Epilepsy Scotland information

Epilepsy explained

epilepsy scotland

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> *Don't stop living!*
> *Don't let epilepsy rule your life and make you give up on your dreams!*

How to use this guide

This guide is intended as a general introduction to epilepsy within a Scottish context. As a Scottish charity we understand that many areas such as education, health and social care services are covered by Scottish rather than UK legislation. When you read our guide, you can be sure that all the information we provide is relevant to Scotland.

Not everything in here may apply to your own situation. You can dip in and out of it as and when required, taking the information you need or read it cover to cover, which may be useful if you are completely new to epilepsy.

Whether you make contact with us via social media, our helpline **0808 800 2200**, email or in person, you will be able to speak to someone about your epilepsy, find out about the support and services we provide, and any other sources of support and services across Scotland. If there is anything we can do to help, make us your first point of contact. We guarantee you a warm and friendly welcome.

Understanding epilepsy

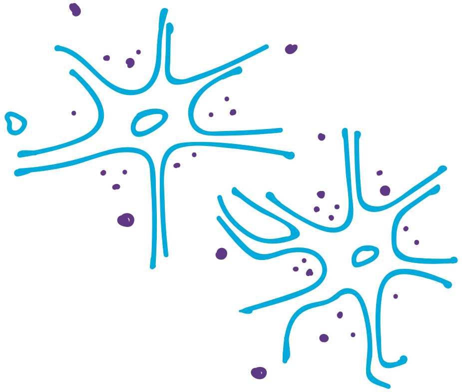
> *Try to stay positive, educate yourself on the facts, there are a lot of scary myths and misconceptions regarding epilepsy out there!*

If you or someone you care for has just been diagnosed with epilepsy and you live in Scotland, you are not alone.

Around 55,000 people in Scotland have epilepsy, that is one in 97.

A new diagnosis will often leave you with many questions. While this guide cannot give any medical advice, we can make it easier for you by explaining epilepsy and what it may mean for you and your family.

If you wish to have more detailed information on any of the following subjects, just let us know and we can arrange for this to be sent to you. You can also contact our helpline on **0808 800 2200** and speak to our trained helpline and information officers.



What is epilepsy?

Epilepsy is one of the most common serious neurological conditions in the world. It is often defined as the tendency to have repeated seizures which start in the brain. A seizure can be triggered by other medical conditions such as a heart condition. These will need to be ruled out first before a diagnosis of epilepsy is made.

A seizure can also be a one off, triggered by extreme events, such as sustaining a serious head injury, being exposed to high temperatures or binge drinking. As many as one in 20 people will have such a one-off seizure in their life.

No two people experience epilepsy in exactly the same way. For one person, epilepsy can mean complete seizure control on medication, for another person it can mean uncontrolled and frequent seizures despite medication.

Epilepsy can affect anyone, irrespective of their age, gender or background, but it is more common in childhood and in later life.

Understanding epilepsy

What causes epilepsy?

Sometimes there can be an identifiable cause, such as an acquired brain injury, which can be following a fall, assault or road traffic accident. An acquired brain injury can also be caused by a stroke, brain tumour, meningitis, or brain haemorrhage (bleeding). Some people also develop epilepsy following a diagnosis of dementia.

Epilepsy can also be caused if the brain has not formed properly in the womb as a result of a genetic fault. This can also be the cause of other neurological conditions. People with Downs syndrome, autism or with learning disabilities are statistically more likely to have epilepsy.

Generally, we now believe there to be a genetic cause for epilepsy if no obvious cause can be identified as mentioned above.

A genetic link can be obvious if epilepsy runs in the family. Genetic, however, does not always mean that it is inherited. Genetic epilepsy can often be caused by a new genetic change. It is rare for genetic epilepsies to be caused by one gene alone. There are usually other genetic and environmental causes as well.

What is a seizure?

Billions of neurons (nerve cells) in the brain pass information to each other via electrical signals. A seizure is a temporary disruption to this normal electrical activity. What a seizure looks like will depend on where in the brain it starts and how much of the brain is affected by the seizure.

There are many different types of seizures and epilepsies.

Seizures tend to last only a short time and usually stop on their own. They can affect the whole of the brain or only part of the brain.

During a seizure that stays in only one part of the brain, the person may or may not be aware of what's going on depending on how much of the brain is affected.

If only a small area of the brain is affected, the person:

- may experience strange sensations such as an unusual taste or smell or twitching, a butterfly sensation in the stomach, a déjà vu sensation, or a sudden sense of dread, fear or (rarely) euphoria.

  These types of seizures are also often referred to as aura sensations or warnings as they may sometimes indicate that a bigger seizure is to come
- knows the seizure is happening but cannot stop it
- will not lose awareness of their surroundings

Understanding epilepsy

If a larger part of the brain is affected, the person:

- may experience strange or unusual feelings
- may lose their sense of time and appear distant from what is happening and who is around
- may behave in an unusual way (ie smacking their lips, pulling at their clothes or moving aimlessly around a room)
- may make repetitive movements (automatism)
- will have some loss of awareness which could put the person in danger (for example walking into traffic)

If a seizure affects the whole of the brain, the person will always lose consciousness. These type of seizures include:

Tonic-clonic seizures

These are the most well known and recognised type of seizures where someone loses consciousness, falls over, and starts convulsing (jerking).

Absence seizures

These are less obvious and usually short lasting. There will be a brief loss of consciousness, and the person will usually remain still and stare into space. Absence seizures can often be confused with daydreaming.

