



## E-newsletter *Edition 1*



### CEO Message

Welcome to the first edition of Epilepsy Action Australia's (EAA) brand new e-newsletter! I hope you will find this an informative and interesting read.

Our e-newsletter replaces the previous quarterly magazine *Epilepsy360°*, produced for the last 8 years, but this newsletter still reflects our intention to cover epilepsy from all angles, so in keeping with this we have kept but slightly abbreviated the name to *E-360°*. EAA made a conscious decision to reduce ongoing costs of producing the printed magazine, but we trust that you will find this e-newsletter to be comprehensive, educational and most importantly relevant. You will receive your e-newsletter on a bi-monthly basis and it will always be completely free.



These newsletters will cover the latest news updates on epilepsy, research and treatments. It will showcase at least two current and/or newsworthy topics as features. It will also feature some of your questions, answered by our service providers and let you know what is happening at EAA, upcoming events and the latest in our service developments. We also have the flexibility to include special features as needed to keep you abreast of the latest epilepsy information.

As always we welcome your feedback so please contact us with any ideas, comments or questions via [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au). This is your e-newsletter and we want it to meet your needs so please don't hold back!

#### **Carol Ireland**

Chief Executive Officer

## Feature 1: Breakthrough seizures. What are they? Why do they happen?

When someone with epilepsy has a long period of seizure control, then suddenly has a seizure out of the blue, it is commonly referred to as a *breakthrough seizure*. When these breakthrough seizures occur, there can be significant lifestyle, employment, medical and psychological consequences for the person.

### What causes breakthrough seizures?

This is a question often asked. Sometimes, there is no identifiable cause, they just happen. But there can be specific causes. Here we go through a number of possible causes of breakthrough seizures.



#### 1. Medication issues

Missing medication is the most common cause of breakthrough seizures. No matter what the reason, busy life style, work demands or memory difficulties, missed medication can trigger seizures in people with both well-controlled and poorly controlled epilepsy. When these seizures happen, they can be more intense or longer than normal.

Sometimes it is difficult to take medications exactly as prescribed, taking it a few hours earlier or later than usual or missing the occasional dose can trigger breakthrough seizures. If you have any difficulties sticking to the scheduled times to take your medication, especially if it is more than once a day, ask your doctor if there are any slow release versions of your medication so you only have to take it once or twice a day.

Any changes or withdrawal from medication should be done slowly and always under the advice and supervision of the prescribing doctor.

There are also many different brands and generic medications on the market for epilepsy and your pharmacist may offer you one of these as an alternative. Be aware that a generic medication may not be exactly the same as the original brand and the non-active ingredients may differ – these include fillers, binders, coating or colouring. While specific guidelines and tests are done to make sure the generic medications are the same, a slight degree of variation is allowed. These slight variations may affect seizure control. Even a minor variation in blood levels of an antiepileptic drug (AED) can lead to a higher risk of seizures – or possibly toxic side-effects for some people taking doses that already border on toxicity. The slightest change can make the difference between a medication not working, a medication working well, or being too strong. If you have a medication that works, do not change brands even if the pharmacist suggests it.

Taking other medications. A new medication or supplement can sometimes mix poorly with AED's. AED's are known to interact with each other, other medications, some over-the-counter drugs, illicit drugs and herbal preparations. Always ask your prescribing doctor or pharmacist about any possible interactions with medications, complementary therapies or supplements. You can also call the

Medicines Line on 1300 888 763 and speak to a pharmacist who can advise you about medication interactions.

There are some medications that are known to lower the seizure threshold, increasing the chances of a seizure. Your specialist should be aware of this.

## 2. Other substances

Caffeine is a stimulant found in coffee, tea, high energy drinks, chocolate and many soft drinks, some supplements and medications, including some diet pills, antihistamines and decongestants.



Excessive amounts of caffeine can cause an increase in seizures. In addition, caffeine may interfere with AEDs.

Guarana is a natural caffeine source and a stimulant. It is a common ingredient in high energy drinks and herbal 'weight loss' teas and can combine with adrenaline to produce an even stronger stimulant effect.

