

**JOINT EPILEPSY  
COUNCIL OF AUSTRALIA**  
Australian Chapter of the International Bureau for Epilepsy



**'LIFE WITH EPILEPSY'**  
Report

*Australia's largest ever nationwide  
survey of people with epilepsy*

## Introduction

This report analyses the key findings from a nationwide survey - the largest epilepsy research ever undertaken of its kind in Australia - conducted by the Joint Epilepsy Council of Australia\* (JECA).

The research was conducted amongst people living with epilepsy and their carers and aimed to quantify the true impact living with epilepsy has on individuals, particularly with regards to quality of life and general awareness of the condition – a crucial step to better understanding the needs of those living with epilepsy. The research also assessed the impact living with epilepsy has on day to day life activities, such as education, employment and transportation.

The 'Life with Epilepsy' Report provides valuable insight into what it means to live with epilepsy and helps to improve understanding of the current issues faced by those living with the condition.

### Key findings include:

- Epilepsy has a considerable impact on a person's quality of life and ability to undertake day-to-day activities such as working or studying
- People with epilepsy live with significantly higher levels of psychological distress than the general population
- Transport remains an issue for people with epilepsy, with a considerable number of people avoiding public transport and having to rely on a family member or friend to get around
- People with epilepsy who live in metropolitan areas have better access to specialists and GPs
- People with epilepsy are experiencing discrimination in Australia
- A life without seizures was deemed the most important treatment goal by people with epilepsy.

*J. Cummins*

Jacinta Cummins  
Chair, Joint Epilepsy Council of Australia

\*JECA consists of community based organisations which provide epilepsy services across Australia and is the Australian Chapter of the International Bureau for Epilepsy (IBE).

## Epilepsy

Epilepsy is the most common serious brain disorder, and is perhaps one of the most universal of all medical disorders. Widely misunderstood, epilepsy has been shown to lead to fear, secrecy, stigmatisation and the risk of social and legal penalties. It is conservatively estimated that approximately 200,000 people have epilepsy in Australia at any one time<sup>1</sup> and as many as three times this many Australians will have epilepsy at some time in their lives.<sup>1</sup>

Epilepsy is a disorder in the activity of nerve cells in the brain which is characterised by unpredictable, recurring episodes known as seizures.

The location of the electrical discharges in the brain determines the parts of the body that are affected by seizure activity.<sup>2</sup>

Epilepsy can affect anyone and has no age, racial, professional or geographic bounds.<sup>3</sup> While the condition can have profound physical and psychosocial consequences, appropriate treatment can in most instances prevent long-term damage.

While there is no cure for the condition, there are various ways people can control or manage symptoms to improve their quality of life, particularly if the condition is identified and managed early.

## The respondents

### Age of first seizure

Almost 60% of respondents had their first seizure under 12 years of age, with the likelihood to experience a seizure reducing with age. In stark contrast, figures from Europe and the USA show that more people over 60 are now diagnosed with epilepsy than those under 12. This raises serious questions about how Australian patients are dealing with seizures and about the capacity of doctors to diagnose and treat seizures among the elderly.

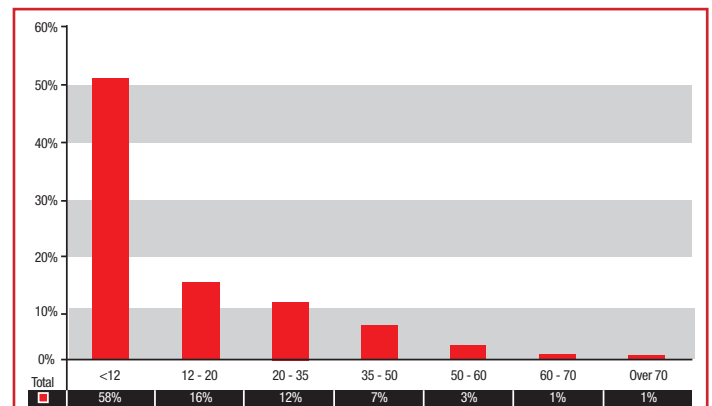


Figure 1: Age at diagnosis (years)

### Diagnosis time

Although half (51%) of cases were diagnosed within 3 months of the first seizure, 42% took anywhere between 3 months and over 5 years and over to be diagnosed with epilepsy.

