



Epilepsy Treatment



www.facebook.com/epilepsy.ie



[@epilepsyireland](https://twitter.com/epilepsyireland)

www.epilepsy.ie

Email: info@epilepsy.ie

Acknowledgements

Epilepsy Ireland wishes to thank the following who contributed sections to this booklet:

Laura Healy, Clinical Specialist Dietitian at St. James's Hospital, and The Irish Ketogenic Dietitians Network, for the section on Ketogenic Diet.

Sinead Murphy, Advanced Nurse Practitioner in Epilepsy, Beaumont Hospital, for the section on Women and Epilepsy and on Anti-Epileptic Drugs.

Patricia Ennis and Breege Staunton, Epilepsy Surgery Nurses, Beaumont Hospital, for the sections on Surgery and Vagus Nerve Stimulation.

December 2020



Epilepsy Ireland
249 Crumlin Road, Dublin 12

Tel.: (01) 455 7500
Email: info@epilepsy.ie
Web: www.epilepsy.ie

Facebook: www.facebook.com/epilepsy.ie
Twitter: [@epilepsyireland](https://twitter.com/epilepsyireland)

Charity Number: 6170 CRA Number: 20010553



Contents

Epilepsy Care and Support

Primary Care	1
Hospital A & E	1
Specialist Neurological Services	1
Specialist Nurses	2
Pharmacists	3
Epilepsy Monitoring and Epilepsy Surgery Programme	3
Neuropsychologists	3
Dietitians	4
Epilepsy Ireland	4
Becoming an Active Healthcare Partner	4

Treating Epilepsy with Medication

When is Medication Prescribed?	5
Beginning Anti-Epileptic Treatment	5
Table of Anti Epileptic Drugs	5
Free Medication Schemes	6
Branded and Generic Drugs	12
Generic Substitution	12
What Form Does the Medication Come In?	13
Emergency Medication	13

Taking Your Medication

What is the Right Dose for Me?	14
What are the Risks of Not Taking Medication?	14
How Do Epilepsy Drugs Work?	15
How Long Do They Take to Work?	15
Will I Ever Have To Change Medication?	15

Will I Need to Take Medication for a Lifetime?	15
How Can I Avoid Missing Doses	16
What if I am Ill?	16
Side Effects and Interactions	17
Do Drugs for Epilepsy Have Side Effects?	17
Interactions with Other Prescribed Drugs	17
Interactions with Over the Counter Medicines	18
Food and Drink	18
Complementary Therapies	19
Herbal Remedies and Supplements	19
Women and Epilepsy Medication	20
Epilepsy treatment and Pregnancy	20
Valproate Concerns	20
Caring For Your Medication	22
Keeping Your Medication Safe	22
Travelling with Medication	22
Non-Drug Treatment Approaches	23
Surgery	23
Vagus Nerve Stimulation	25
Ketogenic Diet	26
Self-Management and Epilepsy	29
Future Directions	31
Cannabis Products	31
Therapeutic Devices	32
Laser Thermal Ablation	32
New Medications	33
Genetic Advances	33

Epilepsy Care and Support

Primary Care

Before a diagnosis of epilepsy is confirmed you may have been seen by your GP. Your GP, as your primary carer, will need to refer you to a consultant neurologist or epileptologist to have investigations for epilepsy. Once your diagnosis is confirmed the consultant will write to your GP to explain the diagnosis and what medication is to be prescribed.

Hospital Accident and Emergency (A&E)

When you first have a seizure you may be admitted to an A&E department nearby. If there is a local neurology service in the hospital you may be seen by a member of that neurology team. Then you may be referred for tests and follow up there, as an outpatient, with a neurologist or epileptologist. If there is no neurology service locally you will be seen by another doctor. On discharge your doctor may refer you to a neurology service at a different hospital as an outpatient.

Specialist neurological services

Epilepsy is a neurological condition and it is treated by consultant neurologists and consultant epileptologists (neurologists who specialise in epilepsy) and their teams. Specialist services are based in public hospitals in Dublin, Cork, Galway, Sligo, Kerry, Letterkenny, Waterford and Limerick.



Location of Public Epilepsy Specialist Services
(Adult service unless otherwise stated)



Some of the bigger neurology services now run outreach epilepsy clinics in some local hospitals. Paediatric neurology services are based at children's hospitals in Crumlin, Temple Street, Tallaght and at CUH and MUH, Cork, and at UHL, Limerick. Children may also attend paediatric units countrywide. Virtual clinics have been running for some time from some hospitals and more widely recently due to the Covid pandemic.

Specialist Nurses

Epilepsy Specialist Nurses are Clinical Nurse Specialists (CNS) or Advanced Nurse Practitioners (ANPs) experienced in epilepsy care and support. They see patients in the clinic and may be contactable by phone between appointments for epilepsy-related queries. The telephone helpline availability varies between services so it is advisable to check with your local service.

Pharmacists

Pharmacists are key members of your care team. It is important to keep using the same pharmacy where possible and get to know your pharmacist. They should be your first port of call for queries about your medication and its interactions. They can blister pack your medication to make it easier for you to remember to take it. They can also advise about free epilepsy medication and other health supports.

Epilepsy Monitoring

In some cases a person with seizures may be referred to a monitoring unit for a video EEG. Video EEG is used for diagnostic assessment to get more detailed information about seizures and testing for surgery suitability. Both Beaumont and Cork University Hospital have monitoring units, with dedicated specialist nurses attached. There are four beds in the Beaumont unit and two in Cork.

Epilepsy Surgery Programme

Surgery services are based in Beaumont Hospital. When monitoring and tests have been completed the epilepsy surgery team will decide if the person is a suitable candidate for surgery. The multi-disciplinary team includes a neurosurgeon, paediatric and adult neurologists, epilepsy nurse specialists, neuroradiologists, psychiatrists, neurophysiologists and neuropsychologists.

Neuropsychologists

Neuropsychologists specialise in the psychology of neurological disorders. There are adult and paediatric neuropsychologists attached to some hospitals. They offer a wide range of clinical services such as assessments of memory and cognitive function.



Dietitians

There is a small number of specialised dietitians offering ketogenic diet therapy services to adults and children in Ireland, see page 28.

