

*epilepsy scotland*

*Scotland's voice for epilepsy*

# **Epilepsy and treatment**



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**Helpline: 0808 800 2200**  
**[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**

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## Anti-epileptic medication

## How do AEDs work?

The most common way to treat epilepsy is with anti-epileptic drugs. This allows up to 60 - 70% of people to live free of seizures. Drugs can control but do not cure epilepsy.

Anti-epileptic drugs (AEDs) have two names – a generic name and a brand name. The generic name is the chemical name. The brand name is the name given to the drug by the manufacturer.

These drugs usually come in tablet form. If you have difficulty swallowing you can get syrups or soluble tablets.

**It is important to make sure you get the same make of drug each time as there can be small differences between different versions or makes of each drug.**

To make sure you always get the same drug, ask your doctor to write the brand name, not the generic name, of your drug on the prescription.

Drugs are absorbed into the body and carried in the blood to the brain. Here, they usually work to stop the spread of unexpected or extra bursts of electrical activity that cause seizures.

**Always take the same amount of your drug at roughly the same time each day.**

It is important that roughly the same amount of drug stays in the bloodstream day and night. Missed doses or taking your medication much later than normally can lower the drug level in the blood. This can lead to seizures. Too much medication can also cause an increase in seizures. So be careful you don't take your medication too early.

Some drugs, such as Tegretol Retard and Epilim Chrono, are usually taken once or twice a day. They are absorbed more slowly into the bloodstream. This gives your body an even level throughout the day. AEDs are not addictive.

## Which drug is right for me?

AEDs act on the brain in different ways. Some are better for certain types of epilepsy than others. Your doctor will give you advice about the best drug for you. They will look at a number of things including:

- the type of epilepsy you have
- your medical history
- your gender
- other drugs you are taking
- your lifestyle

Taking one type of drug (monotherapy) may be enough to control your seizures. But if your seizures are not well controlled your doctor may give you more than one drug (polytherapy).

## Getting the dosage right

Your doctor will try to prevent side effects by starting you on a low dose. With children, doses are usually based on body weight. The drug may be slowly increased to get a balance between seizure control and minimum side effects.

Some people may start having seizures after a time of good control. If this happens to you, you should talk to your doctor or neurologist. You should not increase the number of pills you take without agreement from your doctor or epilepsy specialist nurse.



## What about side effects?

You may be worried about side effects from AEDs. However, most people who do have side effects find that they are mild. You may not have any side effects. The chart on page 10 lists the more common side effects of each drug.

**Tell your doctor straight away if you notice a skin rash.**

**This could be a sign that you are allergic to the drug.**

It is important that you can spot these so you can tell your doctor. Your doctor may adjust your drug dose to help cut side effects. Some medications, for example, may make you put on weight. Eating a balanced healthy diet is helpful.

Everyone reacts differently to drugs. So there may be some trial and error to find the right dose for you. If you keep having seizures or side effects your doctor may change the dose. You may get a different drug to take or an extra AED. Keep a diary of your seizures, note how many you have and what they are like. You should also write down any side effects. This will help you and your doctor to make the best decision about the right medication for you.

## “Don’t let your epilepsy put you off doing anything.”

Among Jane Williams’ earliest memories are that her arms and legs jerked. However, her first ‘proper’ seizure happened when she was 12. After her second seizure, she was diagnosed with juvenile myoclonic epilepsy.

Now, aged 19, she is a full time Strathclyde University student, studying English and history. Jane wants to get into publishing and her long term ambition is to write for a living.

When she was first diagnosed with epilepsy, Jane was prescribed Epilim. This is a common drug for her type of epilepsy. It completely stopped her seizures. But she hated that it made her feel hungry all the time. “I put on so much weight. I had just started high school, and I felt so self-conscious about this. Looking at holiday photos from that period, I looked pregnant! I simply could not stop eating.”

Jane, with her mum’s full support, decided, to stop taking Epilim.

Her doctor slowly reduced this medication until she came off it, and prescribed another drug instead.

