research into driving and epilepsy, has been the laws regarding driving and epilepsy. Most previous research on the impact of driving cessation concerned the older population. The transition to driving cessation in epilepsy differs from that in older people. Epilepsy can result in driving cessation at any age and is usually sudden. In older people driving cessation is often a gradual transition.

People diagnosed with epilepsy may be at risk of having a seizure while driving. This could endanger both the driver and other road users (Lossius *et al* 2011). For this reason there are European regulations, EU directive 208/112 EC, concerning epilepsy and driving. They require a one-year seizure free period in order to drive a group one vehicle (cars, vans, motorcycles) and require a 10 year seizure and epilepsy drug free period for group two vehicles (heavy goods vehicles, busses and lorries) (RSA 2010).

Participation in society is very much determined by the ability to move around the community (WHO 2007). The lack of suitable and reliable transport is a significant issue for people with epilepsy (Bautista and Wludyka 2006). During periods of driving cessation, people are reliant on family members for lifts (Azad *et al* 2002, Bauer *et al* 2003). This reliance causes increased stress on family members (Bauer *et al* 2003, Fonda *et al* 2001, Azad *et al* 2002) and reduces independence and spontaneity (Bauer *et al* 2003, Vrkljan and Polgar 2007).

Internationally occupational therapists play a role both in community mobility and driver education (Steultjens *et al* 2004). To date in Ireland there are no guidelines concerning the role of occupational therapists in the process of assessing fitness to drive (IMO 2009). Few people with epilepsy in Ireland have access to an occupational therapy service during periods of driving cessation.

There is a high desire by people with epilepsy to obtain a driving licence (Rajna *et al* 2003). Driving restrictions are both an important concern (Gilliam *et al* 1997) and one of the most common causes for dissatisfaction in people with epilepsy (Fisher *et al* 2000, Sare *et al* 2007). However, the study by Sare *et al* (2007) included only men. The desire to drive is also evident from studies which have found people with epilepsy not abiding by the driving regulations (Bautista and Wludyka 2006, Berg *et al* 2000, Elliott and Long 2008, Dickey and Morrow 1993, Drazkowski *et al* 2010).

Method

A quantitative survey methodology was selected for this study since surveys are useful for describing characteristics of a large population (Polgar and Thomas 2008). Brainwave, the Irish Epilepsy Association, acted as gatekeeper for the study and identified that a large number of their members were contactable electronically. The electronic survey was anonymous and self administered. This method is convenient for respondents and increases the reliability of the survey since there is no interviewer variability and each participant is presented with the same information in the same way (Vogt 2007). It would not have been possible to access as many participants using a qualitative methodology in the same time frame. Given the dearth of information about the population concerned, it was considered that it was important to first identify information about the population before identifying the reasons behind their behaviours. This could be best achieved through a survey methodology.

Ethical approval was obtained for the study from the University of Limerick Faculty of Education and Health Sciences Research Ethics Committee. Data was collected through an online survey which asked for mostly quantitative data but also included the option for participants to give qualitative comments. The survey was designed based on surveys found in similar studies (Fisher *et al* 2000, Talbot *et al* 2005, Azad *et al* 2002, Bautista and Wludyka 2006, O'Driscoll and Buckley 2010). This improves the reliability and validity of the survey (Bryman 2008). Information for participants was available prior to starting the survey and consent was assumed through participation in the survey. Contact information was provided on the information page prior to commencing the survey to allow people to

contact the principal researcher with any concerns (Appendix A). A pilot study involving five participants was conducted to ensure the questions were understood and the survey operated correctly. Data from the pilot study was not used as part of the overall results.

The survey was advertised through the Brainwave webpage, *facebook* page, *twitter* page and *e-zine* (electronic newsletter). Convenience sampling was used. The survey was available online for 11 weeks. After initially advertising the survey, a reminder was posted on the Brainwave webpage, *facebook* page and *twitter* page one month later. The *e-zine* was sent out seven weeks after the survey went live. An email was sent to Brainwave to post the update and Brainwave carried out the updates to the electronic media. The eligibility criteria are detailed in table 1.

Table 1

Inclusion Criteria	**Exclusion Criteria**
People living in the Republic of Ireland	People living outside of the Republic of Ireland
People aged over 18	People aged under 18
People who have experienced a period of at least one year driving cessation due to epilepsy	People who have not experienced a period of at least one year driving cessation due to epilepsy
People who have never driven due to epilepsy	People who have never driven due to medical conditions other than epilepsy
People who can read and write in English	People who cannot read and write in English
People who have access to a computer	People who do not have access to a computer
People who visit or receive Brainwave information and publications (note people do not have to be a member of Brainwave to access some of the Brainwave publicity)	People who do not visit or receive any Brainwave information or publications
	People who have experienced driving cessation for another reason (for example penalty points or a court driving conviction)

The survey collected the following information: (See Appendix B for a copy of the survey)

- Impact of Epilepsy on Driving and accessing Occupations
- Demographic data
- Epilepsy Experience

Only anonymous data was collected and questions were structured in a way to maximise anonymity such as the grouping of age ranges and locations. Although most of the questions on the survey were innocuous, some of the survey items concerned issues which could trigger an emotional response. Participants were able to skip questions they did not feel comfortable answering and were able to exit the survey at any point.

Quantitative data was analysed using *Statistical Package for the Social Sciences version 18* (SPSS). Descriptive statistics were used to analyse frequencies of responses. Data was recoded into fewer categories where multiple response categories had been offered. Cross tabulation of results was performed to compare frequencies of responses by different groups. The Pearson Chi squared test and the Fisher's Exact test (2 sided) were used to analyse the difference in responses by various groups of participants (Watson *et al* 2006). Statistical significance was carried out at the 5% level of significance (Watson *et al* 2006). Qualitative data was analysed using content analysis (Pole and Lampard 2002). All electronic data was stored on a password protected computer. Electronic data will be safely stored for seven years, after which all electronic files will be deleted. No paper files will be kept.

Results

Demographic Information

The survey received 95 eligible participants. Thirty nine (41.1%) participants were able to drive at the time of the study but had previously experienced a period of driving cessation, 29 (30.5%) participants had driven previously but were not permitted to drive at the time of the study and 27 (28.4%) participants had never driven due to epilepsy. More than twice as many women (64) as men (30) responded to the survey. No participants were aged over 65. The majority (73, 76.8%) of participants lived in a household where someone else could drive. Just over a third (32, 34.0%) of participants came from Dublin city and county. Thirty nine (41.1%) of participants were diagnosed with epilepsy before the age of 18. Epilepsy prevented 16.8% (16) from being able to work and 5.3% (5) were unable to work due to another sickness or disability. See table 2 for demographic details.