Epilepsy Ireland

Epilepsy Ireland is the only national epilepsy patient organisation in Ireland. We provide a range of services including individual and group support, advocacy and representation on issues affecting people with epilepsy as a group. We have offices at 10 locations in Ireland. Our Community Resource Officers are key contacts in your region providing the support and information that you may need. We run Living Well with Epilepsy Toolkit sessions for new diagnoses, education and self-management programmes, support groups, talks, emergency medication training and conferences, as well as family events. We also fund research on epilepsy and run a full time QQI level 5 Access course called Training for Success.

Becoming an active healthcare partner

Being an active partner in your healthcare is very important. You can begin by making a list of key questions to ask your team. This way you will get the information you need to understand your epilepsy and treatment better. Epilepsy Ireland offers a special toolkit support session called Living Well with Epilepsy for adults who are newly diagnosed, or parents of newly diagnosed children, to become well informed about the condition. Review appointments at the neurology clinic are further opportunities to discuss any concerns. When you attend your clinic appointment bring your medication with you and a list of any questions for your team. Keep a diary of seizures and any observations and bring them to the clinic as well. Epilepsy Ireland has developed an app to help with recording seizures and using this app is a good way to be active in your healthcare. Other ways of being informed include using our printed and online resources and joining Epilepsy Ireland for new updates about matters affecting people with epilepsy.

Treating Epilepsy with Medication

When is medication prescribed?

Typically when you are diagnosed with epilepsy you will be prescribed anti-epileptic medication. Up to 70% of people with epilepsy have their seizures controlled with anti-epileptic medication. If you only have had one seizure, medication may not be prescribed straight away. This is because not all first seizures are diagnosed as epilepsy. Epilepsy is the tendency to have repeated seizures. While 1 in 20 people have a single seizure at some point, 1 in 115 will have further seizures and be diagnosed with epilepsy. If the doctor feels there is a high chance of a second seizure based on your history and investigations, then medication may be prescribed. Otherwise, your doctor may prescribe medication if you have had two or more seizures.

Beginning treatment

When your doctor prescribes medication they will choose one they feel is suitable for you, so not everyone with epilepsy will be on the same medication. There are over two dozen types of medication available. Which medication your doctor chooses will depend on your seizure type, how old you are, any other medical conditions you have, other medications you may be on and whether you are a female of childbearing age.

It's helpful to know the terms that are used when describing whether epilepsy drugs are being taken singly or combined. Doctors will typically start you on just one drug. This is called **monotherapy**. The risk of side effects is lower on one drug. You will be trialled on a medication or a combination of medications in order to achieve seizure freedom. This depends on how well you tolerate your medication.

Table of Anti-Epileptic Drugs (AEDs)

A full list of side effects is on the patient information leaflet supplied with your medication.

Seizure terms used below include: **Focal/Partial:** a seizure affecting an area of the brain. **Generalised:** a seizure affecting both sides of the brain. Secondary generalised: a focal/partial seizure which spreads to both sides of the brain to become generalised, also known as **Focal to Bilateral**.

AED names	Seizure type	Side effects
<i>Brand (generic)</i>	<i>Used for</i>	<i>Possible side effects*</i>
Ativan (Lorazepam)	For all seizure types.	Drowsiness, light-headedness.
Briavact (Brivaracetam)	For focal/partial seizures with or without secondary generalisation.	Sedation, dizziness, nausea, balance problems, depression. Changes in mood and behaviour.
Diacomit (Stiripentol)	For tonic clonic seizures in children with Severe Myoclonic Epilepsy of Infancy/Dravet Syndrome.	Reduced appetite, weight loss, insomnia, aggression, nausea, rash, fatigue.
Diamox (Acetazolamide)	Has a role in epilepsy linked to menstruation. It can also be used with other anti epileptic drugs for all seizure types.	Nausea, vomiting, headache, dizziness, increased urine output.



<p>Epanutin (Phenytoin)</p>	<p>For all forms of seizure types except absence seizures. Blood level monitoring is important.</p>	<p>Gastro intestinal disturbance, skin rash, drowsiness, constipation, tremor, unsteadiness and slurred speech. Coarsening of facial features, overgrowth of gums and acne may be a problem with prolonged therapy.</p>
<p>Epidyolex (Cannabidiol)</p>	<p>For seizures associated with severe refractory epilepsies: Lennox Gastaut Syndrome, Dravet Syndrome</p>	<p>Sleepiness, decreased appetite, vomiting, diarrhoea, tiredness.</p>
<p>Epilim Epilim chrono Epilim chronosphere (Sodium Valproate) (Valproic Acid)</p>	<p>For all forms of seizure types.</p>	<p>Drowsiness and tremor are infrequent side effects. Hair loss occurs in some people and on occasions excessive weight gain may occur. However these effects are usually reversible if the dose is reduced. Should not be used in women of childbearing age unless no other drug is effective (see section on foetal anticonvulsant syndrome).</p>
<p>Epistatus/Buccolam (Buccal Midazolam) Emergency medication</p>	<p>As directed by your doctor.</p>	<p>Drowsiness.</p>

Felbatol (Felbamate)	Use is limited to certain severe refractory epilepsies only. Used under strict conditions.	Constipation, diarrhoea, difficulty sleeping, dizziness, headache, loss of appetite, nausea, vomiting. Close monitoring essential due to risk of liver failure.
Frisium (Clobazam)	For all seizure types.	Drowsiness, light-headedness, confusion, gastro-intestinal disturbances.
Fycompa (Perampanel)	Treatment for focal/partial seizures with or without secondary generalisation.	Drowsiness, nausea, balance problems, back pain, dizziness, mood and behaviour changes, weight gain, headache, double vision.
Gabitril (Tiagabine)	Treatment for focal/partial seizures with or without secondary generalisation.	Diarrhoea, dizziness, tiredness, nervousness, tremor, impaired concentration, low mood.
Inovelon (Rufinamide)	Treatment of seizures in Lennox-Gastaut syndrome.	Nausea, vomiting, diarrhoea, weight loss, abdominal pain, drowsiness, insomnia, fatigue, rash.
Keppra (Levetiracetam)	Treatment of all seizure types.	Nausea, vomiting, diarrhoea, abdominal pain, weight changes, cough, drowsiness, dizziness, headache, low mood.