Jane admits that nothing has ever worked quite as well as Epilim. She explains: “Some of them worked better than others. None of them completely controlled my seizures. But I really didn’t want to take Epilim any more because of the weight gain, so I took the risk. Some of the other drugs gave me bad side effects. My speech was affected at one time, I kept slurring my words. I didn’t like this at all, so I changed medication again.”

She eventually settled on a combination of drugs which nearly controlled her seizures but with fewer side effects. This was a compromise she felt comfortable with.

This was until Christmas Day 2005. Jane felt unwell and had a temperature. She took a serious tonic-clonic seizure. “I was semi-conscious and could hear myself scream.

“I could feel myself biting down on my tongue, and I couldn’t see. I don’t think I’ve ever been that frightened in all my life”. She was taken to hospital and given emergency medication.

Jane says that she was so traumatised by this that she needed post-traumatic stress counselling. She was taught some useful techniques to deflect any negative thoughts. She says: “Whenever I started thinking about this seizure, I learnt to simply think about something else. It really helped. I use this technique even now in all sorts of situations.”

After that seizure she was ready to try Epilim again, but at a lower dosage than before. She was also prescribed another drug, Keppra, to take with it. This works fairly well for her but still does not control her seizures completely. Her doctor wants to increase the dosage of Epilim, but Jane is still put off by the thought that she may gain weight again.



“Put it this way, I’d rather have the odd seizure than being constantly self-conscious about my weight. However, if I ever have another big seizure like the Christmas Day one I think I’d take anything. I hope I don’t ever have to experience something like that again.”

Right now, Jane is happy with her life and feels epilepsy is not holding her back in any way. She’s always been outspoken about having epilepsy. She has even shared her experiences with delegates at several fringe events during Scottish party conferences.

“Epilepsy won’t stop me from doing anything, and I just take it as it comes. If I feel it is the right time, I will increase my dosage of medication. But for me right now, on balance, having the occasional seizure is an acceptable compromise.”

If you are taking oral contraception and AEDs you should talk to your doctor about this. Some drugs can make the contraceptive pill less effective.

If you have epilepsy and want to have a baby you should talk to your doctor before getting pregnant.



You will want to make sure that the anti-epileptic medication you take will not damage your baby. In a small number of cases, some AEDs can lead to a slightly higher risk of complications for both mother and baby. This can cause problems for the child's development. If you are already pregnant, talk to your doctor about the best ways to reduce risks to you and your baby. **You should not stop taking your drugs without medical advice.** Taking folic acid before and during the first three months of pregnancy will help protect the unborn baby.

Our Woman's guide to epilepsy can give you a lot more information on this. Phone our Helpline if you want a copy.

You can also get more information on how your anti-epileptic medication may affect your unborn baby from the **UK Epilepsy and Pregnancy Register**. You can phone them on **0800 389 1248**.

Status epilepticus is a medical emergency and needs to be treated differently to your usual seizures. It can happen in two ways:

- you have a seizure lasting more than 30 minutes, or
- you have one seizure after another with no recovery in between the seizures.

Emergency medication will normally stop the seizure. This is prescribed by your doctor and can only be given by someone who is named in a care plan. That person will have been trained to do this. Emergency medication can also be given by medical staff if someone has called an ambulance. If the seizure continues, you will need to go to hospital.

Status is rare and more likely to happen if you have uncontrolled seizures. It is more commonly linked to tonic-clonic seizures. But it can occur in any type of seizure, such as complex partial or absence seizures.

If the seizures are non-convulsive (no jerking), status epilepticus may sometimes be difficult to detect.

Even though status epilepticus is described as 'a seizure which lasts for more than 30 minutes', emergency medication should be given long before this. This could be: **diazepam**, which is given rectally (into the anus) using a special tube; or **midazolam** which is placed into the buccal cavity on the inside of the cheek or dripped into the nose. Either you or someone who can give legal consent on your behalf should give written consent for this procedure.