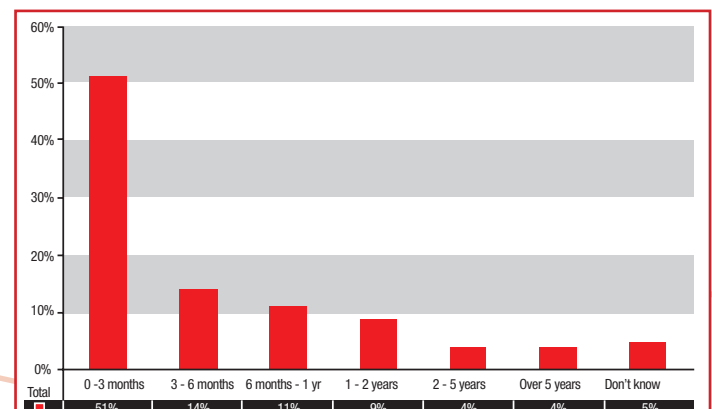


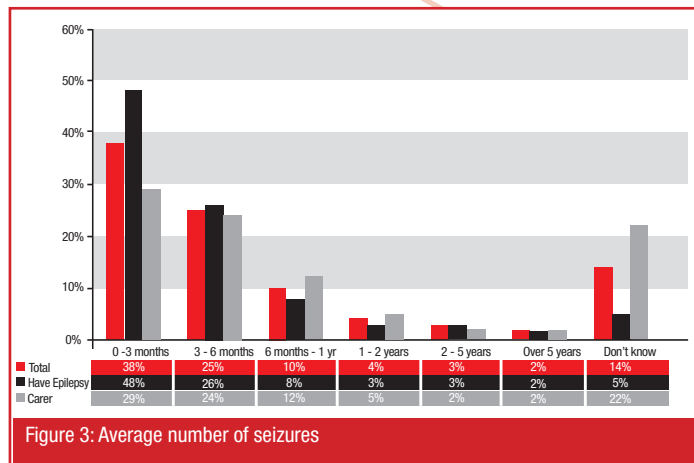
Figure 2: Time to diagnosis

## Average number of seizures

Only around two out of every five respondents were seizure free, with one in 10 having more than 25 seizures per month. It is interesting to note the discrepancy between the responses of those with epilepsy and their carers. Those with epilepsy reported a higher level of seizure freedom than carers responding on their behalf.

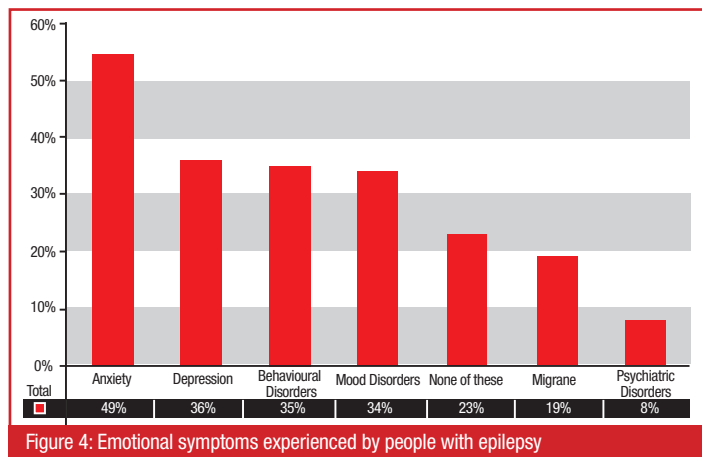
*One in ten experience more than 25 seizures a month.*

Those who have recently been diagnosed with epilepsy are more likely to experience multiple seizures, with these individuals being particularly represented in the 'more than 25 seizures per month' group. These findings provide evidence to confirm that it may take a period of time and the trial of a number of medications in order to find the right one/s to provide seizure control for a person with epilepsy.



## Impact of epilepsy

The biggest impact of epilepsy related to people's ability to participate in the workplace, with only 12% of respondents working full time. For over 33% of those with epilepsy, the condition also has a significant impact on their ability to participate in education, play sport, exercise and socialise.



Nearly half of those with epilepsy experience anxiety and around a third report either depression, behavioural disorders or mood disorders.