Lamictal (Lamotrigine)	Treatment of all seizure types.	Gastro intestinal disturbance, drowsiness, double vision, dizziness and headache, insomnia. Monitoring for skin rash is very important.
Lyrica (Pregabalin)	For focal/partial seizures with or without secondary generalisation.	Dry mouth, constipation, nausea, vomiting, weight gain, drowsiness, dizziness, changes in mood, attention difficulties.
Mysoline (Primidone)	For all seizure types except absence seizures.	Nausea, visual disturbances, unsteadiness and drowsiness may occur initially but sedation and slowing of cognitive performance may persist.
Neurontin (Gabapentin)	Treatment of focal/partial seizures with or without secondary generalisation.	Gastro intestinal disturbance, diarrhoea, dry mouth, drowsiness, dizziness headache, fatigue, weight gain.
Nitrazepam	Infantile Spasms.	Confusion, memory loss, muscle weakness, tremor.
Phenobarbitone (Phenobarbital)	For all forms of seizure types except absence seizures.	Nausea, unsteadiness and drowsiness may occur initially and sedation and slowing of cognitive performance may occur.

Rivotril (Clonazepam)	Add-on for all seizure types.	Drowsiness, fatigue, dizziness, restlessness.
Sabril (Vigabatrin)	Must be initiated and supervised by appropriate specialist, add-on treatment of partial seizures with or without secondary generalisation. Monotherapy in West syndrome.	Drowsiness, nausea, behaviour, mood changes. Monitoring for visual field defects is very important. Psychotic reactions have been reported.
Tegretol Tegretol SR (Carbamazepine)	For partial seizures and secondary generalised tonic-clonic seizures, generalised tonic-clonic seizures.	Nausea, vomiting, dizziness, drowsiness, skin rash, double vision, unsteadiness.
Topamax (Topiramate)	Treatment of generalised tonic-clonic seizures, or of focal/partial seizures with or without secondary generalisation.	Nausea, abdominal pain, diarrhoea, dry mouth, taste disturbance, weight loss, headache, fatigue, dizziness, word finding difficulties, pins and needles in hands and feet, kidney stones.
Trileptal (Oxcarbazepine)	Treatment of focal/partial seizures with or without secondary generalised tonic-clonic.	Nausea, vomiting, constipation, diarrhoea, abdominal pain, dizziness, headache and drowsiness, skin rash.
Valium/Stesolid (Rectal Diazepam) Emergency medication	Emergency treatment for seizures that are prolonged or clustered.	Drowsiness, tolerance of drug.

Vimpat (Lacosamide)	Treatment of partial seizures with or without secondary generalisation.	Nausea, vomiting, dizziness, headache, constipation, depression, double vision, drowsiness.
Zarontin Emeside (Ethosuximide)	Typical absence seizures; it may also be used in atypical absence seizures.	Gastro intestinal disturbance, nausea, vomiting, headache, fatigue, dizziness, weight loss.
Zebinix (Eslicarbazepine Acetate)	Add-on treatment in adults with focal/partial seizures, with or without secondary generalisation.	Dizziness, sleepiness, nausea, headache. More serious side effects include rash and liver problems.
Zonegran (Zonisamide)	Add-on treatment for drug-resistant focal/partial seizures, with or without secondary generalisation.	Nausea, diarrhoea, abdominal pain, weight loss, drowsiness, kidney stones, dizziness, confusion, irritability, skin rash.

**Please note that this list of side effects is not exhaustive. There may be individual side effects and/or other side effects not listed here. For more information see the patient information leaflet accompanying your epilepsy medication, or speak to your epilepsy team or pharmacist.*

Free medication schemes

Epilepsy medication is available free to everyone on the **Long Term Illness Scheme**. You apply to the Health Service Executive (see www.hse.ie) for this scheme. It only covers medication for 16 specified illnesses, including epilepsy. It does not cover other prescriptions you may have. If you have a **medical card (PCRS)** this will cover the cost of all medicines but will mean a prescription charge per item per month. **Medical card holders** can avoid these prescription charges for epilepsy medications by also applying to the Long Term Illness Scheme and having epilepsy medication dispensed free under that scheme instead.

Branded and generic drugs

Each anti-epileptic drug has two forms of product: the branded (trade name of the original manufacturer), and the generic (copy by other manufacturers). The doctor's choice of drug may be due to its effectiveness in controlling a particular type of epilepsy. It's important to know if you are meant to be on a **branded** or **generic** form of the drug and know its name and packaging because of the risks around **generic substitution**. Epilepsy Ireland suggests that having a branded or a specified generic form prescribed reduces the risk of substitution. This should be clearly documented on your prescription by the prescribing clinician.

Generic substitution

It is very important that when you collect your prescription from the pharmacy that you check that you are getting **your correct medication** each time. There are multiple forms of many epilepsy medications. **Branded** versions are the version first produced by the drug company who develop the drug. **Generic** versions are made by other manufacturers. They can be compared to copied versions of the drug, and while they might be cheaper there can be slight differences in the ingredients making up their form. In other medical conditions this may not matter but in epilepsy it can, as the brain can be sensitive to



the slight differences between the drugs. For this reason it is important not to switch from branded to generic or even from one generic to another generic. If you are put on a generic to start with you should continue to take the same generic afterwards. If you are started on a branded medication then it is important to stick with that form too. If your doctor writes **“Do Not Substitute”** on the script you must be given the exact format prescribed. Always check your medication before you leave the pharmacy to be sure it is exactly what is prescribed.

What form does the medication come in?

Anti-epileptic drugs come in many different formats. There are tablets, chewable and crushable pills, coated pills, capsules, syrups, sachets, and liquids. Discuss with the prescribing doctor which form will suit you. Syrups may suit young children best.

Emergency medication

Buccal midazolam (Buccolam, Epistatus) is the preferred choice of emergency medication for many patients and carers. **Buccal midazolam** is administered into the buccal cavity between the cheek and gum. These medications are for use in emergencies involving prolonged seizures and clusters of seizures. Epilepsy Ireland provides training for professionals on use of buccal midazolam. **Rectal Diazepam** is another emergency medication that is more rarely used. It comes in a tube and is inserted into the rectum as prescribed.

