Epilepsy Action Australia

17.12.2025

DRUG RESISTANT EPILEPSY

FACT SHEET

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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 that about 1 in 3 people with epilepsy continue to have seizures despite treatment. This is often called medication or drug-resistant epilepsy.

What is drug resistant epilepsy?

Drug-resistant epilepsy (DRE) is failure to achieve sustained seizure freedom after trying two appropriately prescribed anti-seizure medications (ASM) and used for an amount of time as determined by the specialist (Kwan et al 2010).

Most people who attain seizure control do so with the first or second ASM. The probability of achieving seizure freedom diminishes substantially with each subsequent ASM regimen tried (Chen et al 2018).

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

Why are the medications not stopping the seizures?

If your seizures are continuing despite taking anti-seizure medication, it does not necessarily mean you have drug resistant epilepsy.

Sometimes there are other reasons such as:

- The medication is not the right choice for your seizure or epilepsy type
- Your lifestyle may be affecting your seizures (e.g. 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

While there are many new medications available to treat seizures, the number of people with DRE is still the same.

THE EFFECTS OF DRUG-RESISTANT EPILEPSY

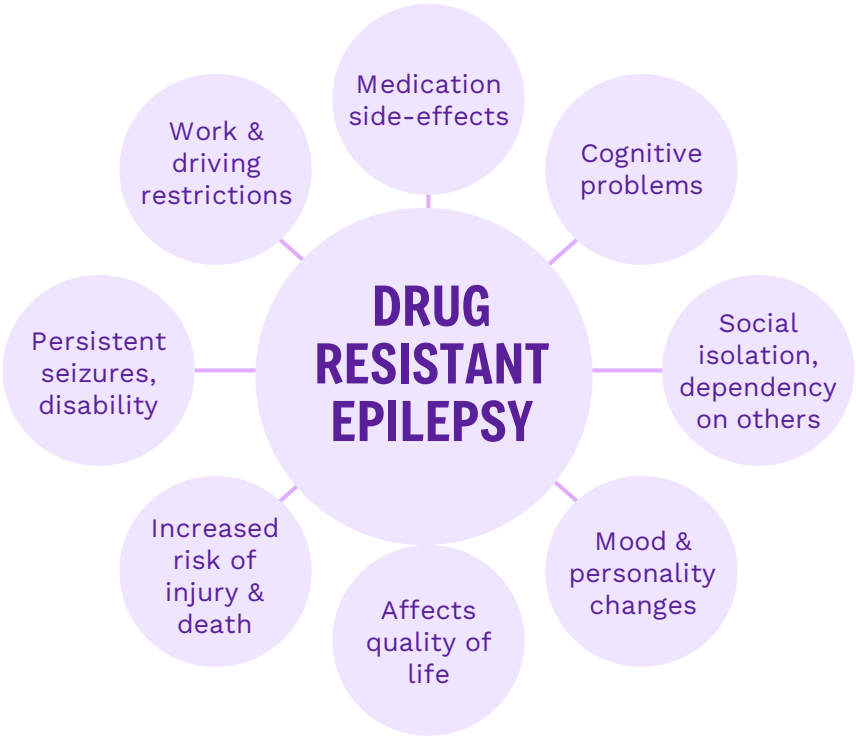


Figure 1. Living with medication resistant epilepsy. Tang, F., Hartz, A., & Bauer, B. (2017). Drug-Resistant Epilepsy: Multiple Hypotheses, Few Answers. Frontiers in neurology

People with drug resistant epilepsy often experience:

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

All of which can take a physical and emotional toll.

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

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

When you are diagnosed with epilepsy, medication is typically the first treatment.

The aim of seizure medication is to control seizures as well as possible, using the smallest dose and fewest medications, with the least side effects.

The neurologist will choose a medication that is appropriate for your type of epilepsy.

Treatment usually starts with a low dose, which is gradually increased until your seizures stop, or unwanted side effects occur. If side effects are intolerable, generally, a different medication 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.

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

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 neuromodulation such as vagus nerve therapy (VNS Therapy ™) is an option. This is a pacemaker-like device implanted in the chest to manage seizures.
- Consider dietary therapies. Examples of diets its currently being used are the ketogenic diet, Modified Atkins Diet, or low glycaemic diet.

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

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

EPILEPSY SURGERY

Epilepsy surgery offers a chance to be seizure-free or have fewer seizures.

A small number of people are suitable for epilepsy surgery. These are generally people who have:

- Focal onset seizures
- Drug resistant seizures & two or more appropriate medications have been trailed
- Seizures (or most seizures) originate from only one small region of the brain
- Seizures that are debilitating or dangerous such as "drop attacks" (tonic or atonic seizures) and/or episodes of status epilepticus.
- Frequent seizures, affecting day-to-day life.
- Have a cause of seizures that requires surgery, e.g. a tumour or abnormal brain tissue.

Listen to Neurosurgeon Erica Jacobsen answer questions about Epilepsy Surgery

VAGUS NERVE STIMULATION (VNS Therapy™)

VNS Therapy is a neuromodulation treatment designed for people with drug-resistant epilepsy.