Other types of seizures affecting the whole of the brain include tonic, clonic, myoclonic and atonic seizures.

We have a separate factsheet about the different types of seizures explaining the terminology in more detail. To request a copy, please contact us on **0808 800 2200**.

Diagnosing epilepsy

> *Ask questions.*
> *Share your experiences.*
> *Do not be afraid.*

It can be difficult to take in and remember all the information given to you by your specialist at the time of diagnosis.

So, if you have any questions or want further information about epilepsy in general, feel free to contact our helpline on **0808 800 2200**.

Connecting with others affected by epilepsy can make you feel less alone. It can also be helpful finding out how other people have adjusted to life after an epilepsy diagnosis and how they have coped with some of the challenges.

You could join a support group if there is one in your area, or you could make contact with others via our social media pages.

Diagnosing epilepsy

First seizure

A GP will usually refer anyone who has had one seizure or seizure-like episode to a first seizure clinic or epilepsy specialist at the hospital. Adults will usually see a consultant neurologist or a consultant physician with a special interest in epilepsy. Children should be seen by a paediatric neurologist or a paediatrician who specialises in epilepsy. A diagnosis of epilepsy should always be made by an epilepsy specialist.

There is no single test to diagnose epilepsy.

A diagnosis is usually made by ruling out any other medical conditions that can cause a seizure. There are some tests that can confirm the suspicion of epilepsy and these are described in the next chapter.

The specialist will do a basic clinical examination and take a detailed medical history. They will also want to speak to anyone who has witnessed the suspected seizure. If you have video footage of the suspected seizure(s), take this with you to the appointment.

Possible tests

You may not need all of the following tests, which are usually done to confirm a diagnosis and can help identify the cause and / or type of epilepsy:

An **ECG** (electrocardiogram) can rule out an irregular heartbeat or other heart condition as the possible cause of a suspected seizure.

A **blood test** can rule out diabetes, or any other medical condition which could cause seizures.

An **EEG** (electroencephalogram) records the brain's electrical activity. During a seizure, this activity is disrupted, and this will show up on the recording if the person has a seizure during the test.

Even if the person has no seizure during the test, test results can still be useful because unusual brain wave patterns can sometimes show up in between seizures.

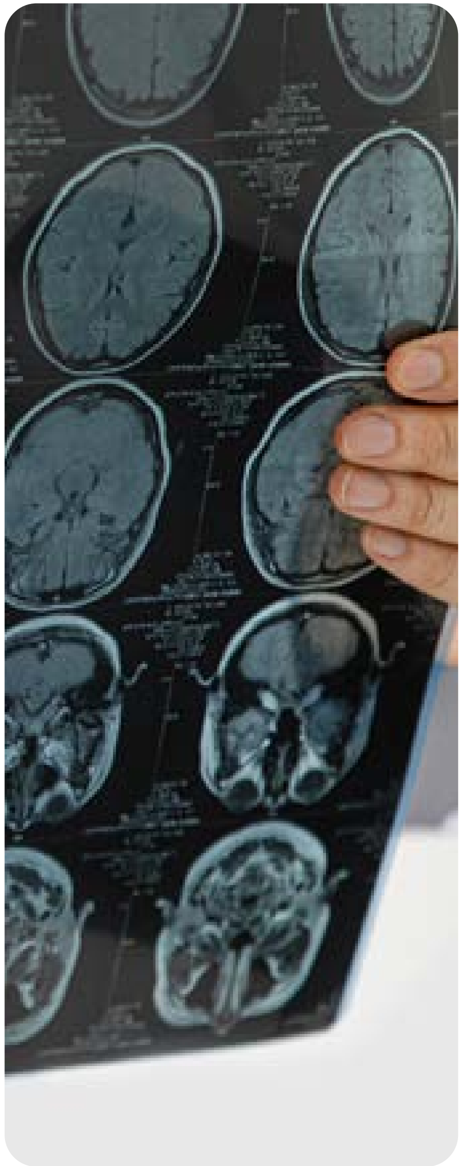
This test usually only forms one part of the investigation. It is important to bear in mind that anyone can have a normal or abnormal EEG. Having an abnormal EEG does not necessarily mean epilepsy and vice versa.

Diagnosing epilepsy

Brain scans can be used to detect anything which may be causing the seizures, such as scarring on the brain or a tumour. The scan is usually an **MRI** (Magnetic Resonance Imaging) scan. Sometimes, you may get a **CT** (Computerised Tomography) scan if the hospital has no MRI scanner.

A clear EEG and brain scan does not rule out epilepsy, in fact many people will be diagnosed with epilepsy even though all their tests have come back clear.

All this means is that there is no identifiable cause for epilepsy.



Treating epilepsy

> *“Don’t be afraid to talk about your epilepsy, help others understand and let them know you still have a life to live and you want to do it.”*

There is no cure for epilepsy, but the majority of people can achieve good seizure control with the right treatment. Many people will become seizure free once they have started treatment.

Anti-epileptic drugs are usually the first treatment of choice. Other treatment options include surgery, device based or dietary treatment options, but they may not always be suitable for everyone. There is no single treatment that works for everybody.

We have a detailed treatment information pack which you are welcome to request from us by contacting us on our helpline **0808 800 2200**. You can of course also phone us with any questions arising from this information.

