epilepsy scotland

FACTSHEET

Treating epilepsy

Epilepsy is a common neurological condition. Around 58,000 people in Scotland are affected by epilepsy. The condition is characterised by seizures which start in the brain and stay in the brain. There is no cure for epilepsy as such, but seizures can often be reduced or even fully controlled with medication.

This factsheet gives you a general overview of different treatment options but please bear in mind that not all options may be suitable for your type of epilepsy. If you have any questions about your treatment, always contact your neurologist, epilepsy specialist nurse or GP.

Anti-seizure medication (ASM)

By far the most common way to treat epilepsy is with anti-seizure medication. The medication works by preventing unexpected or excessive electrical activity in the brain, which causes a seizure.

Generally, between 50 - 60% of people will achieve complete seizure control with medication. Many others will see at least a reduction in their seizure

activities. There will, however, be people whose seizures cannot be controlled by medication.

Your medication usually comes in tablets, but you may also be able to get it as a syrup, liquids, sprinkle capsules or soluble tablets. This can help if you have difficulty swallowing tablets.

Some ASMs are available as a slow release version. These are absorbed more slowly into the bloodstream which gives your body a more even level of the drug throughout the day.

Some people only need to take one type of ASM to achieve good seizure control. Others will need to take two or more ASMs to reduce their seizure activity.

Starting on anti-seizure medication

Your neurologist will start you off on a low dosage and then gradually increase it over a period of time, until you achieve good seizure control. This will allow your body to get used to the medication and reduce the likelihood of side effects.

Making the most of your anti-seizure medication

Always take your medication exactly as prescribed every day at roughly the same time(s). If you take your medication twice a day, spread it out evenly leaving about 12 hours between doses. Forgetting to take your medication even just once can trigger a seizure.

Try linking your medication to a regular activity such as straight after breakfast or brushing teeth. Or you could set an alarm on your smart phone/smart speaker, or use an electronic pill box.

Switching to a different anti-seizure medication

If your seizures are not controlled by your current ASM, your specialist may want you to try a different ASM. There may be other reasons why a switch is advised, for example if you experience too many side effects.

Your neurologist may add a second medication, and increase this, before slowly reducing and stopping the original medication.

Missed your dosage or taken too much?

If you have forgotten to take your medication, do not automatically take a double dose the next time. Always speak to your doctor or epilepsy specialist nurse first to find out what you should do as this may depend on the ASM you take.

As a general rule, if you only take one tablet a day, take the dose as soon as you remember it. If you take tablets twice a day, take the missed dose if you remember within six hours of when you should have taken it. If it is more than six hours late, you may need to wait until the next dose is due.

If you have accidentally taken your medication twice, contact your epilepsy specialist nurse, GP or NHS 24 on 111 immediately for medical advice. You may feel drowsy, sleepy or lethargic if you have taken too much of your medication.

Vomiting and diarrhoea

If you feel sick and have been vomiting soon after taking your medication, some of it may not have been fully absorbed. This could put you at a higher risk of having a breakthrough seizure. Do not automatically take a second dose. Seek medical advice from your neurologist, epilepsy specialist nurse, GP, chemist or NHS 24 before you do anything.

If you have diarrhoea, always seek medical advice as this may affect the absorption and effectiveness of your medication. Also be mindful that common side effects from prolonged diarrhoea such as dehydration or raised temperature can be a seizure trigger for some people.

Generic and branded medication

ASMs, like all medications, have two names:

- a generic name, which is the chemical name (ie levetiracetam), and
- a brand name, which is the name given to the drug by the manufacturer (ie Keppra).

Most medications are available both as a generic version and a branded version. Generic versions are often made by more than one manufacturer, so your medication pack may occasionally look different.

Branded medications are not better than generic medications. Both have the same active ingredient which control seizures, but manufacturers may use different binding or coating materials. This could affect how quickly the drug is absorbed and may occasionally affect seizure control. Not all ASMs

are the same though, and there are many where switching to a different brand will not affect seizure control.

ASMs are basically divided into three categories which indicate whether switching may cause some issues. Category 1 drugs should not be substituted, Category 2 drugs may be substituted depending on a number of factors, and Category 3 drugs are considered to be perfectly safe to be substituted.

