

Joint Epilepsy Council of Australia

Australian Chapter of the International Bureau for Epilepsy

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Submission from the Joint Epilepsy Council of Australia Inquiry into Suicide in Australia

Suicide and epilepsy

People with epilepsy are more likely to die prematurely and suicide is an all too common cause of death.

A recent submission by the Joint Epilepsy Council of Australia to the Parliamentary Friends of Epilepsy “Inquiry into the Impact of Epilepsy in Australia today” comprehensively details the issues facing people living with epilepsy, and is attached for further information (Appendix 1).

Epilepsy

Epilepsy is the world’s most common serious disorder of the brain according to the World Health Organization¹. WHO reports that the burden of epilepsy accounts for 0.5% of the global burden of disease. This can be compared with multiple sclerosis at 0.1% or breast cancer at 0.4%, or diabetes at 1.3%.²

A seizure is a disturbance of movement, feeling, thought, or consciousness occasioned by sudden, inappropriate and excessive electrical discharges in the brain. The tendency to have recurrent seizures will usually attract a diagnosis of epilepsy. Epilepsy doesn’t discriminate – it can happen to anyone of any ability, background, or age (although it is more common in children and those over 65 years of age). Medication is of assistance in controlling seizures in about 70% of people with epilepsy.

The impact of epilepsy

Epilepsy has the potential to have a profound effect on every aspect of someone’s life. The seizures themselves may cause injury and embarrassment. The person may lose their independence – for example losing their driver’s licence, and/or employment, accompanied by a loss of financial independence. Sadly people living with epilepsy often find they become socially isolated – relationships with significant others may deteriorate, their friends reject them, usually due to fear. In the wider community this fear may manifest as discrimination. There are medical tests and trips to medical specialists who may be hundreds, even

thousands of kilometres away. Medication is potentially another source of stress with unwanted side effects including fatigue and cognitive problems. Psychosocial adjustment is not determined by seizure frequency and/or severity. One may have severe epilepsy and cope quite well. Others have less severe epilepsy but become profoundly psychosocially impaired with loss of self esteem and confidence, anxiety, and a sense of diminished control over their life ³. It is true that people with other chronic illnesses may also experience psychological disorders, however a community based study found that people with epilepsy had higher depression scores than people with asthma or in a control group.⁴

Psychological effects

There are many types of seizures and individuals vary considerably in regards to the way seizures manifest and impact. Some may experience psychological effects with their seizures – for example hallucinations, aggression, extreme fear or sadness.

It is well documented in the medical literature that people with epilepsy experience much higher rates of psychological disorders than the general community. The following table from a presentation by Salzberg (2008)⁵ clearly demonstrates the incidence of common psychological disorders in epilepsy.

Psychiatric Disorder	Epilepsy Patients	General Population
Depression	30-50%	5-17%
Generalised Anxiety Disorder	15-25%	5-7%
Panic Disorder	5-21%	0.5-3%
ADHD	12-37%	4-12%
Psychosis	2-9%	1%

Ettinger & Kanner. Psychiatric Issues in Epilepsy. 2nd Edition LWW 2007⁶

Salzberg suggests 4 possibilities for the link between epilepsy and depression:

1. Epilepsy causes depression because it's an understandable reaction and epilepsy has an affect on the brain (underlying disease, seizures, and medication)
2. Stress hormones associated with depression have an effect on the brain, triggering seizures. One hypothesis is that depression is a risk factor for epilepsy onset.
3. There may be shared causation for epilepsy and depression.
4. All of the above.

There is still much to be learnt about the interactions between neurobiological, iatrogenic and psychosocial factors ⁷.

A history of depression is associated with a 4- to 6- fold greater risk of developing epilepsy. Kanner (2003) says that the clinical presentation of depressive disorders in epilepsy can be identical to that of nonepileptic patients, however in a significant percentage of cases the clinical features of epilepsy fail to meet any of the DSM-IV Axis I categories.

In spite of the comparatively high incidence of psychiatric disorders in epilepsy, unfortunately they are under recognized, under diagnosed and under treated. Both the clinician and patient may have a role to play in minimising the significance of the symptoms, because they consider depression and anxiety to be a normal way of responding to the condition⁸, or a belief that antidepressants are ineffective or will exacerbate seizures ⁹.

Epilepsy-related death

A recent report into avoidable mortality in Victoria between 1997 and 2003 found that epilepsy was in the top five causes of death in the 5–29 year age group. It is interesting to note that in the 15–29 year age group the top four causes were all accident-related or due to self-harm. Epilepsy was the only chronic condition listed in the top five.¹⁰


There are approximately 300 epilepsy-related deaths in Australia per annum.¹¹ More than half of these are due to SUDEP (sudden unexplained death in epilepsy).

The risk of suicide in people with epilepsy has been estimated to be 10 times higher than in the general population.¹²

Recommended strategies

- Improve the accuracy and specificity in recording epilepsy-related death, including suicide. Being mindful of the family's need for timely closure would also be of assistance.
- Emergency services staff need to know basic information about epilepsy – how to identify seizures, and how to respond appropriately. In the past inappropriate responses have greatly exacerbated the distressed state of the person with epilepsy.
- JECA applauds the public awareness campaigns undertaken by the government and depression/mental health organisations, however there has been little regard for the needs of people with epilepsy in these programs. We would encourage inservice training about epilepsy for front line workers and those involved in the development of information campaigns.
- Epilepsy support organisations have a great deal of expertise about epilepsy. Funding support for JECA to develop specially tailored programs in collaboration with leading mental health organisations would ensure targeted and effective information and psychosocial support programs for the common psychological disorders. Early intervention will save lives.
- Allocation of mental health research funding to research psychological disorders in epilepsy.
- Implementation of the strategies discussed in the submission for the Parliamentary Friends of Epilepsy inquiry to enhance quality of life generally for people with epilepsy will assist in ameliorating the stresses and challenges that may give rise to psychological disorders and ultimately suicide.

Yours sincerely



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Chair, Joint Epilepsy Council of Australia

Attachment 1: A Fair Go for People Living with Epilepsy: Report to the Parliamentary Friends of Epilepsy

References

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- ⁵ Salzberg M Getting on top of epilepsy: a psychiatrist's view. Top of mind Symposium, 2008.
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- ¹⁰ Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez A. The burden of disease and injury in Australia. Canberra: AIHW, 2007
- ¹¹ Australian Institute for Health and Welfare. Annex Table 2: Deaths by cause, sex and mortality stratum in WHO regions, estimates for 2002. World Health report (document on the internet). Canberra: AIHW, 2004 (cited 2009 June1).
- ¹² Kanner AM. Depression in epilepsy: Prevalence, clinical semiology, pathogenic mechanisms and treatment. *Biological Psychiatry* 2003; 54:388-398.