Table 2

Demographic Information	**n**	*%*
Present driving situation	**95**	
Licensed to drive at time of study but previously experienced a period of driving cessation due to epilepsy	39	*41.1%*
Not licensed to drive at time of study due to epilepsy but previously been licensed to drive	29	*30.5%*
Never driven due to epilepsy	27	*28.4%*
Gender	**94**	
Male	30	*31.9%*
Female	64	*68.1%*
Age	**95**	
18-25	20	*21.1%*
26-35	35	*36.8%*
36-45	23	*24.2%*
46-55	13	*13.7%*
56-65	4	*4.2%*
Principle Work Status	**95**	
Working for payment / Working voluntarily	49	*51.6%*
Looking after home / family	6	*6.3%*
Unemployed / Looking for first job	8	*8.5%*
Student	11	*11.6%*
Unable to work due to epilepsy	16	*16.8%*
Unable to work due to other sickness or disability	5	*5.3%*
Where do you live?	**94**	
The countryside / rural area	22	*23.4%*
A village / town	27	*28.7%*
Another city	13	*13.8%*
Dublin	32	*34.0%*
Living Situation	**95**	
Living alone / House sharing / Living with friends	16	*16.8%*
Living with partner / family / parents	79	*83.2%*
Do any of the other members of your household drive?	**95**	
Yes	73	*76.8%*
No	22	*23.2%*
Age of Epilepsy Diagnosis	**95**	
Birth – 17	39	*41.1%*
18 and above	56	*58.9%*

Note: Percentages are based on those who responded to each separate question and not the overall number of participants in the survey

Driving Practices

Questions regarding previous driving practices were only addressed to participants who had at some point been licensed to drive (n=68). Most (49, 73.1%) respondents had obtained their license before being diagnosed with epilepsy. Fifteen (22.1%) had driven illegally due to epilepsy and six (8.8%) had misrepresented their seizures in order to keep their license. One participant commented *"I think they (the regulations) are excessive, and generally used my own judgement"*. See table 3 for details.

Table 3

Driving Experience	**n**	%
When did you first obtain your driver license?	**67**	
Before being diagnosed with epilepsy	49	73.1%
After being diagnosed with epilepsy	18	26.9%
When driving, how many kilometres did you typically drive per day?	**68**	
Less than 10 kilometres	19	27.9%
10-25 kilometres (6-15 miles)	24	35.3%
26-40 kilometres (16-25 miles)	12	17.7%
More than 40 kilometre (25 miles)	13	19.1%
Have you ever misrepresented your seizures to your doctor in order to keep your license?	**68**	
Yes	6	8.8%
No	62	91.2%
Have you ever driven illegally due to epilepsy?	**68**	
Yes	15	22.1%
No	53	77.9%
Do you think the regulations concerning driving and epilepsy are fair?	**66**	
Yes	42	63.6%
No	24	36.4%

Note: Percentages are based on those who responded to each separate question and not the overall number of participants in the survey

Community Mobility

During periods of driving cessation, the most commonly used form of transport was lifts for all occupations. Sixty four percent (57) of participants used lifts to get to leisure activities, 54.8% (51) for medical appointments, 49.5% (46) for shops and 38.6% (32) for work/study. Public transport (36.1%, 30) was most used for accessing work/study. See figures 1-4 and table 4.

