



## Report

# **‘Out of the Shadows’: needs, perceptions and experiences of people living with epilepsy in Australia**

Findings from Wave 2 of the Longitudinal Survey

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## EXECUTIVE SUMMARY

*In 2011 there were approximately 750 people on the Australian Epilepsy Research Register;*

*The Wave 2 survey of 2010 had 343 from 621 research register participants (response rate 55%);*

- *Wave 2 results demonstrate lower education levels amongst older people and higher school retention amongst the younger; however lower than average employment and possibly underemployment across all ages. Education has not led to employment amongst these respondents with only 16% of the total number having full-time jobs even though the majority of them were of working age;*
- *Income is also generally very low with 49% living below the current Henderson poverty line;*
- *Wave 2 also explored seizure activity and levels of seizure control. This group has less seizure control than reported in the literature with only 33% reporting no seizures over twelve months. There are no data to analyse severity of seizures, however. Injuries and hospitalisations are high amongst this group. This is an important finding which deserves further exploration in the next Wave;*
- *People with epilepsy reported experiencing varying levels of stigmatizing behaviour. While many felt they had been fairly treated and had not suffered any discrimination the numbers who reported unfair treatment were still high at 45%. For some people this led to social isolation;*
- *A substantial proportion (32%) of people with epilepsy reported that they had experienced a lack of understanding from Government bodies that they had turned to for assistance;*
- *Driving remains a highly desirable and necessary component in the quality of a person's life; being a driver or being driven by someone else remains the preferred mode of transport;*
- *The future of the Australian Epilepsy Research Register (AERR): More recruitment from states other than Victoria is required in order to make this a more representative sample of people living with epilepsy in the community. This is proceeding via members of Epilepsy Australia and Epilepsy Action but the AERR requires more entry points for recruitment.*

# 1 BACKGROUND

## 1.1 Establishment of the Register

In 2006 the Epilepsy Foundation of Victoria (EFV) established a Research Participants' Register (RPR) to enable it to collect data from registrants regarding the social impact of living with epilepsy.

In 2011 the Register was expanded to people in other Australian states in order to collect data from a large and representative sample of people living with epilepsy, their families and carers. Epilepsy Australia and all state and territory associations are supporting recruitment to the new register, which is now called the Australian Epilepsy Research Register (AERR). Joining the AERR is voluntary.

When people join the Register they are informed their privacy will be respected and that their details will not be shared with anyone outside the EFV research unit. They are also informed that from time to time surveys will be sent to them, and that it remains their choice to complete the survey.

## 1.2 Prevalence of epilepsy in Australia

There has been substantial progress made to establish a baseline from which to better understand the social impact of epilepsy. In 2006 Brown produced for the first time evidence-based estimates of the prevalence of epilepsy in Australia <sup>(1)</sup>. Using the National Health Survey 2004-5 he established baseline estimates of prevalence of epilepsy in Australia. This prevalence was 0.68 % or 1 in every 147 Australians (133,700 people). Brown also explored the factor of underreporting of epilepsy, where people do not understand their condition as being epilepsy or prefer not to disclose they have epilepsy. He estimated that the prevalence could be as much as 1 in every 73 Australians (or 268,473 people). Additionally, Brown estimated that when households living with a person with epilepsy were taken into account, the combined prevalence was 2.13 % or 1 in every 47 people (or 843,000 people) either having the condition or living in a household with someone with epilepsy.

Collecting these baseline data provides researchers with the basis to establish the optimal sample size for conducting a longitudinal survey.

## 1.3 Sample size

The AERR is the source of participants to collect data on the social impact of epilepsy longitudinal surveys. Currently, there are approximately 750 people on the register and 95 % of these are Victorians as this was the state where the RPR was first established. Thus, the AERR is currently limited to providing information about Victorians living with epilepsy and their carers.

The sample size required for a robust study of Australians living with epilepsy can be calculated by taking the lowest estimated prevalence point (133,700 people), then applying De Vaus' rule <sup>(2)</sup>. Using this method, the national sample size required would be approximately 2000 people with epilepsy. This has the advantage of reducing the bias created by self-selection.

Developing the AERR as a national sample commenced in earnest in 2011 and continues with the participation of Epilepsy Australia members, Epilepsy Action and the development of Australia-wide resources.

## 2 LONGITUDINAL SURVEY

### 2.1 Wave 2 Survey 2010

There were 621 registrants on the AERR when this survey was conducted in 2010. While total numbers had continued to increase, the attrition rate also increased. This attrition may have been due to deaths, people changing address, or some no longer being interested in continuing.

A large survey tool was developed by the Research Working Group of the Epilepsy Foundation of Victoria to investigate a full range of variables associated with the social impact of epilepsy. This included education, employment income, costs of caring for epilepsy, levels of anxiety and depression assessment, treatment for epilepsy and attitudes towards a person with epilepsy as perceived by the respondents.

#### 2.1.1 Characteristics of the respondents

Three hundred and forty three persons responded. Of these:

- 247(72%) were people with epilepsy;
- 52 (15 %) were people who completed the survey on behalf of a person with epilepsy;
- 41(12 %) were family members and;
- 3 (1 %) were paid carers.

Further:

- Eighty seven per cent of the respondents were born in Australia and;
- Five percent were born in the United Kingdom.
- Fifty-seven per cent of the respondents were females and forty-three per cent were males.

#### 2.1.2 Age distribution

The mean age of the total sample was 43.3 years of age (SD =18.8; min = 2; max = 86).

**Table 1: Age distribution**

18-30	31-45	46-60	61+	Missing	Total
88 (26 %)	92 (27 %)	103 (30 %)	55 (16 %)	5 (1 %)	343 (100 %)

## 2.2 Education profile

**Table 2: Highest level of education obtained**

Year 11 or less	Year12	TAFE	Apprentice	Diploma	University	Post-graduate	Missing data	Total
132 (38%)	43 (12.5%)	43 (12.5%)	13 (4%)	29 (8.5%)	30 (9%)	38 (11%)	15 (4.5%)	343 (100%)

Table 2 indicates that 38 % of the total number of respondents had less than year 11 or its equivalent standard. A very small number of the survey group was in trade related education possibly reflecting the restrictions relating to epilepsy.

Twenty per cent of the participants in the survey had a Bachelor's degree or above. In 2010,27% of the Australian population aged between 25 and 64 had this level of education, while in Victoria the same age group with this level of education was 30.5 % <sup>(3)</sup>.

Because of the number of younger people in the 2010 survey it is worthwhile breaking down educational attainment by age.

**Table 3: Educational attainment by age**

Age	<30	31-45	46-60	61+	Total
Yr 11 or less	46 (31 %)	36 (24 %)	44 (30 %)	21 (15 %)	147
Yr 12	20 (47 %)	10 (23 %)	7 (16 %)	6 (14 %)	43
TAFE/Trade	9 (17 %)	27 (48 %)	16 (28 %)	4 (7 %)	56
Tertiary	7 (7 %)	33 (34 %)	34 (35 %)	23 (24 %)	97

The 31 % of respondents under 30 with year 11 education or less probably represents the younger age group remaining at school <sup>(3)</sup>. The above table indicates that educational attainment was harder to achieve in the older age groups with 69 % not having year 11 or its equivalent. This table suggests that recent policies to encourage students to complete their secondary education have had an impact on younger people with epilepsy. There is now a generational gap with regard to education between those 31 and over and those below 30.

## 2.3 Employment status

One hundred and thirty (38 %) of the 343 survey respondents were employed.

**Table 4: Employment profile**

Full time	Part time	Casual	Total
58 (45%)	39 (30%)	33 (25%)	130 (100%)

In raw numbers there are only 58 of the total number of respondents who are working full-time. This is 16% of the total number (343) of the respondents.