Treating epilepsy

Anti-epileptic drugs

This is the most common treatment for epilepsy. Anti-epileptic drugs (AEDs) work by preventing seizures from happening. Between **50-70%** of people can become seizure free with effective medication.

Side effects

Like all medications, AEDs can have side effects. These commonly include tiredness, lethargy, drowsiness, lack of concentration, and weight loss or gain. In many cases, side effects are mild and tend to fade once the body has become used to the drugs. A skin rash or unexplained bruising should be reported to a doctor straightaway as this may be a sign that you are allergic to that drug.

If you are concerned about any side effects, speak to your doctor or epilepsy specialist nurse. Sometimes just adjusting the dosage can reduce side effects. Alternatively, your specialist may suggest switching you to a different drug.

Never stop taking your AED unless being advised to by your medical team.

Making the most of your anti-epileptic drugs

AEDs work best when taken exactly as prescribed. Taken too closely together they can cause side effects. Taken too far apart they can trigger a seizure as there may not be enough of the drug in your body to prevent a seizure. Even forgetting to take AEDs just once can trigger a seizure.

If you are not sure about how to best take your AEDs, talk to your epilepsy specialist nurse.

Interaction with other drugs

Your specialist will always check to make sure there is no interaction between AEDs and any other prescribed or over-the-counter drugs.

You should always mention any over-the-counter drugs, vitamins, supplements or herbal remedies, including CBD oil, you take to your specialist as these can sometimes interfere with the effectiveness of your AEDs.

Women and AEDs

Some AEDs can interact with the contraceptive pill or should be avoided during pregnancy. If you are planning to start a family always seek medical advice before you get pregnant.

If you take sodium valproate (Epilim), you must not get pregnant as this drug can be harmful to your unborn baby. Your specialist will want to switch you to a different drug before you become pregnant.

Never stop your medication without medical advice even if you have an unplanned pregnancy, as this could put you or your unborn baby's life at risk.

Treating epilepsy

Do I have to take anti–epileptic drugs?

If you have capacity, the decision is yours.

To help you decide, consider the type of seizures you have, the risk of injury associated with certain types of seizures, and the impact frequent seizures could have on general health, social and family life, work or education.

Some people may be reluctant to take anti-epileptic drugs because they worry about side effects. A chat with your specialist or epilepsy specialist nurse can often allay any fears you may have about taking drugs or about side effects, and provide you with additional information to help you make an informed decision.

Long term use of anti-epileptic drugs (AEDs)

AEDs are generally well tolerated long term and many people will stay on them for life. Coming off AEDs is an option for some people but this is usually only suggested after being seizure free for a number of years. If you decide to come off your AEDs, bear in mind that there will always be a risk of seizures returning but this depends on a number of factors. These include the cause of epilepsy, age at onset of seizures and type of seizures. Your specialist will be able to give you more specific advice which will help you to make this important decision.

Consider the effect one breakthrough seizure could have, such as the immediate loss of your driving licence. This could in turn impact on your work, family and social life.

Never stop taking your AEDs suddenly and unless advised by your specialist. This could trigger a potentially dangerous breakthrough seizure.

Surgery

Surgery is usually only an option for a small number of people. Suitability will depend on several factors such as the cause of the epilepsy and type of seizures. However, once deemed suitable, there is often a high success rate with surgery, and it can result in full seizure control or at least a significant reduction in seizures.

People are usually only considered for surgery when a number of AEDs have been tried over a period of time without controlling the seizures. The process to assess suitability for surgery can be lengthy and involves detailed tests. This will minimise the risk of surgery affecting important functions like memory or speech. As with all surgery, there are risks and a successful outcome is not guaranteed. If you are deemed suitable for surgery, you will have plenty of opportunities to discuss all of this with your epilepsy specialist and neurosurgeon.

Surgery can be a big decision to make, and if you want to talk to someone about your feelings and some of the issues that come up for you, please contact us on our helpline **0808 800 2200.**

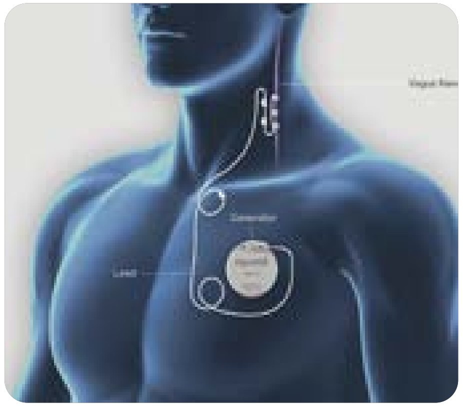
Treating epilepsy

Vagus nerve stimulation

Some people with epilepsy can have their seizures controlled or reduced by vagus nerve stimulation (VNS). This is usually used alongside anti-epileptic drugs rather than instead of them. The VNS device is roughly the size of a pacemaker and is usually inserted under the left collar bone under general anaesthetic. A tiny wire under the skin connects the generator to the left vagus nerve in the neck. It transmits regular electrical impulses from the generator via the vagus nerve to the brain. This can help stop or reduce frequency or severity of seizures.

Latest VNS models can also detect a rapid increase in heart rate which often precedes a seizure, and can respond to this by delivering an extra dose of electrical impulse when needed. There is also a magnet that can be used to stimulate the device when a seizure is about to happen, or for someone else to use the magnet during a seizure. This can often shorten a seizure and can speed up recovery time.