Any substance that is considered a stimulant should be avoided or taken with care and moderation, as stimulants are more likely to increase the risk of seizures.

## 3. The person

Breakthrough seizures can happen in extenuating circumstances. These include sickness, severe emotional stress, sleep deprivation, use of recreational or illicit drugs, alcohol, or metabolic events such as major electrolyte changes in the blood or severe changes in blood sugar levels. Sometimes growth spurts or hormonal changes can trigger breakthrough seizures as well. Other factors such as flashing lights or playing video games have also been known to provoke seizures in people who are photosensitive.

Triggers are events or circumstances that make people with epilepsy more likely to have a seizure. Identifying seizure triggers and trying to avoid them is important for gaining better control of your seizures. Avoiding seizure triggers can be difficult sometimes, so it is important to weigh up the risks and look at overall quality of life.

### **What you can do to help control seizures**

Just taking medication is not always enough to control seizures for most people. It is important to be aware of other things that may help with seizure control. These include:

- Avoiding known or your seizure triggers such as sleep deprivation and stress
- Keeping healthy by eating a balanced diet and exercising regularly
- Having regular check-ups with the doctor
- Speak to the doctor if unwell or having unwanted symptoms or side effects
- Keeping a seizure diary to identify patterns and triggers
- Avoiding taking medications with grapefruit or seville orange juice as these may alter the absorption of some AEDs

To help remember to take medication, some practical tips include:

- Try to make it part of your daily routine like taking your medications at meal times.
- Put your medications in a safe, visible place as a reminder.
- Set the medication reminder in My Epilepsy Diary app on your smart phone
- Set a watch, phone or alarm clock to remind you.
- Use a chart or calendar and tick when you have taken your medications.
- Consider using a pillbox or ask your pharmacist to pack your medications into a pill pack. These usually have the day and time you are supposed to take the tablets.
- Ask someone to remind you.

There are many factors that a doctor needs to consider when selecting the best medication for you. It is not just based on the type of epilepsy and effectiveness of the medication. The decision also includes things, such as potential side effects, age and gender, how easy and how often the medication needs to be taken, cost, other medical conditions and drug interactions.

Good, open communication with your specialist is essential for the best possible treatment. Being honest about any seizures, medication issues or side effects is the only way the doctor knows, and will attempt to change things.

Having a breakthrough seizure may only be a one-off or it may lead to further seizures. Like many circumstances with epilepsy, it is hard to predict. If you do have a breakthrough seizure, it is important to discuss it with your doctor and try to identify any potential triggers or causes so together you can determine the best strategies to minimise your risk of further breakthrough seizures.

**For more information go to:**

EAA Seizure Smart Factsheets: [http://www.epilepsy.org.au/fact\\_sheets](http://www.epilepsy.org.au/fact_sheets)

- Medical Management of Epilepsy
- Self Management

<http://www.touchneurology.com/articles/breakthrough-seizures-approach-prevention-and-diagnosis>

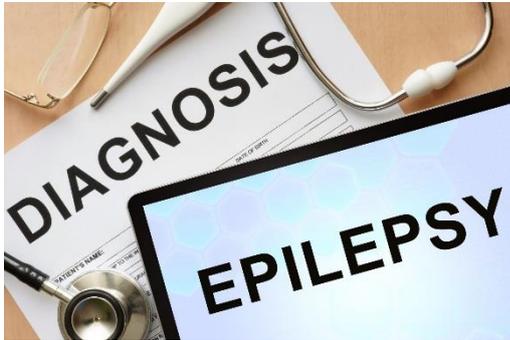
Medicines Line <http://www.nps.org.au/contact-us/medicines-line>

My Epilepsy Diary <http://www.epilepsy.org.au/my-epilepsy-diary>

**References:**

<http://www.epilepsyresearch.org.uk/new-study-into-first-seizures-provides-insight-into-definition-of-epilepsy/>

## Feature 2: Diagnostic delays in epilepsy



Diagnosing epilepsy can, in some instances be easy and straight forward, while at other times prove to be more challenging.

