

MANAGING EPILEPSY

A medical diagnosis of epilepsy can be frightening, but keep in mind that around 70% of people are able to control their seizures through medication,^[1] equating to over 50 million people around the world leading relatively normal lives and going unnoticed within our communities.

However, for the 30% of people whose seizures cannot be controlled through medication, epilepsy can affect their health, safety, work, driving, relationships and more. If this is you - or someone you know - make an appointment with a health specialist or GP to discuss the other treatment options that may be available, or call our epilepsy helpline on 1300 852 853 and speak to one of our trained staff.

A strong support network makes a huge difference to those living with or affected by epilepsy, so **[become a member](#)** of Epilepsy Tasmania and take up our offer of advice, support and friendship.

[1] I. Brodie M. J., Schachter S. C. *Fast facts - epilepsy*. Oxford: Health Press Limited, 1999.

MEDICATIONS

Treatment for epilepsy is usually with antiepileptic drugs also referred to as AEDs or throughout this website simply as 'medication'. Many epilepsy syndromes respond well to a specific drug or to a combination of drugs. Drugs do not cure epilepsy but most seizures can be prevented by taking medication regularly one or more times a day.

Optimally, the doctor and the patient will jointly make the decision about medication based upon:

- Type of seizure
- Likely risk of having other seizures
- Age of the person
- Gender of the person
- Person's general health
- The opinion of the person

For people at risk of recurring seizures, around 70% will achieve complete seizure control from medication within a year.

Commencing medication does not always mean that it must be taken for life. Regular medical reviews are recommended and many people only need medication for a limited time - often just a few years.

Do not suddenly stop taking your medication as this can provoke seizures and possibly a medical emergency. Withdrawing from medication should always be carried out under medical supervision and any changes to dose should be guided by the treating doctor.

Adrenocorticotrophic Hormone	ACTH
Carbamazepine	Tegretol, Teril
Clobazam	Frisium
Clonazepam	Rivotril, Paxam
Ethosuximide	Zarontin
Gabapentin	Neurontin, DBL Gabapentin, Douglas Gabapentin, Gantin, GabaHexal GenRx Gabapentin, Nupentin, Pendine

Lacosamide	Vimpat
Lamotrigine	Keppra
Oxcarbazepine	Trileptal
Phenobarbitone	
Phenytoin	Dilantin
Primidone	Mysoline
Sodium Valproate	Epilim, Valpro
Sulthiame	Ospolot
Tiagabine	Gabitril
Topiramate	Topamax
Vigabatrin	Sabril

Seizure medication can interact with other medications including the contraceptive pill and some common over-the-counter treatments. It's important for people to check for this when a doctor, pharmacist or other medical practitioner suggests new medications.

Any side effects that are thought to be a result of the medication should be discussed with your doctor or epilepsy counsellor. Sometimes the medication can be carefully switched to avoid unwanted side effects.

For many people, medication makes it possible to live normal, active lives that are free of seizures. Others may continue to have seizures, but less frequently.

Some people are particularly sensitive to increased seizures when they miss a dose of their antiepileptic medication.

The longer the break between doses, the lower your blood levels will go and the greater your chance of having a seizure. If you take your medication erratically or you suddenly stop taking all medication you may trigger a severe seizure, a prolonged seizure or a cluster of seizures that will require hospitalisation.

Remembering to take medication regularly can be a problem. Many people with epilepsy experience difficulty with their short-term memory. Using a dosette-box can help. It may also be helpful to carry a daily dose of your medication with you in case you are not at home in time to take the next dose.

The traditional advice on missing a dose has often been to simply pass on it and not to try to catch up. That is not always a good idea. The current view is that you should take the missed dose as soon as you realise it was missed, even if this isn't until the next dose is due. That is, you should catch up. The risk of this is minor overdose, the symptoms of which are not serious and will last no more than a couple of hours, while the risk of not doing so is a seizure. Make sure you discuss this with your doctor, and better yet - don't miss a dose.