**Table 5: Employment and age distribution**

	Full time	Part time	Casual	Total
<30 years	11 (19%)	6 (15%)	9 (27.5%)	26 (20%)
31-45	20 (34.5%)	21 (54%)	14 (42.5%)	55 (42%)
46-60	25 (43%)	9 (23%)	7 (21%)	41 (31.5%)
61+	2 (3.5%)	3 (8%)	3 (9%)	8 (6.5%)
Total	58 (100%)	39 (100%)	33 (100%)	130 (100%)

Part time and casual work is not limited to younger people, who might generally be expected to prefer this kind of work while studying. By far the highest proportion working on a part-time/casual basis are those aged between 31 and 45, with the second highest proportion working aged between 46 and 60. Part time and casual work has implications for quality of life with many people in these employment categories being referred to as 'the working poor' <sup>(4)</sup>. In 2010 63.3% of all Australian employees were full-time while 36.7% of all of them were part-time including

casual <sup>(5)</sup>. Thus full-time employment amongst the survey respondents is vastly lower than the Australian average.

**Table 6: Distribution of those not working**

Retired	Studying	Unable to work due to epilepsy	Unable to work due to another disability	Seeking work	Home duties	Missing data	Total
50 (23.5%)	40 (19%)	42 (20%)	34 (16%)	11 (5%)	24 (11%)	12 (5.5%)	213 (100%)

Two hundred and thirteen of the 343 respondents (62 %) in the survey were not in formal employment. More than 40 % of this group was retired or studying, representing both the older and younger respondents to the survey. However, of those who were unemployed, 36 % were unable to work either due to epilepsy itself or because of another disability. This suggests that a large proportion of the respondents were of a working age but unable to work.

## 2.4 Income and expenditure

**Table 7: Weekly income levels**

<249	250-499	500-749	750-999	1000-1249	1250-1499	1500-1749	>1750	No response	Total
93 (27 %)	90 (26 %)	55 (16 %)	15 (4.5 %)	9 (3 %)	11 (3 %)	5 (1.5 %)	9 (3 %)	56 (16 %)	343 (100 %)

A low income is defined by Centrelink in Australia as \$480 gross per week for a single person and \$834 gross per week per couple in order to qualify for a low income health care card <sup>(6)</sup>. Under Fair Work Australia the national minimum income is 589.30 gross per week <sup>(7)</sup>. Low income, however, is relative and all these figures should be seen in the context of the average weekly income of 1333.30 per week <sup>(5)</sup>. Despite the fact that the majority of the sample was of working age, a high proportion (69 %) were on defined low incomes, while a further 10% were on relatively low incomes in terms of average weekly earnings. This may be partly explained by the numbers who were studying (40 or 19 %) as well as those who were retired. However, there was a large percentage (102 or 58 %) of those not working who were on disability pensions. This might include both those who were unable to work because of their epilepsy (42 people or 21 %) or those who were unable to work due to another disability. Those unable to work because of their epilepsy constitute the single greatest number apart from those who had retired (50 or 25 %) representing almost all of those over the age of 60 in the sample.

Income for people with epilepsy regardless of the reason is relatively low. If students, pensioners and retirees are all in the lowest income brackets they are well under the poverty line of \$352 for a single person or \$471 for a couple in 2010 <sup>(4)</sup>.

Lower incomes may lead to financial distress <sup>(8)</sup> where people have difficulty affording necessary items on a regular basis. Not being able to afford food, clothes, rent or mortgages, health care as well as holidays and entertainment all indicate levels of financial distress. Treatment related costs, despite subsidies from Medicare and the Pharmaceutical Benefits Scheme (PBS), further reduce the level of income available to spend on other necessities and activities, thus augmenting financial distress.

**Table 8: Average monthly costs of medication and treatment-related travel**

	Under \$10	\$11-50	\$51-100	\$101-200	\$201-300	\$300 +	Missing	Total
Medication	57 (16.5%)	159 (46%)	85 (25%)	16 (5%)	4 (1%)	3 (1%)	19 (5.5%)	343 (100%)
Travel	178 (52%)	67 (20%)	38 (11%)	8 (2%)	4 (1%)	4 (1%)	44 (13%)	343 (100%)

Seventy eight per cent of the respondents faced medicine costs between \$11 and \$300 per month, with the greatest number having costs ranging from \$11 to \$50 per month. Fewer respondents had high travel related expenses somewhat easing the burden of treatment-related costs. However for those with expenses above \$11 per month this is a substantial figure where income is as little as \$249 grosses per week.

**Table 9: Respondents unable to attend activities on at least one occasion due to cost**

Activity	Yes	No	Missing	Total
Social engagement (n=316)	110 (32%)	206 (60%)	27 (8%)	343 (100%)
Work appointment (n=285)	33 (10%)	252 (73%)	58 (17%)	343 (100%)
Shopping (n=315)	87 (25%)	228 (67%)	28 (8%)	343 (100%)
Recreational activity (n=316)	114 (33%)	202 (59%)	27 (8%)	343 (100%)

An indication of the level of financial distress experienced by respondents comes from responses relating to the cost of activities. Approximately a third of the sample was unable to attend social or recreational activities due to cost on at least one occasion.

Additionally the level of home ownership amongst the sample suggests that lack of income contributes to greater dependency with regard to living arrangements.

**Table 10: Levels of home ownership**

Fully owned home	115 (33.5%)
Paying mortgage	67 (19.5 %)
Renting	70 (20.5 %)
Other	25 (7 %)
Missing data	66 (19.5 %)
Total	343 (100 %)

The third of the sample (115) owned their own home while a further 67 (19.5 %) were paying off mortgages. Twenty one per cent (70) were renting while there was a much smaller group that had 'other arrangements' such as living with friends or relatives. Home ownership amongst this sample is in stark contrast to the overall Australian picture of housing which is 70% of the Australian population owning or purchasing their own homes <sup>(9)</sup>.

## 2.5 Seizures

Most of the sample had experienced seizures early in their lives. This is shown by their responses to the question on their age at which they first experienced a seizure as well as their responses to when they were diagnosed.

**Table 11: Age at which experienced first seizures**

Age	Seizures first experienced
Less than 1 year	47 (14 %)
1-4 years	32 (9 %)
5-9 years	41 (12 %)
10-15 years	59 (17%)
16-20 years	36 (10 %)
21-25 years	26 (8 %)
26-30 years	19 (5 %)
31-40 years	25 (8 %)
41-50 years	21 (6%)
50 +	31 (9%)
Missing data	6 (2 %)
Total	343 (100 %)

Sixtytwo per cent had experienced their first seizures below the age of 20, with the majority experiencing first seizures below the age of 10, thus in their formative years.

**Table 12: Types of seizures experienced**

Simple partial	Complex partial	Absence	Myoclonic	Tonic Clonic	Tonic	Atonic
145 (42.5%)	143 (42%)	145 (42.5%)	4 (14%)	200 (58%)	38 (11%)	20 (6%)

Of the seven types of seizures, tonic clonic seizures were the most common with 58 % (200) of all respondents experiencing this type of seizure. Absence seizures (42 %), complex partial (41 %) and simple partial (32 %) were the other common types of seizure experienced. Atonic (5 %) and tonic (11 %) seizure were rare for the current sample.

**Table 13: Number of seizures types people experienced**

No of seizure types	No of people
1 type	101 (30 %)
2 types	75 (22 %)
3 types	53 (15 %)
More than 3 types	61 (18 %)
Missing data	53 (15 %)
Total	343 (100 %)

Of the 343 respondents, 101 (30 %) reported only one seizure type, 75 (22 %) reported two seizure types, 53 (15 %) reported three seizure types and 61 (17 %) reported more than three seizure types.

**Table 14: Number of seizures in past twelve months**

None	1-3	4-6	7-9	10-15	16-20	21-30	30+	Missing	Total
125 (36%)	59 (17%)	15 (4.5%)	6 (2%)	15 (4.5%)	13 (4.0%)	7 (2%)	51 (15%)	53 (15%)	343 (100%)



Two hundred and ninety people answered the question on the number of seizures they had experienced in the last 12 months. The data suggest that there is poor control among this group as there were only little more than a third of the respondents who experienced no seizures in the twelve months. Generally, research demonstrates that more than two thirds of people with epilepsy are well controlled with modern medicines <sup>(10)</sup>. Data reported here should thus be treated with caution because the respondents to this survey are self-selected and not representative of the Australian population with epilepsy. Further, the number of seizures may not necessarily correlate with the severity or the type of seizures. For this group however, poor control has consequences for their quality of life. The following tables add to the clinical picture of the consequences of epilepsy among this group.