To find out more about which category your ASM(s) fall into, check out the Medicines and Health Care Products Regulatory Authority (MHRA) website.

If there is a supply issue with a specific ASM, your GP or epilepsy specialist nurse may need to prescribe a different version even for Category 1 drugs. This is still better than not taking it at all or being prescribed a different ASM.

Side effects and interactions

ASMs, like all prescribed or over-the-counter drugs, can have side effects. These may include tiredness, drowsiness, or lack of concentration. For people with a learning disability, you may sometimes notice a change in their mood and/or behaviour.

Be patient and give yourself a few months to allow your body to get used to the medication until side effects settle down. Taking your medication exactly as prescribed and spacing it out evenly can also reduce potential side effects.

If you experience severe side effects, always contact your epilepsy specialist nurse or neurologist for medical advice.

Keep a note of anything which may be different since starting the medication, including any changes in your mood or anxiety levels, and contact your neurology team for advice.

If you notice a skin rash or unexpected or unusual bruising, seek urgent medical advice from your epilepsy specialist nurse or GP. This could be a sign that you are allergic to the medication.

Never stop taking your medication or reduce it without speaking to your epilepsy specialist nurse or neurologist!

You can report unusual side effects to the Yellow Card reporting scheme. If you are unsure whether a side effect needs to be reported, ask your GP or epilepsy specialist nurse.

Always let your neurology team know if you take any other prescribed or over-the-counter medication. This includes vitamins, supplements, herbal remedies or CBD/cannabis based products. Any of these can potentially interfere with ASMs and make them less effective or increase side effects. There's further information on pages 11 and 17 about the recreational use of non-prescribed drugs.

Long term use of anti-seizure medication

Many people take ASMs for years, some even for life. ASMs are usually tolerated well but you may occasionally need a blood test to check on liver

and kidney functions, especially if you also take other prescribed medications.

Long term use of some ASMs may cause a vitamin D deficiency, potentially leading to a risk of thinning bones or fractures. Your neurologist or epilepsy specialist nurse will advise if you may need a bone density test or if you should take any supplements, which will reduce the risk.

Coming off anti-seizure medication

If you have been seizure free for a number of years, you may be able to come off your ASM. There is, however, always a risk of seizures returning, and only your neurologist will be able to give advice on whether you are suitable. Be mindful that even just one breakthrough seizure could have serious consequences, such as losing your driving licence. This could have a major impact on your work or family life.

Never change, reduce or come off your medication unless you have been advised to do so and are closely supervised by your neurologist.

Anti-seizure medication and pregnancy

If you are planning to start a family, always speak to your epilepsy specialist nurse or GP first. Some ASMs should not be taken during pregnancy as these can potentially cause physical and/or developmental problems for the baby. One of these drugs is Epilim/sodium valproate.

For more information, please read our Sodium valproate and pregnancy factsheet.

Always plan your pregnancy to make sure you are on the right medication and the mother/parent has good seizure control before pregnancy. Uncontrolled seizures during pregnancy can also be harmful to the unborn baby. You will also receive specialist support from obstetrics throughout your pregnancy.

As soon as you find out or suspect you may be pregnant, seek immediate medical advice from your, GP, neurologist or epilepsy specialist nurse. Do not stop taking your medication. This could trigger a serious breakthrough seizure, which could be dangerous to both yourself and your unborn baby.

Emergency medication

Keep in mind that most seizures tend to be short, stop on their own, and will never require any intervention.

A neurologist or epilepsy specialist nurse may sometimes prescribe emergency medication which can stop a seizure. This would only be prescribed for seizures which are longer than normal, or which last at least five minutes, or for seizures which happen one after another without full recovery in between.

A prolonged seizure can become a medical emergency if it does not stop. This is referred to as status epilepticus. Having emergency medication to hand allows carers to respond to prolonged seizures quickly and safely.

If you want to find out more about this, read our Seizures explained factsheet.

Types of emergency medication

Midazolam is the most commonly used emergency medication. It is usually administered buccally, ie between the inside of the cheek and gum, and will be absorbed through the lining of the mouth. Some people may be prescribed **diazepam**. This is given rectally (into the anus) using a specially prepared tube.

