Epilepsy Action Australia
E-360
E-newsletter
Edition 24

Feature 1: Trusted resource on Cannabis and Epilepsy

A new website aims to help thousands of Australians living with epilepsy, particularly those with devastating medication resistant types, make informed choices when it comes to medicinal cannabis. Launched by Epilepsy Action Australia, the leading provider of epilepsy support and information nationwide, www.C4E.com.au is the first evidence-based website to provide the latest published research from Australia and around the world, tools, fact sheets, videos, life stories and other resources related to medicinal cannabis and epilepsy.

"While research continues globally, many children and their families live with intractable or medication resistant epilepsy. There are also many adults who have lived for many years with unrelenting seizures that have made it virtually impossible for them to lead a quality life and participate fully in their communities," says Carol Ireland, CEO of Epilepsy Action Australia. "While some have been able to access medicinal cannabis, many others are still hoping for answers and relief from seizures."

"Medicinal cannabis can be life-changing but it is not a 'silver bullet' and it is not advisable for people or carers to consult 'Doctor Google' for something so important. Research is constantly evolving and, like any medicine, the right dose, the right quality and the right treatment plan are essential to success," continued Ms Ireland.

"As with any 'new' protocol, significant research is required prior to a solution being prescribed by the broader medical governing bodies. Ultimately what we are aiming to do with C4E.com.au is to arm people and carers with trusted, up to date information to discuss with their health practitioner and make an informed decision."

Approximately two thirds of people with epilepsy respond well to conventional antiepileptic medication, however the other third have intractable, medication resistant epilepsy and will continue to experience seizures, with some suffering with recurrent severe and damaging seizures on a daily basis.

C4E
CANNABIS 4 EPILEPSY

This group of people has been the focus for research into epilepsy and cannabinoids.

"There is still much research to be done, however evidence suggests that the endocannabinoid system of people living with epilepsy may be altered," says neurologist Dr Kaitlyn Parratt. "It is possible that utilising components of the cannabis plant, such as CBD, may help reduce the likelihood of seizures in people with epilepsy by acting on our endocannabinoid system."

"I am highly supportive of C4E.com.au because it is necessary that patients and carers are educated and provided with reliable and evidence-based information regarding medicinal cannabis. An additional benefit of this resource is that it will significantly improve the ability of patients and carers to have informed discussions with treating specialists," continued Dr Parratt.

Thanks to the funding support of nib foundation and medicinal cannabis company MGC Pharma, C4E.com.au provides trusted information on:

- Published academic articles and findings from clinical research
- Accessing medicinal cannabis and making an application
- Everyday living with medicinal cannabis
- Cannabis factsheets
- Recorded lectures, books and films
- Life stories, self-assessment tools and quizzes
- Information from around the globe

nib foundation Executive Officer, Amy Tribe, said that providing an easily accessible, centralised website where carers and families can access reliable and unbiased information on medicinal cannabis ensures families can make more informed decisions about the health and wellbeing of their child.

"Currently carers find it difficult to make informed decisions due to a lack of credible and easy to understand information about how to best manage their child's condition. This inhibits their

ability to navigate the health system, access regulated medicinal cannabis legally and participate in clinical trials," Mrs Tribe said.

"It's why we teamed up with Epilepsy Action Australia to provide a freely accessible platform that ensures carers can access information from a trusted source, gain access to information on differing government regulations and useful tools to help facilitate questions for discussion with their GP helping to prevent potential harm from misinformation," she added.

For more information visit: www.c4e.com.au

Feature 2: Generalised Onset Seizures

We have previously discussed focal onset seizures (https://www.epilepsy.org.au/e-360-edition-22-focal-seizures/), so now we are covering another group of seizures called generalised onset seizures. These are quite a different category, but there are some people who have both generalised and focal seizures.

A generalised onset seizure is when the seizure activity starts in both hemispheres of the brain at the same time. The most commonly recognised generalised seizure, the tonic clonic seizure, falls into this group*. The outdated term used for these seizures are "grand mal" and some people may also call them convulsions. However, these are not the only type of generalised onset seizures. There are many that fall into this category, some are dramatic and some easily missed.