To diagnose epilepsy, many things are taken into account such as symptoms, a good description of seizures or events, and medical history. The doctor may order tests to help determine the cause of the seizures or events. In some cases, all or many tests for epilepsy

can return normal but this does not mean you don't have epilepsy.

### Epilepsy

Epilepsy is a disease of the brain defined by any of the following conditions<sup>1</sup>:

1. At least two unprovoked seizures occurring more than 24 hours apart
2. One unprovoked seizure with a probability of further seizures
3. At least two seizures considered reflex epilepsy, such as photosensitive epilepsy

### Diagnosis

There is no single conclusive test to diagnose epilepsy. People are usually referred to a neurologist who will arrange the relevant medical tests to help with diagnosis. If these are not conclusive, the doctor will also need to consider other possible causes for the events or seizures.

Going for tests and the process of being diagnosed is often a worrying time for people and their families. Some people get a clear diagnosis soon after they visit the doctor, but for many it can take a long time. Some of the reasons for this can be:

- often tests can come back normal,
- seizures are sporadic and the doctor rarely witnesses one,
- the person having the seizures has trouble describing them due to their level of awareness being impaired,
- seizure symptoms are unusual or similar to other conditions,
- referrals can be delayed or lost.

Needless to say, often a diagnosis is made long after seizures have begun.

### Early onset epilepsy

About 10% of all epilepsy occurs in the first three years of life. When epilepsy begins at such a young age, it can be associated with learning and behavioural difficulties making early recognition of

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<sup>1</sup> <http://www.ilae.org/Visitors/Centre/documents/Definition2014-RFisher.pdf>

seizures and diagnosis of the type of epilepsy and its cause especially urgent. Also, early diagnosis and effective treatment may lessen some effects of seizures on the developing brain.<sup>2</sup>

A study by Dr Anne Berg et al in 2014 found that in 172 children, diagnostic delays occurred in 41% of children. Some relevant factors found in diagnostic delays were:

1. The parents noticed the events but did not understand what they were and did not act for some time.
2. The events were brought to a paediatrician's attention but were not diagnosed as seizures.
3. The neurologist considered epilepsy but deferred the diagnosis due to normal EEG or past febrile seizures.
4. The time from referral to appointment for EEG or neurologist was greater than one month.
5. The child had other serious developmental or medical concerns. These may have contributed to the reasons for delays above. Many of these children were already being seen by other specialists when seizures began.

More than one factor could be present.

### **Late-onset epilepsy**

Additionally, delay in diagnosis of epileptic seizures in the elderly is not uncommon. A multicenter team with the Veterans Affairs (VA) Cooperative Study of late-onset epilepsy, reports that doctors often do not recognise the onset of seizures in elderly people.<sup>3</sup> Diagnostic delays were significant, the average delay being 1.7 years.

Seizures in this age group are often mistaken or misdiagnosed for other ailments including cardiac conditions, transient ischaemic attacks (TIAs) or dementia.

Relevant factors associated with diagnostic delay in people over 65 years include<sup>4</sup>:

1. If dementia is present, and memory function is poor, or the person lives alone, taking a clear history of the seizure-like event from the person can be very difficult.
2. People in this age group are often seen by their GP rather than a neurologist.
3. Focal seizures may be misdiagnosed as confusion, behaviours, dementia or delirium.
4. Falls may be misdiagnosed as just falls, syncope or cardiac events.
5. There may be many other existing health conditions and medications that can cloud the picture.

However, delay in diagnosis is not limited to these two groups. Many people with epilepsy experience difficulties in obtaining a definitive diagnosis.

### **What you can do**

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<sup>2</sup> <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3946922/>

<sup>3</sup> <http://www.medscape.com/viewarticle/465781>

<sup>4</sup> <http://jppr.shpa.org.au/lib/pdf/gt/kilpatrick200206.pdf>

Diagnosing epilepsy is not simple. Doctors usually need to collect a lot of different information and your diagnosis is based on finding out what happened to you before, during and after your seizures.

