

## Feature 1: What do you wish people knew about epilepsy?

Seizures are only one part of epilepsy - it affects day to day life much more than people think. Epilepsy is not only characterised by the tendency to have recurrent seizures but also by its neurobiological, cognitive, psychological and social consequences.

Because you can't see it, people in the general community have a poor understanding of epilepsy and sometimes it's quite misunderstood. There are still age-old beliefs that should have been locked in the cupboard a long time ago.

We recently asked the question to the epilepsy community: *"What do you wish people knew about epilepsy"* and there were many responses. It has raised many topics for future discussion but this is a summary of the common themes of these responses.

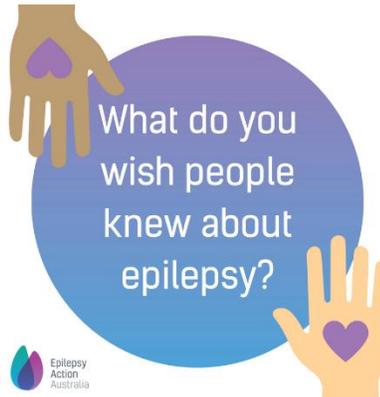
### 1. Not all seizures and no two people with epilepsy are the same - there is no one-size-fits-all treatment.

*"Not all people with epilepsy have convulsions, there's different types of seizures"*

It's complicated. Not all seizures are tonic-clonic seizures, which is what is portrayed in the media. Seizures can look like many different things, including someone staring off into the distance or fidgeting, wandering or repeating an action. Because of this, every person with epilepsy has a unique experience with seizures.

When seizures aren't recognised in a public place, they are often ignored, managed inappropriately or the person is treated poorly or like they are drunk or on drugs.

*"Not all epilepsy is the same"*



### 2. Medication does not always work

*"I feel like I have a stalker, it's called Epilepsy"*

There is no magic drug that will just stop seizures and sometimes, no medication or combination of medications work well enough to stop all seizures. People with epilepsy will often find themselves going through medication after medication without any improvement. Finding the right treatment, surgical or pharmaceutical, is sometimes very difficult.

Sadly about 1 in 3 people with epilepsy will not be able to get seizure control with medication.

*"My medication doesn't totally control the seizures"*

If the first few antiepileptic medications don't stop or control a person's seizures, the chances that a different medication will be successful are greatly diminished. The terms 'intractable, refractory or drug resistant epilepsy' may be used to describe a person's epilepsy when it doesn't respond to medications after trialling 2 or 3 medications.

When seizures don't respond to medication, what other options are there?

Firstly, if you haven't already been to one, be referred to an epilepsy centre. There you will see an epileptologist, who is a neurologist that specialises in epilepsy. The epileptologist may be able to then:

- a. Trial a more appropriate medication or some of the newer epilepsy medications.
- b. Investigate if surgery for epilepsy is possible option. Some epilepsy types are suitable for surgery to help control or stop seizures.
- c. Consider dietary therapies. The types of diets currently being used are the ketogenic diet, modified Atkins diet, or low glycemic diet. Usually people on a dietary treatment will still take seizure medication as well.
- d. Find out if vagus nerve therapy is an option. Vagus nerve stimulation, called VNS Therapy™ is a pacemaker like device implanted to treat seizures that don't respond to medications or when surgery is not possible.

There are also newer types of brain stimulation and surgery, which include: NeuroPace RNS® System, Deep Brain Stimulation, or types of surgery such as thermal ablation (Visualase®) may be possible. While some of these are still being tested, others may be available.

There is no one treatment that's right for everyone. People respond differently to medications and other forms of treatment. If you do have trouble with seizure control, seeing an Epileptologist is a good step to finding out what other treatment options may be suitable for your type of epilepsy.

For more information about treatment go to:  
<https://www.epilepsy.org.au/about-epilepsy/managing-epilepsy/treatment/>

### 3. Seizures and/or medication cause fatigue, tiredness, and pain

There is no doubt that a seizure can leave someone feeling tired and sore. It doesn't necessarily have to be a long or severe seizure either. Immediately after a seizure many people can have symptoms such as confusion, headaches, slurred speech, feeling sick, mood changes and tiredness. Some of these feelings and symptoms disappear after a short while, and others linger.

*"Epilepsy medication makes me feel very tired"*

Medications also cause unwanted effects and some commonly reported ones for antiepileptic medication include:

Drowsiness, dizziness, unsteady walking, weakness, headache, difficulty concentrating, blurred or double vision, tremor, mood change such as agitation, irritability, depression, stomach upsets, and weight gain or loss. Each medication has its individual possible side effects and it is important to ask for the Consumer Medication Information about your medication as well as speak to your doctor or pharmacist.

