

Take control back from epilepsy.

A guide to treatment
options for people
with **drug-resistant
epilepsy.**



LivaNova
Epilepsy



Medication alone can't fully control seizures for 1 out of 3 people with epilepsy

While two thirds of people with epilepsy could have their seizures fully controlled by anti-epileptic medication, for **one third of people** with epilepsy, their seizures remain uncontrolled.

Drug-resistant epilepsy (DRE) is when seizures continue after two anti-seizure medications have been appropriately prescribed and properly used for an amount of time as determined by a doctor.

Being diagnosed with **drug-resistant epilepsy** early allows you to start effective treatment sooner, which may improve your results and give you the best chance to avoid long-term psychological or social difficulties.



Living with drug-resistant epilepsy

You are not alone. There are approximately 23 million people in the world with drug-resistant epilepsy.

Many people with epilepsy live full and active lives, but if you are living with uncontrolled seizures you may be concerned about participating in certain activities, for fear of experiencing a seizure. Some people worry that their education may suffer, or that maintaining their job or independence could be affected.

If you are caring for someone with uncontrolled seizures, you may also have concerns. It is normal for families and caregivers to feel worried about their loved one should they experience a seizure away from home, and be concerned about the impact on family life. For children, uncontrolled seizures can negatively impact brain development and memory.

Epilepsy is more than seizures

Drug-resistant epilepsy brings other challenges beyond uncontrolled seizures, some of which you or your loved one may have experienced.



Despite the challenges of living with DRE, there are options to help you take control back from epilepsy.



A different approach for treating drug-resistant epilepsy

While many cases of epilepsy can be treated with medicine alone, **this type of epilepsy requires a different approach.**

Studies have shown that adding more medications is not likely to control seizures for people with drug-resistant epilepsy. But despite this data and what we know about the risks of living with drug-resistant epilepsy, many people continue to be prescribed multiple medications instead of being evaluated for non-drug treatment options.

It is important that if your seizures have not been controlled after trying two different drugs, either on their own or in combination, that you are seen by an epilepsy specialist to explore other appropriate treatment options.

The treatment options for people with drug-resistant epilepsy work towards:

- ✔ Gaining long-term seizure control
- ✔ Decreasing seizure severity
- ✔ Minimising side effects
- ✔ Improving quality of life



Your journey towards a treatment option that is right for you

There are many treatment options available for people with drug-resistant epilepsy, that do not rely on anti-seizure medication alone. These include different types of **epilepsy surgery**, **dietary therapies** and **neuromodulation therapies**.

Always discuss with your doctor about the right option for you.

Epilepsy surgery

Epilepsy surgery refers to the different types of operations that are carried out on the brain to stop or reduce seizures.

To find out if epilepsy surgery is an option for you, you'll have a number of tests in a specialist epilepsy centre. These might include tests such as MRI scans, electroencephalograms (EEG) and being filmed whilst having an EEG (this is called videotelemetry).

If the tests suggest that one area of your brain is causing the seizures and if there are no important functions (e.g. sight, speech, movement) in that area, that section of your brain could be removed in an operation. This is called **resective surgery**. The operation is usually performed on the temporal lobe, as the start of seizures is often located here.

If it's not possible to remove that section of your brain because important functions are in that area, surgery may be performed to disconnect part of your brain to stop the seizures from spreading to the rest of your brain.



Does epilepsy surgery work to control seizures?

Evidence shows that epilepsy surgery is an effective option for many patients, both for adults and children, with studies reporting approximately 66% of patients being seizure free 5 years after temporal resection. Although it can be a very effective treatment option, many patients with drug-resistant epilepsy are found to be ineligible after the tests have been completed.

Are there any side effects?

Whilst surgical resection for drug-resistant epilepsy has a good prognosis for seizure freedom, surgical risks include deep vein thrombosis and infection, and the procedure can be linked to language and memory difficulties. It's important to discuss these with your doctor.

Neuromodulation therapies

For people with drug-resistant epilepsy who are not eligible for epilepsy surgery, neuromodulation therapies may be an option. Designed to be used alongside medication, two established neuromodulation therapies are **vagus nerve stimulation and **deep brain stimulation**.**

Your suitability for a neuromodulation therapy is determined by a team of healthcare professionals at a specialist epilepsy centre. There may be other neuromodulation options depending on your country.



What is vagus nerve stimulation?

Vagus nerve stimulation involves a device that is implanted under the skin in your chest, then connects with a thin wire lead to the left vagus nerve in your neck during a surgical procedure lasting 1-2 hours. The device (sometimes referred to as a 'stimulator') is programmed by your doctor to send regular, mild electrical signals to the vagus nerve in an effort to control seizures. Your doctor will continue to adjust the settings according to your needs.

Does it work to control seizures?

Evidence shows that vagus nerve stimulation can reduce the number, length and severity of seizures in both adults and children with drug-resistant epilepsy, with individual results varying. It can also improve recovery time after a seizure, and have a positive effect on overall quality of life. Whilst the effect of vagus nerve stimulation may not be seen immediately, results can improve over time.

Are there any side effects?

Possible side effects from vagus nerve stimulation can include hoarseness, sore throat, shortness of breath and coughing - these side effects are usually during stimulation and tend to decrease over time. Because vagus nerve stimulation requires a surgical procedure, surgery itself may pose a risk of infection. It's important to discuss any side effects and risks with your doctor.

