

## ***No one should go it alone***

### **WHAT IS EPILEPSY?**

Epilepsy is a common neurological disease which can occur at any age, with the highest incidences in the first year of life or early childhood and in older people over 65 years old. Although approximately 65 – 70 million people are living with epilepsy worldwide, making it one of the most common, neurological diseases globally, epilepsy remains underfunded compared to other neurological conditions. Medication only treats the symptoms of epilepsy, it doesn't cure the underlying cause.

Some of the known causes of epilepsy are head trauma, central nervous system (CNS) infections, tumours and inherited, developmental or genetic conditions.

1 in 26 people will be diagnosed with epilepsy in their lifetime.

### **EACH DAY SOMEONE'S SON OR DAUGHTER DIES FROM EPILEPSY**

An ABS analysis has shown approximately 300 deaths a year were epilepsy-related in Australia.

People with epilepsy have an increased risk of premature death – they are 2-3 times more likely compared to someone in the general population.

Around half of epilepsy-related death is Sudden Unexpected Death in Epilepsy (SUDEP), where sudden death occurs in a person with epilepsy for no apparent reason. The other half is mainly caused by accidents and injury as a result of a seizure. Drowning in a bath or whilst swimming, or falling from a height are two examples of an accidental seizure related death.

Epilepsy is in the top 5 causes of avoidable death from ages 5-29.

We can stop avoidable deaths by educating people and families to understand and manage the risks of seizures.

### **CHILDREN AREN'T GETTING A GOOD EDUCATION BECAUSE OF THEIR EPILEPSY**

Australian children aren't getting a good education because of their epilepsy. The stigma attached to epilepsy affects their opportunities to create friendships groups with their peers and missing school days affects their learning. Kids are experiencing discrimination in the classroom and schoolyard, often due to ignorance or lack of understanding, and facing exclusion from the journey every student should be entitled to.

### **PEOPLE ARE LOSING THEIR JOBS BECAUSE OF THEIR EPILEPSY**

The stigma attached to epilepsy affects their opportunities for employment. 48% of respondents to our Australian Epilepsy Longitudinal Study report unfair treatment as a result of their epilepsy and the workplace is where most people with epilepsy experience discrimination.

## PEOPLE FEEL SCARED AND ALONE BECAUSE OF THEIR EPILEPSY

The stigma or social consequences faced by people living with epilepsy is often worse than the disorder itself. Anxiety can occur because of the paralysing fear of having a seizure and after a seizure, feelings of depression can heighten. The feeling of being different, outcast and not understood because of epilepsy as well as seizure activity, can lead to isolation and form barriers to meaningful relationships.

People with epilepsy who do achieve control of their seizures (usually with medication) still have to endure –

- Severe adverse side-effects from medication
- Learning and memory problems
- Sleep disorders
- Mental health disorders
- Public misunderstanding and unfair treatment (discrimination)

## DID YOU KNOW?

- 1 in 10 people will have a seizure in their lifetime. If a person experiences a seizure does not mean they have epilepsy.
- A seizure occurs when there is sudden, excessive electrical activity in a group of brain cells. A person who has two or more seizures has epilepsy.
- The main factors to affect depression in people living with epilepsy include high levels of social stigma, being out of paid employment, and having ineffective control of seizures.
- Epilepsy varies considerably among individuals – there are several types and severities which require tailored, individualised treatment.
- Seizures can be convulsive and non-convulsive.
- The profiles and characteristics of all epilepsy subtypes are not well known, making treatment a challenge.
- People with epilepsy who were in in paid employment, found a reduction in their anxiety levels by 11.5 per cent.

## OUR SERVICES

So what services does the Epilepsy Foundation provide? We provide information, advice and support, epilepsy counselling, case management and practical assistance, as well as education and training, social and psychological research for people with epilepsy.

## WHAT TO DO IF SOMEONE HAS A SEIZURE

**Call 000** when a person has a seizure and any of the following apply:

1. If you don't know the person
2. If there is no available Epilepsy Management Plan
3. If the seizure lasts for 5 minutes
4. If the seizure stops but the person does not regain consciousness within 5 minutes
5. If another seizure begins
6. If the seizure activity has resulted in a serious injury
7. If the seizure occurs in water
8. If you believe the person having the seizure may be pregnant

### Tonic-clonic seizure

Is a convulsive seizure with loss of consciousness, muscle stiffening, falling, followed by jerking movements:

- Note the time the seizure started and time until it ends
- Protect the head – if available use a pillow or cushion
- Remove any hard objects that could cause injury
- Do not attempt to restrain the person or stop the jerking or put anything in their mouth
- As soon as possible roll the person onto their side – you may need to wait until the seizure movements have ceased (see pictures)
- Talk to the person to make sure they have regained full consciousness
- Stay with and reassure the person until they have recovered



### Seizure with impaired awareness

Is a non-convulsive seizure with outward signs of confusion, unresponsiveness or inappropriate behavior, care should be taken as this can be mistaken for alcohol or drug intoxication:

- Note the time the seizure started and time until it ends
- Avoid restraining the person and guide safely around objects
- Talk to the person to make sure they have regained full consciousness
- Stay with and reassure the person until they have recovered



## References

- Australian Bureau of Statistics (ABS). 3303.0 Causes of death, Australia, 2012. Canberra: ABS; 2014
- Brodie MJ, Schachter SC, Kwan P. Fast Facts: Epilepsy 3rd Ed. 2005. Health Press Limited, UK.
- deBoer, H, Mula, M, Sander, J. The global burden and stigma of epilepsy. *Epilepsy Behaviour* (2008); 12: 540-6
- Epilepsy Association of South Australia Inc. Fact sheet: What is epilepsy? 2008a. Available at: <http://www.epilepsycentre.org.au/info/understanding/whatisepilepsy.html> [Last accessed 21 March, 2014].
- Fisher, RS, van Emde Boas, W, Blume, W, Elger, C, Genton, P, Lee, P, Engel Jr, J. Epileptic Seizures and Epilepsy: Definitions Proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia*. April 2005; 46(4): 470-472.
- Joint Epilepsy Council of Australia (JECA). Submission. Parliamentary friends of epilepsy: inquiry into the impact of epilepsy in Australia today. October 2009b.
- International League Against Epilepsy (ILAE) Guidelines for epidemiological studies on epilepsy. *Epilepsia*, 34(4):592-596, 1993.
- Mohanraj et al, Mortality in adults with newly diagnosed and chronic epilepsy: a retrospective comparative study .*Lancet Neurology* 2006; 5(6):481-7.
- Peterson, C, Walker, C and Shears, G. The social context of anxiety and depression: Exploring the role of anxiety and depression in the lives of Australian adults with epilepsy. *Epilepsy & Behaviour*. 2014; 29 – 33.
- Ngugi A et al. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. *Epilepsia* 2010; 51: 883 – 890.
- Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez A. The burden of disease & injury in Australia. Canberra: AIHW, 2007.