



Getting on with life





SOME

55,000 PEOPLE

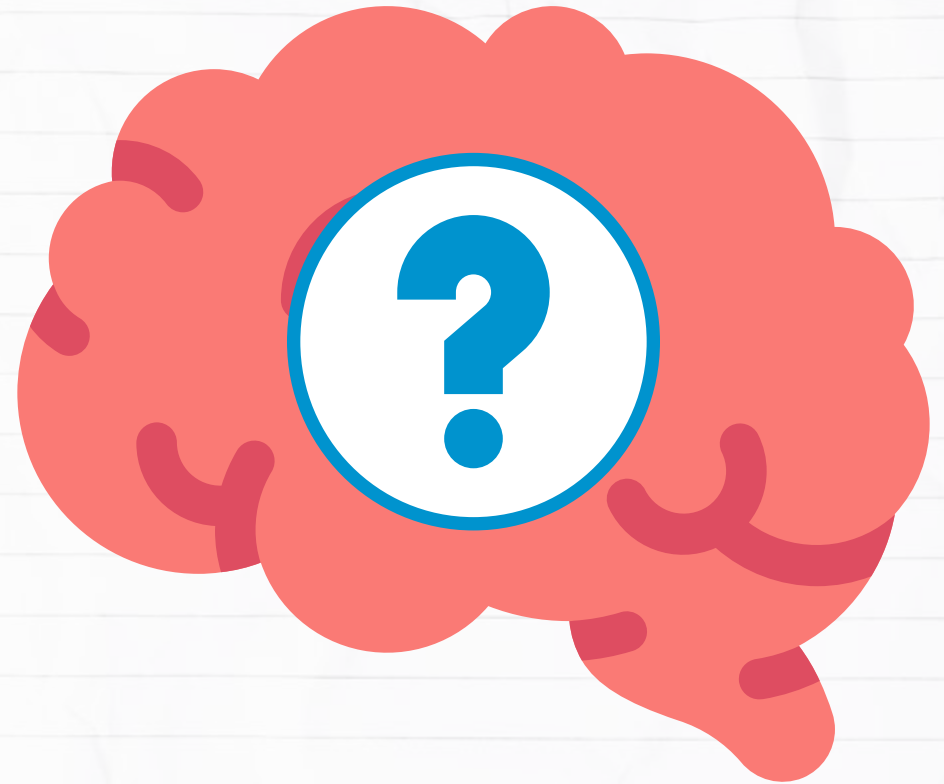
in Scotland have epilepsy,
so you are not alone.

If you have just been diagnosed with epilepsy or have had it for a while, this booklet is for you. It will help you understand epilepsy better.

If you need to talk and don't know where to turn to, please get in touch with us. We are here for you.

You can find us on Instagram, Twitter, Facebook and TikTok.

We also have a confidential and free helpline
0808 800 2200.



What is epilepsy?

Epilepsy is a condition which affects the brain.

It is often referred to as a neurological condition. Epilepsy is usually diagnosed if you have had more than one seizure which starts in the brain.

A seizure is like a temporary electric storm in your brain.

Are all seizures the same?

No, you can have many different types of seizures, and every person experiences a seizure in a different way.



Generalised seizures

You can have generalised seizures which affect the whole of your brain. With a **generalised seizure** you always lose consciousness, even just for a split second.

This can be a **tonic-clonic seizure**, where you suddenly fall down and start jerking. Some people wet themselves during a tonic-clonic seizure. You can't help it when this happens.

An **absence seizure** is also a generalised seizure.

They look a bit like the person is day-dreaming. Usually people recover quickly from an absence seizure, but they can still feel out of sorts for a while.



Focal seizures

You can also have seizures that affect only one part of the brain.

These are called **focal seizures**.

During a focal seizure you may be fully aware that you are having a seizure but can't stop it.

If a bigger part of your brain is affected by the seizure, you are likely to be very confused. You won't know what is going on around you, but you are still conscious. You may make repetitive movements or noises and might not make much sense when you talk.

These are now called '**focal seizures with impaired awareness**'. Some people still call this type of seizure by their old name, which is '**complex partial seizure**'.

There are many more different kinds of seizures.

Some people have a mixture of different seizures.



Why does epilepsy happen?

Many people are born with it and doctors cannot find a clear reason why they have it. They might, however, suspect there is a genetic link. Genetic does not always mean it's inherited.