*"It's not the danger of the seizure itself, it's the injuries, migraine and up to two days in bed afterward that is the part that she struggles with."*

### 4. Memory loss

*The single most common response was how the effects of epilepsy, seizures and medication affected memory.*

Many people with epilepsy report having memory problems more often than the average person. A lot of things can affect one's ability to remember, such as health, tiredness, depression, anxiety, how well we concentrate and how motivated we are to remember.

*"... its very scary with the memory loss all the time and struggle concentrating in busy places as well..."*

Seizures certainly do affect memory and there is some individual variation with this. Your memory for what happens during a seizure is usually lost. Seizures can also affect your memory for what happens when you are coming out of a seizure.

*"I have no short term memory and I am terrified every time I go out, even with someone with me I feel lost and alone most days"*



## 5. Epilepsy carries risks

Just like asthma and diabetes, epilepsy also has an associated risk of death. This is the most tragic outcome of epilepsy and many people who have lost a loved one were never aware it could happen.

In Australia, there are approximately 300 epilepsy-related deaths each year – but this figure is likely to be underestimated. Some of these deaths are due to:

- accidents
- drowning
- seizures that don't stop - status epilepticus
- suicide
- SUDEP - more than half of these deaths are thought to be due to Sudden Unexpected Death in Epilepsy.

It can be scary to think about the risk of death related to any health condition; however, by knowing the risk exists, you can take positive actions to keep yourself or your family member as safe as possible.

*"We lost our 19-year-old daughter last year. We were never told she could die and not once did they tell us about SUDEP. It's devastating."*

### SUDEP

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with epilepsy dies suddenly and prematurely and no reason for death is found. SUDEP occurs in approximately 1 per 1000 people with epilepsy (1 in 4,500 children).

SUDEP deaths are often unwitnessed with many of the deaths occurring during sleep. The cause is not yet known. However, having tonic clonic seizures that aren't controlled can put you at higher risk of injury and death.

*"EVERY person with epilepsy needs to be made aware of this... his death may have been prevented if someone in the medical profession had bothered to tell us."*

There are steps you can take to reduce seizure related risks, injury or death. These include:

1. Get the best seizure control possible.
2. Take your medication as prescribed
3. Speak to your doctor if you are not happy with your current medication or side effects
4. Regular reviews with your doctor

Be involved in self-management

5. Avoid any known seizure triggers for you
6. Avoid drinking too much alcohol
7. Know when your seizures are most likely to occur
8. Get enough sleep
9. Be healthy
10. Manage stress

Make sure those close to you know what to do in case of a seizure.

There are a number of devices and monitors for night-time seizure monitoring now available for use in the home. They are designed to recognise a seizure or changed breathing patterns. This triggers an alarm so that help – either a family, friend or emergency services – can be notified.

*"My son is 34 & I still check on him before I go to bed"*

Monitors and alarms don't guarantee safety or detection of all seizures, but they can help a great deal for some people and provide some peace of mind.

For more information on these products go to <https://www.epilepsy.org.au/how-we-can-help/epilepsy-products/>

For more about epilepsy risk, go to: <https://www.epilepsy.org.au/about-epilepsy/epilepsy-and-risk/>

## 6. Employment can be tough

The second highest response from people was in regard to employment, and this topic continues to be a problem across the board.

*“Don’t treat people like they’re stupid and incapable of doing their job!”*

*“... you legally can’t be fired for having it.... but they can make life so uncomfortable for you that you just leave.”*

Whether someone’s epilepsy affects their work depends on whether their seizures are controlled, what their seizures are like and how often these happen. It also depends on the type of work they do, and any risks that having seizures at work might bring. Anyone having seizures may not be able to do jobs that risk personal safety or the safety of other people. As with anybody, the type of work also depends on skills, qualifications and experience. It may also depend on how your epilepsy affects you.

*“I have 3 types of seizures. I haven’t been able to work for over 8 years now. No one will give me a chance”*

However, we still receive many calls from people who have been discriminated against, either directly or indirectly, or the workplace fails to make reasonable adjustments or has treated the person unfairly. Many people do not disclose their epilepsy in fear of losing their job. Not having a drivers license can impact significantly on work choices and independence as well.

Having epilepsy does not necessarily stop someone from doing the job they want, but there are some issues which can affect them at work.