**Note: if a tonic clonic seizure follows on from a focal seizure, then the onset is focal and the seizure activity then spreads to both hemispheres. These types of tonic clonic seizures aren't considered generalised onset.*

New terms

Seizure classification, naming and grouping had a complete review in 2017. Seizures are now divided into groups depending on:

- where they start in the brain
- whether or not a person's awareness is impaired
- whether or not seizures involve movement

Depending on where they start, seizures are described as either focal onset, generalised onset or unknown onset.

Generalised onset seizures

Generalised onset seizures are sorted into 2 groups, defined by whether the seizure involves (significant) movement or not. Movement may include rhythmic jerking (clonic), muscles becoming weak or limp (atonic), muscles becoming stiff or rigid (tonic), brief muscle jerks (myoclonus), or epileptic spasms (body flexes and/or extends).

The list of generalised onset seizures includes:

Involves movement	No obvious movement
Tonic-clonic	Absence seizures
Tonic	• Typical absence
Atonic	• Atypical absence
Myoclonic	• Myoclonic absence
Epileptic spasms	• Absence with eyelid myoclonia
**There are some variations to these seizures*	

Table 1 Reference https://onlinelibrary.wiley.com/doi/full/10.1111/epi.13709

Although there may be some movement, such as brief twitches, with some types of absence seizures, they are classified as non-movement.

As you would expect, the EEG recording of a generalised seizure can look quite dramatic because it involves both sides of the brain. Generalised onset seizures also have a sudden onset without warning so injuries are more likely in some of these seizure types.

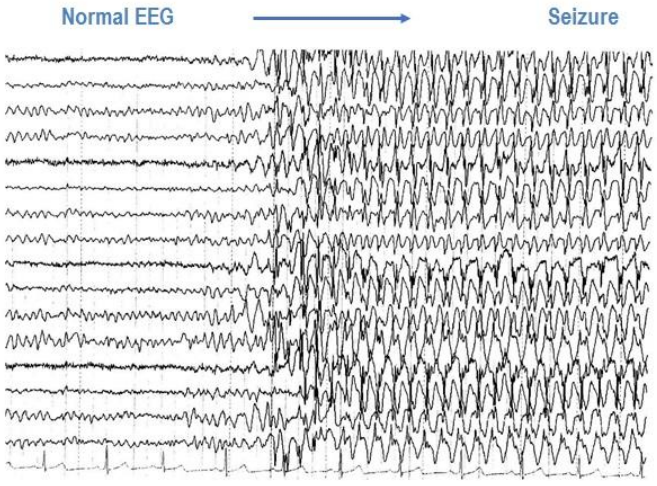


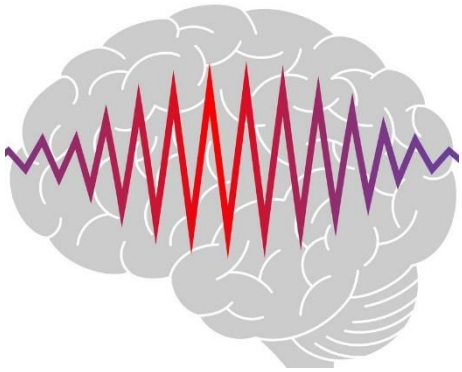
Figure 1 Image from http://what-when-how.com/acp-medicine/epilepsy-part-1/

This is a summary of the most common types of generalised onset seizures.

1. Tonic Clonic Seizures

A tonic clonic seizure is a seizure that has a tonic (muscle stiffening) and a clonic (muscle jerking) component, typically in this order. The older terms for tonic clonic seizures are “grand mal” or convulsion.

Tonic clonic seizures are the most recognised seizure type and can be frightening to witness. There are slight variations, but a typical tonic clonic seizure will last less than two minutes, and look like this:



- A sudden loss of consciousness, sometimes with vocalisation or crying out
- The eyes, head and body may turn in one direction
- The body becomes stiff (tonic), followed by jerking of the muscles (clonic)
- If standing, the muscle stiffening will cause the person to fall
- Breathing is compromised during the seizure which may cause the lips and face to look greyish/blue
- The person will not respond when spoken to
- Excess saliva may come of the person’s mouth, and there may also be blood if they have bitten their tongue or the inside of their cheek
- There may be loss of bladder control or less commonly bowel control
- Immediately after the seizure breathing can be quite laboured and sound like heaving snoring. This should rectify itself within a minute
- After the seizure there is usually a period of confusion, headache, soreness and sleepiness.