Taking Your Medication

Most epilepsy medications are prescribed to be taken once or twice a day. You will need to take it at the same time each day so that the level of medication is kept stable in your blood and doesn't dip or peak. Missed doses can lead to low drug levels and seizures. Doses taken too close together may cause drug levels to be too high, which can cause side effects, so it needs to be kept just right. If you do miss a dose don't double up on doses to make up for it. This could lead to too much medication in your system and could result in seizures too. It's important to take the dose prescribed and not alter it unless your doctor advises it.

What is the right dose for me?

Each epilepsy medicine has a different maintenance dose. Doctors tend to 'start low and go slow' with low doses and increase slowly over some weeks. This is called **titration** and it limits the risk of side effects. What is most effective varies from person to person. Newly diagnosed people will normally be treated with one drug at first. Your response to the medication is monitored and the dose altered if necessary. A combination of drugs may then be tried if one alone is not working. The combination will usually be kept as simple as possible to lessen side effects and make it easier to take.

What are the risks of not taking medication?

The main risk is that seizures will continue if they are untreated and this increases the risks of injuries and sudden unexpected death in epilepsy (SUDEP). You should never stop your treatment suddenly. There is an increased risk of withdrawal seizures, severe seizures, or prolonged seizures like status epilepticus as well as a range of withdrawal symptoms. If you are a driver and you stop taking medication suddenly, seizures may return, which has implications for driving. If you have concerns about taking medication talk to your doctor. It is important to weigh up any concerns against the risks of untreated seizures.



How do epilepsy drugs work?

Anti-epileptic drugs do not cure epilepsy, they aim to control it and stop the seizures from occurring. Some drugs work by calming overactive brain cells. Others lower the brain cells' ability to send abnormal signals to each other. The drugs need to be taken regularly over time to build up in your system; they don't work if taken only when you feel a seizure might come on.

How long do they take to work?

Your medication needs to be built up slowly to a dose that's right for you, often over a number of weeks. Epilepsy medication often needs time to work. If you had frequent seizures you may see an improvement soon, but if not you may need to wait longer to see if the medication is working.

Will I ever have to change medication?

If seizures are not coming under control, or you are having side effects that are a problem, then your doctor may decide to change your medication. This will be done gradually over time, and you may increase a new medication while being weaned off your current medication at the same time. Medication should never be started or stopped suddenly as it takes time for you to adjust to it. During the changeover period there is a risk of breakthrough seizures. If you are legally eligible to drive you may be advised not to drive for a time.

Will I need to take medication for a lifetime?

For most people the answer is 'yes'. However, some people can be weaned off medication after a period of being seizure-free. Usually this is no less than two years. Weaning off medication should only be done gradually under the supervision of your neurologist. In some cases seizures don't return but if they do your doctor may advise going back on treatment. If you have epilepsy surgery you will need to continue taking your medication afterwards for as long as directed by your neurologist.

How can I avoid missing doses?

It is important to take the correct dose at the same time each day. If you are worried you might forget here are some tips to help you remember.

- Use a daily or weekly dose pill box which can be bought through a pharmacy.
- Ask your pharmacist to blister pack your tablets with daily doses counted out.
- Use an app with a reminder, like the **Epilepsy Ireland** app for a mobile phone.
- Use the alarm or timer on mobile devices as reminders.
- If you are likely to be away from home carry some spare doses of medication in case you are delayed or unable to get home.
- Always check you have enough medication to last during holiday periods like Christmas and Bank Holidays when pharmacies may be closed.
- Always bring a supply of medication and your most recent prescription if you have to go to hospital for any reason.

What if I am ill?

If you are ill with fever you may be more likely to have seizures as high temperature can be a trigger factor. Also diarrhoea, vomiting and dehydration can mean your medications are not being absorbed properly and this can result in a greater risk of seizures. If you become unwell it's good to seek prompt advice from your doctor or pharmacist before purchasing any over the counter medications.

Side Effects and Interactions

Do drugs for epilepsy have side effects?

All medications have potential side effects and anti-epileptic drugs (AEDs) are no different in this regard. AED's act on the brain, sometimes causing drowsiness, sedation, nausea and unsteadiness when the drug is first taken and these effects should soon wear off. If side effects persist they should be reported back to the doctor. Other side effects may be common or rare, mild or serious. Your doctor or pharmacist can explain what side effects to watch out for on your medication. Watch for any unusual symptoms or behaviours and report these to your medical team. Rashes on some drugs (**Lamotrigine especially**) can become serious and even life threatening and require prompt medical attention. Other AED's may have side effects which include dizziness, drowsiness, weight gain or loss, tremor, nausea, mood change, double vision and concentration difficulties. A table of medications and side effects is on pages 6-11.

Chronic side effects may occur when drugs are taken over a long time. However, these effects can be reduced. Bone health may be affected by some medications over a long time. If you are at risk of this, your doctor may suggest a DEXA bone scan to see if your bones are becoming thin or brittle as there is a risk of osteoporosis. Your doctor may also recommend you take calcium supplementation. Always report suspected side effects to your team but don't stop taking your medication unless your doctor advises you to. Drug level monitoring is relevant with some drugs. Make sure to read the patient information leaflet supplied with your medication to see the full list of possible side effects.

Interactions with other prescribed drugs

Some prescribed drugs for other medical conditions can affect epilepsy or interact with epilepsy medication. Certain antibiotics, anti-malaria drugs, pain medications, steroids, broncho-dilators and anti-histamines are just some that can do this. Other prescribed medications that can have these effects include

anti-depressants, anti-psychotics and benzodiazepines. Epilepsy drugs can also affect some oral contraceptives. When you are being prescribed other drugs always mention your epilepsy treatment and discuss possible interactions with your doctor or pharmacist.

Interactions with over the counter medicines

If you are choosing to buy over the counter medicines and supplements, it is important to check with the pharmacist if there will be any problems taking these with your epilepsy and your medication.

Food and Drink

Grapefruit and grapefruit juice can interact with many medicines, including some epilepsy medications such as carbamazepine and oxcarbazepine, and emergency medications such as midazolam and valium. Energy drinks with high levels of caffeine can provoke seizures too. Alcohol is a trigger for seizures and should be kept to moderate levels (no more than 2 units in any one day), or as guided by your doctor.