**Status epilepticus is always a medical emergency.**

Epilepsy Scotland provides training on emergency medication administration. Call **0141 427 4911** and ask our training department for more information.

# Anti-epileptic medication chart

Name: Generic/Brand	Seizure type	Possible side effects
acetazolamide/Diamox	tonic-clonic, juvenile myoclonic, absence, partial seizures	headache, lethargy, nausea, diarrhoea, pins and needles, dizziness, irritability, depression, loss of appetite and weight
carbamazepine/Tegretol	partial or generalised seizures (but not absence or myoclonic)	skin rash, sedation, blurred or double vision, unsteadiness, headache, drowsiness and problems for women, such as, (but rarely) foetal abnormalities
clobazam/Frisium	tonic-clonic, myoclonic and partial seizures	drowsiness, dizziness, blurred vision, irritability, depression
clonazepam/Rivotril	tonic-clonic, myoclonic and partial seizures	drowsiness, sedation, dizziness, poor co-ordination
ethosuximide/Emeside	absence seizures	skin rash, drowsiness, headache, nausea, vomiting, irritability, dizziness, depression, anxiety

Name: Generic/Brand	Seizure type	Possible side effects
gabapentin/Neurontin	partial or secondary generalised	drowsiness, dizziness, blurred vision, irritability, depression
lamotrigine/Lamictal	partial, secondary generalised, absence, myoclonic, tonic, clonic, and tonic-clonic seizures	skin rash, headache, dizziness, drowsiness, double vision, insomnia
levetiracetam/Keppra	partial, secondary generalised seizures	drowsiness, dizziness, headache, tremor, nausea, irritability, insomnia
oxcarbazepine/Trileptal	partial, secondary generalised seizures	skin rash, double vision, unsteadiness, headache, nausea, diarrhoea, confusion
phenobabital/or Primidone/Mysoline	tonic-clonic, myoclonic, partial seizures	drowsiness, sedation, mental slowing, aggression, depression, behavioural problems in children

<b>Name: Generic/Brand</b>	<b>Seizure type</b>	<b>Possible side effects</b>
phenytoin/Epanutin	tonic-clonic, partial seizures	skin rash, drowsiness, unsteadiness, slurred speech, headaches, overgrowth of gums, coarsening of features, acne-like symptoms
piracetam/Nootropil	myoclonic	skin rash, dizziness, insomnia, nausea, diarrhoea, weight gain, depression, drowsiness, agitation
pregabalin/Lyrica	partial, secondary generalised seizures	dizziness, drowsiness, blurred or double vision, mood changes, weight gain, concentration difficulties
rufinamide/Inovelon	Lennox Gastaut Syndrome	dizziness, sleepiness, headache, nausea, sickness
sodium valproate/Epilim	generalised, partial seizures	skin rash, sedation, nausea, vomiting, hair loss, weight gain, tremor, irregular menstrual cycle and, rarely, foetal abnormalities

<b>Name: Generic/Brand</b>	<b>Seizure type</b>	<b>Possible side effects</b>
tiagabine/Gabitril	partial, secondary generalised seizures	dizziness, fatigue, drowsiness, diarrhoea, headache, tremor, anxiety, depression, confusion
topiramate/Topamax	tonic-clonic, myoclonic, partial, secondary generalised seizures	dizziness, fatigue, drowsiness, poor memory, mental slowing, weight loss, headache, pins and needles, tremor
vigabatrin/Sabril	partial, secondary generalised seizures	drowsiness, headache, fatigue, weight gain, depression, agitation, confusion, visual disturbance
zonisamide/Zonegran	partial, secondary generalised seizures	dizziness, drowsiness, nausea, diarrhoea, confusion, weight loss, stomach pain

## Missed doses

It is important to take your drugs at regular times. You can link this with a regular activity, such as meal times or using a pill box divided into days. For more information contact our Helpline. If you have missed a dose, don't take a double dose later. Contact your doctor as soon as possible and ask what to do. This will depend on things like the medication and dose you are taking. If you have missed a dose, avoid risky activities such as driving or swimming.