Some of the things you can do to remind yourself to take your medication is:

- make it part of your daily routine by taking it with meals or as you get up or go to bed
- keep your tablets on top of your pillow or in the kitchen
- use a digital watch alarm to remind you when your medication is due

It is more important to take your medication at a time when you are more likely to remember than at exactly 12 hourly [or 8 hourly] intervals.

Remember:

- seizure medication may be started slowly with the dose gradually increased

- the treating doctor should guide changes to the type or dose of medication
- a new medication is often introduced whilst the old medication is being reduced
- sometimes a combination of medications is used
- try not to miss a dose – but ask your doctor what to do if this happens
- a dosette-box can help people to remember their medication
- tell your doctor if you are still having seizures whilst taking medication
- plan ahead so you do not run out of medication
- illness, diarrhoea and vomiting may affect the absorption of medication
- seizure medication should not be stopped suddenly

A generic drug is a drug based on a branded product but made by a different manufacturer. Research suggests that the minute difference between two versions of the same drug may cause problems for people with epilepsy if they are switched from one to another.

While the chemicals used are exactly the same, there can be slight variations between the drugs due to the manufacturing process. For the vast majority of drugs this has little or no impact on the person taking the medication. However due to the way antiepileptic drugs work, even the slightest variation in the amount of the drug taken appears to cause problems for some people with epilepsy.

Many generic formulations of some antiepileptic medications are now available In Australia and it is now government policy for pharmacists to ask if a cheaper brand would be preferred. It appears that any switch in medication whether it be branded to generic, generic to branded, or generic to generic may cause an increase in drug side effects, an increase in seizure frequency or breakthrough seizures in people whose seizures were previously controlled.

People with epilepsy are advised to continue taking their prescribed medication:

When a prescription is filled check the tablets are the same size, shape and colour as normal and that the packaging carries the same name as prescribed by your doctor. If your pharmacist suggests that switching to another product can save you money, politely refuse and insist on your usual medication. **Switching drugs is not worth the risk.**

Internationally respected neuropharmacologist Professor Frank Vajda addresses the controversial issue of generic substitution and epilepsy in the following reports: Bullet point these:

- [Generic substitution in epilepsy: a controversial issue.](#) *The Epilepsy Report*, Issue 2, 2006.
- [Generic medication consumer update](#) *The Epilepsy Report*, Issue 1, 2009.

Our national partner Epilepsy Australia continue to lobby the Federal government for antiepileptic medications to be excluded from those PBS medications flagged for substitution.

Online Pharmacy Caution:

There has been an influx of online pharmacies offering discounted products by mail order. Whilst this may be perfectly safe for ordering vitamins and other over-the-counter products, caution should be taken if considering ordering prescription medication this way.

As it is Australian Government policy to allow pharmacists to offer generic substitutions, you may have no control over the possible substitution of your prescribed medication and the inherent risks such substitution can have on your level of seizure control.

OTHER TREATMENT OPTIONS

Surgery

Epilepsy is sometimes caused by an area of abnormal brain tissue.

There are many reasons why an abnormality occurs and it may be unimportant unless it causes seizures. The size and position of the area, referred to as the **epilepsy focus** varies between individuals.

If surgery can remove the epilepsy focus, seizures can often be prevented. The chance of successful surgery and the risks of complications differ for each patient.

Surgery is usually only used where medication fails and is not intended to be a substitute for medication. If surgery is considered to be a possible treatment for your epilepsy, several months of extensive testing and counselling are undertaken before surgery is performed.

Your doctors will discuss possible outcomes from surgery in your case, so that you can make an informed choice. If you would like further information, Epilepsy Tasmania can provide you with specialised literature on this topic.

Vagus Nerve Stimulation Therapy

Vagus Nerve Stimulation Therapy [VNS Therapy] uses a small medical device (the pulse generator) that sends small electrical pulses to the left vagus nerve in the neck.

The vagus nerve has many connections to areas in the brain instrumental in producing seizures and by stimulating the vagus nerve the brains potential to generate or spread abnormal seizure activity can be reduced.

Implanting a vagus nerve stimulator is generally only considered if antiepileptic drugs are not controlling the seizures satisfactorily and other surgical options have been ruled out.