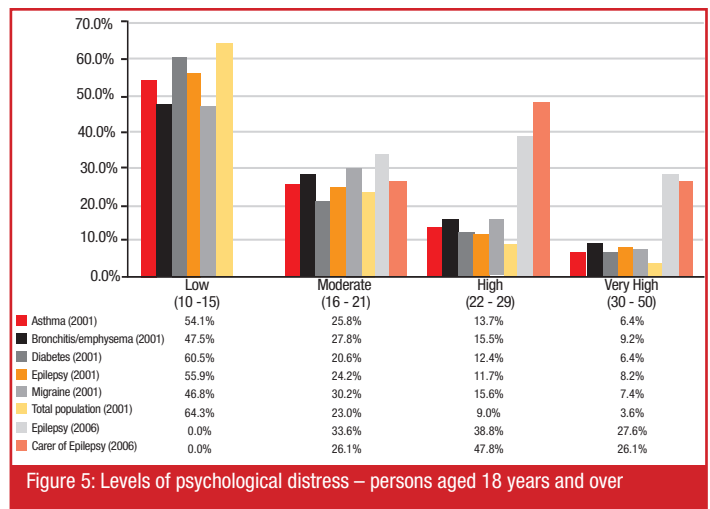
Epilepsy has a big impact on the mental and physical wellbeing of those with the condition. Over half experience feeling 'tired out for no good reason' for some of the time or more frequently. Two-in-five experience 'feeling nervous' or 'feeling restless or fidgety' and around one-in-five experience 'being sad' or 'feeling worthless' some of the time or more frequently.

People with epilepsy live with significantly higher levels of psychological distress than the general population.

Some 67 percent of people with epilepsy report living with high and very high levels of psychological distress, as compared to 13 percent of the general population who reported high and very high levels of psychological distress in the 2001 National Health Survey.

People with epilepsy also reported living with higher levels of psychological distress than those surveyed in 2001 with other conditions such as asthma and diabetes.

*67% report living with high and very high levels of psychological distress*



*Note: Survey respondents were asked the same ten questions - Kessler 10 - included in the 2001 Australian National Health Survey. Kessler 10 is a scale that measures non-specific psychological distress.*

## Epilepsy and transport

Transport and travel is something that most people take for granted, but it is clearly very difficult for many people with epilepsy to get from place to place. Only one third of people with epilepsy drive their own car and of this group, over half have had their driving licence suspended at some time.

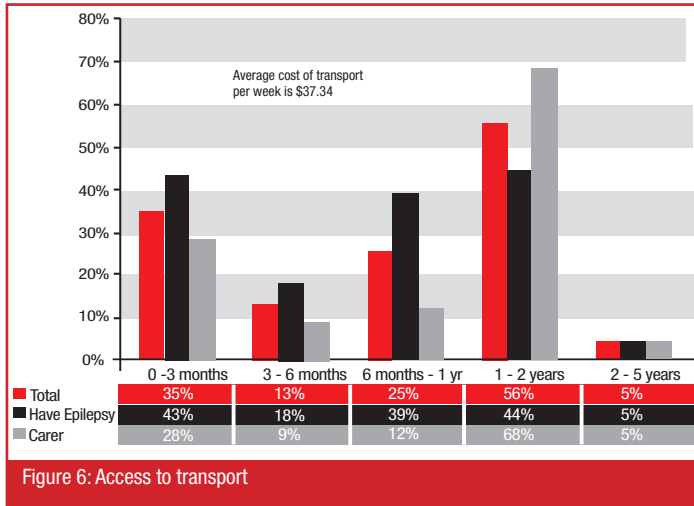


Figure 6: Access to transport

## 56% need a family member or friend to drive them

People with epilepsy spend an average of \$37.42 a week on transport. The cost of taxi transport limits travel for over half of those with epilepsy, with 23% unable to afford to travel by taxi. This is doubtless due to a number of factors from the inability of many people with epilepsy to work full time and their consequently lower incomes, the generally heightened costs of living with chronic illness, fear of having a seizure while on public transport, and the inadequacy [as well as the national inconsistency] in travel assistance for people with epilepsy. In fact the survey found that 40% of people with epilepsy avoid public transport either occasionally, sometimes or always.

## Epilepsy and discrimination

Unfortunately, 53% of those with epilepsy have experienced discrimination at some point and of those, 51% have experienced discrimination in the last 12 months. The most common place for discrimination is the workplace, followed closely by education institutions.