**Table 15: Number of different epilepsy medicines taken**

No drugs	1 type	2 types	3 types	4 types	5 types	6 or more	Missing	Total
16 (5%)	112 (33%)	99 (29%)	68 (20%)	30 (9%)	5 (1%)	9 (2%)	4 (1%)	343 (100%)

Sixty one per cent (211) of the respondents were on multiple medicines for their epilepsy. The numbers in the survey who were on three or more anti-epileptic medicines suggests that this was because of ineffective control with only one medicine <sup>(11)</sup>. Those on more than two anti-epileptic medicines are unlikely to be seizure-free <sup>(12)</sup>.

**Table 16: Control of seizures by medication**

No seizures at all	103 (31%)
Rarely have seizures	108 (32%)
Seizures some of time	72 (21%)
Frequent seizures	52 (15%)
Missing	4 (1%)
Total	343 (100%)

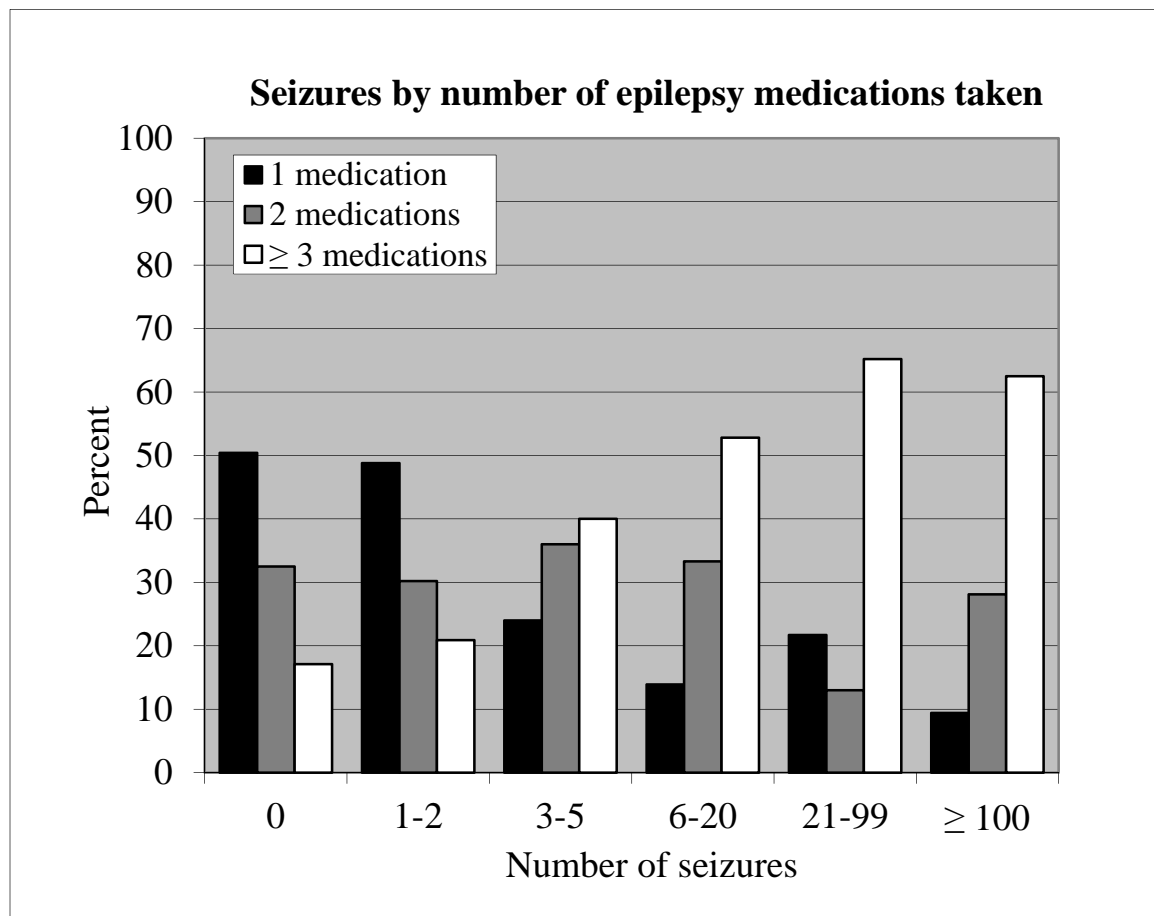
Only 31 % of respondents in the sample had full control of their epilepsy with medication. The remainder had less well controlled or perhaps had worse or more complex epilepsy than the general epilepsy population <sup>(10)</sup>. Another explanation may be related to subjective interpretations of what constitutes a seizure. This deserves further exploration in further surveys, since, regardless of the explanations, the consequence for people with poorly controlled epilepsy is poor quality of life.

Table 17 below has different totals for the number of seizures to Table 16. This represents the different ways the questions were asked indicating that some of the sample take no anti-epileptic medicines and that some people did not answer both questions.

**Table 17: Seizures by epilepsy medications taken**

	0 seizures	1-2	3-5	6-20	21-99	100 +	Total
1 drug	59 (50.4%)	21 (48.8%)	6 (24%)	5 (13.9%)	5 (21.7%)	3 (9.4%)	99 (35.9%)
2 drugs	38 (32.5%)	13 (30.2%)	9 (36%)	12 (33.3%)	3 (13%)	9 (28.1%)	84 (30.4%)
3 or more drugs	20 (17.1%)	9 (20.9%)	10 (40%)	19 (52.8%)	15 (65.2%)	20 (62.5%)	93 (33.7%)
Total	117 (100%)	43 (100%)	25 (100%)	36 (100%)	23 (100%)	32 (100%)	276 (100%)

People who took one anti-epileptic medicine only were most likely to be those who had no seizures in the last 12 months (50.4 %), followed by 1-2 seizures (48.8 %). People who took 3 or more anti-epileptic medicines were more likely to be those who had 21-90 seizures (65.2%), followed by those who had 100 or more seizures (62.5%). This demonstrates that the fewer seizures, the smaller number of drugs, while the more seizures the larger number of drugs <sup>(11)</sup>.

**Chart 1: Seizures by number of epilepsy medications taken**

**Table 18: Seizures by epilepsy medications taken among those employed**

	0 seizures	1-2	3-5	6-20	21-99	100 +	Total
1 drug	30 (50.8%)	12 (60%)	5 (41.7%)	1 (8.3%)	2 (33.3%)	0 (0%)	50 (44.2%)
2 drugs	21 (35.6%)	6 (30%)	4 (33.3%)	5 (41.7%)	0 (0%)	1 (25%)	37 (32.7%)
3 or more drugs	8 (13.6%)	2 (10%)	3 (25%)	6 (50%)	4 (66.7%)	3 (75%)	26 (23%)
Total	59 (100%)	20 (100%)	12 (100%)	12 (100%)	6 (100%)	4 (100%)	113 (100%)

For those currently employed there is a higher proportion experiencing 1-2 seizures in the past 12 months on one AED, followed by those who are seizure-free using one drug only. As before, those experiencing 100 seizures or more within 12 months (3 or 75%) are most likely to be taking three or more AEDs, followed by those with 21-90 seizures. On this basis and though the numbers are small, refractory epilepsy increases the likelihood of not being employed.

Finally, in this section on seizure activity and employment, Table 19 demonstrates that those who are employed who answered the question about seizure activity (322 or 94%), mostly experience no seizures (42 %) or rarely experience seizures (41 %). Amongst those who are unemployed answering this question about seizure activity 50 % reported having seizures either some of the time or frequently. Fifty per cent of the unemployed in Table 19 reported no seizures or few seizures. These respondents are likely to be retired or students. Seizure control therefore is an important component in being able to work.