Because this seizure type causes considerable after effects, it is always important to have someone stay with the person until they are fully recovered.

Having a tonic clonic seizure in public places can create panic and people almost always call an ambulance. We recommend that people wear some form of medical ID if they do not wish to have an ambulance called.

2. Tonic and Atonic Seizures

A **tonic** seizure is when there is sudden increased muscle tone of the body. These are usually very brief, lasting only a few seconds. If the person is standing, they will suddenly fall stiffly to the ground. Tonic seizures also occur during sleep and in clusters of varying intensity of tonic stiffening. The person is unaware of these nocturnal tonic seizures, but as an observer you may hear an exhalation or loud sigh sound and notice a slight stiffening movement.

An **atonic** seizure is when there is a sudden loss of muscle tone. If standing, this will cause the person to suddenly slump to the ground. If sitting, a simple head nod (like the person is trying to fight off sleep) may be seen. These seizures are very brief, less than 2 seconds and may involve the head, body or limbs.

Both tonic and atonic seizures often occur in people with more complex epilepsies and difficult to control seizures. They are also called “drop attacks” because they cause the person to suddenly fall. Because of these falls, the seizures can frequently cause head or facial injuries and a protective helmet is usually required. Even though they are brief, they can be quite disabling because of their potential for injury.

3. Myoclonic Seizures

A myoclonic seizure is a seizure where a single brief muscle jerk or series of single muscle jerks occur. The jerks are frequently seen in the upper body, neck shoulders and arms. A person having a myoclonic seizure usually has these sudden jerks on both sides of the body at the same time. They vary in severity but can cause someone to spill or drop what they are holding or even fall off a chair. If severe enough, a myoclonic seizure can also cause a fall.

The person usually has awareness that these are happening.

These seizures are often mistaken for clumsiness before diagnosis.

Note: Many people experience myoclonus or sudden jerks upon falling asleep. These are not seizures.

www.epilepsy.org.au | Email : epilepsy@epilepsy.org.au | Tel: 1300 EPILEPSY (37 45 37)

4. Absence Seizures

A typical absence seizure is very subtle and easily missed or misinterpreted as daydreaming or inattentiveness. The seizure starts and ends suddenly, is very brief with impaired awareness during the seizure. The older term for absence seizures is “petit mal”.

Absence seizures usually begin in childhood (but can occur in adolescents and adults) and typically will:

- start with the person suddenly stopping their activity
- followed by staring blankly and not responding
- eye blinking or upward eye movements may be seen
- last from two to 20 seconds
- recovery is immediate and the child resumes their previous activity without awareness a seizure has happened
- usually there is no memory of what happened during the seizure

These seizures can happen numerous times a day causing learning to be disrupted. Absence seizures generally respond well to medication.

It’s not unusual for someone not to know the type of seizure or epilepsy they have. Often seizures are diagnosed based on descriptions of what an eyewitness has seen. These descriptions may not be fully complete, or one can’t tell where a seizure begins from this information.

Unfortunately, seizures can quite easily be misunderstood or mistaken for other events. Diagnosis can take some time if this happens.

Knowing the correct diagnosis gives a clearer picture of prognosis and what treatment may work best.

In the News – The latest on epilepsy

ADHD medications safe with epilepsy – study finds
People with epilepsy often also have attention-deficit/hyperactivity disorder (ADHD). Now, new research provides reassurance that taking ADHD medications won't increase the risk of seizures.
https://www.webmd.com/add-adhd/news/20190312/adhd-meds-safe-with-epilepsy-study-finds

Scientists discover rare genetic variants associated with epilepsy in large-scale study
For the first time, scientists have mapped out the genes associated with epilepsy. An Australian study is one of the largest of its kind to look into the genetic make-up of people with epilepsy.
https://transition.meltwater.com/cus/follow/20190805.ITkI89uuBi.0