The device can have side effects such as a hoarse voice, cough, or tickling in the throat. These tend to be temporary and can often be reduced by adjusting the VNS settings. The battery for this device can be changed under local anaesthetic. The device can be switched off and removed should this be required.



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Dietary treatment options

The most commonly known option is the ketogenic diet. This prescription-only diet can be a genuine alternative when children and adults do not respond to drug treatment. The diet can be successful for some people by reducing the frequency and severity of seizures or by completely controlling them. For others it will have no effect and seizures will continue. The ketogenic diet is primarily used for children, but a modified version of this diet is also available for adults. Some adults also follow a modified Atkins diet which is a similar prescription only diet.

The diet is very high in fat, adequate in protein and very low in carbohydrates. Carbohydrates are our primary source of energy, and without these present in a diet, the body has to burn fat for energy. During this fat burning process, ketones are produced. We still do not fully understand the process, but this state of ‘ketosis’ can often have a positive effect on seizure control.

A neurologist will need to make a referral to a ketogenic dietician who will implement and supervise a prescriptive dietary plan.

Due to its restrictive nature this diet should never be attempted without medical supervision. Regular check-ups with your medical team will ensure that any adverse side effects from the diet are monitored and managed.

These diets are not for life and are usually stopped after a number of years. Often any positive effects gained from the diet will remain even after the diet has stopped.

Treating epilepsy

Complementary therapies

Complementary therapies are not considered to be an alternative to drug treatments. They do, however, have the potential to help with some seizure triggers such as insomnia or stress. Identifying and addressing seizure triggers with complementary therapies can sometimes be of benefit to seizure control.

A reputable and qualified complementary therapist will never claim to be able to cure your epilepsy or ask you to stop taking your drugs. They should always ask about medical history and will know if their therapy is safe to use for anyone with epilepsy.

Some herbal preparations or aromatherapy oils can interact with anti-epileptic drugs. These include St John's Wort, hyssop, rosemary, sage, sweet fennel and wormwood.

This is not an exhaustive list, and it is essential to seek advice from a qualified therapist before taking any over-the-counter herbal remedies.

Cannabis oil

Cannabis based medicinal products, including those that contain the psychoactive compound tetrahydrocannabinol (THC) can now be prescribed by the NHS in limited circumstances. For more detailed and up to date information on cannabis/CBD oil, please contact our helpline on **0808 800 200**.

Managing your epilepsy and seizures

> *Remind yourself epilepsy is just one part of you. Under the surface there is so much more.*

Many people affected by epilepsy talk about feeling powerless and out of control. Not knowing when your next seizure will happen can often be difficult to deal with. It can leave some people with low confidence and poor self-esteem.

If you can identify possible seizure triggers and then focus on the things you can do to achieve better seizure control you may feel more in control of your life.

Managing your epilepsy and seizures

Keep a seizure diary

A seizure diary can be useful to gather detailed information about your seizures.

Write down what happened before the seizure, as this may help you identify what triggered it. Not everyone has a trigger for their seizures but in many cases, people find that they are more likely to have a seizure in certain situations.

Ask yourself:

- Did I feel stressed or anxious about something?
- Did I have disrupted sleep the night before?
- Did I forget to take my medication?
- Did I feel unwell?

For example, you may find that your seizures tend to occur more when you are tired or first thing in the morning.
If you are a woman, you may find that you are more likely to have a seizure around the time of your monthly period.

Ask us for a free copy of our paper seizure diary to use. Alternatively, you can use one of the many apps available to record seizures.

Identifying seizure triggers

Please bear in mind that some seizure triggers can be rare and unique to a person and may not be on this list, or you may not have any triggers at all.

Not taking medication regularly

Taking your medication too late or forgetting it just once can trigger a seizure.

Feeling ill or hot

Running a temperature, fighting off an infection or just feeling hot and overheated can sometimes trigger a seizure.

Stress / anxiety or boredom

You may not always be able to avoid stress, but you can try and change how you respond to a stressful situation. Complementary therapies, counselling or mindfulness techniques may help to counter stress.

Lack of sleep and tiredness

If you are affected by insomnia, your GP may be able to prescribe something that helps you sleep or refer you to a sleep counsellor. Having a good bedtime routine is essential. This includes switching off television and any mobile devices one hour before you go to bed, as the blue light emitted from these devices can affect the production of the hormone melatonin, which is essential for sleep.

Missed meals / low blood sugar

If this is a trigger for you, eating regular meals can help prevent seizures. If you are planning a fast or a restricted weight loss diet including meal replacement shakes, always seek medical advice first as this may have an effect on how well your medication works.

Managing your epilepsy and seizures

Dehydration

This can sometimes be a trigger for seizures. Drink plenty of water, especially if the weather is hot, or if you have a fever. Diarrhoea and / or vomiting can also make you dehydrated.

Alcohol

Always seek medical advice first from your GP, specialist or chemist to check that alcohol is ok with the medication you take. Moderate drinking tends to be fine, but there are some anti-epileptic drugs that do not mix well with alcohol. Avoid binge drinking as this can make you more vulnerable to seizures. Never skip your medication before a night out as this greatly raises the risk of having a severe seizure.

Beware of the after-effects of a hangover. Disrupted or limited sleep, being dehydrated, taking your morning medication possibly much later than prescribed, or not eating much can all put you at risk of having a seizure.