**Table 19: Number of seizures by employment status**

	Employed	Not employed	Total
No seizures at all	54 (42%)	46 (24%)	100 (31%)
Rarely have seizures	53 (41%)	51 (26%)	104 (32%)
Seizures some of the time	13 (10%)	58 (30%)	71 (22%)
Frequent seizures	9 (7%)	38 (20%)	47 (15%)
Total	129 (100%)	193 (100%)	322 (100%)

The most compelling evidence of subjective severity of seizures and their impact on the person's life comes from data on injuries and hospitalisations.

**Table 20: Injuries and hospitalisations**

	Yes	No	Missing data	Total
Have you been injured as result of seizure	188 (55%)	150 (44%)	6 (1%)	343 (100%)
Did you require hospital treatment	121/188 (64%)	67/188 (36%)	–	188

Of the 338 people who responded, 188 (55%) had been injured as a result of a seizure and 121 of the 188 (64%) required hospital treatment for their injuries.

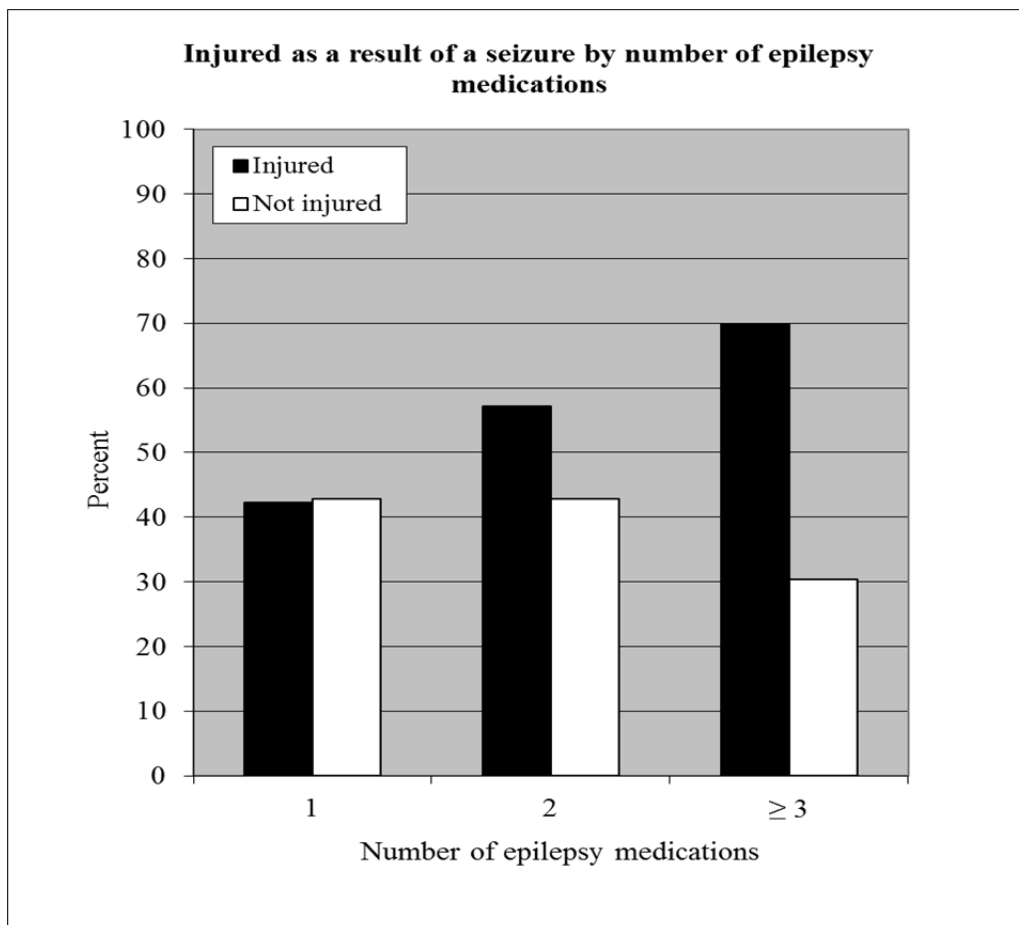
Two hundred and ninety nine people responded to both questions about injuries and the number of AEDs they were on providing an insight into the relationship between the number of AEDs and injuries.

**Table 21: Injury as a result of a seizure by number of drugs**

	1 drug	2 drugs	3 or more drugs	Total
Injured	47 (53 %)	56 (57%)	78 (70 %)	181 (60.5 %)
Not Injured	42 (47 %)	42 (43 %)	34 (30%)	118 (39.5 %)
Total	89 (100%)	98 (100%)	112 (100%)	299 (100%)

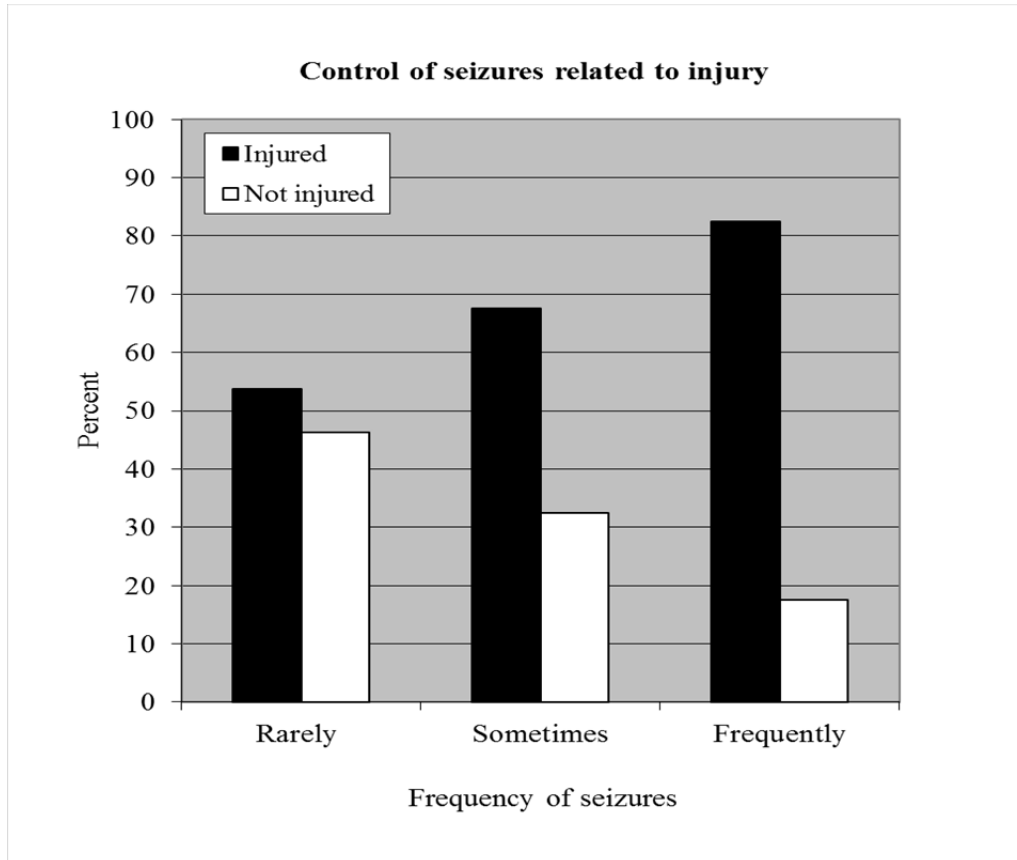
Those taking three or more drugs are those most likely to report an injury as a result of seizure. Seventy eight people (70%) taking three or more AEDs reported an injury as a result of a seizure while far fewer on one or two AEDs reported an injury. However from the above table it is evident that amongst these respondents an injury is likely to occur in more than half of the group.