Epilepsy diagnostics group win award
Epilepsy diagnostics start-up *Seer* won Start-up Victoria’s Best of Start-up State pitch night in Melbourne.
https://www.smartcompany.com.au/startupsmart/news/seer-medtech-epilepsy-diagnosis/

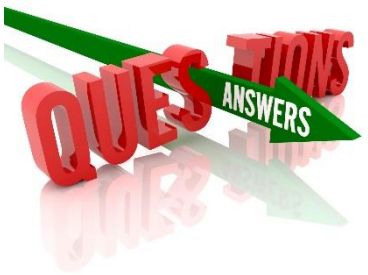
Australians left in pain by expensive and limited access to medicinal cannabis
Medicinal cannabis was legalised in Australia for a limited number of illnesses in November 2016. But it’s still very expensive, and only available to a fraction of the people who potentially need it. https://7news.com.au/sunday-night/medical-cannabis-debate-australians-left-in-pain-by-expensive-and-limited-access-to-drug-c-378990

Early success in neuromodulation treatment for intractable epilepsy
The University of Alabama at Birmingham recently created a neuromodulation clinic for people with epilepsy in an attempt to fill the treatment gaps as 15% to 40% still experience seizures.
https://www.neurologylive.com/clinical-focus/neuromodulation-clinic-shows-early-success-epilepsy-treatment

Neurons could slow progression of epilepsy in newborns
A recent study has uncovered an innovative approach to possibly slow the progression of epilepsy and reduce seizures in newborns.

https://www.deccanchronicle.com/lifestyle/health-and-wellbeing/230719/neurons-could-slow-progression-of-epilepsy-in-newborns.html

Q&As – Our service providers answer your questions



Q: Does Vitamin B affect seizures?

A: Vitamin B6 is closely associated with functions of the nervous, immune, and endocrine systems and it is essential for nerve function. A deficiency in Vitamin B6 may cause seizures and these are usually seen in children but can also be seen in adults who are heavy drinkers. Treatment will not respond to antiepileptic drugs but will respond with B6 administration. B12 deficiency, which is more likely to occur in people following a vegan or vegetarian diet, has also been known to cause seizures and is treated with B12 supplementation.

If your diet isn't great or you follow a vegetarian or vegan diet speak to your doctor about having your blood levels tested and possible vitamin supplementation.

Q: I have a puppy that is showing signs of alerting to my seizures. Is there an organisation that can help with training my puppy to respond in an appropriate manner and become qualified as an assistance dog?

A: There are many assistance dog organisations across Australia, however, most of these prefer to train a dog for a certain purpose before going to the owner. I have sourced A.W.A.R.E. Dogs Australia Inc. but you may find other services in your area.

A.W.A.R.E has services that are provided nationally. They obtain the majority of their animals from shelters and rescue groups. The program primarily supports members to train their own dog and are dedicated, where possible, to assist clients achieve full certification as assistance dogs.

I encourage you to have a look at their website. You can also call 1300 99 22 13 to gain a deeper understanding.
https://awaredogs.org.au/

Q: I have a child with autism and I'm worried that he may also have epilepsy. Is there a connection between the two?

A: Compared to the general population, people with autism spectrum disorder (ASD) are at an increased risk of developing epilepsy and people with epilepsy are at a higher risk of being on the autism spectrum. The figures differ but are approximately 20 percent risk in both cases, however the rate of ASD in epilepsy is much higher in people with an intellectual disability.

It may be difficult to recognise seizure activity in ASD, sometimes because of the communication barriers and an overlap of symptoms such as:

- Frequent behaviours such as repetitive purposeless behaviours ("stimming") of ASD can resemble automatisms seen in seizures.
- Attention deficit hyperactivity disorder, anxiety and sleep disorders are also common in both epilepsy and autism.
- Cognitive delay, impaired social interactions, and aggressive and irritable behaviour can be seen in some children with epilepsy and ASD.

If you are concerned that your child may be having seizures, then it is worth asking your GP for a referral to get an EEG (electroencephalogram) as a starting point.

