

epilepsy *action*

Your epilepsy



[epilepsy.org.uk](https://www.epilepsy.org.uk)
Epilepsy Action Helpline: 0808 800 5050

About epilepsy



Having seizures or a diagnosis of epilepsy can be a confusing and worrying time.

Epilepsy Action is here for you. **Go to page 8 to see some of the ways we can help.**



This booklet can help you to find the information and support that you need. Some of it might be helpful now, and some of it might be helpful in the future. You might also want to share it with friends and family.

Our website has a whole section called 'About epilepsy'. You can visit the website here: **epilepsy.org.uk/info** or you can scan this QR code to go straight there. Each page is printable.

Some of the topics we cover include:

- Getting a diagnosis
- Seizure triggers
- First aid for seizures and planning for seizures that last too long
- Epilepsy medicines and other treatments
- Sudden unexpected death in epilepsy (SUDEP)

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“ Although it has been hard to accept that my epilepsy may be permanent, I have developed willpower and feel mature, confident and comfortable in who I am. ”

Tayyibah, Coventry

What is epilepsy?

Epilepsy is a condition that affects the brain and causes seizures.

Epilepsy is one of the most common neurological conditions in the world. It affects around 630,000 people in the UK.

This means that around 1 in 100 people in the UK have epilepsy. Around 80 people are diagnosed with epilepsy in the UK every day. So there's a big community of people who can help and support you if you need it.



**We run face-to-face
and online Talk and
Support groups:
[epilepsy.org.uk/
support](https://epilepsy.org.uk/support)**

Why do I have epilepsy?

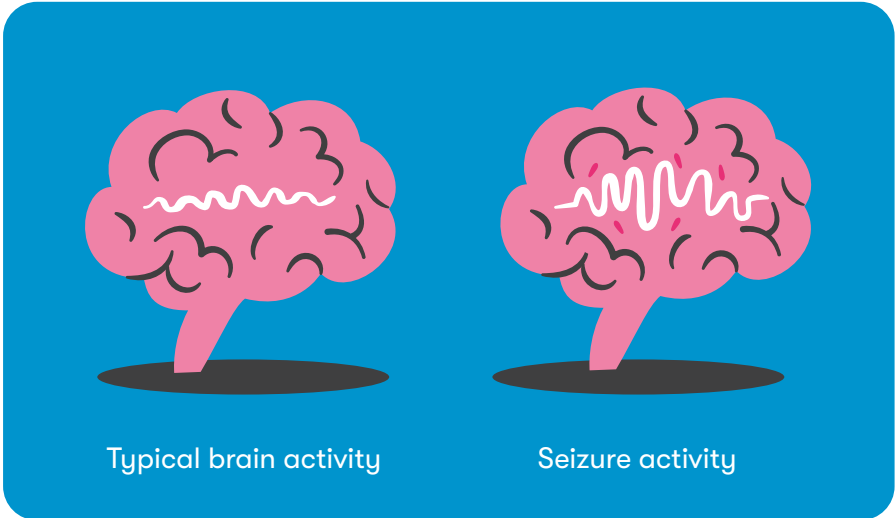
It might be a shock to find out you have epilepsy. It can affect anyone at any age and there are lots of different types. For around a third of people with epilepsy, doctors don't know what causes it. Some possible causes include:

- Brain damage, for example damage caused by a stroke, head injury or infection
- Brain tumours
- The way the brain developed in the womb
- A genetic cause

Researchers have found a number of genes linked to particular types of epilepsy. There are many types that doctors think are likely to be genetic, but they don't yet know which genes are involved. If your epilepsy does have a genetic cause, this doesn't always mean it can be passed on (inherited) to your children.

What are seizures?

Electrical activity is happening in our brains all the time, as networks of tiny brain cells send messages to each other.



These messages control all our thoughts, movements, senses and body functions. A seizure happens when there is a sudden, intense burst of electrical activity in the brain. This causes the messages between cells to get mixed up. The result is an epileptic seizure.

There are many different types of seizures and you might have more than one type.

When people think of epilepsy, they often think of tonic-clonic seizures where a person falls to the floor and their whole body shakes (convulsions).

But there are many other types of seizure. With focal seizures, one part of the brain is affected. You might be aware of what is happening during the seizure, or you might be totally unaware until the seizure ends.

Some types of seizure might cause you to have sudden muscle jerking (myoclonic seizures), or your body might become very stiff (tonic), or your muscles relax all at once (atonic). You might have absence seizures where you appear distant for a moment.