Nearly 70% of people with epilepsy feel uncomfortable telling new friends about their condition. For each age group except the over-81-years age group at least two-thirds of respondents reported that they felt

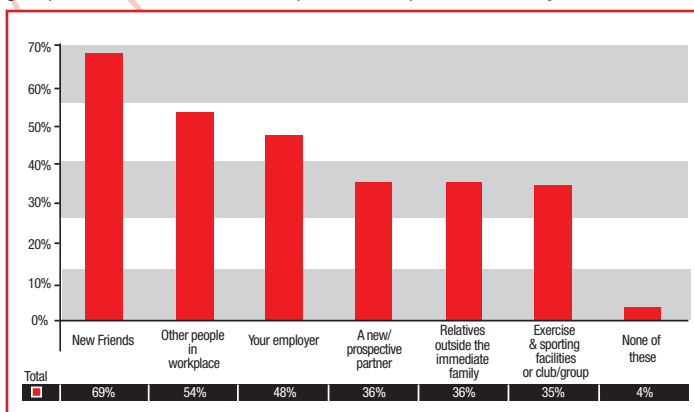


Figure 7: Who do you feel uncomfortable telling about your epilepsy?

uncomfortable telling new friends. Interestingly, although it would be expected that this would be high among younger people; in fact, the high proportion of people reporting feeling uncomfortable were the 41-50 years age group (84%) and 71-80 years age group (100%).

## Access to medical care

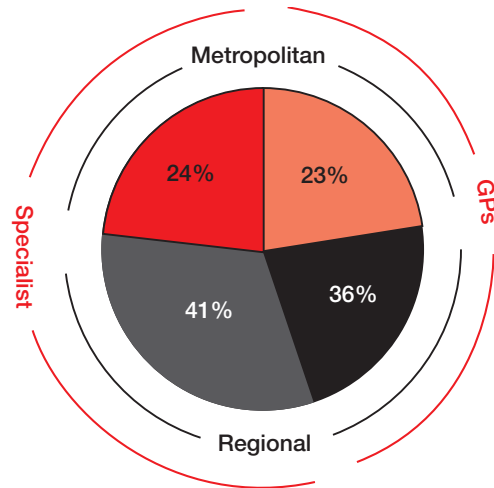


Figure 8: % of people with epilepsy with no or poor access to medical care

Overall, respondents report fairly good access to medical care. However, as would be expected, those respondents living in metropolitan areas had better access to both specialists and GPs compared to their regional peers.

41% of respondents living in regional areas have either no or poor access to a specialist. Nearly the same amount (36%) of respondents living in regional areas also reported no or poor access to a GP.

*41% living in regional areas have either no or poor access to a specialist*

## Epilepsy treatments and seizure control

### Treatment Goals

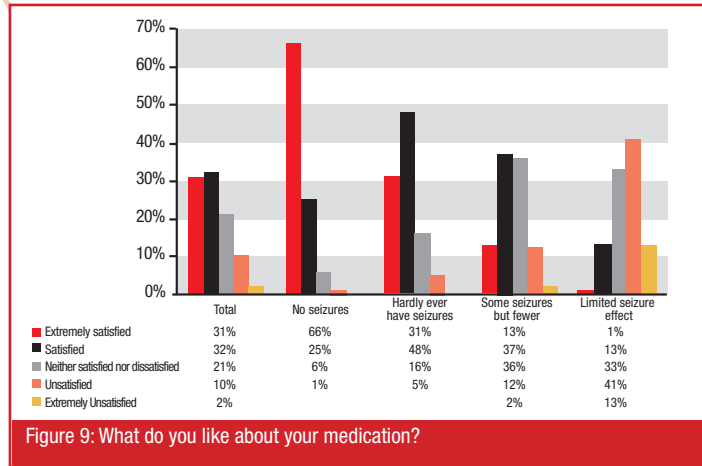
Not surprisingly, a life without seizures was deemed the most important treatment goal for people with epilepsy. This was followed by treatment with few side effects, access to specialists and great improvement with treatment in this order.

### Treatments and Satisfaction Levels

Sodium valproate was the most common medication used (44%), followed by carbamazepine (27%) and lamotrigine (27%). On average, 2.04 different types of medications were used by each person with epilepsy to control their seizures. In terms of satisfaction, over two-thirds of those