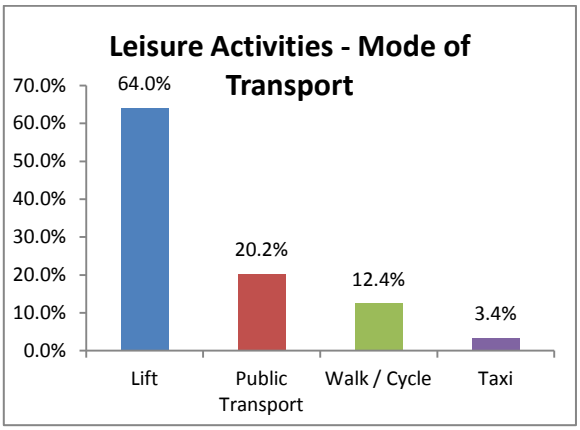

Figure 1

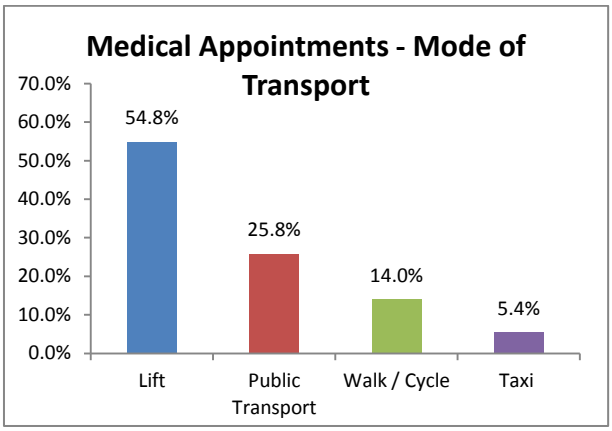

Figure 2

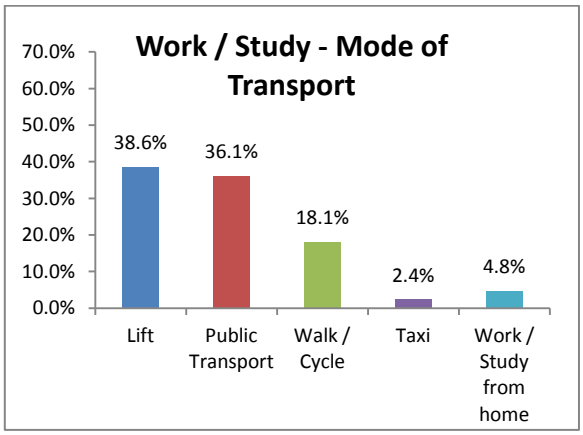

Figure 3

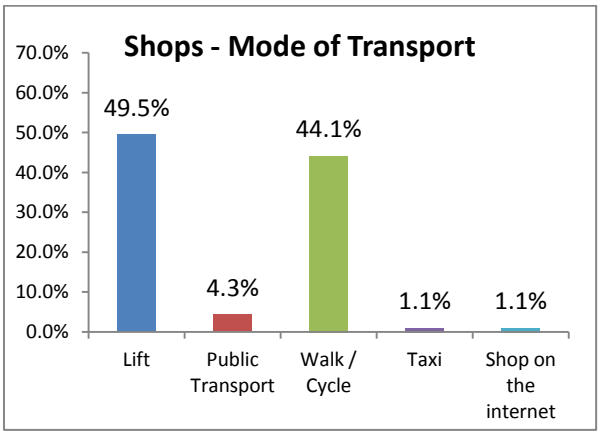

Figure 4

Table 4

Community Mobility	**Lift**		**Public Transport**		**Walk / Cycle**		**Taxi**		**Work / Study from home**		**Shop on the Internet**		**Total**
	n	%	**n**	%	**n**	%	**n**	%	**n**	%	**n**	%	**n**
How do you access the following places?													
Leisure Activities	57	*64.0%*	18	*20.2%*	11	*12.4%*	3	*3.4%*	n/a		n/a		**89**
Medical Appointments	51	*54.8%*	24	*25.8%*	13	*14.0%*	5	*5.4%*	n/a		n/a		**93**
Shops	46	*49.5%*	4	*4.3%*	41	*44.1%*	1	*1.1%*	n/a		1	*1.1%*	**93**
Work / Study	32	*38.6%*	30	*36.1%*	15	*18.1%*	2	*2.4%*	4	*4.8%*	n/a		**83**

Note: Percentages are based on those who responded to each separate question and not the overall number of participants in the survey.
n/a indicates that answer option was not applicable to the specific question

A public transport service was available within a 10 minute walk of their home to 78.9% (75) of participants. Only 27.4% (26) of participants had access to a service with a frequency of at least every 15 minutes. One participant commented that there were *"two buses per day available to travel to Dublin (nearest city) none on Sundays or Bank Holidays."* People living in cities used public transport services significantly more often than people living outside of cities (p=0.001 Fisher's exact test – 2 sided). Details of public transport usage and availability are detailed in tables 5 and 6.

Table 5

Public Transport Availability	**n**	**%**
Is there public transport available within a ten minute walk from your home?	**95**	
Not Available	20	*21.1%*
Available (split into frequency categories below)	75	78.9%
Every 15 minutes or more often	26	*27.4%*
Every half hour	16	*16.8%*
Every 45 minutes	4	*4.2%*
Every hour	13	*13.7%*
Less frequent	16	*16.8%*

Note: Percentages are based on those who responded to each separate question and not the overall number of participants in the survey.

Table 6

Public Transport Usage	**How frequently do you use public transport?**				
		At least a few times a week		**Less often**	
	p value*	**n**	*%*	**n**	*%*
City V Rural	**0.001**				
People living outside of a city		6	*13.3%*	39	*86.7%*
People living in a city		20	*46.5%*	23	*53.5%*

*Statistical test performed: Fishers Exact Test at the 5% significance level
A p value of less than 0.05 indicates a significant difference between groups

Impact of driving cessation

"It's very hard having something you depend on so much taken away from you, for something that you have no control over and that has ruined your life." Driving cessation impacted most on participants in the form of restricted access to places (81, 88.0%), more time taken to get around (80, 86.0%) and a reliance on others for transport (74, 79.6%). The reliance on others for transport was also highlighted through qualitative comments *"I really rely on my husband, in laws, family and friends for getting places, they never have a problem with bringing me however I do hate asking for the lift…"* Many participants were forced to give up activities (56, 60.9%). Occupational disruption had deeper implications as outlined by one qualitative comment. *"I've also given up my social activities and feel house bound a lot which can have a huge negative impact on my self esteem".*

A majority of participants responded that leisure and social activities (58, 63.7%), quality of life (52, 57.8%) and how they feel about themselves (51, 56%) were negatively affected. One participant commented *"There is a perception that if you can't drive you are stupid…"* The consensus was that romantic relationships (56, 65.9%), work (46, 52.3%), study (54, 73.0%), friendship (51, 56.0%) and family involvement (56, 62.9%) were not negatively affected. See details in table 7.

Table 7

Impact of Not Driving	n	%
I cannot access as many places	**95**	
Agree	81	*88.0%*
Neutral / Disagree	11	*12.0%*
The cost of transport for me is higher	**92**	
Agree	45	*48.9%*
Neutral / Disagree	47	*51.1%*
It takes me more time to get places	**93**	
Agree	80	*86.0%*
Neutral / Disagree	13	*14.0%*
I am always reliant on others to go places	**93**	
Agree	74	*79.6%*
Neutral / Disagree	19	*20.4%*
Do you feel your family involvement was positively or negatively affected by not being able to drive?	**89**	
Not affected or positively affected	56	*62.9%*
Negatively affected	33	*37.1%*
Do you feel how you feel about yourself was positively or negatively affected by not being able to drive?	**91**	
Not affected or positively affected	40	*44.0%*
Negatively affected	51	*56.0%*
Do you feel your friendships were positively or negatively affected by not being able to drive?	**91**	
Not affected or positively affected	51	*56.0%*
Negatively affected	40	*44.0%*
Do you feel your leisure and social activities were positively or negatively affected by not being able to drive?	**91**	
Not affected or positively affected	33	*36.3%*
Negatively affected	58	*63.7%*
Do you feel your quality of life was positively or negatively affected by not being able to drive?	**90**	
Not affected or positively affected	38	*42.2%*
Negatively affected	52	*57.8%*
Do you feel your romantic relationships were positively or negatively affected by not being able to drive?	**95**	
Not affected or positively affected	56	*65.9%*
Negatively affected	29	*34.1%*
Do you feel your study was positively or negatively affected by not being able to drive?	**74**	
Not affected or positively affected	54	*73.0%*
Negatively affected	20	*27.0%*
Do you feel your work was positively or negatively affected by not being able to drive?	**88**	
Not affected or positively affected	46	*52.3%*
Negatively affected	42	*47.7%*
Are there activities that you have had to give up or had difficulty participating in	**92**	
Yes	56	*60.9%*
No	36	*39.1%*

Note: Percentages are based on those who responded to each separate question and not the overall number of participants in the survey.