Genetic can also mean that there have been genetic changes during your lifetime which can lead to epilepsy. However, some people may have epilepsy because one of their parents or someone else in the family has it.

You can also develop epilepsy if you have had an accident causing a serious head injury. A brain tumour or a bleed on the brain can also cause epilepsy.



What's it like having a seizure?



Some people talk about feeling **weird, dizzy, tired** or **spaced out**.

You may not really feel like doing anything. You may feel **scared** or **confused** because you have no control over how you feel. You may be **upset, angry** or **depressed** after a seizure. Some people feel embarrassed by their seizures. You can also feel **sick** or have a **headache** after a seizure. All of this is completely normal.

Some people may not be able to talk properly for a while after a seizure.

Most people recover from a seizure after a few hours, but for some it can take several days before they feel normal again.

If you have hurt yourself during a seizure, then recovery may take longer.

Is there anything I can do to stop my seizures?

Yes and no. Some seizures just happen, and there is nothing you can do to prevent or stop it.

The most important and most effective thing you can do is take your medication every day exactly as prescribed by your doctor.

You can also try to find out if there is a trigger for some of your seizures. A trigger is something that makes a seizure more likely to happen.

If there is, then you may be able to get help with your triggers. This could mean fewer seizures for you.

What can trigger a seizure?

Here are some of the common things that can trigger a seizure:



Forgetting to take your medication or taking it much later than usual



Drinking alcohol or taking recreational drugs



Not sleeping well or feeling tired



Drinking high energy drinks which contain lots of caffeine



Feeling stressed or anxious



Not eating regularly, having low blood sugar



Not feeling well, having the flu, running a temperature



Monthly period (for women)



Not drinking enough water / fluid



Flashing or flickering lights (this only affects some 3% of people with epilepsy)

Start by writing down or using a seizure app to record any seizures you have. Also make a note of what may have happened before your seizure.

For example:

Did you not sleep well?

After a while you might notice that it's often the same thing that triggers a seizure.

Did you forget to take your medication?

Some triggers are less clear, and it's not always easy to spot them.

Did you feel unwell?

Some people don't have any triggers for their seizures.

Did you stress out over something?

For girls, did you have your period?

Is having a seizure dangerous?

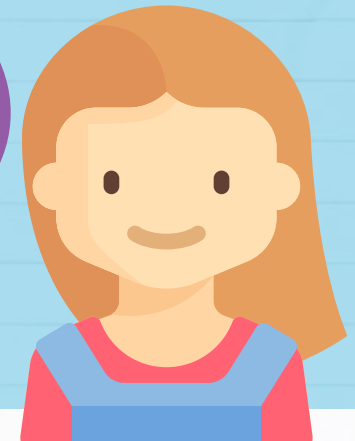
When you have a seizure, there is always a risk of hurting yourself. This risk might be smaller if you get a warning before a seizure because you have time to sit down or take yourself to a safe space. The risk of injury is also smaller if you stay conscious during a seizure.

The fewer seizures you have, the less of a risk there is for you. First and foremost, keep taking your medication. Your medication is there to help prevent seizures. You might not like taking medication every day, but they will help keep you as safe as possible.

If you still have seizures, you need to think about what could happen if you have a bath on your own. It only takes a few inches of water to drown during a seizure. It really isn't worth the risk. Have a shower instead if you can.

If you do want to have a bath, you must make sure an adult is always there with you. This person must be able to hold your head above water during a seizure. Privacy is important for all of us but so is your safety. This is one area where you may need to compromise.

Your epilepsy specialist nurse will keep you right with more safety advice. You can also contact us for lots more information.



Keeping yourself safe during a seizure

It's important that the people you are with, such as your friends and family, know what to do if you have a seizure. First aid for seizures is not complicated, everyone can do it. Here's what someone can do to help.

Make sure you pass this information on:

If the seizure is **NOT a tonic-clonic seizure**, ie there is no jerking, just stay with the person. Make sure they are safe and ok. Wait until they have fully recovered.

Only gently move them if they are in danger, for example if they happen to cross a road while having a seizure.