A wide range of symptoms can happen during a seizure. Some people have only one symptom while others experience several. The part of brain the seizure affects has an impact on what happens during a seizure.

You might feel strange sensations (this is sometimes called an aura, which is actually a type of focal seizure) before the seizure happens, or you might behave in an unusual way before, during or after seizures.

Seizure triggers

Some people notice triggers that can make a seizure more likely. Some common ones are stress, lack of sleep, not taking epilepsy medicines regularly, or their monthly period cycle (catamenial epilepsy). There are others and you can find out about these and how to avoid triggers on our webpage: [epilepsy.org.uk/triggers](https://www.epilepsy.org.uk/triggers)

Being diagnosed with epilepsy

We have lots of information on our website about the steps you might go through while being assessed for epilepsy. You should be referred to an epilepsy specialist, usually a neurologist (for adults) or a paediatrician (for children). If it's not mentioned, you could ask if there's an epilepsy clinic or Epilepsy Specialist Nurse in your area.

Epilepsy Action has lots of ways to support you and your family if you are diagnosed with epilepsy.

Scan the QR code or go to our webpage **epilepsy.org.uk/newdiagnosis** to read about:



- Preparing for your appointments
- The tests you might have, like EEG or MRI tests
- Managing your epilepsy
- Support for you

“The support of my family and friends has helped me through the many challenges I’ve faced and has helped me to live a ‘normal’ life.”

Harry, Wrexham



If you need advice, information or support with epilepsy, Epilepsy Action is here for you.



If you want to talk to other people about life with epilepsy, you're welcome to come to one of our **talk and support** groups to meet and share your experiences either online or face-to-face.

talk and support



Not everyone's ready for a group, though – one-to-one support through **befriending** might be better for you. We'll connect you to a volunteer who will offer you a friendly listening ear either on the phone or online.

befriending



Counselling can be really helpful when things get tough – we're ready to help in Wales and Northern Ireland. Our professional **counselling** team can provide the support you need online or over the phone.

counselling



Epilepsy doesn't just affect the person with the diagnosis – that's why our **family support** service is there for family members and carers in Northern Ireland.

family support Northern Ireland



helpline

Epilepsy can be very confusing. Our [helpline team](#) are ready to answer any questions you might have on the phone, via live chat or email.

Freephone 0808 800 5050

Email helpline@epilepsy.org.uk

epilepsy.org.uk/helpline

Staff are text relay trained and able to offer advice and information in 150 languages, via an interpreting service.

Live chat

Visit epilepsy.org.uk to chat with a member of the helpline team. We usually reply to chat requests within 2 minutes.



“ I found Epilepsy Action in January 2020, but I wish I’d found them sooner. I’ve learnt so much about epilepsy and about myself, which has been a relief. ”

Anne, Fermanagh

How is epilepsy treated?

For around two thirds of people with epilepsy, their seizures can be controlled with epilepsy medicines. It can take some time to find the right medicine for you, as there are lots of different types available and everyone's situation is different.

Your specialist should explain which medicines may be suitable for you and tell you about any possible side effects or risks.

Some seizure medications, such as sodium valproate, can cause harm to babies during pregnancy. We have more information about this here: [epilepsy.org.uk/living/having-a-baby](https://www.epilepsy.org.uk/living/having-a-baby)

It's important to not stop taking your medication without speaking to a medical professional first.

If medicine does not work well for you, your specialist might suggest some other treatment options, like surgery, vagus nerve stimulation or a special medical diet (ketogenic). Scan the QR code or visit our website to find out about these.



We have many different webpages about all of these topics and more:

- Managing side effects
- Taking epilepsy medicines while you are pregnant
- Switching between medicines
- Medical cannabis
- Being referred for surgery
- What to expect if you live in different parts of the UK, including Wales and Northern Ireland
- Complementary treatments

Amanda's story

“ When I had my first seizure, everything turned upside down... the road to being fully diagnosed was a long one. I just wanted to get it under control as it really impacted me quite hard.

I really needed someone to help me through that early period. When I got in touch with Epilepsy Action, I didn't have a clue what I was asking for, I just knew that I needed some help. They really listened and really understood what was going on.

Thanks to Epilepsy Action and my support networks I now feel like I'm getting there and I am hopeful about my future.”

Amanda, Wallsend

You may have lots of questions about your epilepsy and your treatment options. You could ask your specialist about talking to an epilepsy specialist nurse. They can answer your questions and give you practical advice on things like managing side effects, or reducing your risks.