**Chart 2: Injuries as a result of a seizure by number of medications**



The level of control of seizures plays a role in injuries sustained by people with epilepsy in this survey group. Those who have the most frequent seizures are those who most report an injury (82%), while those who rarely have seizures report the least injury (54 %).

**Chart 3: Seizures and injuries**



One hundred and twenty people out of the 180 reporting an injury due to a seizure reported being hospitalised.

Chart 4 shows a higher proportion (68 %) of those using three or more drugs have been hospitalised for an injury related to a seizure than those taking fewer AEDs. Those taking one drug are least likely to have been hospitalised. This is consistent with the injuries related to the numbers of AEDs in Table 21.

Chart 4: Number of medications and hospitalisations

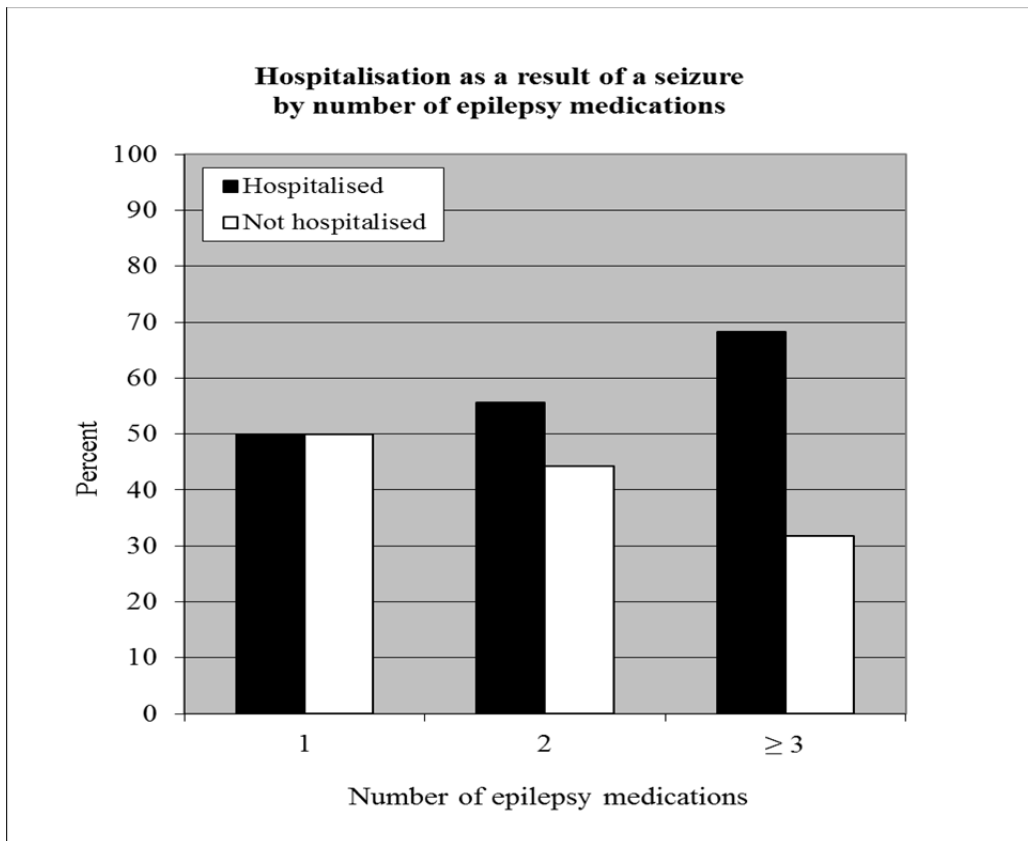
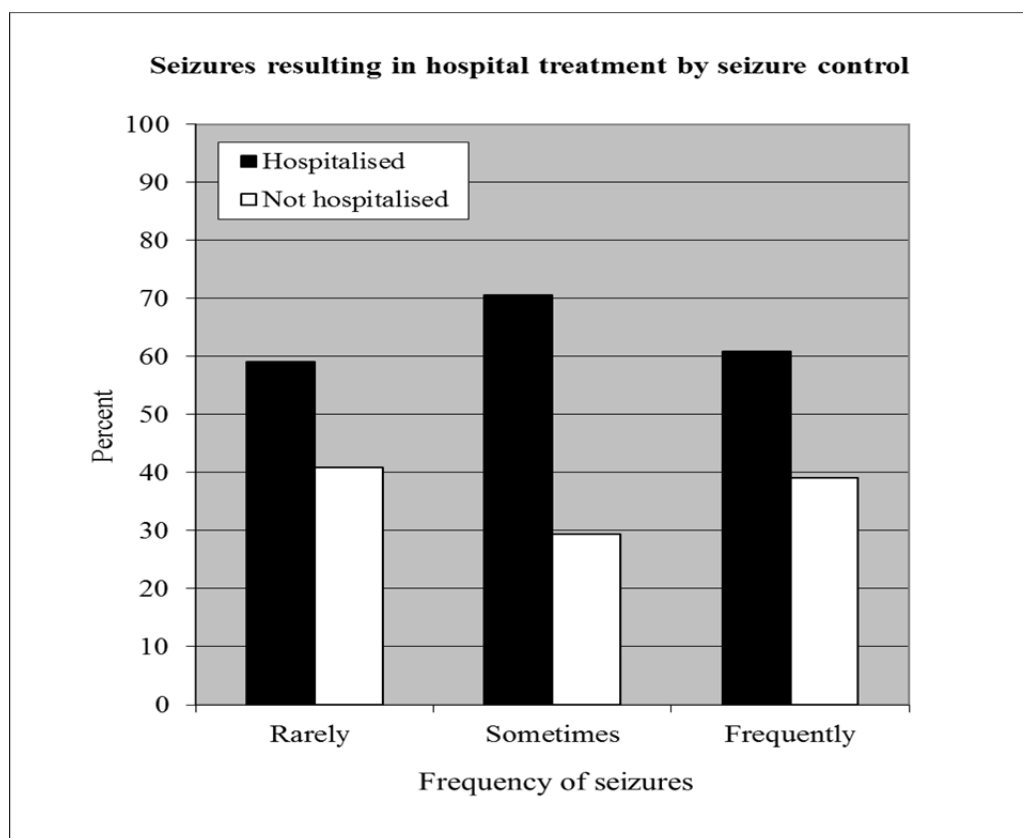


Table 22: Seizure resulting in hospitalisation by seizure control

	Rarely have seizures	Seizures some of the time	Frequent seizures	Total
Hospitalised	39 (59%)	36 (70%)	28 (61%)	103 (63%)
Not hospitalised	27 (41%)	15 (30%)	18 (39%)	60 (37%)
Total	66 (100%)	51 (100%)	46 (100%)	163 (100%)

Interestingly, this trend is not followed with regard to seizure control and hospitalisation. Of the 103 people reporting seizure frequency and answering the question regarding hospitalisation, the greater proportion of those who have seizures some of the time (36 or 70 %) have been hospitalised, followed by those with frequent seizures (28 or 61 %). Those whose seizures are controlled with one AED remain the least likely to be hospitalised for an injury. Table 22 demonstrates that amongst this group of people with epilepsy, regardless of the level of control, approximately 50% are more likely to be hospitalised for a seizure related injury. However, improved seizure control appears the most likely road to reducing hospitalisation.

Chart 5: Seizures resulting in hospital treatment by seizure control



## 2.6 Stigma and discrimination

Table 23: Unfair treatment in the past 12 months

	Yes	No	Missing data
Perceived unfair treatment due to epilepsy (n=343)	164 (48%)	165 (48%)	14 (4%)
Perceived unfair treatment in last 12 months (n=164)	73 (44.5%)	91 (55.5%)	

Personal perceptions of stigma play an important part in the person's ability to participate in the community. Nearly half of the survey respondents (164 or 48 %) considered they had been unfairly treated because of their epilepsy at some stage in their lives. Of that number 73 (44 %) said this had occurred in the last 12 months.