However, analysis of responses by different groups revealed that there were statistically significant differences between the responses of some of the groups. Significantly more males than females felt that driving cessation negatively impacted on romantic relationships (p=0.024 Fisher's exact test – 2 sided), figure 5. A participant commented *"The fact that I am not able to drive has changed my social life, especially since I am 20 and having a car at this age it seems is almost essential to getting a girlfriend."*

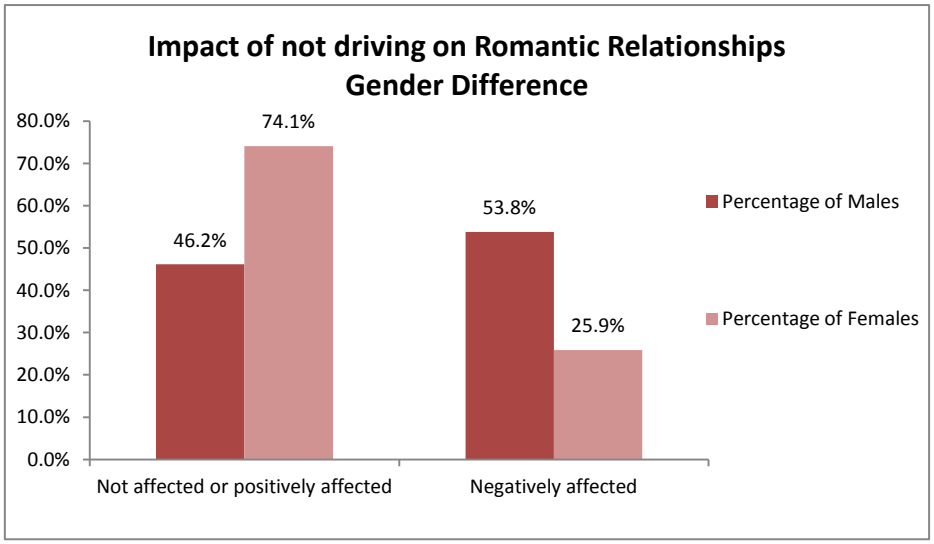

Figure 5

Significantly more people living outside of cities than in cities perceived the cost of transport to be higher during periods of driving cessation (p=0.036 Fisher's exact test – 2 sided), figure 6. Qualitative comments identified that many participants did not feel that public transport adequately met their needs. *"There is little or no public transport in rural areas, which is crushing for those who cannot drive, be it for epilepsy, age, disability, or any other reason."*

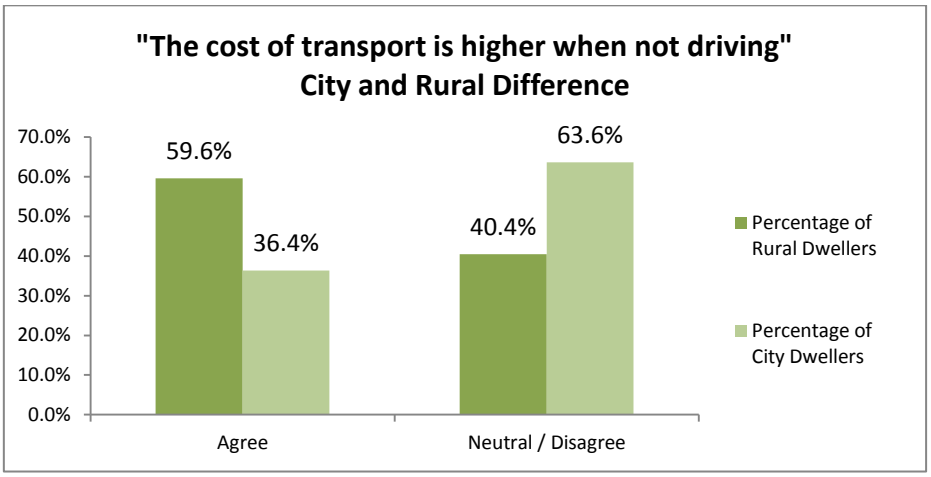

Figure 6

Significantly more people diagnosed with epilepsy in adulthood than those diagnosed in childhood perceived the cost of transport to be higher (p= 0.035, Fisher's exact test – 2 sided) during periods of driving cessation and their quality of life to be lower (p= 0.029, Fisher's exact test – 2 sided). See table 8 for details.

Table 8

Differences between groups			**What is your gender?**		**Do you live in a city or outside of a city?**		**Do you live with family/partner or with friends/alone?**		**Do any of the other members of your household drive?**		**At what age were you first diagnosed with epilepsy?**	
			Male	Female	rural	City	alone or friends	family	Yes	No	Birth - 17	18 and above
The cost of transport for me is higher		**p value***	0.257		**0.036**		1		0.224		**0.035**	
Agree	**n**		11	34	28	16	8	37	37	8	13	11
	%		*39.3%*	*54.0%*	*59.6%*	*36.4%*	*50.0%*	*48.7%*	*52.9%*	*36.4%*	*35.1%*	*47.8%*
Neutral/ Disagree	**n**		17	29	19	28	8	39	33	14	24	12
	%		*60.7%*	*46.0%*	*40.4%*	*63.6%*	*50.0%*	*51.3%*	*47.1%*	*63.6%*	*64.9%*	*52.2%*
Do you feel your quality of life was positively or negatively affected by not being able to drive?		**p value***	0.818		0.399		0.397		1		**0.029**	
Not affected or positively affected	**n**		11	27	18	20	8	30	29	9	20	18
	%		*39.3%*	*44.3%*	*38.3%*	*47.6%*	*53.3%*	*40.0%*	*42.7%*	*40.9%*	*57.1%*	*32.7%*
Negatively affected	**n**		17	34	29	22	7	45	39	13	15	37
	%		*60.7%*	*55.7%*	*61.7%*	*52.4%*	*46.7%*	*60.0%*	*57.4%*	*59.1%*	*42.9%*	*67.3%*
Do you feel your romantic relationships were positively or negatively affected by not being able to drive?		**p value***	**0.024**		0.647		0.765		0.423		0.107	
Not affected or positively affected	**n**		12	43	26	29	9	47	41	15	20	36
	%		*46.2%*	*74.1%*	*61.9%*	*69.1%*	*60.0%*	*67.1%*	*63.1%*	*75.0%*	*55.6%*	*73.5%*
Negatively affected	**n**		14	15	16	13	6	23	24	5	16	13
	%		*53.9%*	*25.9%*	*38.1%*	*31.0%*	*40.0%*	*32.9%*	*36.9%*	*25.0%*	*44.4%*	*26.5%*

*Statistical test performed: Fisher's Exact Test at the 5% significance level
A p value of less than 0.05 indicates a significant difference between groups

Assistance

When asked what to put in order of preference four areas of assistance, 47.8% (43) of participants rated a free travel pass as their first preference and 40.0% (36) rated improved public transport. Details are in table 9. The free travel pass was something that one participant felt entitled to *"…my issue is that if I'm banned from driving due to a "disability" then I should be entitled to a free travel pass – or at the very least discounted …"*

Table 9

First preference for assistance when not able to drive	n	%
Better public transport	36	*40.0%*
Free travel pass	43	*47.8%*
More information about transport options	2	*2.2%*
Peer support - talk to other people in a similar situation	9	*10.0%*

Discussion

Driving is a form of transport that facilitates engagement in occupation. When living in a society which is largely built around the use of the car, there are implications for people who cannot drive. The challenges associated with getting around affect occupational participation and quality of life.