Complementary therapies

Therapies such as massage, acupuncture, homeopathy, reflexology or aromatherapy can help with reducing tension and stress and improving well-being. Complementary approaches are not recommended as the only treatments for epilepsy. It's important to stay on your epilepsy medication while using complementary therapies. Some people find that they can lower the frequency of their seizures by using stress reduction techniques. More research is needed to be clear about which approaches work best for people with epilepsy and how they work. Always check that the practitioner is fully qualified, insured and registered with a professional body and make sure to tell them about your epilepsy and any treatment you are on. Some essential oils such as sage, fennel, hyssop, rosemary, camphor, spike lavender and eucalyptus are not recommended for use by people with epilepsy. Oils such as ylang ylang, jasmine, and lavender have been claimed to be helpful. It is advisable to seek medical advice before using any complementary therapies.

Herbal remedies and supplements

It's best to check with your doctor before using herbal remedies or nutrition supplements. Just because a product is natural, doesn't mean it is always safe to take. If you use supplements or remedies always ask your doctor or pharmacist if these are likely to interfere with your medication or provoke seizures. Supplements containing evening primrose and starflower oil have been reported to be linked to seizures in some people with epilepsy. The herbs St. John's wort, kava kava and schizandra have also been reported to be linked to increasing seizures.

Women and Epilepsy Medication

Epilepsy treatment and pregnancy

If you are planning a pregnancy it is advisable to speak to your neurologist, epilepsy specialist nurse or obstetrician about your medication in case changes need to be made. Some drugs are safer than others in pregnancy. Certain epilepsy medications can affect foetal development and it is important to discuss any risks with your consultant or nurse before becoming pregnant. Most women with epilepsy have healthy pregnancies and healthy babies while on medication, but good preconceptual counselling and antenatal care is very important. Many pregnancies are unplanned so speaking to a specialist nurse is very important if this should happen. You should not stop taking your medication without medical advice as seizures pose risks to you and your baby. The higher dose (5mg) of folic acid is recommended for women with epilepsy of childbearing age. Epilepsy Ireland provides information for women with epilepsy relating to family planning and pregnancy, see epilepsy.ie.



Valproate Concerns

Sodium Valproate, also known as Epilim, has been shown to cause birth defects and developmental delays in the babies of women who took it during pregnancy. Even low doses pose risks and the risks increase with higher doses. Valproate should be avoided for women and young girls unless no other treatment is available.

For pregnant women taking Valproate the risk of a birth defect is approximately 10 out of 100 babies, which is 3-5 times higher than in the general population. These birth defects can include malformations of the spine, face, skull, limbs and organs. Also 30-40% of babies may have developmental delays which can range from mild to severe, including delayed milestones, intellectual delay, speech and language delays, ADHD and autism.

If you are a woman of childbearing age taking sodium valproate then it's essential that you have annual reviews with your medical team. If you are a woman taking any other seizure medicine you should discuss your individual risk with your neurologist or epilepsy specialist nurse prior to becoming pregnant. If you become pregnant while taking any epilepsy medication, do not stop taking your medication but speak to your doctor or epilepsy specialist nurse as soon as possible. For further information contact Epilepsy Ireland.

Caring for Your Medication

Keeping your medication safe

Your medication needs to be kept out of the reach of children and in a safe place where you will be able to find it easily. Avoid carrying tablets in glass containers as these may break during a seizure. Most pharmacists can supply plastic pill boxes or handy blister packs which have the tablets divided into days and doses. Always keep some spare doses with you in case you are delayed or away unexpectedly.



Travelling with medication

When travelling you will need to take enough medication to cover the time you will be away, plus some extra doses to cover any delays. Anti-epileptic drugs are sold under different brand names in other countries and are not always easily identifiable. However, the generic compound name is the same. If you are travelling by air, carry your medication in its original packaging in your hand luggage. If you are going on a long haul flight to a country where there is a big time difference, your medical team can advise if you need to change your dose schedules before travelling. Carry a copy of your prescription also. If your medication gets lost you may need to have it prescribed again by a local doctor. EU countries can dispense on each other's prescriptions but countries outside the EU will not. The International Bureau for Epilepsy (IBE) **Traveller's Handbook** contains information about the European Health Insurance Card (formerly the E111) which entitles EU citizens to public care in other member states. The EHIC can be applied for from the HSE (see www.hse.ie). Travel insurance is still important to cover any shortfall on the EHIC as levels of public health service vary between EU member states. For more information about travel with epilepsy see www.epilepsy.ie for details.

Non-Drug Treatment Approaches

Surgery

Epilepsy surgery may be considered when seizures are not responding to medication. The aim of surgery is to stop or reduce seizures when:-

1. Seizures do not respond to anti-epileptic medication.
2. Seizures are disabling and impacting seriously on quality of life.
3. A surgical focus is identified and can be safely removed.

Detailed pre-surgical testing aims to locate the area in the brain where the seizures start. Tests will be done to see if it is safe to remove this area and reduce the seizures. The assessment stage before surgery can be a long process. A number of tests are carried out and some of these will require a stay in hospital. The epilepsy surgery nurses at Beaumont Hospital have produced a booklet which describes the epilepsy monitoring service in depth. The pre surgical evaluation includes the following tests:-

Video EEG: prolonged EEG inpatient monitoring in hospital.

Imaging: specialized scans such as MRI, CT and PET scans.

Neuropsychology: testing memory, language and speech impact.

Psychiatry: may assess how surgery may affect mood.

Intracranial video EEG: is used in some cases to find the exact location of seizure focus by placing electrodes directly on the brain.

After the tests there will be a surgery review conference where the multidisciplinary epilepsy surgery team will recommend a plan to treat the person's seizures with surgery. If surgery is not recommended they may suggest other options to be considered.

Main types of surgery

Resection procedures involve removing the area of the brain that is causing seizures. Resections may be temporal, if in the temporal lobe, or extratemporal, meaning in one of the other lobes of the brain.

A **lesionectomy** is another type of resection and involves removing lesions such as tumours, scar tissue, haematomas or abnormal blood vessels.

Disconnection includes hemispherectomy, the removal or disconnection of the side of the brain causing seizures, and hemispherotomy, disconnecting the cortex of one side of the brain without removing it.

Corpus callosotomy involves cutting the corpus callosum, which connects the two sides of the brain, to prevent the seizure activity spreading. No brain tissue is removed.