The operation to implant a vagus nerve stimulator takes approximately two hours with the device implanted under the skin just below the left collar bone or close to the armpit. A second small incision is made in the neck to attach two tiny wires to the left of the vagus nerve. The wires are threaded invisibly beneath the skin from the pulse generator to the vagus nerve in the neck.

Over the following two days, the device is programmed to automatically deliver stimulation on a regular, frequent basis, usually every 300 seconds, around the clock.

Not all types of epilepsy will respond to this treatment. While results are mixed, there seems to be a significant number of people with this device whose seizure frequency has reduced radically or whose seizures have stopped altogether. Your neurologist can determine if this treatment is an option for you.

In relation to any surgery, while the best possible outcome is anticipated for each patient no surgical procedure is risk-free. Successful surgery however can prevent seizures from occurring, or dramatically reduce seizure frequency and thereby change a person's life forever.

For further information on VNS Therapy visit www.vnstherapy.com

Ketogenic Diet

The Ketogenic diet is a strict, medically supervised diet that may be a treatment option for some children with epilepsy.

It involves a restricted fluid, high fat and very low carbohydrate and protein diet that ensures the body will burn fat rather than carbohydrate and protein for energy, thus producing ketones. In some ways, the diet mimics the body's metabolic state during fasting or illness.

This high ketone state (ketosis) decreases seizure activity in some circumstances by mechanisms, which are not fully understood. The diet deliberately maintains this build up of ketones by a strictly calculated, individual regimen with rigid meal plans.

The ketogenic diet is not a "natural therapy". Less is known about the beneficial and adverse effects of the ketogenic diet than other treatments for epilepsy eg. antiepileptic medications, surgery. The ketogenic diet has not been subjected to the usual clinical trials that establish efficacy and safety of a treatment for a medical condition.

The ketogenic diet is generally only suitable for children with poorly controlled seizures. Assessment by a paediatric neurologist experienced in epilepsy management and monitoring of the diet and drug therapy is a prerequisite.

Generally, young children with mixed myoclonic seizure disorders are thought to respond best to the ketogenic diet.

Some centres have reported success with adult patients and patients with other epilepsies.

For more information about the Ketogenic Diet [click here](#).

Complementary Therapies

Complementary therapies may assist a person with epilepsy by improving overall health and wellbeing.

However, research does not suggest that complementary therapies are likely to improve seizure control in most cases. In some situations they have been shown to trigger seizures.

If you believe that using a complementary therapy in conjunction may be of benefit, discuss this with your doctor. It is recommended that you do not stop your antiepileptic medication unless advised to do so by your doctor.

The following downloadable resources may be helpful. If you're unable to download the links please ask us for a copy to be sent by post.

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[My Medical Appointment](#) - An easy form to help the patient and their support person prepare for a medical appointment.

[Epilepsy Wellbeing Map](#) - Use this tool to discuss what's important to you when visiting your neurologist.

Epilepsy Management Plan:

- [Developing an Epilepsy Management Plan](#)
- [A template to complete](#)
- [Guidelines to Help You Write an Epilepsy Management Plan](#)

Seizures - Understanding seizures and first aid responses:

- [First Aid Poster](#)
- [All About Seizures](#)

- [Seizure Diary](#)

[Videos](#)

[Sudden Unexpected Death in Epilepsy \(SUDEP\)](#)

Midazolam:

- [Emergency Medication Management Plan for Midazolam](#) - A document to help prescribing doctors identify doses, route and seizure type for administration.
- [Prescription Guidelines](#)

Rectal Valium:

- [Emergency Medication Management Plan for Rectal Valium](#) - A document to help prescribing doctors identify doses, route and seizure type for administration.
- [Prescription Guidelines](#)

[Ketogenic Diet](#)

[Australian Epilepsy Register](#)

[Australian Pregnancy Register for Women on Antiepileptic Medication Register](#)

[Medical Marijuana](#)

[Share Your Epilepsy Experience](#)

[Diagnosing Epilepsy](#) - An easy to understand booklet answering common questions about epilepsy.