Community Mobility

The most commonly used mode of transport during periods of driving cessation was lifts which is similar to previous findings (Azad *et al* 2002, O'Driscoll and Buckley 2010). Qualitative comments identified that participants did not like asking for lifts and felt guilty about it, a finding consistent with previous studies (Bauer *et al* 2003, Scannell and Buckley 2011). Being reliant on family members for transport placed increased demands and stress on family members (Fonda *et al* 2001, Azad *et al* 2002) and reduced independence and spontaneity (Bauer *et al* 2003, Vrkljan and Polgar 2007).

Research has shown that people perceive public transport further than a 5-10 minute walk as unattractive (Hine and Scott 2000). Although most participants (75, 78.9%) had access to some public transport service within a 10 minute walk from their home, few participants (26, 27.4%) had access to a service with a frequency of at least every 15 minutes. Work/study was the activity where public transport usage was highest. This suggests that public transport was

most useful for routine activities or it may indicate that work/study locations were better served by public transport. The percentage of participants using public transport to get to work/study was substantially higher than the percentage of the general population using public transport to get to work which was 9% (CSO 2011). Table 10 and figure 7 illustrate the differences. This appears to suggest that participants, when unable to drive due to epilepsy did use public transport as an alternative. The two samples are not entirely comparable however. The figure for the general population included people from age 15 and related only to travel to work (CSO 2011) whereas this study addressed people age 18 and above and included travel to both work and study.

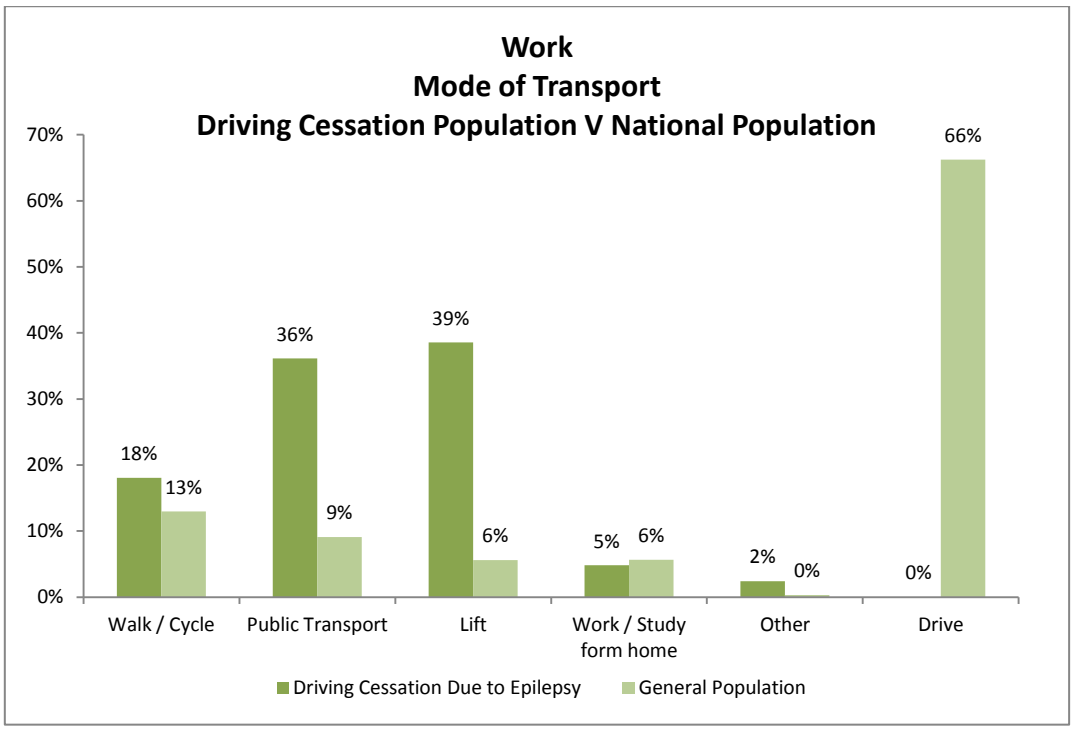

Figure 7

Table 10

	Driving Cessation Due to Epilepsy	General Population (CSO 2011)
Walk / Cycle	*18%*	*13%*
Public Transport	*36%*	*9%*
Lift	*39%*	*6%*
Work / Study form home	*5%*	*6%*
Other	*2%*	*0%*
Drive	*0%*	*66%*

It was found that people living in cities used public transport significantly more frequently than those living outside of cities. This suggests that public transport usage may also be a function of service availability, proximity and frequency. Significantly more people living outside of cities than those living in cities perceived the cost of transport to be higher when not driving. This could suggest that the availability of public transport helped mediate for some of the transport costs while unable to drive. Cost was the only area where any statistically significant difference was found between rural or city dwellers.

Qualitative comments identified that participants did not feel that public transport adequately met their needs a finding reflected in other studies (Azad *et al* 2002, Scannell and Buckley 2011). The lack of a suitable and reliable public transport is a significant issue for people with epilepsy (Bautista and Wludyka 2006) and people are frustrated with public transport especially in rural areas where waiting times can be very long (Scannell and Buckley 2011).

Despite their frustrations with public transport, participants did see public transport as having the potential to assist them in remaining independent. This was evident through the high number of participants rating either improved public transport or a free travel pass as the number one factor that would assist them when they could not drive. Currently, most people in Ireland with epilepsy under the age of 66 would not be eligible for a free travel pass (Ireland, Department of Social Protection 2011). In the United Kingdom (UK) people who are excluded from driving due to epilepsy are entitled to concessionary public transport fares (Disabled Persons Railcard 2012).