**Table 24: Unfair treatment according to location**

	Yes	No	Unsure
Workplace(n=288)	81 (28 %)	182 (63%)	25 (9%)
School/University (n=299)	64 (21 %)	215 (72%)	20 (7%)
Public places(n=306)	61 (20%)	225 (73.5%)	20 (6.5%)
Community organization(n=305)	47 (15.5 %)	232 (76 %)	26 (8.5%)

By far the greater proportion of respondents felt they had not been unfairly treated in workplaces, educational places and the broader community though a quarter of the responses reported experiencing discrimination in one or more of the four contexts. Considering that legislation operates nationally to address discrimination it is telling that this proportion of the respondents felt unfairly treated in contexts which play such an important role in all people's quality of life.

**Table 25: Levels of comfort in disclosure in social situations**

How uncomfortable do you feel when talking about your epilepsy?	Very uncomfortable	Somewhat uncomfortable	Not sure	Somewhat comfortable	Very comfortable
When talking to your employer (n=229)	56 (24.5%)	50 (22%)	31 (13.5%)	38 (16.5%)	54 (23.5%)
When talking to other people in the workplace (n=236)	44 (18.5%)	58 (24.5%)	30 (13%)	47 (20%)	57 (24%)
When talking to a new partner (n=219)	46 (21%)	51 (23%)	54 (25%)	28 (13%)	40 (18%)
When talking to a prospective partner (n=223)	52 (23%)	53 (24%)	65 (29%)	19 (9%)	34 (15 %)
When talking to a new friend (n=291)	42 (14%)	83 (29%)	52 (18%)	56 (19%)	58 (20%)
When talking to a prospective friend (n=285)	40 (14%)	81 (28.5%)	54 (19%)	54 (19%)	56 (19.5%)
When talking to immediate family (n=303)	20 (6.5%)	35 (11.5%)	14 (5%)	61 (20%)	173 (57%)
When talking to relatives outside of the immediate family (n=296)	32 (11%)	49 (16.5%)	34 (11.5%)	79 (26.5%)	102 (34.5%)
When talking to sport team mates (n=250)	30 (12%)	45 (18%)	63 (25%)	54 (22%)	58 (23%)

Answers to the question on how uncomfortable people felt about disclosing their epilepsy in various social contexts contribute to a picture of how people perceive stigma as a barrier to their participation. While almost half felt uncomfortable or very uncomfortable talking about their epilepsy with their employer or their workplace colleagues, a similar proportion felt comfortable to very comfortable. This might suggest some workplaces are better than others, or it might indicate that those with good epilepsy control find it easier to talk about it than do those with poorer control.



**Table 26: Avoidance of social situations**

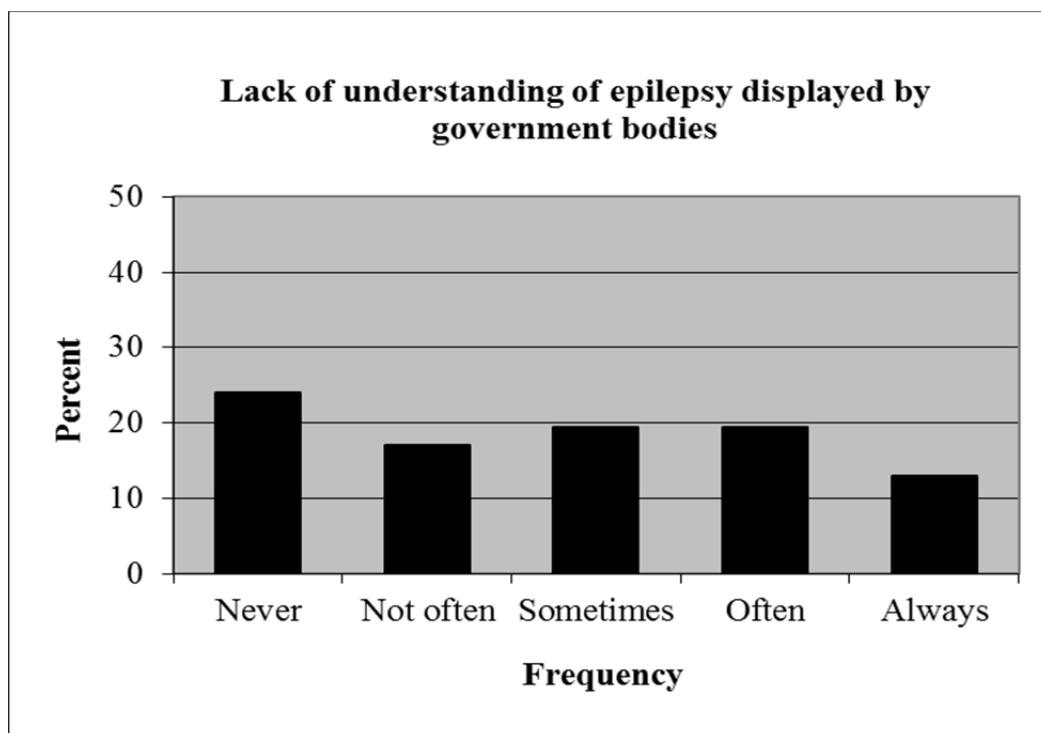
	Always	Often	Some of the time	Not often	Never	Missing data	Total
Frequency public functions were avoided	10 (3%)	34 (10%)	56 (16%)	55 (16%)	174 (51%)	14 (4%)	343 (100%)

Another perspective on the impact of stigma comes through the responses to the question about avoiding public functions, such as attending cinemas, theatres or concerts. By far the greater proportion (51 %) never avoided public functions. There are those for whom social situations are a great concern, with 26 % often or sometimes avoiding public functions. Those who responded 'not often' possibly demonstrate that despite good seizure control there are times that a seizure makes it difficult to socialise.

**Table 27: Understanding by government bodies**

	Never	Not often	Some of the time	Often	Always	Missing	Total
Frequency government bodies were perceived to lack understanding	82 (24%)	58 (17%)	67 (19.5%)	69 (19.5%)	44 (13%)	23 (7%)	343 (100%)

When asked, 'How often have you found that a lack of understanding of epilepsy is displayed by government bodies that are supposed to help you', 320 responded. Only 24% felt they had had a constant positive experience. Seventy-six per cent of the respondents to this question reported experiencing some lack of understanding from government, ranging from 'not often' to 'always'. Nearly a third of those responses were in the 'often' and 'always' categories. These responses suggest that government bodies require information about epilepsy and its impact on people's lives to improve the quality of their service delivery to people with epilepsy.

**Chart 6: Understanding by government bodies**

**Table 28: Impact of epilepsy according to activity**

Activity	No impact at all	Not much impact	Not sure of the impact	Some impact	A lot of impact
Work activity in the work place (n=272)	82 (30%)	48 (17.5%)	18 (6.5%)	68 (25%)	56 (21%)
Relationship with partner (n=246)	101 (41%)	36 (15%)	22 (9%)	57 (23%)	30 (12%)
Relationship with friends (n=318)	106 (33%)	54 (17%)	36 (11%)	85 (27%)	37 (12%)
Ability to drive a car (n=298)	81 (27%)	46 (15.5%)	11 (4%)	34 (11.5%)	126 (42%)
Overall health (n=322)	54 (17%)	57 (18%)	42 (13%)	110 (34%)	59 (18%)
Standard of living (n=321)	95 (30%)	49 (15%)	31 (10%)	90 (28%)	56 (17%)
Relationship with family (n=325)	121 (37%)	54 (17%)	34 (10.5%)	67 (20.5%)	49 (15%)
Social life (n=326)	76 (23%)	53 (16%)	28 (9%)	85 (26%)	84 (26%)
Self-esteem (n=319)	66 (21%)	55 (17%)	40 (12.5%)	91 (28.5%)	67 (21%)
Future plans and ambitions (n=325)	61 (19%)	36 (11%)	35 (11%)	94 (29%)	99 (30%)
Confidence (n=321)	57 (18%)	59 (18%)	25 (8%)	95 (29.5%)	85 (26.5%)
Parenting ability (n=265)	109 (41%)	40 (15%)	33 (12.5%)	38 (14.5%)	45 (17%)
Decision making ability (n=318)	77 (24%)	40 (12.5%)	44 (14%)	85 (27%)	72 (22.5%)
Memory (n=324)	30 (9%)	21 (7%)	42 (13%)	94 (29%)	137 (42%)

People with epilepsy perceive the impact of epilepsy across their entire social lives. As a multiple choice question some respondents would have considered epilepsy impacted in many areas.