Both are benzodiazepines, which get absorbed into the blood stream. They are sedatives and can reduce or stop seizures. Midazolam clears quicker out of the system, so the sedative effect is shorter than that of diazepam.

A small number of adults and children are prescribed rectal **paraldehyde** if midazolam or diazepam are not effective**.** It has a very distinctive smell.

Emergency medication protocol

A doctor needs to prescribe emergency medication. This comes with a plan detailing the exact steps to take, such as when to give the medication, how much, and when to call an ambulance. This plan can be called different things depending on which health board area you live in, such as care plan or emergency medication protocol.

The plan also details other important information on the person's usual seizure types and pattern. It will also have a space where the person who administers the medication needs to record when and how much emergency medication has been given.

Some emergency protocols include a list of people who can administer this medication, but usually, anyone with current training can give it. The care plan must be signed and dated by a doctor, and by the person receiving the medication or someone who can sign on their behalf. This could be a legal guardian.

Emergency medication can also be given by medical staff including most paramedic staff.

Side effects of emergency medication

Side effects for midazolam and diazepam can include drowsiness, confusion, lightheadedness, unsteadiness, or, less commonly, unusual increase in aggression. More serious side effects, often as a result of receiving too much of the medication, include low blood pressure, excessive drowsiness, confusion, overexcitement or shallow breathing.

Side effects for paraldehyde include breathing difficulties, irritability, rash or sedation.

If there any concerns about the person's breathing or other side effects, always call an ambulance.

Storing emergency medication

Emergency medication needs to be stored at room temperature. Avoid a sunny windowsill or fridge. If stored incorrectly, it can go off and become ineffective. Always check the bottle before using it to make sure the liquid has a clear colour. If it is cloudy or crystallised around the top of the bottle,

do not use it. Keep the bottle upright at all times and the cap firmly closed to avoid crystallisation or clouding.

Keep the medication in a secure place, one where small children cannot get to, but with easy and quick access for when it is needed.

Cannabis based products

If you take cannabis based products to help with seizure control or anxiety, always let your neurology team know. This is because cannabis can interfere with your ASM's effectiveness resulting in more seizures or more side effects. Never stop your medication without medical advice or substitute your medication with non-prescribed cannabis products.

The NHS has been able to prescribe cannabis based medications under very limited circumstances since 2018. However, only one cannabis based medication for epilepsy has so far been licensed for NHS use. Specialists usually only prescribe it to children affected by severe epilepsy syndromes, such as Dravet syndrome. If there are exceptional clinical circumstances, it can sometimes be prescribed to adults, but this is rare.

Epilepsy surgery

Brain surgery (neurosurgery) can be an option for a small number of people whose epilepsy remains uncontrolled despite trying at least two ASMs.

Although only a small number of adults and children are deemed suitable for surgery, the success rate for those can potentially be high.

Whether you are suitable for surgery will depend on a number of factors including the type of seizure you have and what is causing the seizures. You will also need to go through some detailed tests, and it can take several months, and up to a year, before all tests are concluded and a decision is made whether surgery can be done safely with minimum risks.

All surgery carries a risk, which may increase if you have other health problems. Specific risks of brain surgery include infection on the brain, bleeding or a stroke after surgery. If there are complications, you may need to stay in hospital for a longer period.

Surgery may also affect some of your functions, such as your memory or speech. You will have plenty of time to discuss this with your neurosurgeon and weigh up possible risks and benefits.

Most people will need to stay on ASM(s) after successful surgery, as the surgery may leave scarring on the brain's surface, which may trigger a seizure.

Device based treatment

For some people whose seizures are not controlled by medication, device based treatment options can sometimes offer seizure control, or at least a reduction in the frequency and/or severity of seizures. This device is called a vagus nerve stimulator (VNS).

VNS is like a pacemaker for the brain. It is usually inserted under a full anaesthetic during surgery, and is programmed to send regular electrical impulses to the brain via the vagus nerve. It can also detect changes in the

heart rate, which often is a precursor for seizures. In response to that, it can deliver an additional dose of electrical impulses to the brain. A magnet worn like a wristband can also be used to stimulate the device in response to a seizure warning.

VNS may have other positive side effects such as improving your alertness, memory, or mood. The device is also sometimes used to help control depression.