If the seizure is a **tonic-clonic seizure**, which means you suddenly lose consciousness, fall down and start jerking, do the following:



Time

Check the time to see how long the jerking part of the seizure lasts



Injury

Move anything away from the person that could cause an injury



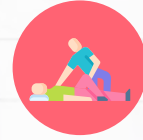
Cushion

Put something soft under the person's head, this could be a rolled-up jacket



Safety

Loosen any clothing round the neck, and remove glasses



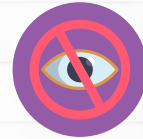
Recovery

Turn the person onto their side



Breathing

Tilt the head slightly back, this will help the person breathe better



Privacy

Stop anyone from watching, make sure the person has some privacy



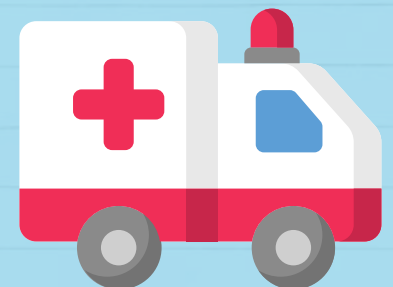
Stay

Stay with the person until they have fully recovered

There is no need to call 999 for an ambulance every time.

You would only do this if:

- the seizure lasts longer than five minutes
- if the person has seriously injured themselves during a seizure
- if they were in the middle of eating or drinking and may have inhaled food or drink



Facts not fiction!

Time to bust some myths about epilepsy:



Facts

Never put a spoon in a person's mouth during a seizure!

This could be dangerous.

Never hold a person down while they are having a seizure!

You could hurt the person.



Fiction

"Epilepsy is contagious"

No, it isn't. You can't catch epilepsy from helping someone who has a seizure!

"You can swallow your tongue during a seizure"

No, you can't. It is impossible to swallow your own tongue!

You need to take this medication every day. If you forget to take it, even just once, you can have a big seizure. This is because you no longer have enough of the drug in your system to prevent a seizure.

There are other ways of treating epilepsy too. Some

people might be suitable for surgery. Some people have a small device called the Vagal Nerve Stimulator (VNS) implanted. Some people follow a special diet called the Ketogenic diet. Epilepsy is unique to the person who has it. What works for one person may not work for another.

Does my medication have side effects?

Anti-epileptic medication can have side effects, just like any other drug. Even medications you can buy over the counter from your chemist have side effects.

Common side effects are tiredness, low energy, feeling spaced out, mood swings, weight gain or weight loss. Not everyone has the same side effects.

Your body needs to get used to the medication and you will find that side effects will often get easier over time. If you have side effects which

you find difficult to cope with, speak to your epilepsy specialist nurse.

Some anti-epileptic drugs can make you feel very low in mood. Some people can even feel suicidal, but this does not happen often. If this happens, let an adult know. It's not always easy to talk about these things but you must not bottle this up. The good news is that when your medication is changed, you will often feel better again.

Is there a cure for epilepsy?

There is no cure as such for epilepsy, but seizures can often be prevented by medication. Many people will be seizure-free on medication.

When you are diagnosed with epilepsy, your specialist will usually prescribe anti-epileptic medication.

They work by preventing the electric storm in your brain which causes a seizure.



z z The importance of sleep



Avoid late nights. Try and switch off any mobile devices one hour before you go to sleep. This is because the blue light emitted from mobile devices can stop you producing melatonin. This is a hormone we all need for good sleep. If your phone or device has a blue light filter, switch this on.

Give yourself some down time before you go to bed. Switch off the TV and put down your phone. This will help you sleep better. If you have problems sleeping, talk to your epilepsy specialist nurse or doctor. A sleep counsellor may also be able to help.

Feeling tired, or not sleeping well can trigger a seizure in some people. Even if tiredness is not one of your triggers, good sleep is important to keep you well and healthy. It can also make a difference as to how well you cope with your epilepsy.

Feeling stressed or anxious

Being diagnosed with epilepsy can sometimes feel like your world's been turned upside down. It's normal to feel upset, sad, stressed, anxious or even angry. If you are struggling to cope, there is no shame in admitting this.

Speak to people you trust. This could be a member of your family, a teacher or your epilepsy specialist nurse. Let them know how you feel and let them help you.

You may find that once you open up to others, you feel better about yourself and your epilepsy. You are not alone. This is how many young people (and adults!) feel when they have been diagnosed with epilepsy.

It can also help to find out as much as you can about epilepsy. When you understand a medical condition, it can feel less scary, and you may feel more in control of your life.



What to do if you are being bullied

You will find that most of your friends and classmates will want to help and support you if you are having a tough time with your epilepsy and seizures.