Recreational drugs

Recreational drugs, whether legal or not, are unregulated so you can never be sure what you are taking. Stimulants are thought to be more likely to trigger a seizure, but any recreational drug has the potential to trigger a seizure or interfere with the effectiveness of anti-epileptic drugs. Taking more than one type of drug or taking it with alcohol can further increase the risk of seizures.

Caffeine

Caffeine is a stimulant, and if consumed in large quantities, it can trigger a seizure. If you drink large amounts of coffee or tea, or regularly consume high caffeine energy drinks, seek advice from your epilepsy specialist nurse.

Hormonal changes

Some women tend to have more seizures around their monthly period or mid cycle. Pregnancy, labour and going through the menopause can also make seizures more likely for some women.

Flickering or flashing lights, or repetitive patterns

This is called photosensitive epilepsy. While this is fairly well known, only an estimated two per cent of people with epilepsy are affected by this.

Watching TV is the most common trigger for photosensitive epilepsy. While flat screens are considered to be safe, seizures can also be triggered by a flashing or flickering content during a television programme, film or computer game. Strobe lighting effects or natural light sources such as sunlight reflecting off water or through trees can also trigger seizures in some people with photosensitive epilepsy.

If you are suddenly faced with strobe lighting or other flashing or flickering light effects, instantly turn away from the source and put one hand over one eye. It is thought this can disrupt the process in the brain that causes a seizure.

Food triggers

Some people suspect that certain additives or even certain types of food may be a seizure trigger for them. For example, monosodium glutamate (MSG), a flavour enhancer, or aspartame, an artificial sweetener, are thought to trigger seizures in some people. Keep a detailed seizure diary for a while recording details of food and drinks consumed. If you begin to see any possible link, then seek medical advice.

Staying safe with epilepsy

> *Your epilepsy doesn't need to hold you back but be sensible and respect it.*

Once you have a better understanding of what could potentially trigger a seizure, you can start making informed decisions about your safety.

So, for example, if you have forgotten to take your medication, you may want to avoid riskier activities for the day and let people around you know that there may be an increased chance of you having a seizure.

Assessment of care needs

A formal assessment to look at your home environment can be done via your local social work department. This is called a community care or single shared assessment (or section 23 assessment for children).

This assessment looks at and potentially addresses any safety concerns in your home. It includes any adaptations to your home and any other support you may need. The assessment could, for example, result in you receiving a few hours a week to help with chores or shopping, or help getting out and about if you are feeling isolated due to your epilepsy.

To request this assessment, contact your local social work department, your GP, community nurse or health visitor. Some of the things mentioned below can be assessed in this way, but there is obviously a lot you can do yourself or with the help of someone you trust.

We have a dedicated 'Staying safe with Epilepsy' guide providing more detailed information on assessing and minimising risks.

Taking medication exactly as prescribed

This will give you the best possible chance to get your seizures under control and help reduce risks you may face due to seizures. Find ways to remind yourself to take your medication on time, such as setting a reminder on your phone. If you have difficulty with remembering to take your medication, speak to your specialist or epilepsy specialist nurse.

Never change your dose unless advised to do so by a medical professional.

Staying safe with epilepsy

Safety around the house

Risks of injury during or following a seizure will depend on the type of seizure(s) you have and whether you get a warning. Your epilepsy specialist nurse or an occupational therapist may be able to help with identifying risks and making suggestions to reduce these risks.

For example, a stair gate at an appropriate height at the top or bottom of internal stairs may stop you from falling downstairs during a seizure, or stop you from climbing stairs during a focal seizure with impaired awareness (also known as complex partial seizure).

Shaped plastic covers which go over sharp furniture edges, and soft floor coverings especially in the bedroom, could reduce risks of injury.

Bath or shower?

Each person's circumstances and needs are unique, and an assessment should take this into account. Generally, taking a bath is usually not safe for anyone with epilepsy because of the risk of drowning during a seizure, unless this is supervised. This is particularly important if you live on your own.

A shower with level access or wetroom tends to be safer as this stops water from being trapped at the bottom. Also avoid using very hot water to reduce the risk of burns.

Sitting down can reduce risks of a fall injury if your seizures mean you suddenly drop to the floor. You can also prevent possible injuries by replacing a glass screen with a plastic shower screen or fabric curtain.

Epilepsy alarms

A community care assessment will be able to assess you for a community care alarm.

If you know you are going into a seizure, you can pull a cord or push a button to alert a designated person or call centre to you having a seizure. It will also allow you to call for help after a seizure if you have been injured.

While alarms may be able to give added peace of mind, they can also miss genuine seizures and may trigger false alarms. Different types of epilepsy alarms suit different types of seizures. Some may pick up on the typical movement with a tonic-clonic seizure, some may pick up on breathing rate changing which could indicate a seizure. Others may raise the alarm if you wander during a focal seizure with impaired awareness. Before you choose an alarm, make sure this is suitable for your type of seizures. Your epilepsy specialist nurse can advise on this.

Seizure warning

If you get a warning before a seizure, you can sometimes use that time to put yourself in a safer position away from possible danger. Not every person gets a seizure warning, but if you do, it may take you a while to get to know your own seizure warning. You may feel a certain way, or experience a smell or other unexpected sensation, which may then allow you to act on it.

Staying safe with epilepsy

Sleep seizures

These are often referred to as nocturnal seizures but they can happen at any time when a person sleeps.

Sleep seizures can have their own risks. For example, the force of a tonic-clonic seizure can sometimes turn a person onto their stomach burying their head into a pillow.