Living with epilepsy

Epilepsy is more than just seizures. It can affect all aspects of life, including work, education, driving and relationships. This can be hard to manage. On top of your physical symptoms, you may need support with your mental health.



Our website has a whole section called ‘Living with epilepsy’. You can visit the website here: epilepsy.org.uk/living or you can scan this QR code to go straight there. Each page is printable.

Safety, risk and daily life

There are some things it is important to know. Depending on the type of epilepsy you have there could be some risks, and if you know about these you can take steps to lower your risk. We have a lot more information about this on our website, but here’s an introduction to some of the topics:

Safety

Seizures can put you at risk of accidents and injury, so it’s a good idea to think about safety. You’ll often



find you can still do things you enjoy, with some simple measures to reduce any risks.

You might want to carry an ID card to help people know what to do if you have a seizure. You can order these or print them from our website: **epilepsy.org.uk/IDcard**

You might want a more detailed summary of your epilepsy and how you manage your seizures by completing a care plan. We have a blank one that you can fill in: **epilepsy.org.uk/careplan**

Work

You don't automatically have to tell your employer about your epilepsy, if you don't believe it will affect your ability to do your job safely and effectively. But if you do tell them, they must put in place reasonable adjustments that would reduce or remove any disadvantage caused by your condition.

If there's a chance you'll have seizures at work, it's a good idea to draw up a seizure action plan with your employer. Epilepsy Action has an employment toolkit and a seizure action plan template that you can fill in together: **epilepsy.org.uk/work**



Status epilepticus

Status epilepticus is when a seizure lasts a long time or when you have one seizure after another without recovering in between. It is a medical emergency that can happen with any type of seizure.



A tonic-clonic seizure lasting more than 5 minutes, or going from one seizure into another without recovering in between, needs urgent medical attention.

For some people who are at high risk, emergency medicine is sometimes prescribed to use in case of status epilepticus. You would also need a care plan and someone trained to give the medicine. We have more information about this on our webpage.

Non-convulsive status epilepticus can also be very serious for some people, depending on the cause of the seizure.

SUDEP

SUDEP is the sudden unexpected death of someone with epilepsy.



SUDEP is rare, affecting around 1 in every 1,000 people with epilepsy each year. This figure is for people with epilepsy in general. Your individual level of risk will depend on what type of seizures you have and how well-controlled they are.

Although it may feel worrying, it's important to know about all the possible causes of epilepsy-related death. Knowing about the risks means you can take steps to reduce your risk and keep yourself as safe as possible.

No one knows the exact cause of SUDEP and there may be no single explanation. Research shows that it is connected with seizures, particularly tonic-clonic seizures. It is thought that a seizure may sometimes lead to changes in the person's heart rate or breathing.

Visit our webpage to find out more about reducing your risk of SUDEP.



Seizure diaries can be a really helpful way to understand more about your epilepsy.

You can use it to identify what types of seizures you're having and when, and what might possibly be triggering them.

epilepsy.org.uk/diary

How should I feel?



Having a diagnosis of epilepsy can come as a shock, and living with seizures can be hard at times. People respond to this in different ways and there is no 'right' way. If you feel stressed, anxious or depressed, we have more information about how to understand and manage these:

- **Low mood depression and epilepsy**
- **Anxiety and epilepsy**
- **Fatigue and tiredness**
- **Stress and epilepsy**

“After being diagnosed, I became withdrawn. I thought I’d never be able to do the things a normal teenager does.

But, I proved people wrong. I began to do all the things anyone without epilepsy would. Now, I have a job doing something I love and I’m planning my wedding. I have epilepsy. Epilepsy does not have me.”

Megan, Liverpool



Talking to your medical team about your feelings is a good place to start, as they may be able to offer support or treatments. As well as this, having a good support network can really help.

Looking after your wellbeing can help you to have as few seizures as possible. It can also improve how you feel about having seizures. Some things you can do to improve your wellbeing are:

- Eat a well-balanced diet
- Get active
- Limit how much alcohol you drink
- Have a good sleep routine
- Take your epilepsy medicine as prescribed
- Recognise and avoid your seizure triggers



Depending on individual circumstances, people with epilepsy are entitled to certain benefits. These might include a Disabled Person's Bus Pass and Railcard, a Blue Badge, freeprescriptions and Personal Independence Payments or Universal Credit.

**We have more information about benefits
epilepsy.org.uk/living/benefits**

Our wellbeing course...