VNS is usually only available to people whose seizures are not controlled by a number of different ASMs, or who or are not eligible for neurosurgery. Your doctor or specialist nurse will discuss with you if this is an option.

VNS is unlikely to completely stop seizures, but it can be effective in reducing the severity and number of seizures. VNS can take a while, sometimes up to two years, to reach its full effect. At that point medication can sometimes be reduced but most people will need to continue taking ASMs.

Side effects can include some discomfort in the throat, a cough, difficulty swallowing or a hoarse voice. These side effects may fade away over time. It is also possible to adjust the settings of the device to try and reduce side effects. If VNS does not work, the device can be switched off and most parts removed safely.

Dietary treatment

The following are specialist prescription-only diets, these are not diets you can attempt yourself. You will need to be supervised by a medical team throughout for adverse health effects.

Ketogenic diet

This is not the Keto diet often used for weight loss. The ketogenic diet for epilepsy is a special diet used to treat children who have uncontrolled epilepsy despite trying a number of ASMs. To access this diet, the child needs to be referred to a ketogenic dietician by their paediatrician or neurologist.

Repeated studies have shown that the ketogenic diet can reduce seizures in up to 60% in children whose epilepsy is drug resistant. For these children, a third can have a 50% reduction in seizures, and a third can have a 90% reduction in seizures or become completely seizure free. However, for the remainder the diet will have no positive effect.

The diet is very high in fat, has adequate protein and is very low in carbohydrates. The body has to use fat instead of the usual carbohydrates to produce energy. During this process, ketones are produced, which can help with seizure control.

This diet can only be prescribed by a qualified dietitian trained in working with the ketogenic diet. Throughout this process the child will also need to be regularly monitored by medical staff for adverse health effects.

The diet is not for life. The children are usually only on the diet for a maximum of two years and can then be weaned off it. The positive effects from the diet will remain for the vast majority of children even after the diet has finished. The diet can sometimes be given for longer if necessary.

To find out more about this treatment option, and to find your nearest ketogenic diet clinic in Scotland, check out the charity Matthews Friends www.matthewsfriends.org.

Dietary treatments for adults

A modified ketogenic diet, modified Atkins diet or low glycaemic index diet is the adult version for the ketogenic diet. These work in similar ways to the ketogenic diet, and the effects are broadly similar to children on the ketogenic diet.

Always get advice from your neurologist or epilepsy specialist nurse first. You will need to get medically screened to make sure it's safe for you to go on this restricted diet. You will then need to be referred to a specialist ketogenic service. While you are on the diet, you need to be carefully monitored for adverse side effects.

As with the ketogenic diet, adults usually stay on these diets for around two years after which time they are weaned off it.

For more information on adult dietary treatment options, check out Matthews Friends at www.matthewsfriends.org.

Self-management

The unpredictability of seizures can make you at times feel powerless and out of control. If you can identify triggers for your seizures, then you may be able to work on these triggers to try and reduce your seizures. This can often give you a better sense of control. Please bear in mind that not everyone has a seizure trigger, seizures can just happen for no obvious reason.

Have a look below at some of the steps you can take to maximise your chances of better seizure control.

Keep a seizure diary

Keeping a record of your seizures can help you identify possible triggers. Add additional information such as how you felt before the seizures, such as tired or stressed, or whether you forgot to take your medication. If someone witnessed you have the seizure, add their description too!

Take medication exactly as prescribed

If you forget to take your ASM or take it too late, the level of your medication can very quickly fall below the level which is required to prevent seizures. Set up an alarm reminder on your phone or smart speaker, or use a pillbox. Link the taking of medication with daily routines such as brushing your teeth.

Go easy on the alcohol

Stick to moderate drinking. Always follow your epilepsy specialist nurse's advice on alcohol as some of the ASMs don't mix well with alcohol. Avoid binge drinking as this can trigger a seizure, even in those who do not have a diagnosis of epilepsy.

Beware the after-effects of a hangover. Disrupted sleep, dehydration, forgetting to take your ASMs or taking them much later than usual, not eating anything/low blood sugar etc are all potential triggers for seizures.

Avoid recreational drugs

Many recreational drugs are stimulants which can affect brain chemistry potentially triggering a seizure, especially if mixed with alcohol. Each person reacts differently to each drug, and there is no way of knowing how you will react to a drug.