You can help by:

- Recording information about your events or seizures – write things down as they happen and how you remember it. Ask a witness to provide a good description of the event, including before, during and after details. Ask a friend or family member to record a seizure on video to show the doctor.
- Keep a diary of when, where, how often they occur and how long they last. Include other relevant factors such as what you were doing at the time, if you were unwell for some reason or over tired or stressed.



Diagnostic delays and misdiagnosis of epilepsy are far from uncommon. Unfortunately, this leads to treatment delays. For many people this can impact their lives. A good seizure history and diarised events remains the key to a correct diagnosis with video recordings also being very useful.

**For more information about diagnosis go to:**

<http://www.epilepsy.org.au/about-epilepsy/medical-aspects/diagnosis>

<http://www.webmd.com/epilepsy/guide/diagnosing-epilepsy>

EAA Seizure Smart Factsheets [http://www.epilepsy.org.au/fact\\_sheets](http://www.epilepsy.org.au/fact_sheets)

- Evaluating Epilepsy.
- Observing and Recording seizures.
- You and Your Doctor

My Epilepsy Diary <http://www.epilepsy.org.au/my-epilepsy-diary>

## In the News

### The latest on epilepsy



#### First pills made by 3D printer

A new form of levetiracetam has been created using 3D printing technology, to make the medication easier to administer as it can be dissolved in a small amount of water. This makes it particularly useful when administering to children or the elderly. Read more <http://www.medicaldaily.com/fda-approves-first-ever-3d-printed-epilepsy-drug-aprecia-set-create-more-central-346004>



#### Poor sleep common amongst people with epilepsy

Recent research has found that sleep disorders are more common in people with epilepsy, with the severity of the epilepsy making sleep problems more likely. Read more. <http://www.epilepsyresearch.org.uk/sleep-disorders-a-common-issue-for-epilepsy-patients-study-shows/>

#### Self management training can improve quality of life in people with epilepsy.

Self-management training programmes can have a positive impact on health-related quality of life among people with epilepsy. Read more <http://www.epilepsyresearch.org.uk/self-management-training-can-improve-quality-of-life-in-epilepsy-patients/>

Go to “Patients Like Me” to find a way for you to share your real-world health experiences in order to help yourself, other patients like you and organisations that focus on your conditions.

<https://www.patientslikeme.com/>

## Q&As

### Our service providers answer your questions

**Q: My son recently had an injury in a sports game, and I thought he fainted afterwards, but there was some twitching and jerking of his limbs for a few seconds. Is this a seizure?**



A: Not all convulsive episodes are a seizure. Fainting can be accompanied by jerking and other movements, which can mimic a seizure. Fainting is caused by a sudden decrease in blood flow to the brain which can lead to an abrupt and short-lived loss of consciousness. It can be triggered by many different things including injury and pain.

Fainting is commonly confused with epilepsy or seizures because the person can experience brief jerks, twitching or convulsive movements while they are unconscious, especially if they don't get into a lying down position quickly. Generally a faint is much briefer than a seizure and recovery is much faster.

Up to 50% of children and adolescents, and 6% of the general population experience episodes of fainting. Like epilepsy, fainting is identified through a clinical diagnosis, and an eyewitness account is invaluable. A good history of the episode can often help to differentiate between a faint and a seizure.

When someone has a seizure immediately following a faint, it is called *Convulsive Syncope*. While convulsive syncope can be difficult to tell apart from a seizure, the condition is benign and usually very easy to manage. It will not lead on to epilepsy.

**Q: I have epilepsy and just turned 18. I'm wondering what the limit of drinking alcohol is because I'm getting to the stage of wanting to drink with friends but I can't. Sometimes when I go to parties friends ask if I'm drinking and I say no and make up an excuse like I have to get up early for work the next day. So I would like to know if I could have one or two drinks. I haven't had a seizure for 2 years.**



A: Opinions vary, but some doctors say to avoid alcohol when taking antiepileptic medications, while many say a moderate amount (1-2 drinks) will do no harm. Drinking alcohol in small amounts usually does not cause or increase seizures or drastically affect the blood levels of your medications. The effects of alcohol are different for everyone. Some people choose to drink low alcohol drinks, or substitute a soft drink or water every alternate

drink. If you have a bad reaction to alcohol or feel like you may have a seizure then don't drink at all.