Impact of Driving Cessation

During periods of driving cessation, the majority of participants experienced restricted access to places they wished to go and many participants had to give up some activities. This is similar to previous findings in studies on the older population that driving cessation caused a reduction in activity levels (Marottoli *et al* 2000, Liddle *et al* 2005, Ragland *et al* 2005, Whitehead *et al* 2006, Azad *et al* 2002). This highlights the concept put forward by Stav (2008) that driving facilitates the engagement in many other occupations and the community therefore being an occupation enabler. The ability to engage in activities outside the home contributes to ones sense of wellbeing and can provide a sense of freedom (Spinney 2009).

As well as the physical restrictions imposed by not being able to drive, more than half of participants reported a reduced quality of life and a negative impact on how they felt about themselves which was also reflected in qualitative comments. Previous studies into the older population have reported similar findings such as reduced quality of life (Vrkljan and Polgar 2007), increased depressive symptoms (Fonda *et al* 2001, Ragland *et al* 2005) and reduced self worth (Whitehead *et al* 2006, Marottoli *et al* 2000).

Differences

A new finding from this study was that significantly more men than women felt that not driving had a negative impact on their ability to form romantic relationships. No previous research investigating the impact of driving cessation due to epilepsy or conditions in the older population has reported this finding. It may however help to identify why the effect of epilepsy on driving status was the most common cause of dissatisfaction in men with epilepsy (Sare *et al* 2007) and why the marriage rate in their sample of people with epilepsy was lower than that of the overall population (Fisher *et al* 2000). What we do helps shape our occupational identity (Kielhofner 2008). Cars, especially in the media, are portrayed as linked to and enhancing masculinity an idea embedded in the car culture which now exists (Vick 2003). Using the concept described by Vrijklan and Polgar (2007) perhaps men experience an occupational identity crisis as a result of the restriction on their ability to drive and are forced to adapt to a new occupational identity.

Another new finding from this study was that people diagnosed in adulthood (age 18 and above) experienced driving cessation differently to those diagnosed in childhood (birth – 17). Significantly more participants diagnosed with epilepsy in adulthood felt that the cost of transport for them was higher when not permitted to drive and that their quality of life was lower. One possible explanation for this could be that the loss of the ability to drive has a greater impact when a person's life already revolves around driving (Szaflarski *et al* 2006), something more likely to occur for people who receive a diagnosis in adulthood rather than in childhood. It could also be related to the requirement for people diagnosed in adulthood to make two adjustments at once. People diagnosed in adulthood would have to deal with both the diagnosis of epilepsy and driving cessation at the same time whereas people diagnosed in childhood would meet these adjustments separately.

Driving Illegally

Similar to findings from other studies (Bautista and Wludyka 2006, Elliot and Long 2008), 22.1% of people reported driving illegally due to epilepsy and 8.8% reported having misrepresented their seizures to their neurologist in order to keep their licence. Some previous studies have found lower rates 8% (Dickey and Morrow 1993) and 10% (Drazkowski *et al* 2010) of people either driving illegally or driving against medical advice. Although one participant noted in a qualitative comment that they did not expect people to honestly answer questions about driving illegally, others seem to have found the anonymous nature of the study as a forum for disclosure. A qualitative Irish study (Scannell and Buckley 2011) found results contrary to those found in the published quantitative literature. None of the five participants interviewed reported having ever driven illegally. The small sample size and lack of anonymity in many qualitative studies may reduce the willingness of participants to divulge sensitive information.

Limitations

This study has a number of limitations. A convenience sampling method was used so the sample is not representative of the general population (Vogt 2007). The survey was only available to people who could use a computer with access to the internet. This may indicate why no participants over the age of 65 completed the survey. The survey was anonymous and data was collected online. As a result, it was not possible to verify who had participated in the study, to collect data on those who did not participate in the study or to calculate a response rate. Participation in the study was voluntary resulting in volunteer bias and non response bias. These limitations challenge the external validity of the study (Pole and Lampard 2002).

More than twice as many women as men responded to the survey suggesting that this form of survey is more appealing to females, that the promotion method of the survey better reached females or that males are less willing to discuss their experiences. There were a small number of participants who also had a significant disability other than epilepsy which prevented them from being able to work. Although participants were asked to report on the impact of not driving due to epilepsy, it may have been difficult for participants with co morbid conditions to separate their experiences. The sample size was small which meant that statistical tests of some groups were not valid.

Role for Occupational Therapy

The insufficiencies in alternative transport options show that occupational therapists need to have a role in town and urban planning to ensure that those who are less mobile have access to facilities. Studies have shown that providing facilities within walking distance is the most effective way to ensure that activities are accessible even to those who have mobility difficulties (Kim 2011).

The importance of occupation for health and well being especially at times of transition demonstrates the importance of facilitating people with epilepsy to participate in their daily occupations as they adjust to driving cessation. Occupational therapists could assist people who have to stop driving due to epilepsy to find ways to continue participating in occupations, activities and their community. This would help people to maintain a positive identity, a sense of independence, autonomy and self worth (Whitehead *et al* 2006).

Driving illegally is a concern for the Road Safety Authority and neurologists but also highlights a role for occupational therapists. Occupational therapists often discuss driving and transport options in relation to independence with clients (Unsworth 1999). A number of participants commented that their general practitioner (GP) did not correctly advise them on the driving regulations and that they did not know where to go for such information. Varley *et al* (2011) in a qualitative Irish study found similarly that GP's lacked the expertise to manage the condition of epilepsy. Previous studies have identified that people with epilepsy did not have access to sufficient information regarding driving regulations and the risks of risks of driving with epilepsy (Drazkowski *et al* 2010) and they often did not know where to go to get such information (Scannell and Buckley 2011).

Since driving is an occupation and occupation enabler, occupational therapists are well placed to deal with the problems that arise from driving cessation. Further education and support is needed for people who cannot drive due to epilepsy.

Future Studies

Future research could address in more detail the effect not driving has on young males especially in terms of developing romantic relationships. Although the usage of public transport was higher than in the general population, many participants commented that public transport did not meet their needs, further investigation of why this is the case would be

useful. Further research is also required into physician's knowledge of the driving regulations, the information they provide to people with epilepsy, who they direct people with epilepsy to for further information and their understanding of how occupational therapists could assist people with epilepsy.

Conclusion

Driving is both an occupation and an occupation enabler (Stav 2008). Independent access to the community and to daily occupations is often dependent on a person's ability to drive. People with epilepsy are required to stop driving until their seizures are controlled in line with the regulations (RSA 2010). This study investigated the impact of the inability to drive on the lives of people with epilepsy.