Bullying is never ok. If you experience bullying or online bullying, this can make you feel intimidated, sad, lonely or even scared. You've done nothing wrong. It's not your fault.

There are many ways you can deal with bullies. Bullies want to see you react. They want to see you upset. If you can, don't react, walk away, block them online. If they don't get a reaction from you, they often lose interest, and you take away the power they have over you.

Speak to an adult you trust. You can also phone a bullying helpline such as National Bullying Helpline **0300 323 0169** for more support and help.

How else will having epilepsy affect me?

Having epilepsy means different things to different people.

If your seizures are well controlled by medication, life is not likely to change much for you. Even if your seizures are not controlled, with some sensible precautions to keep you safe, life can still be exciting and good.

Here are some common questions we hear a lot:

Q Why is my memory so bad at the moment?

When you have a seizure, your memory gets interrupted. This means that you may not be able to remember what's happened before the seizure. You may also find it difficult to remember any information given to you immediately after a seizure. People with epilepsy often have some difficulty with their short-term memory. Memory often improves when your seizures are better controlled.

Q Will I ever be able to drive?

Having epilepsy does not mean you will never be able to drive! As soon as you have been seizure free for one full year, and of course provided you are old enough, you can apply for your provisional driving licence.

Q Can I go clubbing?

Yes, you can, provided you are old enough of course. If your seizures are triggered by flashing or flickering lights (this is called photosensitive epilepsy), you may need to avoid clubs and places that use strobe lighting.

Stay safe, don't drink too much alcohol (if you are 18 and over) and don't do recreational drugs. Never ever skip your medication before you go out! This can put you at risk of a serious seizure.

Q What jobs will I be able to do?

This is a difficult question to answer because it depends on your own epilepsy. Remember, epilepsy affects every person in a different way.

If you have had a seizure after the age of five, you can't join the Armed Forces.

There will be other professions which may be off limits to anyone who has seizures, such as train drivers or pilots. You should also avoid jobs which involve working at heights, with machinery or on open water.

But there are plenty of jobs anyone with epilepsy can do safely and effectively. Don't let epilepsy dampen your dreams. Think big and seek careers advice when the time is right.

Q Can I still be active?

Yes, you can! In fact, staying active and exercising is good for you. If you feel healthier in general, this may make you feel better about your epilepsy or even reduce your seizures.

There are some sports and activities you may need to think a bit more carefully about before you do them. Your epilepsy specialist nurse can give you more information on what is safe for you.

For example, if you love swimming, speak to the lifeguard and let them know you have epilepsy so they can keep an eye on you. Or you may want to swim with someone who can keep you safe if you have a seizure in the swimming pool.

If you love riding a bike, avoid busy roads or cycling along a canal, just in case you have a seizure. It's always a good idea to take someone with you. Always wear a helmet!

So, whatever your favourite activity or sport is, speak to an adult, find out how you can make it safe, then go for it.

What else is there to help me?



Youth groups

Here at Epilepsy Scotland we currently have two youth groups which meet in Edinburgh and Glasgow, and an online youth group open to anyone living in Scotland. Get in touch with us to find out more. We also offer one to one support by phone, in person or online.



Seizure diaries

Your specialist will want to see how many seizures you have, what kind they are, and when they happen. This helps them find out if your medication is working. Recording your seizures in a diary is one way of keeping a record. We have free seizure diaries for you. All you need to do is contact us.



Apps

You can get apps that allow you to record your seizures. You can also get apps where you can check in with family and friends to make sure you have arrived somewhere safely. This might give you a bit more independence. Parents always worry, and they may feel happier knowing you are safe.



Epilepsy cards

Some people find it useful to have a small card on them that tells others they have epilepsy. The card also has space to write important information such as who to contact in an emergency. These free cards are available from us.



Bracelets or necklaces

There are types which show you have a medical condition. They are a bit more visible than a small card in your pocket. We can tell you where to get one.

I need more help!

If this leaflet leaves you with even more questions, don't panic, get in touch with us.

We are on **Instagram, Facebook, Twitter and TikTok**, and you can private message us for a chat. Speak to us, and don't believe everything you read online. We want you to get the right information.

You can also email us at
contact@epilepsyscotland.org.uk.

And there is our helpline on **0808 800 2200.**
It can be a big step asking for help.



**Do it, contact us, we are all friendly and want to help.
It's good to talk.**

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