Multiple subpial transection is usually done when it's not possible to remove the area of the brain causing the seizures. Shallow cuts are made to the cortex to control the spread of seizure activity.

Recovery

It is recommended that the person return home to a relative or friend for up to a week if possible. During the recovery following surgery it's important to get rest. This also means staying home from school or work for some time until your post operative review when the surgeon may advise returning.

What are the risks of Epilepsy Surgery?

No surgery is without risks, and each case is unique and dependent on the focus of the seizures. The outcome of epilepsy surgery differs with each individual. It may be more harmful to continue having seizures than to proceed with surgery. The surgery nurses at Beaumont Hospital can provide information on the surgery process to you.

Outcomes

Success rates for epilepsy surgery depend on the seizure focus and on the surgery involved, for example, statistics suggest that up to 70% of people having temporal lobe surgery may be seizure free after surgery. Others may find they have fewer seizures, or milder seizures, than before. Your Neurologist and neurosurgeon will discuss the expected seizure outcome with you at length during your pre-operative appointment.

Vagus Nerve Stimulation

Vagus Nerve Stimulation (VNS) therapy is a form of treatment for people whose seizures are not controlled with medication alone, or may have failed surgery, or do not want surgery. The aim of VNS therapy is fewer seizures, as well as shorter and less severe seizures. It is used together with medication.

The VNS is a device powered by a battery, and it is placed under the skin of the chest wall, on the left side, with a wire attached to the left vagus nerve. The vagus nerve is a very important nerve which runs from the body to the brain and carries important signals to the brain from the body. The VNS sends regular, mild electrical stimulation along this nerve to the brain. This stimulation can reduce the frequency and intensity of seizures in some people with epilepsy. Hand held magnets may also be used to help control seizures by giving the VNS extra stimulation boosts when these are needed.

There are several models of VNS devices, the current and newest model being implanted in Ireland is the Sentiva 1000. This device has a seizure detection mode as well as delivering stimulation automatically. The battery life of a VNS device depends on the settings. On average it can last for 3-5 years, before being replaced. An operation is required to replace the VNS battery once it has run out.

VNS therapy may cause brief side effects during the time that the nerve is being stimulated. These side effects usually reduce over time or with adjustments to the VNS setting. Some common side effects are sore throat, hoarseness and coughing. The response to VNS therapy varies between people

and may take time, even up to a year after the device is implanted for some. Other benefits that might be seen from VNS therapy can be improvements in mood, memory, and alertness.

Ketogenic diet therapy for Epilepsy

What is the Ketogenic diet therapy?

Ketogenic diet therapy (KDT) is an extremely low carbohydrate, high fat diet used to treat epilepsy which has not responded to other treatments. The diet was first developed 100 years ago, before most anticonvulsant drugs were discovered, and was used to treat both adults and children. The diet is designed to force your body to burn fat instead of sugar for energy. This produces ketones, which give the diet its 'keto' name.

Is the diet effective?

All ketogenic diet therapies have shown to be successful in the treatment of epilepsy. Some people become completely seizure free on the ketogenic diet while others have fewer seizures. Studies show up to 25% children can achieve seizure freedom and 80% reducing seizures. Among adults approximately 40-50% achieve seizure reduction of 50%, and 13% gain seizure freedom^{1,2,3}. In addition to reduced frequency of seizures, both children and adults following ketogenic diets can benefit from a reduction in the intensity of seizures and faster recovery. Those who respond to KDT, also report an improvement in mood, alertness, memory, sleep or attention span⁴.

Why is medical supervision and support required?

KDT is effectively an antiepileptic in food form. It needs to be supervised by a neurologist and a dietitian, and integrated into the medical treatment plan, alongside existing epilepsy medications. It requires detailed medical and nutrition assessment to ensure that there are no underlying conditions that would make a KDT trial dangerous. It is also important to check a range of baseline blood measurements before starting the diet, and to repeat these at regular intervals throughout KDT to check that the liver and kidneys are working well, and that there are no deficiencies in vitamins or minerals. For most adults, commitment to a three-month trial of supervised KDT is required to assess the impact on seizure symptom control and quality of life, to see if it is

an option worth pursuing in the longer term. When successful, KDT may enable doses of epilepsy medications to be reduced or weaned and the treatment may continue for two years or longer, depending on personal choice and medical ketogenic team review. If a three-month trial of KDT does not deliver adequate benefits, normal dietary choices are gradually reintroduced.

Day to day practicalities of KDT delivery that need to be considered?

KDT means a big change to normal eating patterns. It brings with it a new personal 'responsibility' for delivering your epilepsy treatment correctly, alongside a need for tracking of food intake and symptoms. Even with the best preparation, training and support from the keto-team, this can feel time-consuming and stressful, especially in the early weeks. However, like learning any new skill, it becomes easier with time. If symptoms start to improve, the sense of empowerment can be immense. The level of involvement, understanding and support of family, close friends and any caregivers, can make a significant difference to the ketogenic therapy experience and outcome. There are a wide range of special nutrition products, ranges that have made KDT easier to follow. If you do not eat food there are special ketogenic tube feeds that can be used.

The food: KDT requires considerable change in food choices; cooking meals from scratch (much of the time) and weighing or controlling food portions. Meals generally need to be made from simple raw ingredients, so a willingness to cook, or regular help from a willing family member or caregiver, is essential. Outside the home, the availability of keto-friendly meals and snacks is limited, therefore forward planning and the packing up of meals and snacks to take to school, work, college etc. is essential. Moral and practical support from friends, family, school staff, and even work colleagues can really make a lot of difference.

The record keeping: KDT requires careful monitoring and adjustment. This involves keeping accurate records of food intake, seizures, blood ketones (or urine ketones), blood glucose and body weight, and sharing this information regularly with the managing keto-team. In this way, the impact of the diet can be tracked, and the prescription adjusted to optimise control of seizure symptoms and manage any side effects if they arise.

In summary: KDT is an 'active' therapy choice that may deliver seizure symptom management and quality of life improvements where other medical

approaches have failed. However, for various medical, social or lifestyle reasons, it may not be suitable option for all.

How can you or your loved one gain access to ketogenic diet therapy?