Data was collected in this study through an online survey which recruited 95 eligible participants. Brainwave the Irish epilepsy association acted as gatekeeper. Participant recruitment was carried out using electronic media through Brainwave. Quantitative data was analysed using SPSS and content analysis was used with qualitative comments.

The results of this study highlighted many issues that are present for people with epilepsy who have to stop driving or who never get the opportunity to drive. Some are similar to previous research into driving cessation in the epilepsy population and the older (non epilepsy) population. These included a dependency on others for transport, a restricted access to places, having to give up activities, a reduced quality of life and lowered self perception. However, the prevalence of people with epilepsy continuing to drive against neurologist recommendation may be higher than previously thought. Other findings were new and not previously reported in literature concerning driving cessation. The first was that significantly more men than women believed that driving cessation negatively impacted on romantic relationships. The second was that significantly more people diagnosed in adulthood than people diagnosed in childhood felt that both cost of transport and their quality of life were negatively affected during periods of driving cessation.

Although participants could not drive they remained very much reliant on the car. Lifts from friends and relatives was the most used form of transport during periods of driving cessation.

Public transport usage was substantially higher than that of the general population yet less than a third of the population had easy access to frequent public transport. People did however see public transport as having the potential to assist them through having an improved public transport system or a free travel pass.

Occupational therapists could assist people who have to stop driving due to epilepsy in a number of ways. They could provide education concerning the laws around epilepsy and driving and the risks associated with driving and epilepsy. Occupational therapists could also help people adapt to other forms of community mobility which would allow them continue with their occupations even when they cannot drive. A third is to advocate for the needs of people with epilepsy in relation to town and transport planning and in relation to travel benefits such as a free travel pass.

There are a number of areas which require further research. The first is to investigate in more detail the impact of driving cessation on young males. The second is to examine in further detail how public transport could better meet the needs of people with epilepsy. The third is to investigate physician's knowledge of the laws concerning epilepsy and driving and where they direct people who cannot drive due to epilepsy for support and assistance.

Although many people with epilepsy live normal lives, there are others for whom getting around is not easy. When an occupation is taken away from us it can cause major disruption in our lives. Driving though is not just one occupation, it is an occupation enabler allowing people to engage in work, leisure and social activities. Driving cessation impacts on occupational identity, social participation, wellbeing and independence (Vrkljan and Polgar 2007, Fonda *et al* 2001, Marottoli *et al* 2000). Further information and support is required for people who have cannot drive due to epilepsy. Occupational therapists have a role to play in the provision of such information and support.

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Appendix A

UNIVERSITY of LIMERICK

OLLSCOIL LUIMNIGH

As part of the MSc Occupational Therapy degree at the University of Limerick, I am completing a study about driving cessation in people with epilepsy. The study investigates how people access their community when they cannot drive due to epilepsy. For this study I am looking for people with epilepsy living in Ireland, who have experienced driving cessation or who have never driven, aged 18 or older to participate in an online survey.

- Participation in the survey is voluntary.
- The survey will take approximately 10-15 minutes to complete.
- All information provided will be confidential and anonymous.
- Please only complete the survey once.

By clicking the next button below to begin the survey you are giving your consent to participate in the survey. If you wish to stop the survey at any point select the exit survey button. You will be asked questions about demographics, epilepsy, driving practices, transport experience and daily activities.

If you have any questions about the survey please contact:
Clare Sullivan
09000091@studentmail.ul.ie

This research has received ethical approval from the University of Limerick Research Ethics Committee. If you have concerns regarding this study, please contact:
Chairman, Education and Health Sciences, Research Ethics Committee
EHS Faculty Office
University of Limerick
Tel (061) 234101
Email: ehsresearchethics@ul.ie

Appendix B

(**Note:** based on the answer selected to question 1, questions were filtered using question logic options available on Survey Monkey in order to ensure only relevant questions were asked to participants. Through the use of question logic and filtering, the tense of the question was also changed to account for people who were answering questions based on a current period of driving cessation and those who were answering questions based on a period of driving cessation in the past. This was done so as to minimise question confusion. Questions labelled ** were only relevant to people who had at some stage held a driving licence.)

Survey: Driving Cessation in Epilepsy

1. Which of these statements best applies to you? (Please tick one)
   - ☐ I am licensed to drive at present but in the past I experienced a time when I had to cease driving due to epilepsy
   - ☐ I am not licensed to drive at present due to epilepsy but in the past I drove
   - ☐ Due to epilepsy I am not licensed to drive and have never driven
   - ☐ Other _____

SECTION 1: Epilepsy and Driving

2. **When did you first get your driving licence?
   - ☐ Before being diagnosed with epilepsy
   - ☐ After being diagnosed with epilepsy
3. **While permitted to drive, what distance did you typically drive per day? (Please tick one)
   - ☐ Less than 10 kilometres (6 miles)
   - ☐ 10-25 kilometres (6-12 miles)
   - ☐ 25-40 kilometres (12 -24 miles)
   - ☐ More than 40 kilometres (24 miles)
4. **Do you think the regulations concerning driving and epilepsy are fair?
   - ☐ Yes
   - ☐ No

   Comment _____

5. Please indicate which of the following public transport options are available to you within a 10 minute walk from your home and the approximate frequency of the transport option.

	Not Available	Every 15 minutes or more often	Every half hour	Every 45 minutes	Every Hour	Less frequent
Bus	☐	☐	☐	☐	☐	☐
Luas	☐	☐	☐	☐	☐	☐
Dart	☐	☐	☐	☐	☐	☐
Train	☐	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐	☐

6. How many cars are there available in your household?
   - ☐ None
   - ☐ 1
   - ☐ 2
   - ☐ 3 or more

7. How often do you use the following forms of transport?

	Every Day	A few times a week	A few times a month	Less often	Never
Walk	☐	☐	☐	☐	☐
Cycle	☐	☐	☐	☐	☐
Bus	☐	☐	☐	☐	☐
Luas	☐	☐	☐	☐	☐
Train	☐	☐	☐	☐	☐
Taxi	☐	☐	☐	☐	☐

Other (please specify) _____

8. **Have you ever misrepresented your seizures to your doctor in order to keep you r licence?
   - ☐ Yes
   - ☐ No

9. **Have you ever driven illegally due to epilepsy?
   - ☐ Yes
   - ☐ No
10. **When was your most recent period of driving cessation? (Please select one)
   - ☐ I am not driving at present
   - ☐ Less than 1 year ago
   - ☐ 1-5 years ago
   - ☐ Longer than 5 years ago
11. **For how long was this most recent period of driving cessation? (Please select one)
   - ☐ Less than 1 year
   - ☐ 1-2 years
   - ☐ 3-5 years
   - ☐ 5 years or longer

SECTION 2: Driving Cessation

12. As a result of not driving due to epilepsy do you agree or disagree with the following statements?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
It takes me more time to get places	☐	☐	☐	☐	☐
I cannot access as many places	☐	☐	☐	☐	☐
I am always reliant on others to go places	☐	☐	☐	☐	☐
I feel discriminated against by others since I cannot drive	☐	☐	☐	☐	☐
I feel embarrassed about not being able to drive	☐	☐	☐	☐	☐
The cost of transport for me is higher	☐	☐	☐	☐	☐

13. Do you feel each of the following aspects of your life were positively or negatively affected by not being able to drive?