This could restrict breathing. A special safety pillow with holes can reduce the small risk of suffocation.

Generally, you want to make your bedroom environment as safe as possible by covering sharp furniture edges or making sure you have something soft to land on should you fall out of bed during a seizure.

Status epilepticus

Most seizures are short, stop on their own and do not require any intervention. The section on seizure first aid in the next chapter will take you through the simple steps of how to time a seizure, how to keep a person safe during and after a seizure, and under what circumstances to call an ambulance.

On rare occasions, a seizure will not stop on its own.

This can become a medical emergency if:

- a tonic-clonic seizure lasts five minutes or longer
- a focal seizure lasts 10 minutes or longer
- if an absence seizure lasts 10-15 minutes or longer

This is called status epilepticus.

It can be managed by administering emergency medication. Emergency personnel or a nominated family member or carer can administer this emergency medication, which can give added peace of mind knowing you have this medication to hand. Talk to your specialist or epilepsy specialist nurse about emergency medication if you or someone you care for has had a prolonged seizure.

Sudden Unexpected Death in Epilepsy (SUDEP)

Although rare, sadly, people can die from epilepsy. This may be because of an injury or accident following a seizure. People can also suddenly and unexpectedly die, the cause of which may be linked to a suspected seizure. This is called SUDEP.

This is never an easy subject to talk about, but it is important information as there are certain factors that can increase the risk of SUDEP. These include having uncontrolled seizures, particularly tonic-clonic seizures, living alone, having seizures during sleep, and not taking anti-epileptic drugs as prescribed. Your epilepsy specialist nurse or neurologist will be able to explain these risks to you, and advise on what you can do to reduce the risk of SUDEP. You can also contact our helpline for support and general information about SUDEP.

Getting to know first aid

> *Speak openly to other people about your epilepsy and let them know how they can help you if you have a seizure.*

Make sure family, friends and work colleagues know basic seizure first aid so they can help you if you have a seizure. If you care for someone with epilepsy, find out what to do to keep them safe.

Seizure first aid is simple, and you do not need to be a qualified first aider to do it. As most seizures will stop on their own, they will not require any intervention.

This chapter will take you through the simple steps of keeping someone safe during and after a seizure. Our training courses also cover first aid for seizures.

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What to do

If you are with someone who has a **tonic-clonic seizure**, do the following:

- time the (convulsive part of the) seizure
- wipe away any vomit or saliva to keep the airway clear
- move any objects that could cause injury
- put something soft like a rolled-up jacket or cushion under the person's head
- loosen tight clothing around the neck
- remove any glasses
- reassure others and stop other people from crowding around
- if the person is a child, turn them onto their side during the convulsive phase, if this is possible

Once the convulsive (jerking) phase has stopped;

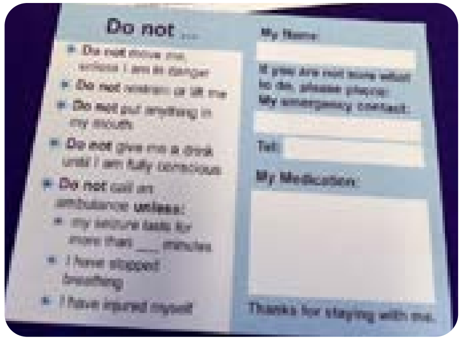
- maintain their airway by tilting their head slightly backwards, if possible
- check if they have injured themselves
- turn the person onto their side (recovery position)
- check nothing has blocked their airway, such as dislodged dentures or inhaled food
- stay with the person until their breathing and colour has returned to normal
- provide reassurance until fully recovered

Getting to know first aid

Some people carry medical identification such as a bracelet or necklace, or a small card. Check for this as it can give more information on the person's epilepsy.

We can also post you our free 'I have epilepsy' cards.

If you know the person has a care plan, this will give you more information about their seizures and if / when to give emergency medication.
The care plan usually also specifies who can give emergency medication and when to call an ambulance.



Do not …

My Name:

Tel:

My Medication:

Thanks for staying with me.

What not to do

- DO NOT move the person unless they are in danger, ie on a busy road or at the top of stairs
- DO NOT try to stop the convulsing or restrain the person
- DO NOT put anything in the person's mouth or between their teeth
- DO NOT offer the person anything to eat or drink until they are fully conscious and fully recovered

With all other types of seizure, simply stay with the person to keep them safe until they have fully recovered.

When to call an ambulance

It is not necessary to call an ambulance, unless:

- this is the person's first seizure as far as you are aware
- the person is badly injured
- the person may have inhaled food, drink or vomit
- the convulsions last for five minutes, or longer than is normal for that person
- one seizure follows another with no recovery time in between
- the person is having problems breathing after the seizure has stopped

Always phone an ambulance if you have any concerns.

Living with epilepsy

> *Give yourself time to adjust and remember you may have epilepsy but epilepsy doesn't have you. Live your life your way and take one seizure at a time.*

The previous chapters should have given you a better understanding of what epilepsy is, how it is diagnosed, what treatment options may be available and how you can keep yourself safe to reduce the risk of injury. You may now be able to recognise possible seizure triggers and know how you can use this information to better manage your epilepsy.

This chapter attempts to describe the impact epilepsy can have on a person's life. Remember, the better your seizures are controlled, the less impact epilepsy will have on your life.

Your first point of contact should always be your epilepsy specialist nurse, specialist or GP if you want to talk about any issues you experience. Our helpline can also offer you support and more information, as well as a listening ear and an opportunity to talk.