In Ireland we are lucky to have both established paediatric and adult ketogenic diet therapy services. If you wish to consider a trial of ketogenic diet therapy speak to your Consultant Neurologist or Epilepsy Nurse Specialist to see if a trial in KDT may be suitable for you and to discuss referral options.

Ketogenic Diet Therapy Centres in Ireland	
Hospital	Service
Cork University Hospital Co. Cork, Ireland.	Adult and Paediatric
Children’s Health Ireland at Temple Street, Dublin 1, Ireland.	Paediatric
Children’s Health Ireland at Crumlin, Dublin 12, Ireland.	Paediatric
St James Hospital, Dublin 8, Ireland.	National. Adult only

REFERENCES

1. Payne NE, Cross JH, Sander JW, Sisodya SM. The ketogenic and related diets in adolescents and adults—a review. *Epilepsia* 2011 52(11): 1941-8.
2. Fang Ye, Xiao-Jia Li, Wan-Lin Jiang, Hong-Bin Sun et al. Efficacy of and Patient Compliance with a Ketogenic Diet in Adults with Intractable Epilepsy: A Meta-Analysis. *J Clin Neurol* 2015; 11(1): 26-31.
3. Liu H, Yang Y, Wang Y, Tang H et al. Ketogenic diet for treatment of intractable epilepsy in adults: A meta-analysis of observational studies. *Epilepsia Open*. 2018 Feb 19; 3(1): 9-17.
4. Roehl K, Falco-Walter J, Ouyang B, Balabanov A. Modified ketogenic diets in adults with refractory epilepsy: Efficacious improvements in seizure frequency, seizure severity, and quality of life. *Epilepsy & Behavior* 2019; 93: 113–118.

Information compiled by the Irish Ketogenic Dietitians Network.

Self-Management and Epilepsy

Self-management and self-care describe ways in which a person with epilepsy can take control over the lifestyle and emotional impact of their condition. This can be done by reducing or avoiding triggers but also by increasing personal wellness and coping skills.

Epilepsy Ireland's Self-Management Programmes

Epilepsy Ireland runs free courses in self-management – called STEPS training programmes – around the country. These programmes are for adults with epilepsy and for parents of children with epilepsy. For adults who complete STEPS, Epilepsy Ireland runs a follow-on meditation programme called Innerwise.

STEPS for Adults consists of one group session per week for 6 weeks and the modules include self-management strategies, living with epilepsy, medical care, memory, safety issues, support systems, communication, managing emotions and stress, diet, exercise and sleep, self-confidence, and planning ahead for the future.

STEPS for Parents consists of one group session per week for 4 weeks and covers the impact of epilepsy, safety issues, medical care, needs of children with epilepsy, education, school and learning, challenging behaviours, positive parenting, stress management and coping skills, and talking to children and adolescents about epilepsy.

Innerwise is a self-development and meditation programme delivered in one day, two day and evening formats which teaches meditation, mindfulness and mental health wellbeing practices for people with epilepsy. It helps to further reduce stress levels, improve wellness and develop inner resources to support positive health.

For more information on STEPS Programmes and Innerwise in your area contact your local Epilepsy Ireland office.

Which recreational activities can help?

Mind-body approaches such as gentle yoga, mindfulness, meditation, stress management classes and relaxation activities can give much benefit to people with epilepsy. Gentle exercise and creative and expressive arts can all help to reduce tension and are encouraged and promote well-being. Some complementary approaches can be useful in managing stress and supporting people with epilepsy to control triggers and their lives in general.

Physical well-being

Getting regular meals and exercise is important for everyone. It's best to eat a balanced diet making sure to get regular, healthy meals every day. Regular exercise is also recommended for physical and mental well-being. Our STEPS programmes can help you work on these issues.

Sleep

Sleep is very important for people with epilepsy. Lack of sleep is a common trigger for seizures. If sleep is a problem talk to your doctor and try some of our tips for a good night's sleep on www.epilepsy.ie.

Education Clinics

Education Clinics are run at some hospitals to support people with epilepsy and their families and carers, and provide them with information to improve epilepsy management.

Epilepsy Ireland staff work with Epilepsy Teams in these Education Clinics to provide support around self-management strategies. Ask your hospital team for more information.

Future Directions

Medical Cannabis

Studies have been ongoing internationally for some time into the use of various forms of medical cannabis, or CBD, in the treatment of epilepsy. Epidyolex is a CBD-based medication which, unlike other CBD-based products and cannabinoids, has had its effectiveness supported by clinical trial data. It has been shown in clinical trials to be effective in treating two rare and intractable epilepsies, Dravet Syndrome & Lennox-Gastaut Syndrome. At time of writing (December 2020), the drug can be prescribed in Ireland but as it is not yet approved for reimbursement, it means that families must pay for it. Epilepsy Ireland made a submission in September 2020 to the National Centre for Pharmacoeconomics regarding the reimbursement of Epidyolex. A decision on this is expected in early 2021. Please see [epilepsy.ie](https://www.epilepsy.ie) for further information. Patients can also access cannabis-based treatment under the Ministerial Licencing route. Additionally, for updates on the progress of the Medical Cannabis Access Programme see <https://www.gov.ie/en/publication/90ece9-medical-cannabis-access-programme/>.

Cannabis Products

There are differences between cannabis oils, cannabis medication and recreational cannabis. Recreational cannabis has been known to worsen seizures in some people with epilepsy. Cannabis oils are non-pharmaceutical products which are not licensed in Ireland for medicinal use. The manufacturing process for cannabis oils differs from product to product and from that required for medications. It is not always possible to know precisely their ingredients, the strength of their compounds, or their potential to interact with epilepsy medications. To date none have met the standards of efficacy and safety that would be required for a licensed medication. Some cannabis oils contain CBD, the non-psychoactive ingredient of cannabis, while other cannabis products can include THC which is the psychoactive ingredient. Concerns remain around the effectiveness and safety of cannabis oil products, especially those that contain THC, especially when used with children.

Therapeutic Devices

Therapeutic devices which produce electrical signals may provide further new options for treating difficult to control epilepsy. The stimulation provided by the devices may be able to control abnormal electrical activity in the brain that could lead to seizures.

Vagus nerve stimulation has already been available for some time in Ireland. However, newer models of VNS devices may offer improved chances of reducing seizures.