	Positively Affected Greatly	Positively Affected Somewhat	Not affected	Negatively Affected Somewhat	Negatively Affected Greatly	N/A
Working	☐	☐	☐	☐	☐	☐
Studying	☐	☐	☐	☐	☐	☐
Friendship	☐	☐	☐	☐	☐	☐
Romantic Relationships	☐	☐	☐	☐	☐	☐
Leisure and Social Activities	☐	☐	☐	☐	☐	☐
Family Involvement	☐	☐	☐	☐	☐	☐
How you feel about yourself	☐	☐	☐	☐	☐	☐
Your overall quality of life	☐	☐	☐	☐	☐	☐
Other (please specify)	☐	☐	☐	☐	☐	☐

14. How do you access where you need to go, given that you do not drive?

For each activity, please indicate the mode of transport used to access the activity.

	Driven by family member I live with	Driven by family member not living with me	Driven by friend / neighbour	Walk	Cycle	Taxi	Bus	Luas	Dart	Train	Work/ Study from Home	Shop on the internet
Work / Study	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Medical Appointments	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Shop / Post Office etc.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Leisure and Social Activities	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other (Please specify)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Please also indicate how frequently you participate in each activity?

	Daily	Several Times a week	Once a week	Several times a month	Once a month	Less often	Never
Work / Study	☐	☐	☐	☐	☐	☐	☐
Medical Appointments	☐	☐	☐	☐	☐	☐	☐
Shop / Post Office etc.	☐	☐	☐	☐	☐	☐	☐
Leisure and Social Activities	☐	☐	☐	☐	☐	☐	☐
Other (Please specify)	☐	☐	☐	☐	☐	☐	☐

15. Are there activities that you have had to give up or had difficulty participating in, given that you do not drive?
    - ☐ No
    - ☐ Yes (Please give details) _____
16. Please indicate in order of preference which of the following you feel would assist you, given that you do not drive?
    (1 is what you feel will most assist you and 4 is what you feel is of least assistance)

	Better public transport	Free travel pass	More information about transport options	Peer support – talk to other people in a similar situation
1 (of most assistance)	☐	☐	☐	☐
2	☐	☐	☐	☐
3	☐	☐	☐	☐
4 (of least assistance)	☐	☐	☐	☐

Other (please specify) _____

SECTION 3: GENERAL INFORMATION

1. Gender:
   - ☐ Male
   - ☐ Female
2. What is your age? (Please select one)
   - ☐ 18-25
   - ☐ 26-35
   - ☐ 36-45
   - ☐ 46-55
   - ☐ 56-65
   - ☐ 66-75
   - ☐ 76+
3. Where do you live? (Please tick one)
   - ☐ The countryside/rural area
   - ☐ A village
   - ☐ A town
   - ☐ Cork City, Limerick City, Galway City
   - ☐ Dublin City (postcodes 1-12)
   - ☐ Dublin City (postcodes 13-18)
   - ☐ Dublin suburbs and county (postcodes 20, 22, 24 and county Dublin)
   - ☐ Another city
4. How would you describe your present principal work status? (Please select one)
   - ☐ Working for payment or profit
   - ☐ Working voluntarily
   - ☐ Looking after home / family
   - ☐ Looking for first regular job
   - ☐ Unemployed
   - ☐ Student
   - ☐ Retired from employment
   - ☐ Unable to work due to epilepsy
   - ☐ Unable to work due to other sickness or disability
   - ☐ Other (please specify) _____
5. What is your current living situation (Please select one)
   - ☐ Living alone
   - ☐ House sharing (with people other than close friends)
   - ☐ Living with friends
   - ☐ Living with partner / spouse (no children)
   - ☐ Living with family (partner / spouse and / or children)
   - ☐ Living with family (parents and / or siblings)
   - ☐ Other (please specify) _____
6. Do any other members of your household drive?
   - ☐ Yes
   - ☐ No
7. Are you currently receiving any of the following benefits? (Tick as many as appropriate)
   - ☐ No entitlements or benefits
   - ☐ Free travel pass
   - ☐ Disability allowance
   - ☐ Other _____

SECTION 4: EPILEPSY EXPERIENCE

1. At what age were you diagnosed with epilepsy? (Please select one)
   - ☐ Birth – 17
   - ☐ 18-25
   - ☐ 26-35
   - ☐ 36-45
   - ☐ 46-55
   - ☐ 56-65
   - ☐ 66-75
   - ☐ 75+
2. How long ago is it since you were first diagnosed with epilepsy? (Please select one)
   - ☐ Less than 1 year
   - ☐ 1 month to 1 year
   - ☐ 2-5 years
   - ☐ 6 years or longer
3. When did you experience your last epileptic seizure? (Please select one)
   - ☐ Within the last week
   - ☐ Within the last month
   - ☐ Within the last 6 months
   - ☐ Within the last year
   - ☐ Longer than a year ago
4. How frequent do you usually experience epileptic seizures? (Please select one)
   - ☐ Once a day or more often
   - ☐ A few times a week
   - ☐ A few times a month
   - ☐ A few times a year
   - ☐ Once a year
   - ☐ Less frequent than once a year
5. Are your seizures classified as any of the following? (Please select as many as appropriate)
   - ☐ Provoked Seizures (Seizures caused by a recognized provoking factor)
   - ☐ Sleep Seizures (Seizures that only occur when asleep)
   - ☐ Seizures that do not influence consciousness
   - ☐ Other (please specify) _____

Section 5 – Open question for other comments

6. Please note any other comments or feelings you have regarding driving cessation due to epilepsy.

_____
_____
_____
_____
_____
_____

Thank you for taking the time to participate in this survey.