Emotional wellbeing

It is completely normal to feel a whole range of emotions after a diagnosis of epilepsy. You may be shocked, angry, upset or even depressed. You may be grieving for the life you used to have and the future you imagined for yourself.

Give yourself time to adjust, and most importantly time for your treatment to work.

Some people may find it difficult to move on from the initial shock and upset of a diagnosis.

Signs that someone is struggling include feeling sad most of the time, losing interest in the things they used to enjoy, change in appetite, having difficulty sleeping or feeling tired all the time. If this is the case with you or someone you care for, seek professional help.

It is important to bear in mind that many of the symptoms associated with depression can also be as a result of seizure activity or possibly side effects from anti-epileptic drugs.

Make an appointment with your doctor or contact your epilepsy specialist nurse or specialist to discuss this. You may be given the option of seeing a counsellor. In some cases, anti-depressant medication may be offered to you.

Our helpline **0808 800 2200** can also offer emotional support and further information on any local sources of support.

If you or someone you care for is feeling suicidal, get immediate medical advice. Some anti-epileptic drugs can make a person feel suicidal, but this will usually stop once the person has been taken off the drug and / or changed to a different drug by their specialist, if appropriate.

Until you get to speak to your doctor, phone our helpline 0808 800 2200, Breathing Space 0800 83 85 87 or the Samaritans on 116 123.

Living with epilepsy

Memory issues

Many people affected by epilepsy can experience problems with their memory. A seizure often affects a person's short-term memory. Some people with frequent and uncontrolled seizures can find it difficult to remember things from their past.

Memory issues often arise from seizure activity in the part of the brain which controls memory. People with temporal lobe epilepsy are more likely to experience memory loss as the temporal lobe is where memories are formed.

A person's memory can also be directly affected before, during and after a seizure. This could mean that events which happened shortly before a seizure will not be remembered. Or a person may not be able to retain information given to them in the recovery phase of a seizure.

Common side effects of some anti-epileptic drugs, like poor concentration or drowsiness, can also affect how well the memory functions.

If you have just started taking anti-epileptic drugs, give it some time. Any memory issues you experience either as a result of seizures or side effect of medication may lessen or even disappear once your seizures are brought under control and your body has become used to the medication. If memory issues continue, ask for a referral to a memory clinic for further testing and specialist advice.

Try focusing on one thing at a time, making lists and notes, using a camera to record events, or using smartphones for reminders. Stress and boredom can also affect your memory, so leading an active and healthy life can often help with memory issues too.

Confidence and self-esteem

The fear of having a seizure in public can make some people reluctant to go out on their own. If you are affected by this, you may feel more confident by asking a friend or family member to go with you. Make sure that person knows what to do if you have a seizure. Think about wearing a medical bracelet or necklace, or carry one of our epilepsy cards, which give details of your epilepsy, medication and emergency contact numbers.

Let those around you know how you feel, talk about it, and if necessary, seek professional help if you find yourself unwilling to leave the house.

Personal relationships

Having a supportive network of friends and family can make a big difference in the first few months after diagnosis. Your partner, family or friends may feel helpless and unsure as to what to say and do.

Being open and honest about how you feel will help them find the right way to support you. This means you may need to become more assertive about what you need from others.

Uncontrolled seizures or side effects of medication can sometimes change a person as their priorities shift. For a while you may need to be more focused on yourself. You may not have the energy to take on new responsibilities or carry out prior commitments. You may feel upset or even angry about having epilepsy and it is easy to take this out on others.

If you feel you need some help either alone, as a couple or as a family, ask your GP for formal counselling. A skilled counsellor can help you come up with coping strategies that will improve your personal relationships. If you do not know who to turn to, please phone our helpline on **0808 800 2200.**

Living with epilepsy

Women and epilepsy

Puberty, contraception, monthly periods, pregnancy, labour and menopause are all times in a woman's life which requires further expert advice. Seizure control may vary during times when hormones change, and some women find they have more seizures around the time of their period.

An epilepsy specialist nurse will be able to help you manage these times when you are at higher risk of seizures.

Most women with epilepsy will be able to have a healthy pregnancy and baby. If you are planning to start a family, always seek medical advice before you get pregnant.

This is to make sure your seizures are controlled as well as they can be, and that you are not taking an anti-epileptic drug, such as Epilim / sodium valproate, which can be harmful to your unborn baby.

Education

With good seizure control and no other associated problems, epilepsy will not usually have an impact on learning at school.

Children and young people who have frequent and uncontrolled seizures have a right to receive adequate and effective support in their education. These rights to additional support are covered by various pieces of legislation.

The Equality Act 2010 also makes it unlawful for education bodies to discriminate against a child or young adult for a reason relating to their disability.

A child or young person's epilepsy specialist nurse can often liaise with the education body and provide additional information and support to parents and teachers.

A child is much more likely to cope with their epilepsy if they are accepted and supported by teachers and the other children at school. Our free schools' awareness talks can help with this. To find out more, contact us on our helpline
0808 800 2200.

We also have dedicated resources for teachers, parents and children.

These can help increase understanding of epilepsy and enable teachers to positively support a child affected by epilepsy.

Work and career

Anyone affected by epilepsy has a right to be treated fairly when in employment or looking for work. Under the Equality Act 2010, an employer has to make reasonable adjustments to allow a person with epilepsy to safely carry out their duties and tasks in the workplace.