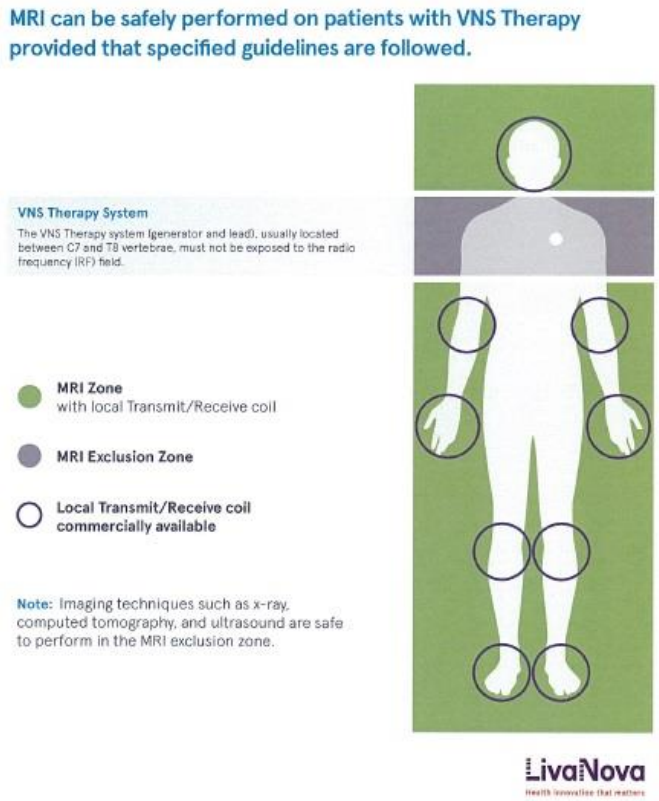
Q: I have a Vagus Nerve Stimulator implanted for my epilepsy. Am I able to have a MRI scan?

A: MRI can be safely performed with your implanted VNS Therapy system provided that specific guidelines are followed. Your neurologist should be familiar with these MRI guidelines.

You may need to take a few steps first:

1. The neurologist should add comments to the referral regarding your VNS
2. When you ring to make the appointment, let the staff know you have an implanted VNS. They may want to know the model number and your referring neurologist. NOTE: it is quite likely that your neurologist will arrange the booking MRI in the same hospital that they work, and you don't need to do anything here.
3. Inform the radiologist and MRI technicians of your implanted VNS Therapy device and your seizure disorder.
4. Do not bring your magnet into the MRI scanner room.
5. If you feel any discomfort during the MRI, immediately notify the MRI technician.

There are some exclusion zones outlined here by LivaNova https://www.livanova.cyberonics.com/:



Q: Can Lamotrigine cause anxiety?

A: Lamotrigine is an antiepileptic drug that is sometimes prescribed as a mood stabiliser (including anxiety). This doesn't mean it will manage anxiety in everyone, and although many people report it has a positive effect on their anxiety, some people report it makes it worse.

If you have anxiety and it has correlated with starting lamotrigine as a new drug, or with dose changes of lamotrigine, then it may be connected. It might be worth looking back as seeing if this is the case.

This site has quite a bit of information, including user reviews. Use the tabs at the top to navigate around https://www.drugs.com/mtm/lamotrigine.html

If you feel that the lamotrigine is the cause of your anxiety, and no other interventions have worked, then you will need to speak to your doctor to review it. As you probably know, it's quite an effort to change medication, but worth it if this is impacting your daily life.

Taking Action – What's happening at Epilepsy Action

The Purple Project

Have you taken the **Purple Pledge** yet? The **Purple Project** outlines the **Priorities** we have set for our work in order to minimise the impact of epilepsy on children, adults and whole families, and **provide** opportunities for better lives and futures.

THE PURPLE PROJECT (our 3 Ps):

- **PROVIDERS:** Working towards better access to specialist health care providers for all people with epilepsy.
- **PREVENTION:** Tackling epilepsy related deaths, especially those resulting from Sudden Unexpected Death in Epilepsy (SUDEP), and others that are clearly preventable.
- **POSSIBILITIES:** Supporting research and advocating for new accessible and affordable treatment options, including the newly emerging area of cannabinoid therapeutics.

Epilepsy Action needs your support to **Promote** the **Project** and work with us in **Partnership.** Click below to join us and take the **Purple Pledge** today**!**

Visit https://www.epilepsy.org.au/purple-project/