**Table 29: Subjective experience in social situations**

	Never	Not often	Some of the time	Often	Very often
I feel different from others who do not have epilepsy (n=313)	82 (26%)	57 (18%)	88 (28%)	49 (16%)	37 (12%)
People will not like me if they know I have epilepsy (n=312)	118 (38%)	87 (28%)	54 (17%)	31 (10%)	22 (7%)
Other people without epilepsy are uncomfortable with me because of my epilepsy (n=314)	91 (29%)	85 (27%)	85 (27%)	24 (8%)	29 (9%)
People will not want to be my friend if they know I have epilepsy (n=309)	140 (45%)	78 (25%)	54 (18%)	16 (5%)	21 (7%)
People will not want to go out with me if they know I have epilepsy (n=306)	140 (46%)	69 (22%)	48 (15%)	26 (8.5%)	23 (8.5%)
People will not want to invite me to parties if they know I have epilepsy (n=307)	150 (49%)	66 (21%)	47 (15%)	22 (7%)	22 (7%)
I feel embarrassed about having epilepsy (n=313)	114 (36%)	74 (24%)	59 (19%)	32 (10%)	34 (11%)
I keep my epilepsy a secret from others (n=310)	107 (34%)	58 (19%)	61 (20%)	34 (11%)	50 (16%)
I try to avoid talking to other people about my epilepsy (n=315)	81 (26%)	63 (20%)	62 (20%)	45 (14%)	64 (20%)

The above table presents people's subjective responses when in social situations. This is not the same as being exposed to overt discriminatory behaviour but relates to internalised values about how others who do not share their condition might feel towards them. Those who never feel 'bad' about themselves or different to others or who feel they will be excluded if their condition is known are in the single overwhelming majority. However, those who sometimes, often and very often feel constrained in their social lives when dealing with others who do not share their condition are in the combined majority. The answers to individual questions are revealing. Not being liked because one has epilepsy was of paramount importance to more than 34 % of respondents, while nearly 34 % felt that people would not want to be friends with them. In both questions responses ranged from 'some of the time' to 'very often'. A far greater number (47 %) kept their epilepsy secret 'some of the time' to 'very often', while 54 % avoided talking about their epilepsy from 'some of the time' to 'very often'. This suggests that some people do not feel different or worry about being disliked or not having friends because they have chosen not to disclose their condition. It also suggests that those who answered 'not often' or 'some of the time' discriminated about whom they chose to disclose their condition.

## 2.7 Transport

A common issue for all adults with epilepsy is the loss of a driving licence for a set period of time related to their seizure activity. In the Australian car-dominated community, not being able to drive has a range of consequences which include inconvenience, loss of job options, difficulty in accessing services and the stigma of not engaging in a socially acceptable activity <sup>(13)</sup>.

**Table 30: Epilepsy and driving**

Activity	Yes	No
Do you have a driver's licence (n=296)	185 (62.5%)	111 (37.5%)
Have you driven anywhere in the past 4 weeks (n=288)	159 (55.2%)	129 (44.8%)
Have you driven when you have been told not to (n=288)	42 (14.6%)	246 (85.4%)
Have you ever had an accident while driving (n=285)	116 (40.7%)	169 (59.3%)
If yes, was it associated with seizure (n=179)	36 (20%)	143 (80%)
Do you have any other licensed drivers in your household(n=289)	209 (72.3%)	80 (27.7%)

Many of the respondents had a licence, with more than half driving in the past four weeks of the survey. Some 15% reported driving when they had been told not to. It is not clear from the survey question whether being told not to drive was on the advice of a clinician or was a restriction from a driving licensing authority.

**Table 31: Modes of transport**

Mode	Never	Rarely	Sometimes	Most frequently	Always
Drive own car (n=305)	139 (46%)	5 (1.5%)	11 (3.5%)	68 (22%)	82 (27%)
Drive other person's car (n=290)	188 (65%)	56 (19%)	40 (14%)	4 (1%)	2 (1%)
Taxi (n=312)	101 (32.5%)	101 (32.5%)	88 (28%)	15 (5%)	7 (2%)
Bus(n=309)	101 (32.7%)	87 (28.2%)	63 (20.4%)	31 (10%)	27 (8.7%)
Train(n=316)	76 (24%)	90 (28.5%)	98 (31%)	32 (10%)	20 (6.5%)
Tram(n=304)	106 (35%)	94 (31%)	73 (24%)	23 (7.5%)	8 (2.5%)
Airplane(n=307)	120 (39%)	115 (37.5%)	69 (22.5%)	1 (0.3%)	2 (0.7%)
Bicycle (n=305)	186 (61%)	52 (17%)	52 (17%)	12 (4%)	3 (1%)
Others drive me (n=321)	39 (12%)	50 (15.5%)	85 (26.5%)	49 (15%)	98 (31%)

A high proportion of households where there were other drivers suggest that people with epilepsy could rely on another driver for transport. This is confirmed by Table 31 where the most common form of transport (72.5 %) for people with epilepsy was being driven by someone else, whereas driving one's own car was done by just over half the respondents (52.5 %). The most common form of public transport was train (47.5 %) followed by bus (39 %) and then tram (34 %). In many cases, respondents would have used combinations of transport; perhaps travelling at times by car, bus, train and tram.

### 3 DISCUSSION

In 2010 there were 612 people on the research register. Three hundred and forty three people responded to the 2010 survey.

The results of the survey show that employment remains an issue for people with epilepsy. Younger people are remaining in education, while the survey also demonstrated that many older people had not completed their secondary schooling. However, even well-educated respondents did not necessarily have employment. It was evident that education was not an avenue towards employment opportunities among this group. This resulted in people with epilepsy having low incomes, fewer owning their own homes and in some cases living below the poverty line.

From the Wave 2 survey in 2010 it is possible to conclude that a significant number of people of working age were unemployed because of their epilepsy or another disability.

Employment has implications for income. Respondents in Wave 2 were on low incomes, with many reporting themselves in income brackets below the 2007 poverty line and few reporting they were on the average weekly income of \$1333.30<sup>(4, 5)</sup>.

In exploring financial distress, other costs such as medicines and treatment related costs including travel add to this level of distress since they reduce disposable income. Note that sixty per cent were on multiple AEDs and with an already low income this adds to financial distress. While those who are employed have fewer AEDs they are likely to pay the higher PBS subsidy. Those with more AEDs despite probably being eligible for the lower PBS subsidies have more AEDs to purchase.

Not being able to attend social or recreational activities is an indicator of financial distress<sup>(8)</sup>. Importantly, home ownership also indicates a level of poverty and distress. For respondents to Wave 2 all these factors were present. Home ownership was much lower than home ownership for the Australian population, while costs were a factor in not attending social or recreational activities.

The relationship between having epilepsy and financial distress is supported by other studies. Jennum et al<sup>(14)</sup> found in their study of Danish people with epilepsy that there were a greater percentage of people with epilepsy on social security incomes and consequently significantly lower incomes than those in the Danish control group. Lower incomes for Danish people with epilepsy were generally a consequence of a lower employment rate. They concluded that epilepsy had a significant effect on indirect costs (out of pocket costs) which generally accounted for three quarters of the total costs. Loss of labour market income was the most significant factor. Jeon et al also found that the rising out of pocket costs for health services in Australia was a significant factor in making access to health difficult as well as causing greater distress<sup>(15)</sup>.

The section on seizure activity and its impact on people's lives should be treated with great caution. Data reported here are based on people's memories of events as well as based on their perceptions of their condition. At the same time, validity of data is difficult to determine in that some people did not answer all the questions while some people gave differing answers to subsequent questions.