Generally, you cannot be discriminated against simply because you have epilepsy. A risk assessment carried out at work should take into account your individual risks in relation to your seizures and the tasks of the post. Only if work cannot be made safe with reasonable adjustments, is it then possible to be dismissed on health and safety grounds.

The Armed Forces are the only body not subject to the Equality Act. They are allowed to prevent anyone who has had a seizure over the age of five from joining.

Other professional careers, however, often have strict criteria and restrictions on justifiable health and safety grounds. If seizures are well controlled, there is usually no barrier to most jobs.

People whose seizures are frequent and unpredictable will need to think more carefully about the type of work they do and enlist the help and support of specialist employment agencies or disability employment advisers.

Our helpline can help with further information on rights and responsibilities under the Equality Act. If you need legal or employment advice we may be able to signpost you to another agency.

Driving

If you have had one seizure, no matter what kind, including an aura sensation, you must stop driving and by law notify the DVLA (Driving Vehicle Licensing Authority) of your seizure. You can either voluntarily surrender your licence or wait for the DVLA to formally revoke it. After twelve months with no seizures (with or without taking medication) you can apply to get your ordinary car licence back. In addition, your doctor will also need to be satisfied that you are safe to drive again. Different, often stricter rules apply for other types of licences.

We have a dedicated factsheet on driving and epilepsy.

Contact us on our helpline if you want a copy sent to you, or if you have any queries about seizures and driving. Calls to our helpline are strictly confidential.

Anyone who has only sleep seizures but never any seizures while awake will usually get their licence back after a qualifying period even if they continue to have sleep seizures. For one off or provoked seizures, the DVLA can apply some discretion which means a person may get their licence back sooner than the required one year.

Losing a driving licence can often have a considerable impact on work, social and family life. If you have to give up your licence due to epilepsy, you will be entitled to a free nationwide bus pass in Scotland. Have a look at the chapter ‘Entitlements and benefits’ for more information on this.

Entitlements and benefits

> *At the time it feels like you are the only person to deal with it! But there is always so much support.*

No two people are affected by epilepsy in exactly the same way. For one person it could mean complete seizure control with medication, for another frequent and uncontrolled seizures, and possibly linked to other health conditions.

What welfare benefits and support a person may be entitled to will depend on how epilepsy affects that person on a day to day basis. Getting advice from professional benefits experts is crucial to getting the best possible outcome.

Free Scotland wide bus pass

Anyone in the UK aged 16 and over who has had a seizure in the last 12 months and is receiving treatment for epilepsy will be entitled to a free Scotland wide bus pass (National Entitlement Card). Some people may get a companion card if they are in receipt of certain benefits. A companion card will allow another adult to travel with them free of charge.

A child or young person of fare paying age (aged five and over) but under 16 can also get a companion card if they are in receipt of qualifying benefits. There are plans to extend the availability of companion cards to children under five, but the legislation has not come into force yet.

The bus pass is usually valid for one year, after which time you can get it renewed if you have had one seizure in the last 12 months. We can send out relevant forms together with information on how to apply to anyone who lives in Scotland.

Contact our helpline for updates and latest information on the bus pass.

Disabled Person's Railcard

Anyone in the UK who has epilepsy and who still has regular seizures despite taking anti-epileptic drugs, will be entitled to a Disabled Person's Railcard. You have to buy this card for a yearly fee which then gives you one third off train fares for travel across the UK. An adult travelling with you will also get one third off the fare.

Entitlements and benefits

Welfare benefits

Entitlement to welfare benefits will depend on how a person is affected by their epilepsy on a day to day basis, and their personal circumstances. Unpaid carers may also be entitled to financial help.

Important: please seek advice from a professional benefits adviser such as your local Citizens Advice Bureau or a welfare rights service before you complete any benefits application forms to maximise your chances of success.

Some benefits such as Personal Independence Payment or Disability Living Allowance are not means tested which means that even if you are in full-time employment you may be entitled to it.

Taxi card scheme

Some local authorities in Scotland will provide a taxi card for those who have permanent and severe mobility issues. If these stop you from using public transport and you have no other means of transport, you may get this card, allowing you to travel by taxi at a reduced fare. You need to contact your own local authority to find out about potential taxi schemes in your area.

Blue Badge scheme

This scheme is designed to help people with severe mobility and other problems to travel independently as either a driver or a passenger. The badge allows you to use special disabled parking spaces and to park where other drivers cannot. Your local council can give you more details on this scheme and how to apply for a Blue Badge.

Getting further help and support

> “ *Ask for help - there are lots of lovely people out there!* ”

The most important message we want to give you is that you are not alone. We can be your first point of contact for any enquiries.

If you do not know who to turn to, simply need to talk, or want to find out about our services and the help and support we can provide, please contact us on our helpline **0808 800 2200**, email us at **contact@epilepsyscotland.org.uk** or contact us via social media.

We will provide you with a safe and non-judgmental space to talk and ask questions.

We can also tell you about other services and support that may be available in your area.

We also have a wide range of information leaflets, which are free to download from our website **www.epilepsyscotland.org.uk**, or free to request from us.

We are here to support and guide you through this journey.

Helpline: 0808 800 2200
Text: 07786 209 501
www.epilepsyscotland.org.uk

Epilepsy Scotland,
48 Govan Road, Glasgow G51 1JL
General enquiries: 0141 427 4911
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