Watch your caffeine intake

Caffeine is a stimulant and can trigger seizures if taken in large quantities. Many drinks and products also contain caffeine such as energy or fizzy drinks, caffeine shots and pills, or over-the-counter cold and flu remedies.

Prioritise your sleep

Set up a good sleep routine. Sleep is important for seizure control, as well as your general physical wellbeing and mental health. Lack of sleep is one of the most common seizure triggers. Avoid caffeine in the evening, give

your brain some time to switch off after watching television and switch off electronic devices an hour before you go to bed or put them into night mode to filter out the blue light. It interferes with the production of melatonin, a hormone essential for sleep. If you are struggling with your sleep, seek medical advice.

Address stress/anxiety

This is another common seizure trigger. You may not always be able to avoid stressful situations but you can potentially change how you respond to them. Take yourself for a walk, meet up with friends or listen to music. Learn some basic breathing techniques, or start yoga classes. Whatever works for you. The more tools you have in your box, the better your resilience. Always seek medical help if stress and anxiety take over your life.

Be mindful of feeling unwell

Running a temperature, feeling unwell or being in pain can make seizures more likely. Vomiting and diarrhoea can also stop your ASMs from being fully absorbed by your body leaving you more vulnerable to seizures. If you become unwell, give yourself plenty of rest, stay well hydrated and make sure you take you ASMs to reduce the risk of seizures.

Eat a healthy and balanced diet

Looking after your physical health will make you more resilient to the setbacks in life. It can also help maintain good emotional and mental health.

Eat regular meals and reduce processed foods if possible. Don't let your blood sugar drop too low as this can sometimes trigger a seizure.

Exercise your body

Staying active can help with seizure control. Everyone can do something. If your seizures are uncontrolled seek advice from your epilepsy specialist nurse first. With some precautions, most activities can be made safe. Staying active will help you maintain good physical and mental health.

Stay hydrated

Keep your fluids topped up all the time. Dehydration can trigger a seizure. This is particularly important when you are exercising, when it is hot outside when you are on holiday in a hotter climate, or when you are unwell with vomiting and/or diarrhoea.

Be mindful of hormonal changes

Some women/people may have more seizures at a particular point in their menstrual cycle. Monthly hormonal fluctuations can make it more likely to have a seizure. These fluctuations may also occur during pregnancy or peri/menopause, making them more susceptible to seizures at these times. Always seek medical advice if you notice an increase in your seizures at certain times. Your specialist may be able to prescribe additional medication you can take.

Be mindful of flashing/flickering lights

Only around 2-3% of people with epilepsy are photosensitive, which means their seizures tend to get triggered by flashing or flickering lights. Light effects created by sunlight streaming through trees or a fence can create a similar flicker effect potentially triggering a seizure. Even the flickering/flashing content of a TV programme or computer game can trigger a seizure for those who are photosensitive.

For more information on photosensitive epilepsy and ways to manage potential triggers, check out our factsheet on Photosensitive epilepsy.

Getting further help and support

Your first point of contact for any treatment related questions should always by your neurologist, epilepsy specialist nurse or GP. Your local pharmacist can also give you more information on the medication you take and speak to you about possible side effects.

Have a look at our website www.epilepsyscotland.org.uk for general information about epilepsy and our services. You can download our information leaflets from our publications section or request printed copies from us.

If you want to speak to someone about your epilepsy, contact our helpline on 0808 800 2200 or email us at contact@epilepsyscotland.org.uk. You can also private message us on our social media platforms.

Our friendly helpline officers will be on hand to listen, signpost and provide general information about epilepsy and treatment. We are unable to give medical advice though.

Our resources are always free. If you would like to support our work, please text FACTS to 70085 to donate £3. Texts cost £3 plus one standard rate message.

epilepsy scotland

www.epilepsyscotland.org.uk

Freephone helpline: 0808 800 2200

Email: contact@epilepsyscotland.org.uk

Head Office:
48 Govan Road
Glasgow
G51 1JL
Tel: 0141 427 4911

/ epilepsyscotland

/ epilepsyscotland

/ epilepsy_scot

/ epilepsyscotland