VNS Therapy™ is an approved treatment option for both paediatric and adult patients with DRE. It is a form of neuromodulation and has been proven to be safe and effective.

VNS Therapy™ is a small device that is implanted under the skin in the chest and connected to the vagus nerve in the neck. The device delivers mild pulses to the brain through the vagus nerve to help prevent seizures before they start and help stop them if they do.

VNS Therapy can help to not only reduce the number of seizures - it may also reduce the length and severity of seizures that do occur and improve recovery after seizures.

Many people have reported other benefits including:

- An improvement in thinking, alertness, memory, energy levels and general quality of life
- Improvements in mood
- Improved safety, including reduced SUDEP risk
- Shorter seizure length and severity and faster recovery
- Using the VNS magnet to abort or reduce the severity of a seizure.
- Less hospitalisations, A&E visits, and injuries.

What are the side effects?

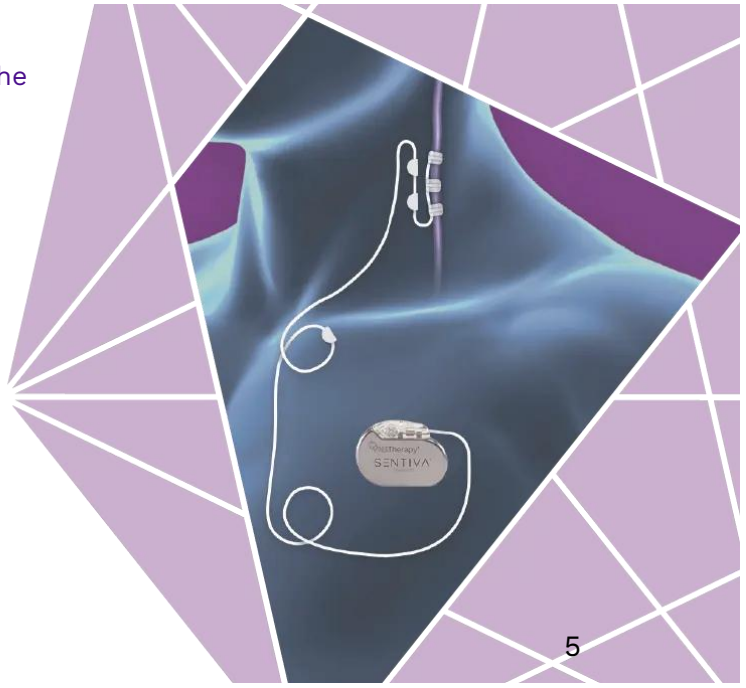
VNS may cause side effects in some people. The most common include:

- 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.

- Other somatic side effects such as sleep apnoea, have also been reported.

! VNS Therapy™ effectiveness improves over time



For more information go to: What is VNS Therapy

DIETARY THERAPIES

Dietary therapies have long been used to control seizures in people with complex epilepsies and DRE.

The classic ketogenic diet was originally developed over a century ago for seizure management. The modified Atkins diet is more recent and a less restrictive diet that helps with seizure control in adults and children. Other diets are Low Glycaemic Index Treatment & Medium-Chain Triglyceride diet.

Classic Ketogenic Diet (CKD)

This is a strict diet high in fats and low in carbohydrates which mimics the fasting state, altering the metabolism to use fats as a primary fuel source.

It is primarily used in children with DRE but can be used for any age group.

The CKD represents the treatment of choice for GLUT1 deficiency syndrome and pyruvate dehydrogenase complex deficiency. Infantile spasms, Dravet syndrome and myoclonic-astatic epilepsy are epilepsy syndromes for which CKD should be considered early in the therapeutic pathway.

It can help reduce seizures by greater than 50 percent in 38-60 percent of people. Approximately 10-15 percent of children and young people become seizure free.

While there is evidence that the CKD is an effective non-pharmacologic treatment for some people with epilepsy, how it works is still not completely understood.

Modified Atkins Diet

This diet is a less restrictive and more palatable alternative to the classic ketogenic diet, which makes it a better option for adults and adolescents, and easier to follow.

This diet is “modified” from the original weight loss 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.

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

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

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.

SUMMARY

Drug-resistant epilepsy (DRE), also known as refractory or intractable epilepsy, is when seizures are not effectively controlled by appropriate trials of two or more antiseizure medications.

This means that even with the best efforts to manage seizures with medication, a person continues to have seizures.

DRE can significantly impact a person's quality of life, increasing their risk of injury, social isolation, and psychological distress

Specialised epilepsy centres are best equipped to assess people who have DRE and offer a better chance at finding the most appropriate treatment.

Epilepsy Centres

It is recommended that Australians with DRE 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.

All states have a comprehensive epilepsy centre apart from Tasmania.

To find the closest comprehensive epilepsy centre in your state contact us on:

Phone: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

Visit our website

To learn more about epilepsy go to our online training.

This resource was funded and developed with support from LivaNova Australia. Many thanks for their contribution and assistance with this material.