What is deep brain stimulation?

Deep brain stimulation involves a device that is implanted under the skin in your chest or abdomen during surgery. For this type of neuromodulation therapy, the device is connected to thin wire leads that are placed in your brain. The device is programmed by your doctor to send controlled electrical stimulation directly to the specific areas of your brain involved with seizures. Your doctor will continue to adjust the settings according to your needs. Deep brain stimulation is indicated for adults only.

Does it work to control seizures?

Evidence shows that over time, many patients experience positive results with deep brain stimulation for drug-resistant epilepsy and are satisfied with the therapy. Results vary by person, but many people report a reduction in their overall number of seizures and a reduction of their most severe seizures, as well as experiencing fewer epilepsy-related injuries.

Are there any side effects?

Possible side effects related to the device, stimulation or surgery include implant site pain, tingling sensations, ineffective stimulation and implant site infection. Other potential side effects include depression or memory problems, status epilepticus, and changes in seizures. It's important to discuss any potential side effects and risks with your doctor.

Dietary therapies

Specialist medical diets such as a ketogenic diet is one that has a higher fat, lower carbohydrate content than a typical diet.

Suitability for a dietary therapy is determined by a team of healthcare professionals at a specialist epilepsy centre. There are also two modified ketogenic diets - the modified Atkins diet (MAD) and the low glycaemic index treatment (LGIT) diet.

What is the ketogenic diet?

The ketogenic diet is much higher in fats and lower in carbohydrates than a typical diet. It is a strict diet requiring the weighing of food and is usually prescribed to children between 1 and 12 years of age with drug-resistant epilepsy. The diet is introduced gradually and is closely monitored by a team of healthcare professionals. The specific requirements, vitamins and supplements must be determined for each individual.

What are the modified ketogenic diets?

Other variations on the diet tend to be less strict and do not require food to be weighed. The Modified Atkins diet (MAD) is low in carbohydrates and high in fats with no restriction on protein intake. The low glycaemic index treatment (LGIT) diet restricts both carbohydrates and protein, and increased intake of fat is encouraged.



Do dietary therapies work to control seizures?

The ketogenic diet and related diets change your body's metabolism to burning fat for energy instead of carbohydrates. This high fat approach is designed to maintain a high level of ketones in your body which can help to reduce seizure activity.

There has been more research into the use of this type of diet in children than in adults. Evidence shows that dietary therapies can reduce seizures in children with drug-resistant epilepsy. The effectiveness may vary depending on the type and severity of the epilepsy.

Are there any side effects?

Dietary therapies can be difficult to maintain in the long-term and daily life. There is limited evidence on how tolerable the diet is for adults. Side effects may include nutrient deficiencies, constipation and dehydration. It's important to discuss these with your doctor.

Your next step towards taking control back from epilepsy

To take the next step, start by asking your doctor about the treatment options for drug-resistant epilepsy.

To get the most out of your next appointment, you may find it useful to prepare by using the **Epilepsy Discussion Guide** on the following pages.

Completing this short questionnaire may help you and your doctor to understand your current situation and determine your interest in treatment beyond additional anti-seizure medication.

The Epilepsy Discussion Guide focuses on:

- Describing your seizures
- Treatment you currently take and have previously taken
- Your lifestyle
- Your hopes and dreams for the future



Epilepsy Discussion Guide

A framework for a meaningful discussion

Your seizures

How many seizures do you have and how regularly?

- | | |
|---|---|
| <input type="checkbox"/> Usually 1 per month | <input type="checkbox"/> Usually 1 per day |
| <input type="checkbox"/> Usually 2 or 3 per month | <input type="checkbox"/> Usually 2 or 3 per day |
| <input type="checkbox"/> Usually 1 per week | <input type="checkbox"/> 4 or more per day |
| <input type="checkbox"/> Usually 2 or 3 per week | <input type="checkbox"/> Other - please write below |

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How would you describe your seizures?

- | | |
|---|--|
| <input type="checkbox"/> I have dizzy spells | <input type="checkbox"/> I stare into space and don't hear others or can't respond |
| <input type="checkbox"/> I feel nauseous | <input type="checkbox"/> I suddenly fall down |
| <input type="checkbox"/> I have a funny taste in my mouth | <input type="checkbox"/> I lose consciousness |
| <input type="checkbox"/> I hear a ringing sound | <input type="checkbox"/> My body shakes |
| <input type="checkbox"/> I feel like I'm having an out-of-body experience | <input type="checkbox"/> Other - please write below |
| <input type="checkbox"/> I feel tingling in my arms or legs | |

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Your current and previous treatment

How many anti-seizure medications are you currently taking?

- 1 to 2 3 to 4 5 to 6 7 or more

In the past, how many anti-seizure medications have you tried that did not work for you?

- 1 to 2 3 to 4 5 to 6 7 or more

Have your anti-seizure medications caused you any problems or resulted in side effects?

- Yes No





This brochure contains general disease state information related to drug-resistant epilepsy and is intended for educational purposes only. Patients should always seek information and advice from a registered healthcare professional that is familiar with their medical history.

This brochure was created by LivaNova. LivaNova is the manufacturer of VNS Therapy™ which is a vagus nerve stimulation device.

References available upon request.

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Epilepsy

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