Most seizures associated with alcohol are because of chronic alcohol abuse or drinking large amounts.

People with epilepsy should be mindful that alcohol:

- can mix poorly with antiepileptic medications changing the levels in the bloodstream.
- can trigger seizures when drunk in large amounts.
- can cause dehydration which can trigger seizures
- is often associated with late nights, sleep deprivation, missed meals and forgotten medications, all of which can trigger seizures.
- can make a person taking antiepileptic medications more sensitive to the effects of alcohol and will feel intoxicated much faster

## Taking action

### What Epilepsy Action Australia is up to!

#### Self Management tools and resources

Epilepsy Action Australia has an ever expanding range of self management tools and resources available to people living with epilepsy on our website.

These include:

**E-quip** – this youth resource is a self-paced online tool to assist young people to cope with the psychological, social and lifestyle demands of living with epilepsy.

**Strong Foundations** – this resource includes information to help parents and carers of children with epilepsy decide if their child may need assistance and provides a guide for accessing available supports.

**Psychosocial Wellbeing** – designed to provide you with good information about epilepsy and the kinds of information people with epilepsy find helpful for managing their psychosocial wellbeing.

**Seizure Management Planning (SMP)** – the interactive online Seizure Management Plan Tool allows you to create your own SMP

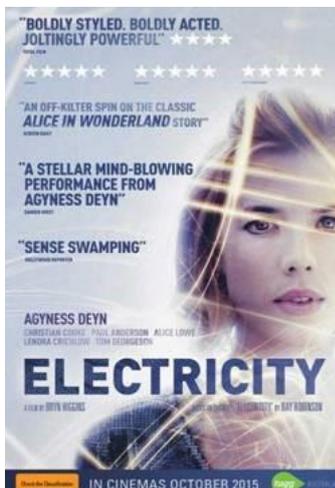
Visit [www.epilepsy.org.au](http://www.epilepsy.org.au) to find out more or email [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au) to access these FREE tools!



#### Electricity – Movie Premiere

Epilepsy Action Australia has partnered with Tugg to bring the film ELECTRICITY to Australia!

ELECTRICITY is the poignant yet raw story of a young woman's journey with *epilepsy*, through altered realities and visual perceptions, as she leaves her safe, routine life and searches for her long lost brother. The film shows how epilepsy colours her life, and how everyday objects and places become obstacles and dangers.



**We would like to invite you to one of the below Premiere's happening around the country:**

- **Wednesday 7th October - NSW: 6pm for 6:30pm at Event Cinemas George St, Sydney**
- **Monday 12th October - VIC: 6pm for 6:30pm at Village Cinemas - Crown, 8 Whiteman St, Shop 50, Southbank**
- **Monday 12th October - TAS: 6pm for 6:30pm at Village Cinemas, 181 Collins St, Hobart**

- **Wednesday 14th October - QLD: 6pm for 6:30pm at Event Cinemas Moggill Road, Indooroopilly Shopping Centre**
- **Wednesday 14th October - SA: 6pm for 6:30pm at Wallis Cinemas Piccadilly, 181 O'Connell St, North Adelaide**
- **Monday 19th October - WA: 6pm for 6:30pm at Event Cinemas, 57 Liege Street, Innaloo**
- **Monday 19th October - NT: 6pm for 6:30pm at Event Cinemas, 76 Mitchell Street, Darwin**

If you can't make the above dates/locations, you can always [host your own screening](#) at a time and location that's convenient for you, or [make a donation](#) to help support those impacted by epilepsy in Australia.

Hosting a screening simply means you register your preferred time and location on the [Tugg platform](#) and then you drive your friends, family and colleagues there also to book tickets to the screening. We will also be publicising your showing of the film on our Facebook page that has a community following of over 40,000 to help promote it.

Let's get Australia talking about epilepsy!

A percentage of ticket sales will be donated to Epilepsy Action Australia.

Visit <https://tugg.com.au/electricity/> for further information and to purchase your tickets.

If you have any questions or would like any further information, please email us at [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au).



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