

# Drug Resistant Epilepsy

In Australia, approximately 14,000 people are diagnosed with epilepsy each year and around 250,000 people are currently living with epilepsy. What many people don't know is about **1 in 3 people with epilepsy continue to have seizures** despite treatment. This is called medication or drug-resistant epilepsy (DRE).

Despite the introduction of many new anti-seizure medications in the last 30 years, there is still the same proportion of people with epilepsy that continue to have DRE.

## What is drug resistant epilepsy?

DRE is when seizures are not fully controlled after trying two appropriately prescribed anti-seizure medications and used for an amount of time as determined by the specialist. This type of epilepsy can also be called refractory or intractable epilepsy.

Having DRE can be a heavy burden and very much affect quality of life.

## The effects of drug-resistant epilepsy

### Drug Resistant Epilepsy

- Poor quality of life
- Increased risk of injury & death
- Persistent seizures, disability
- Work & driving restrictions
- Medication side effects
- Cognitive problems
- Social isolation, dependency
- Mood and personality changes

*Figure 1. Modified from: Living with medication resistant epilepsy. Tang, F., Hartz, A., & Bauer, B. (2017). Drug-Resistant Epilepsy: Multiple Hypotheses, Few Answers. Frontiers in neurology*

## Other reasons seizures continue

If your seizures are continuing despite taking anti-seizure medication, it does not always mean you have DRE. Sometimes there may be other reasons such as:

- The medication is not the right choice for your seizure or epilepsy type
- Your lifestyle may be affecting your seizures (eg stress, poor sleep, alcohol) or you may not be aware of all your seizure triggers, or not avoiding them as best as you can
- The diagnosis is wrong. Misdiagnosis is relatively common

## Let's talk about medication

When you are diagnosed with epilepsy, medication is the first treatment. The aim of anti-seizure medication is to get the best seizure control with the lowest dose, and the least amount of unwanted side effects. The neurologist will choose a medication that is appropriate for your type of epilepsy.

Treatment usually begins using one medication starting at a low dose, which is slowly increased until your seizures stop, or unwanted side effects occur. If your seizures are not controlled or side effects are intolerable with the first medication, generally, a different one is added and the first slowly reduced and withdrawn. If your seizures are not controlled with a single medication, then another one might be added to be used in combination with the first. Finding the right medication can sometimes take time.

People with drug resistant epilepsy often experience:

- Frequent medication changes,
- Taking two or more medications at the same time,
- Unwanted medication side-effects,
- More frequent visits to the doctor, emergency department or hospital

**Studies show that adding more medications is not likely to control this kind of epilepsy.**

## When seizures don't respond to medication, what's next?

**Firstly, if you haven't already done so, get a referral to a specialist epilepsy centre.**

There you will see an epilepsy specialist who may be able to:

- Suggest a more appropriate medication or trial a newer epilepsy medication
- Investigate if epilepsy surgery is an option. Some epilepsy types are suitable for surgery to help control or stop seizures
- Find out if vagus nerve therapy is an option. A vagus nerve stimulator (VNS) is a device implanted in the chest to manage seizures that don't respond to medication or when surgery is not possible.
- Consider dietary therapies. Examples of diets currently being used are the ketogenic diet, Modified Atkins Diet, or low glycemic diet.

There is no one treatment that's right for everyone. People respond differently to medication and other forms of treatment.

If you have trouble with seizure control, seeing an epilepsy specialist is a good step to finding out what other treatment options may be suitable for your type of epilepsy.



**Medication alone isn't the answer for 1 in 3 people with epilepsy**

## Other treatment options include

### Epilepsy Surgery

[Epilepsy surgery](#) offers a chance to be seizure-free or at least to have fewer seizures. Surgery may also allow antiseizure medications to be reduced – although ongoing medication is often necessary. This will depend on your circumstances. **Only a small number of people are suitable for epilepsy surgery.**

Those suitable are generally people who:

- Have focal onset seizures (which may or may not develop into tonic clonic seizures)
  - Seizures are drug resistant & two or more appropriate medications have been trialed
  - Seizures (or most seizures) originate from only one small region of the brain
- Seizures are particularly debilitating or dangerous such as “drop attacks” (tonic or atonic seizures) and status epilepticus (very long seizures)
- Have frequent seizures, affecting day-to-day life considerably
- Have a cause of seizures that requires surgery, e.g. a tumour or abnormal brain tissue

[Listen here](#) to neurosurgeon Dr Erica Jacobsen answer questions about epilepsy surgery.

Speak with your doctor about surgery as an option for you.

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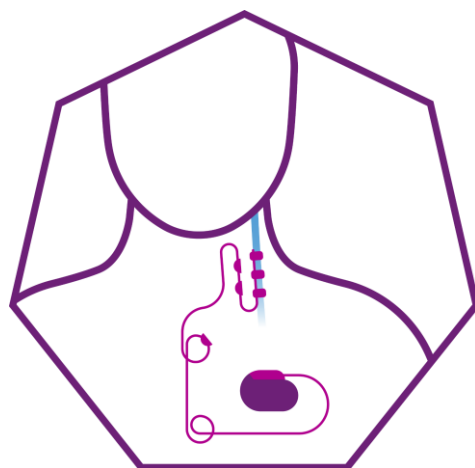
### Vagus Nerve Stimulation (VNS Therapy™)

[VNS Therapy™](#) is used for children and adults with focal and generalised seizures with DRE.

It is a form of *neuromodulation* that offers another way to manage seizures and has been proven to safe and effective.

The VNS Therapy™ System includes a pulse generator that is implanted under the skin and connected via leads to the left vagus nerve in the neck. The generator sends mild pulses through the vagus nerve to the brain.