Responsive neurostimulation (RNS) uses a neurostimulator device placed under the scalp to monitor brain signals and detect signal patterns that could lead to seizures. The device can then apply stimulation to disrupt the seizure activity. RNS is not currently used in treating epilepsy in Ireland.

Deep brain simulation (DBS) uses a neuro-stimulator device which is placed in the skin near the left shoulder or in the skin near the chest or stomach. There is a lead which is placed in the brain area where seizures come from through a small hole in the skull and an extension wire linking the lead to the device. It offers potential benefits for people with neurological conditions including drug resistant epilepsy. DBS is not currently used in treating epilepsy in Ireland.

Laser Thermal Ablation

Laser thermal ablation is a technique being increasingly used in many forms of surgery. Using precision measurements the laser can target specific areas to deliver treatment to. Unlike open surgery it is not invasive and in this way it lowers risks of post-operative complications following surgery and speeds up recovery time. This technique holds promise for certain forms of epilepsy surgery such as temporal lobe surgery. Laser thermal ablation is not currently used in Ireland for epilepsy treatment.

New Medications

A number of new medications are in various stages of development and clinical trial phases currently. These can be divided into two broad groups. Some that were developed for the treatment of other neurological conditions, but which may also be effective in epilepsy, include everolimus and fenfluramine. Others which have been specifically developed to treat epilepsy include cannabidiol and cenobamate.

Genetic Advances

Genes play an important role in medicine generally and in many types of epilepsy also. The genetic basis of epilepsy is very complex. In some cases there may be a family history of epilepsy but not all genetic conditions are inherited as there may be new mutations involved. Recent advances in this area have found the genes underlying certain syndromes and more genes are being identified as having a role in the development of epilepsy.

There are well known epilepsies with genetic components such as childhood absence epilepsy, juvenile absence epilepsy, benign rolandic epilepsy and juvenile myoclonic epilepsy. Some of the rarer types include benign myoclonic epilepsy of infancy, myoclonic-astatic epilepsy, Rett syndrome, Dravet syndrome and progressive myoclonus epilepsies to name but a few.

Currently genetics informs practice in regard to treatment. When a person is known to have a genetic condition this is taken into consideration in their management. In this way treatment is patient-centred and personalised. In time to come genetic based therapy may be a possible option for the treatment of some genetic forms of epilepsy.



**Epilepsy Ireland
249 Crumlin Road, Dublin 12**

**Tel.: (01) 455 7500
Email: info@epilepsy.ie
Web: www.epilepsy.ie**

**Facebook: www.facebook.com/epilepsy.ie
Twitter: [@epilepsyireland](https://twitter.com/epilepsyireland)**

**Registered Charity Number 20010553
CHY Number: 6170**

**Brainwave the Irish Epilepsy Association
trading as Epilepsy Ireland is a company limited
by guarantee. Registered in Dublin 77588**

Web: www.epilepsy.ie
Facebook: facebook.com/epilepsy.ie
Twitter: [@epilepsyireland](https://twitter.com/epilepsyireland)
YouTube: youtube.com/BrainwaveEpilepsy

Head Office

249 Crumlin Road, Dublin 12
Tel.: 01 455 7500
Email: info@epilepsy.ie
National Information Officer: Geraldine Dunne
Email: gduenne@epilepsy.ie

East

Covering: Dublin, Kildare & Wicklow
Community Resource Officer:
Dublin North, West & Kildare: Edel Curran
Dublin South & Wicklow: Carina Fitzgerald
249 Crumlin Road, Dublin 12
Tel.: 01 4557500
Email: ecurran@epilepsy.ie
Carina: cfitzgerald@epilepsy.ie
Mobile: Edel : 085 806 3959
Carina : 085 876 6587

North West

Covering: Donegal, Leitrim & Sligo
Community Resource Officer: Agnes Mooney
Letterkenny Office, Grand Central Complex, Floor 2B,
Canal Road, Letterkenny, Co. Donegal
Tel.: 074 9168725
Email: amooney@epilepsy.ie
Mobile: 085 868 9433

West

Covering: Galway, Roscommon & Mayo
Community Resource Officer: Edel Killarney
Westside Resource Centre, Seamus Quirke Road,
Westside, Galway
Tel.: 091 587640
Email: ekillarney@epilepsy.ie
Mobile: 085 876 6625

Mid-West

Covering: Limerick, Clare & Tipperary North
Community Resource Officer: Veronica Bon
Social Service Centre, Henry St. Limerick
Tel.: 061 313773
Email: vbon@epilepsy.ie
Mobile: 085 876 6629

Kerry

Covering: Kerry
Community Resource Officer: Kathryn Foley
Glenwood Park Road, Killarney, Co. Kerry.
Tel.: 064 6630301
Email: kfoley@epilepsy.ie
Mobile: 085 876 6627

Cork

Community Resource Officers:
South Lee & West Cork: Niamh Jones
North Lee & North Cork: Sharon O'Connell
Unit 1, 83 Beech Road, Muskerry Estate, Ballincollig,
Co. Cork.
Tel.: 021 4274774
Email: njones@epilepsy.ie
Sharon: soconnell@epilepsy.ie
Mobile: Niamh : 085 876 6628
Sharon : 085 876 6626

South East

Covering: Kilkenny, Wexford, Carlow, Waterford
& Tipperary South
Community Resource Officer: Miriam Gray
Email: mgray@epilepsy.ie
Mobile: 085 876 6584

Midlands

Covering: Offaly, Longford, Laois & Westmeath
Community Resource Officer: Cliona Molloy
The Charleville Centre, Church Avenue, Tullamore
Tel.: 057 9346790
Email: cmolloy@epilepsy.ie
Mobile: 085 876 6585

North East

Covering: Louth, Meath, Monaghan & Cavan
Community Resource Officer: Mary Baker
Unit 1a, Partnership Court, Park St. Dundalk, Co. Louth
Tel.: 042 9337585
Email: mbaker@epilepsy.ie
Mobile: 085 876 6583

Training for Success

Manager: Maire Tansey
Institute of Technology Sligo, Ballinode, Sligo
Tel.: 071 915 5303
Email: Tansey.Maire@itsligo.ie
Mobile: 085 876 6588



Our Funders



Rialtas na hÉireann
Government of Ireland