*“Unable to work - my partner lost two jobs because WorkCover wont insure him”*

*“I’ve been ‘relieved’, and seen as ‘unfit for duty’, from three jobs over 17 years, I’ve no licence, and my tickets for heavy machinery are no longer valid. So I lost my career.”*

*“Have suffered for almost 20 years now, been broke, homeless, sacked, told to lies about it to get cash in hand work, and*

*insulted at Centrelink. I now work nights with a crappy supermarket .... I know I can’t disclose any issues here. It’s hard enough facing disrespect in your personal life, let alone at work.”*

However, we also receive positive reports of employers giving people a chance and making adjustments to support the person with epilepsy as much as they can. Employers (and other people) need to realise that while some people have regular seizures, up to 70% of people with epilepsy have their seizures controlled (with the right medication) so their epilepsy may have little or no effect on their work.

There are many disability employment service providers across Australia. People’s experience is somewhat mixed and can be reliant upon whether they have a good case worker or not. To search for a disability employment provider near you go to:

<https://disabilityemployment.org.au/provider-search/vic/>

## 7. It’s often not recognised as a disability

*“...there are few agencies that have any idea what it means, including Centrelink and NDIS...”*

Epilepsy seems to slip through the cracks when it comes to getting additional support and services. Because it is an “invisible” condition and seizures occur sporadically, it can be difficult to find help with disability funding or unemployment funding. Government services don’t recognise or understand that having seizures can impact on all aspects of life, despite the evidence that it does.

*“...my daughter can’t get disability pension or NDIS...”*

*“my partner took 17 years to get Disability Pension. We are fighting for NDIS with a tribunal hearing on Tuesday”*

*“Wish the education department would recognise epilepsy as a disability, so that*

*children/adults could obtain much needed support”*

## 8. People don't understand...

Although there is improved understanding of epilepsy in the general community, knowledge is still lacking and seizures are often mismanaged or misunderstood in a public setting.

*“I wish they knew a lot more then they think they know”*

*“I wish they cared more to know more about it”*

*“I'm so tired of no one understanding and constantly being told that I have to suck it up and get over it”*

*“That people with epilepsy are actually NORMAL people”*

*“People don't understand what it is like to not be able to drive, live on your own, and to be relying on others for simple things. Not being able to just have a bath to destress without someone supervising you.”*

*“Life can be lived with Epilepsy, other people's arrogance towards Epilepsy is what hurts the most”*

*“Teaches you how to be strong and brave. I'm on this journey almost nineteen years, this disorder shaped every part of my personality and my life.”*

## Feature 2: New Training Courses – Living with Epilepsy & Disability

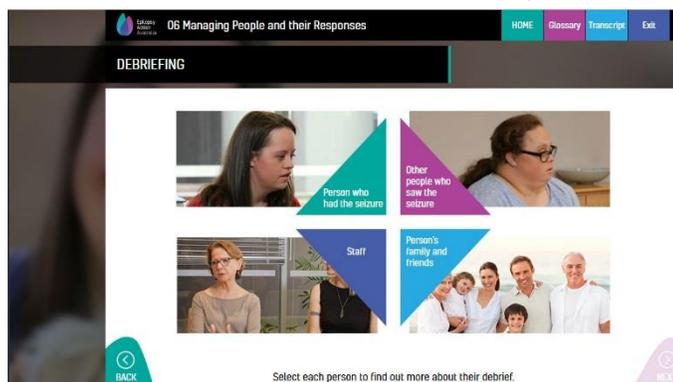
It is estimated that 30,000 Australians living with intellectual disability also have epilepsy and as many as 1 in 4 are misdiagnosed, largely due to seizures not being recognised. Epilepsy is not only more common in people with intellectual disability than the rest of the population but seizures can be more difficult to control; often meaning more medications, more side effects and health and safety concerns.

It is easy for anyone to misinterpret seizure activity, particularly if seizures are subtle or mistaken for movements or mannerisms sometimes seen in people with intellectual and physical disabilities. When seizures are missed and remain undiagnosed they cannot be treated which can significantly affect the quality of life for the person and their family and, in some instances, can lead to avoidable deaths.

Epilepsy Action Australia has taken a proactive approach to training disability support workers to better recognise and manage seizures for the people they support. This will have a direct impact on better diagnosis and treatment for people living with epilepsy and disability, and will have an immense impact on their quality of life.