VNS Therapy™ can lead to fewer, shorter and less severe seizures and better recovery after seizures



### What have studies shown?

VNS Therapy effectiveness has shown to improve over time

In a 10-year study that tracked the effectiveness of VNS Therapy at reducing the frequency of seizures:



From Year 1 to Year 10,  
patients experienced a  
**45%**  
IMPROVEMENT IN  
SEIZURE REDUCTION

## Vagus Nerve Stimulation (VNS Therapy™) cont...

### Are there other benefits?

Many people have reported other benefits including:

- an improvement in alertness, memory, energy levels and general quality of life
- improvements in mood – VNS Therapy™ is also used to treat depression
- improved safety, including reduced SUDEP risk
- shorter seizure duration and severity and faster recovery
- people can use the VNS magnet to abort or reduce the severity of a seizure.

### What are the side effects?

VNS may cause side effects in some people. The most common include:

- Changes in voice
- Hoarseness or throat discomfort
- Coughing
- Tingling or pain in the throat or neck

These effects are generally related to the stimulation settings and diminish over time or after a change in the stimulation settings.

Speak with your doctor about VNS Therapy™ as an option for you.

For more information go to [What is VNS Therapy™](#)

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## Dietary Therapies

Dietary therapies have long been used to control seizures in people with severe epilepsies and DRE. The dietary therapies used today for epilepsy are all low in carbohydrates and high in fat.

The *classic ketogenic diet* was the original epilepsy diet developed for children, but it is also used in adults. The *modified Atkins diet* is a less restrictive diet that helps with seizure control in adults and children.

Other diets include *Low Glycemic Index Treatment* & *Medium-Chain Triglyceride* diet

### Classic Ketogenic Diet

The classic ketogenic diet is a recognised and proven therapy for epilepsy since the 1920's. It has primarily been used in children with DRE, but it can be used for any age group. It is now standard treatment with specific epilepsy syndromes and can help reduce seizures in two out of three children and may stop seizures completely in one out of three.

The classic ketogenic diet is a strict diet high in fats and low in carbohydrates. This makes the body burn fat for energy instead of glucose – mimicking a fasting state, which causes a process called ketosis. It does not restrict protein intake or daily calories.

While there is evidence that this diet is an effective treatment for some people with epilepsy, how it works is still not completely understood.

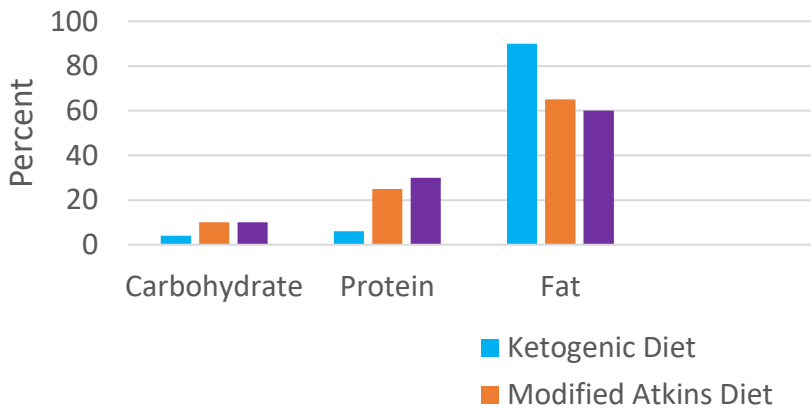


Dietary Therapies cont...

**Modified Atkins Diet**

The modified Atkins diet is a less restrictive and a more palatable alternative to the classic ketogenic diet. The Atkins diet was developed in 1970 for the purpose of weight loss. The modified Atkins diet is “modified” from the original Atkins diet as the “induction phase” of the diet limiting carbohydrates is maintained indefinitely, eating fat is encouraged, and seizure control is the goal rather than weight loss.

Diet Comparisons



Both diets have shown comparable effectiveness, but more studies are needed to clarify this further.

**Side effects** with following these diets long-term can include:

Low bone density and bone fractures.	Kidney stones.
Constipation.	Slower growth than typical (children)
High cholesterol.	Weight loss
Sluggishness (tiredness).	

**NOTE:** Always speak to your doctor about any treatment changes you are considering & do not start any dietary treatment for epilepsy without advice. These diets are to be closely monitored & done under medical supervision.

Poor seizure control has been associated with increased risk of injury and death, difficulties with education and gaining employment, social isolation, anxiety and depression and consequently poor quality of life

**It is important to explore other approaches to treatment if medication does not work**

### Epilepsy Clinics

Fortunately for Australians, there are comprehensive epilepsy centres in nearly every state, allowing for people with drug-resistant epilepsy to be referred to optimise their treatment plan.

These centres are best equipped to evaluate people who have drug resistant epilepsy and offer a better chance at finding the best treatment.

It is recommended that Australians with drug-resistant epilepsy should be referred to a comprehensive epilepsy centre to gain a clearer diagnosis, review of their epilepsy and targeted management as soon as possible to improve their seizure control.

**Epilepsy centres are best equipped to evaluate people who have DRE and offer a better chance at finding the most appropriate treatment.**

To find an epilepsy centre in your state, [search your state](#), or contact us on 1300 37 45 37 or email [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au)

**For more information:**

**Listen to Professor Terry O'Brien answer questions about [drug resistant epilepsy](#).**

**Listen to Professor Patrick Kwan answer questions about [drug resistant epilepsy](#).**

[Drug Resistant Epilepsy](#)

[Managing Epilepsy](#)

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