### Travel

When going abroad on holiday, take a full supply of your drugs with you. Keep a supply in your hand luggage in case your suitcase gets lost. It may not always be possible to get the same drug in a foreign country. You should also carry a letter from your doctor explaining what your drugs are for, and a prescription in case of emergencies. Always carry your drugs in their original packet.



## Stopping anti-epileptic medication

Some people with epilepsy will need to take AEDs throughout their lives. Others may only need to take them for a limited time. This depends on a number of things, such as the type of epilepsy. If you have been seizure-free for two to three years you could talk to your doctor about the possibility of slowly coming off your drugs. There is always a risk that your seizures return when you come off drugs. Your doctor will be able to advise you on how likely this is.

You may want to think about the effects a seizure could have on your life. If for example you have your driving licence back and you have a seizure, you will immediately lose your licence. It may also restrict you in the kind of job you do or the leisure activity you enjoy.

**It is important that you do not come off your drugs on your own. Your doctor will need to carefully monitor you during this time.**



## Surgery

## Vagus/Vagal Nerve Stimulation (VNS)

## Ketogenic diet

For a small number of people surgery is a possible treatment. This depends on where seizures start in the brain. Removing the part of the brain which is causing the seizures may stop them. You will usually only be considered for surgery if you have not responded well to a combination of drugs over a period of time.

If your doctor thinks you could benefit from surgery you will have a pre-surgical assessment. First of all, the neurologist needs to check if the specific area of your brain can be operated on. They will want to work out how the operation may affect, for example, your speech and memory. They will consider how successful the surgery is likely to be.

Surgery is usually not suitable for people with generalised epilepsy. This is because all of the brain is involved with these types of seizures.

A small electrode is fitted in your neck and attached to the vagus/vagal nerve. This electrode is linked to a small generator that is put into your chest. The device has a very low electrical pulse. It is programmed to stimulate this nerve to reduce seizures. There is also a magnet you can use to start the electrical pulse if you feel a seizure coming on.

VNS may be an option if your seizures are still poorly controlled after you have tried more than one AED.



VNS magnet

The ketogenic diet can help to reduce seizures in some children who have epilepsy which is hard to control. They need to follow the diet strictly for it to be successful. It is a high fat and low carbohydrate diet, which is sometimes difficult for children to stick to.

Do not try to introduce the diet on your own. Your child will need close medical supervision. A dietician will work out the details of the diet for your child. The diet has had some success but usually only for a limited time of around one year. In most cases your child will stay on AEDs but sometimes drugs can be withdrawn.

If you want more information on the Ketogenic diet, you can contact **Matthews Friends** on **0788 4054811** or visit their website at [www.matthewsfriends.org](http://www.matthewsfriends.org)



# Complementary therapies

The therapies talked about in this section are 'complementary' and not 'alternative' therapies. This means that they are used **with** AEDs and **not instead** of them. If you want to try one of these therapies you should keep taking your AEDs as prescribed.

Some people find these therapies helpful for epilepsy. There are currently few scientific studies about this. If you are interested talk to your doctor first. There is a wide range of therapies available and we have described just a few here.



Make sure that you tell the therapist you have epilepsy before the treatment begins. Many therapists will have been taught about epilepsy during their training.

## Aromatherapy

Aromatherapy is usually a form of massage with plant oils. These are called essential oils. Each oil is chosen for a specific effect. Some are calming and relaxing and may help to control your seizures if stress is a trigger for you.

However, there are some essential oils that have a stimulating effect and may trigger a seizure in some people. These oils are hyssop, rosemary, sweet fennel, sage and wormwood. A qualified practitioner will know to avoid using these oils on a person who has epilepsy.

## Biofeedback

Biofeedback is a form of behaviour therapy where you can learn to have some control over your seizures. Over a series of sessions you train your brain in a similar way to how people learn to ride a bike. This technique is used more widely in Germany and the USA. There are currently very few Biofeedback practitioners in the UK.