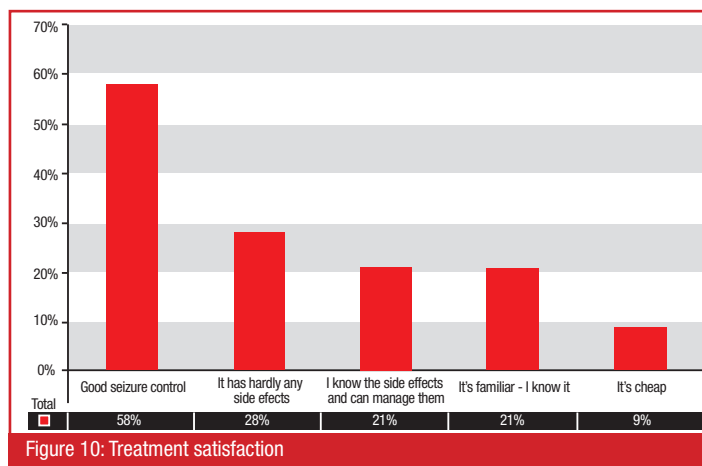
with epilepsy are satisfied or extremely satisfied with their treatment; however 12% are either dissatisfied or extremely dissatisfied.

Interestingly, each medication is associated with both perceived extreme satisfaction and extreme dissatisfaction; again demonstrating how each person's response to a medication is individual.



Not surprisingly, satisfaction with current treatment was highest where seizure control was greatest.

*One third would try a new medication even if there was an equal chance seizure control could either improve or worsen*



## Likes & dislikes about treatment

As would be expected, good seizure control was the element most liked by respondents (58%). In addition, limited or manageable side effects were cited by 49% of respondents and familiarity of medication by 21%.

When asked what they did not like about their treatment, just over a quarter of respondents cited side effects as their main cause for dislike.

For half of those with epilepsy the biggest concerns about treatment were difficulties with memory and thinking issues. Around a third are concerned with mood swings (35%), seizure control (30%) and the increased need to sleep (30%) and 23% by weight gain.

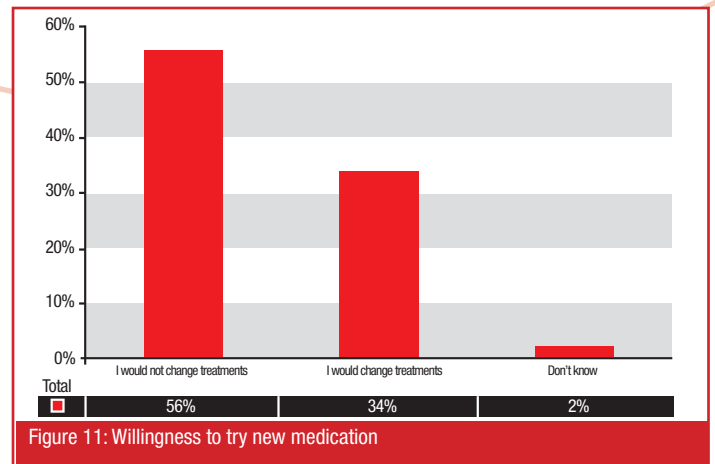
## Medication and generic substitution

A total of 204 respondents had had their medication brand substituted for a generic\* type by the pharmacist and for one in five this resulted in an increased number of seizures.

\*A generic is a drug that is no longer protected by trademark where multiple versions of the same drug are available. The Therapeutic Goods Administration (TGA) allows for slight differences between branded medicines and their generic substitutes in the way they are absorbed into the body. It is thought that small changes in the absorption of anti-epileptic medicines may result in poorer control of seizures.<sup>4,5</sup>

## Trying a new medication

One third of people with epilepsy would try a new medication even if there was an equal chance that their seizure control could either improve or worsen.



## Methodology, sample and demographics

• Please note that figures throughout the report may not add up to 100% as not all respondents answered each question.

### Methodology

• Postal and online surveys completed by JECA member organisations database during August and September 2006

### Total number of respondents:

• 467 individuals with epilepsy  
• 496 carers of those with epilepsy

• It is important to note that because this report is drawn from responses of people already part of the epilepsy support community, it is not totally representative of all Australians with epilepsy. Hence while it provides good indicative data on the feelings and issues of people with epilepsy and their carers, caution needs to be taken not to make assumptions regarding the epilepsy community at large.

- State-based

- ACT 83 respondents
- VIC 245 respondents
- QLD 199 respondents
- SA 185 respondents
- WA 116 respondents
- TAS 66 respondents
- NT 16 respondents
- NSW 12 respondents

Note: Some 41 respondents did not disclose their state of residence

- Of those with epilepsy 33% were male and 47% female (20% of respondents did not disclose their sex). In contrast, their carers were 9% male and 91% female.

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March 2007

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Note: This report has been developed with the support of an unrestricted educational grant from UCB Pharma.

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