It is important that disability support workers are familiar with common seizure types and how to recognise and manage them appropriately to lessen the disruption, risk and improve the well-being of the people they care for. EAA has developed a nationally accredited course, Course in Epilepsy Management - *Living with Epilepsy and Disability* which is offered in conjunction with the

Australian Red Cross College. Additionally, there are three concise courses on *Observing & Recording Seizures, Minimising Risk and Living with Epilepsy & Disability*. The courses on recording seizures and minimising risk are relevant to anybody with epilepsy, regardless of



whether they have a disability. The courses cover some of the challenges faced, recognising types of seizures, improving quality of life and practical ways to reduce risks. All the courses are user friendly and have interactive and engaging activities, video demonstrations and animations.

These courses were made possible with the generous support of The Ian Potter Foundation, Gandel Philanthropy and John T Reid Trust.

Learn more about these and other courses on offer at: <https://www.epilepsy.org.au/education-training/online-training/>

## In the News – The latest on epilepsy



### Gut bacteria play key role in anti-seizure effects of ketogenic diet

Scientists have identified specific gut bacteria that play an essential role in the anti-seizure effects of the ketogenic diet. The study is the first to establish a causal link between seizure susceptibility and the gut microbiota - the 100-trillion-or-so bacteria and other microbes that reside in our intestines.

<https://www.sciencedaily.com/releases/2018/05/180524141700.htm>

### Prediction method for epileptic seizures developed

System designed to use data from non-surgical devices powered by AI and machine learning

<https://www.sciencedaily.com/releases/2018/05/180530113210.htm>

### Prescription drug, Epidiolex, made from cannabis, approved in the US.

The Food and Drug Administration (FDA) approved the medication Epidiolex, to treat two rare forms of epilepsy that begin in childhood. The strawberry-flavoured syrup is

a purified form of a compound (CBD) found in the cannabis plant. Read more

<http://www.abc.net.au/news/2018-06-26/epilepsy-drug-made-from-marijuana-approved/9909378>

### Does epilepsy surgery offer long term benefits?

Epilepsy surgery has been used for many years to treat epilepsy that does not respond to medication but little is known about its long-term success. Read more

<https://www.epilepsyresearch.org.uk/does-epilepsy-surgery-offer-long-term-benefits/>

### Epilepsy and autism link

Early life epileptic seizures have been linked to autism and other disorders, but precisely why this relationship exists is not entirely clear. Read more

<https://www.epilepsyresearch.org.uk/autism-and-epilepsy/>

### Funding cuts affecting epilepsy families

When the National Disability Insurance Agency cut 18-year-old Josh Grey's existing support plan earlier this year, his family was driven to desperation.

<https://www.theguardian.com/australia-news/2018/jun/06/gut-wrenching-the-ndis-changes-driving-one-family-to-desperation>

Ella Gray has suffered seizures for nearly all eight years of her life. Read more <http://www.abc.net.au/news/2018-03-26/epilepsy-recognition-health-issue-disability-purple-day/9580406>

## Q&As – Our service providers answer your questions

**Q: I was diagnosed with epilepsy a year ago at age 78. My husband has noticed the medication is making me sleepy and inactive most of the time, when I used to be a very active person. The doctor says I am taking an average dose range for this drug. What is the average dose range and could I be taking too much?**

**A:** Every person is different and the dose of medication they need will depend on many factors. The 'best dose' is

the one that controls seizures with the least amount of side effects. This differs from person to person.

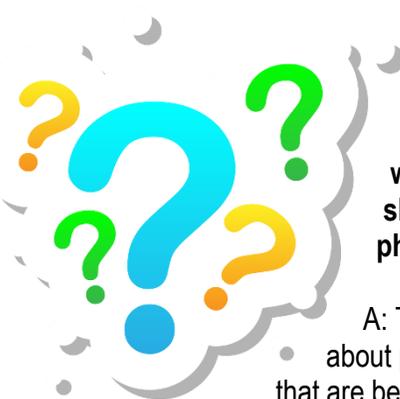
For example, a recommended adult dose range for an antiepileptic drug may range from 400–2000mg per day. These figures are a very general guide but they are not individualised to each person: some people may have their seizures controlled on a dose lower than the bottom dose or higher than the top dose. In older people, the dose tends to be toward the lower end of the spectrum. Some things that affect the best medication dose for an individual include:

- Age: Older people often need lower doses than younger adults. Children’s bodies break down medicines differently too, depending on their age.
- How the medication works: Some need to be given in higher doses than others. Some work best at low doses.
- Other medications being taken: some may affect how a drug is absorbed or metabolised in the body.
- Other health problems: can mean that the epilepsy medication may have more side effects or not be absorbed as well.