## Hypnotherapy

Hypnotherapy can help you to feel more relaxed and confident. You can use hypnotherapy to face specific fears. It may make you feel more relaxed and reduce stress. Ensure the therapist knows you have epilepsy so they will bring you round slowly after a session.

## Other complementary therapies

There are lots of other complementary therapies such as herbal medicine, homeopathy and acupuncture. Complementary therapies can be used to lower stress and help you relax. This is particularly useful if stress is a seizure trigger for you.

There are some herbal medicines you should avoid such as St Johns Wort and evening primrose oil. This is because there are some concerns about how these remedies affect people with epilepsy. If you are thinking of taking herbal medicines talk to your doctor first and always consult a qualified practitioner.

**With any complementary treatment it is important to find a qualified therapist who is a member of a professional body.**

# Lifestyle

The information in this leaflet should help you understand what treatments are available to control your seizures. However, some people will continue to have them. If you are one of these people, you can look at other ways to try and reduce the frequency of your seizures.

You may find that certain things are more likely to trigger a seizure. Keeping a seizure diary will help you to identify these. Once you know your triggers, you can take steps to reduce the number of seizures you have.

We have listed just a few of the most common seizure triggers. Here is what you can do to reduce any risk:

- **Missing medication:** take your medication every day. Avoid situations that are likely to make you forget to take your medication, such as drinking too much alcohol.
- **Alcohol and recreational drugs:** if you drink alcohol, a sensible daily limit would be one to two units. On average, there is one unit of alcohol in a half pint of beer or lager, one glass of wine or one single measure of spirits. But some alcoholic drinks will have a higher alcohol content so make sure you check this out first. You can find information on this and much more on **Alcohol Focus Scotland's** website [www.alcohol-focus-scotland.org.uk](http://www.alcohol-focus-scotland.org.uk). Taking certain recreational drugs can also make you more likely to have a seizure.

- **Stress:** find ways to reduce any stress and anxiety. There are many ways to do this, such as exercising, yoga, or using complementary therapies.
- **Boredom:** keep active to avoid boredom. There is plenty to get involved in. You can do some volunteering, take up a hobby or leisure activity. We all need a level of positive stress in our lives to keep us alert.
- **Lack of sleep:** try to get plenty of sleep and avoid having too many late nights.
- **Missing meals:** make sure you have regular meals and eat a well balanced diet.
- **Dehydration:** drink plenty of water to keep your mind and body working well.



## And finally..... medical research

We are moving one step closer to understanding what causes epilepsy. Research into genetics has led to major breakthroughs in recent years. This may lead to better treatment and diagnosis of epilepsy.

Advances have also been made in medical scanning which will help us to understand epilepsy better.

And finally, a lot of research is going into developing and finding new epilepsy drugs.

Finding new treatments which control seizures and have fewer side effects is what most people living with epilepsy want to see.



## Further information

Epilepsy Scotland can give you further information on:

<b>Factsheets:</b>	<b>Guides:</b>
<ul style="list-style-type: none"><li>• Diagnosis</li><li>• Driving</li><li>• Employment</li><li>• First aid for seizures</li><li>• Leisure</li><li>• Memory</li><li>• Safety</li><li>• Seizures</li><li>• Triggers (includes information on alcohol and photosensitive epilepsy)</li></ul>	<ul style="list-style-type: none"><li>• A guide to epilepsy - what you need to know</li><li>• A parent's guide to epilepsy</li><li>• A woman's guide to epilepsy</li><li>• An employer's guide to epilepsy</li><li>• Epilepsy and later life</li><li>• Guidelines for teachers</li><li>• Men and epilepsy</li><li>• Looking after someone with epilepsy and learning difficulties</li></ul>

We also have information leaflets designed for people with learning difficulties. These include:

- All about epilepsy
- Safety and epilepsy
- Living with epilepsy

If you have questions after reading this leaflet, please call our Helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format or language, please call **0808 800 2200**.

# epilepsy scotland

Scotland's voice for epilepsy

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