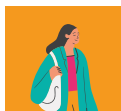
Epilepsy and your wellbeing is a **free** online course for people with epilepsy. It's designed to help you manage your epilepsy and take steps to improve your wellbeing.

It's packed with tips, tools and information to help you feel good and function well.

Find the course at epilepsy.org.uk/wellbeing or scan the QR code below:



You will learn about:



How wellbeing links to epilepsy



Ways to manage epilepsy



Coping with stress



Physical and mental health



Next steps for you



If you are feeling that life is too much, contact the Samaritans on 116 123 or text 'Shout' to 85258. They are both available any time, day or night. If you need help straight away, call 999.

What else could epilepsy affect?

Memory

A lot of people with epilepsy have problems with their memory. This could be because of seizure activity, side effects of epilepsy medicines, or an after effect of surgery. Our webpage has more details on the causes of memory issues and tips on how to manage this: epilepsy.org.uk/memory

Driving

If you have a driving licence, or want to get one, you need to tell the driving agency about your epilepsy. Many people with epilepsy are able to drive, as long as they meet the driving rules for their type of seizures.

You can find out what to do if you're told to stop driving, the rules for when you can drive again, and how to apply or reapply for your licence: epilepsy.org.uk/driving

Epilepsy Action members understand what it means to live with epilepsy, and you're invited to join the community, the biggest of its kind in the UK.

If you'd like to get a free copy of our member magazine, *Epilepsy Today*, you can at: epilepsy.org.uk/freemagazine



Ellie's story

“ I was suddenly diagnosed at 21, after having a tonic-clonic seizure one morning. My life completely changed.

I felt angry, frustrated and confused, but Epilepsy Action has provided endless amounts of information to me from the first seizure to today.

I'm now six years into a career helping people with their finances. I've made good progress and feel more optimistic about the life I now live. People should know that, despite epilepsy, you can continue to live as the best person you can possibly be; hopefully helping others on the way.”

Ellie, Oxford

We have lots of other pages to help you understand and manage your epilepsy. Here are a few examples:

- Sex and contraception
- Pregnancy, birth and looking after a baby
- Periods
- Menopause
- Bone health
- Epilepsy syndromes
- Seizure triggers
- First aid and looking after someone while they are having a seizure
- Seizure alarms
- Just for kids
- Epilepsy Space
- Employment toolkit
- Epilepsy and learning disabilities
- The latest epilepsy medicines news (Drugwatch)
- Fasting
- Drinking alcohol
- Epilepsy and your rights
- Epilepsy training
- Support for school staff
- Stories for children

People with epilepsy helped to make this booklet. This is what they'd like to say to you:

“ We know that epilepsy can be scary and isolating, but it's also important to remember that you're not alone.

The good news is that this information and support is here for you. Many of us had our epilepsy diagnosis a long time ago and wish we'd had this sort of information back then.

It would have helped us to understand our seizures and we could have used it to educate others. We often found that people would give us the wrong information – or even the wrong medication.

But things have come a long way and people now have every reason to be hopeful.

We've each met some brilliant specialists who have given us good and practical advice. Some of us have been seizure free for years, and don't really feel the impact of epilepsy day-to-day. There may not be a 'quick fix' for your epilepsy, but stick with it because if you follow the medical advice, the chances are life will be relatively normal.

We'd also encourage you to embrace the support Epilepsy Action offers – talking to others who really understand what epilepsy means can make such a big difference. Epilepsy isn't always easy, but by sharing experiences, advice and companionship, you can learn to understand, accept and see life beyond epilepsy.

We hope you found this information helpful. ””

Chris, Christine, Tony, Anthony, Sally, Fiona, Mark, Martha, Rachel and Ruthanna



Get involved with fundraising, volunteer with us or take part in research

There is a huge community of people out there supporting people with epilepsy, through volunteering, fundraising and more. And you're welcome to be part of that community – there are so many ways to get involved.

Go to epilepsy.org.uk/get-involved when you're ready to get started.

It can be difficult to keep track of all the information relating to your epilepsy. Use this page to jot down any important details, or questions you might want to ask someone.

Notes / Questions I have:

If you have tonic-clonic seizures, you might want to share this video with your friends and family. It explains the simple steps to follow to keep you safe during and after a seizure: **[epilepsy.org.uk/care](https://www.epilepsy.org.uk/care)**



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Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
tel. 0113 210 8800 **email** epilepsy@epilepsy.org.uk **[epilepsy.org.uk](https://www.epilepsy.org.uk)**
Got any thoughts about this booklet? Share them with us at:
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