Sometimes blood levels can be taken, but once again this can be used as a general guide. The most effective way to monitor if a drug is working is seizure control.

An antiepileptic medication is usually started at a low dose which is slowly increased until you reach the lowest amount of drug that will control seizures and not cause side effects. Sometimes experience helps your doctor know how much to give you and when to change the dose. Other times, there’s a bit of a ‘trial and error’ approach to find out what is best for each person.

If you have been experiencing these symptoms since starting anti-epileptic medication, they may be the cause of your sleepiness. It would be worth raising your concerns with your doctor and ask for the medication to be reviewed.



**Q: Sometimes when I get up in the night, I've turned on the lights and had a seizure. I'm wondering if our lights are the wrong type for someone with epilepsy. What type of light bulbs should I have indoors if I have photosensitive epilepsy?**

A: There really isn't conclusive evidence about particular types of lighting or light bulbs that are better for people with photosensitive epilepsy. The main perpetrator for many people seems to be faulty or flickering bright lights. From your description it appears the sudden change from darkness to bright light may be the issue. Some people with photosensitivity have seizures triggered by the change of moving between the muted lighting found inside and the bright sunlight outside. To counter the degree of contrast, you could consider using a lower wattage or soft-focus light bulbs in your home or a dimmer device. A quick and economical solution could be to install a low wattage bedside lamp or use of nightlights that provide a glow rather than stark bright lighting.

The Zeiss Z1 blue lenses have been shown to stop seizures for many people with photosensitive seizures <http://dsptom.com.au/photosensitive-epilepsy>

**Q: I have epilepsy and I want to have children in a few years. Can I get genetic testing to see the likelihood of passing it on?**

A: Although epilepsy that runs in families is uncommon, genetics play a part in many types of epilepsy. Genetic forms of epilepsy can present with generalised, focal, or even multiple seizure types. Most genetic forms of epilepsy begin in infancy, childhood, or adolescence.

However, a few genes have been identified that can cause seizures starting in adulthood. Genetic testing is appropriate for anyone with a suspected genetic cause of their epilepsy. You will need to discuss this with your doctor.

The chance of finding a genetic cause for epilepsy is higher if you have other family members who have similar

symptoms. However, people with no previous family history of epilepsy may also have a disease-causing mutation in an epilepsy gene.

Identifying a genetic cause of your epilepsy can:

- confirm your type of epilepsy, especially if the diagnosis is not clear, based on EEG findings or symptoms.
- help with decisions about treatment choices for your epilepsy.
- provide information about associated neurological or other health problems that you may arise in the future.
- help clarify the prognosis and expectations for your epilepsy.
- identify your family members who are at risk of developing epilepsy or having a child with epilepsy.

Usually, genetic testing requires a blood or saliva sample to be taken from the person with epilepsy. The sample is then sent to a laboratory for genetic testing. The test looks at the DNA in the person's blood or saliva. The sample is analysed for mutations or changes in a subset of genes that have a known association with different types of epilepsy.

If a gene is identified in a person with epilepsy, then other family members can be tested, regardless of whether they have epilepsy or not.

Find more information about genetic information:

<https://www.epilepsy.com/learn/diagnosis/genetic-testing>  
[https://www.genedx.com/wp-content/uploads/crm\\_docs/91040\\_Epilepsy-Patient-Guide.pdf](https://www.genedx.com/wp-content/uploads/crm_docs/91040_Epilepsy-Patient-Guide.pdf)



## Taking Action – What's happening at Epilepsy Action

### BECOME A MEMBER

Have your say in shaping the future of Epilepsy Action Australia by becoming a member!

For the small annual fee of \$75 you get to:

- have a direct say in the governance of the organisation for instance, you will be invited to the Annual General Meeting and receive a copy of the annual report
- opportunity to subscribe to various specialist newsletters of your choice just like this one
- but most importantly, support Epilepsy Action in its resolve to assist Australians with epilepsy to lead optimal lives.



Membership is available to individuals aged over 18. To join visit <https://www.epilepsy.org.au/get-involved/become-a-member/> or call 1300 37 45 37.

### GET ACTIVE

Running season is in full swing! **Get Active for epilepsy** in an event in your area and grab your family and friends for a fun (or challenging) day out.

Whether you run, walk or crawl with us you will be helping to make a difference. **Find an event here**  
<https://www.epilepsy.org.au/fundraise/active-fundraising/>