The onset of epilepsy reported by Wave 2 respondents began early in the majority of people's lives, with many experiencing it in their formative years of childhood and adolescence. A large proportion reported having more than one type of seizure. There appears to be poor control amongst this group with only thirty per cent reporting good control.

Sixty one per cent of the respondents were on multiple medicines for their epilepsy. People who took one drug only were most likely to be those who had no seizures in the last 12 months. People who took 3 or more drugs were more likely to be those who had more than twenty seizures in twelve months. This demonstrates that the fewer seizures, the smaller number of drugs, while the more seizures, the larger number of drugs.

At this stage this provides little evidence of the impact of their epilepsy on the quality of people's lives, since those medicines may have been contributing to relatively better control. As the longitudinal study proceeds comparative data will become available and contribute to a fuller picture. The likely economic impact in terms of costs is noted above however.

A better indication of the impact of epilepsy on the lives of the respondents comes by looking at employment and seizures. People who were seizure-free or experiencing one or two seizures in the past twelve months were the highest proportion of those employed. It is interesting to note that amongst the employed there were people who were experiencing 100 or more seizures in twelve months and taking multiple AEDs. However there is no means of verifying the type of seizures associated with this.

Amongst those not employed currently, those who are seizure-free over 12 months are the highest proportion taking 1 drug, while those with 21-90 seizures in the past 12 months were the highest proportion taking 3 or more drugs.

Overall the data suggest that effective seizure control plays an important part in being employed and consequently in quality of life.

Most compelling evidence of the impact of epilepsy on quality of life comes from data on injuries and hospitalisations. More than half claimed to have been injured as a result of a seizure and nearly two thirds of them required hospital treatment for their injuries. Those on more AEDs and reporting more seizures were the most likely to be injured but even those with less frequent seizures reported injuries. The level of hospitalisation due to seizure-related injuries suggests at least interruption to quality of life, though once again it is not possible to assess whether hospitalisation was preventable or if the admission was for a serious injury.

The responses to the questions on discrimination and experiences of social situations provide good examples of both felt and enacted stigma<sup>(16)</sup>. Enacted stigma occurs when there are overt acts of discrimination against people with epilepsy for no other reason than they have epilepsy; felt stigma may be best described as internalised by the person with epilepsy as a sense of shame at their condition which predicates avoidance of encountering enacted stigma. Issues related to disclosing one's condition are part of felt stigma but may be based on having experienced enacted stigma previously.

Responses to the questions represented in Tables 26 to 31 inclusive are accounts of the subjective experience of epilepsy in various social situations. They are examples of internalised felt stigma as there is an awareness of the condition's social and cultural unacceptability<sup>(16)</sup>. These examples include non-disclosure in order to avoid enacted stigma from being shunned by potential friends and colleagues. Some people had far less difficulty with felt stigma but it is likely that they had arrived at a point where they were confident they could adequately assess the situation and decide when it was appropriate to disclose their condition or not. Others clearly functioned on the basis that it was better to avoid a situation producing the enactment of stigma.

It is not possible to assess from these tables if actual acts of discrimination took place, since the questions are based on people's perceptions of how they were treated or how they would be

treated if they disclosed their condition. However, it is safe to argue that non-disclosure is adopted as a strategy based on previous experience.

Many of the respondents had a licence, with more than half driving in the past four weeks of the survey. Some 15% reported driving when they had been told they should not do so. It is not clear from the survey question whether being told not to drive was on the advice of a clinician, friendly advice or was a restriction from a driving licensing authority. However, a small number reported having had an accident related to a seizure.

In this survey there was also a high usage of public transport, possibly reflecting the metropolitan-based sample. At the same time, the results also indicate that if a person was not able to drive, their preference was to be driven by someone else. This is consistent with other research showing that people with epilepsy prefer not to use public transport <sup>(17)</sup>.

There are a number of limitations related to the 2010 survey. At present the survey is biased representing a group of people with less well controlled epilepsy. It is not possible to extrapolate from the results to the broader community of people living with epilepsy. The results also largely reflect a Melbourne-metropolitan group rather than people living with epilepsy from all states in Australia.

At this stage these survey results are best viewed as reflecting the perceptions and responses of people with epilepsy who access EFV services. While this is a limitation as a community-based survey, it nevertheless provides a picture of the impact of epilepsy on the quality of life of people whose epilepsy is less well controlled and who require ongoing services to cope.

The 2010 survey provides indications for improvement in the future. More recruitment, especially from other Australian states is required to make this a more representative sample of Australians living with epilepsy in the community. Other state-based epilepsy associations and Epilepsy Australia are already undertaking recruitment. Entry points through clinics are being explored.

In order to make the survey more robust a number of modifications will be introduced before the next wave is undertaken. These include the use of ID numbers for each respondent which will allow for cross-sectional changes to be studied so that changes over time for individuals can be analysed. Survey questions will be modified to provide more comparable data. There are now a number of well-developed and reputable longitudinal studies established in Australia, including the MS Longitudinal Survey <sup>(18)</sup> and The Housing, Income and Labour Dynamics (HILDA) Survey <sup>(19)</sup>. Having a survey tool which produces data comparable to the data from these studies will provide an even more interesting and valid set of data on the quality of life of people with epilepsy in Australia.

In developing comparable survey tools the length of the survey tool will be considered to ensure that respondents do not develop 'questionnaire fatigue' leading to questions remaining unanswered or answered only with a view to completing the survey as quickly as possible.

Issues of attrition are constant problems in longitudinal surveys and many of the longitudinal studies such as HILDA have already dealt with these problems. Keeping people engaged and demonstrating to them that they are valued, through newsletters and items of interest, is important. At the same time the use of statistical measures of weighting and imputation are also important considerations to ensure validity of data.

Another modification that may be considered is to explore some of the results qualitatively. Interviews or focus groups have the advantage of providing detail to explain the responses. For example it would only be by a qualitative study that it would be possible to know more about why people felt government bodies were not helpful or the circumstances that led to a person

knowing they had suffered discrimination. Additionally, interviews could provide better detail on what people understood about their diagnoses and the circumstances leading to injuries and hospitalisations. These qualitative methods are employed in other longitudinal studies.

## 4 Conclusion

The results reported here are based on the responses by people who are members of the Australian Epilepsy Research Register. These results reflect the experiences, perceptions and beliefs of a group of people with epilepsy, largely from metropolitan Melbourne.

The results indicate that this group of people with epilepsy had less well-controlled epilepsy; were possibly unemployed and underemployed despite having reasonable educational levels; lived with a level of chronic financial distress as indicated by their housing, their ability to enjoy social activities and participate in other activities. Many had not received the help they sought from government bodies.

The data on seizure activity and number of AEDs, as well as injury and hospitalization, was difficult to interpret because of lack of valid and consistent responses in this area. However, there are indications that the group was generally struggling with seizure control and that there had been a substantial proportion of injuries and hospitalisations related to epilepsy. It is not possible to conclude whether those hospitalisations were preventable or indeed appropriate at this stage. Further research in this area is required.

Feeling that discrimination had taken place was reported by about half the respondents. Additionally feeling a level of comfort in social and work situations was also only felt by about half the sample. This suggests that disclosure remains an important consideration for all people with epilepsy but especially for those whose epilepsy is poorly controlled. This has implications for issues related to driving. Not being able to drive is perceived as impractical but also stigmatising. This has implications for a small group of people who continue to drive when advised they should not.

This survey provides Epilepsy Australia and its members, along with other researchers interested in further exploring the social impact of epilepsy with much needed baseline data. There are now clear directions where future research will benefit people with epilepsy. Future research should be aimed at the relationship between educational status, employment opportunities and income; hospitalisations due to injury and seizure activity; the impact of stigma and discrimination in the workplace and the broader community and finally the role of government bodies in assisting people with epilepsy. Targeted research of this nature can then be used to develop programs to address these issues.



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