

Epilepsy: an introduction



Epilepsy Action – together we can change lives

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

Together we can:

- Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
- Run local events and support groups, so that fewer people have to face epilepsy alone
- Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

It's only your support that can make this life-changing work possible.

Please donate today.

You can call the Epilepsy Action fundraising team on 0113 210 8851 or donate online at **epilepsy.org.uk/donate**
You can also stay up-to-date with all the latest epilepsy news and information by joining Epilepsy Action. Membership starts from just £1 a month - join today by calling 0113 210 8800 or sign up online at **epilepsy.org.uk/join**

Thank you.



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Introduction

If you or someone you care about has just been diagnosed with epilepsy, then this information is for you. You might have questions about what epilepsy is and how it's treated, or about living with the condition. We hope this booklet helps to answer some of those questions.

We asked people with epilepsy about their experience of living with the condition, and what advice they would give to someone who has just been diagnosed. You can read their comments throughout this booklet.

If you would like to know more about any of the information in this booklet, or would like to talk to someone about epilepsy, the Epilepsy Action Helpline is here for you. See page 27 for ways to contact us.

What is epilepsy?

Epilepsy is a condition that affects the brain. When you have epilepsy, it means you have a tendency to have epileptic seizures.

Anyone can have a one-off seizure, but this doesn't always mean they have epilepsy. You will usually only be diagnosed with epilepsy if your doctor thinks that there is a high chance you could have more.

Epilepsy can start at any age. There are many types of epilepsy. Some types last for a short time, and some types can last for the whole of your life.

How common is epilepsy?

Epilepsy is one of the most common serious neurological conditions in the world. Epilepsy affects around 630,000 people in the UK. This means that around 1 in 100 people in the UK have epilepsy.

Don't be afraid to talk about it – there are more people out there either with epilepsy or who know people with epilepsy than you think.



What causes epilepsy?

Possible causes of epilepsy include:

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

Your doctor should tell you if they know what's caused your epilepsy. But for over one third of all people with epilepsy, doctors don't know the cause.

It's thought that our genes play a part in who does and who doesn't develop epilepsy. This may explain why some people develop epilepsy following, for example, a serious head injury whilst others do not. Researchers have found a number of genes linked to particular types of epilepsy. There are many types that doctors suspect are genetic, but they don't yet know which genes are involved.

What are epileptic seizures?

Electrical activity is happening in our brain all the time, as the cells in the brain send messages to each other. A seizure happens when there is a sudden burst of intense electrical activity in the brain. This causes a temporary disruption to the way the brain normally works. The result is an epileptic seizure.

There are many different types of seizure. What happens to you during a seizure depends on what part or parts of your brain are affected, and how far the seizure activity spreads. With some types of seizure, you remain alert and aware of what's going on around you, but may have unusual sensations, feelings or movements. With others, you may lose awareness and behave oddly, or become stiff, fall and jerk. After a seizure, it can take a while for your brain to fully recover and you may feel confused.

Find out more: [epilepsy.org.uk/seizures](https://www.epilepsy.org.uk/seizures)

My advice to anyone (or their carers) who is newly diagnosed is read as much as possible around the subject.



How is epilepsy diagnosed?

If your doctor thinks you may have epilepsy, they should arrange for you to see a specialist doctor with experience in diagnosing and treating epilepsy. This is usually a neurologist. The specialist will base their diagnosis on what they are told about your seizures by you, and ideally by someone who has witnessed your seizure. Usually, they will also ask you to have some tests.

These tests may include blood tests, an EEG (recording of your brainwaves), and a brain scan. These tests can help the specialist decide if you have epilepsy, and if you do, work out the type and cause of your epilepsy.

Don't be afraid to ask questions - no matter how trivial or daft you feel it is ask it anyway! If you don't understand get them to explain it until you do.



What is the treatment for epilepsy?

The main treatment for epilepsy is medicine to stop your seizures, or reduce how often they happen and how severe they are. You may hear these medicines called anti-seizure medications (ASMs) or the older term anti-epileptic drugs (AEDs). To keep things simple, we call them epilepsy medicines.

Did you know?

If you live in England and are prescribed epilepsy medicine, you can get a medical exemption certificate to get all your prescriptions for free. Ask your doctor or GP practice for an application form. In Scotland, Northern Ireland and Wales, prescriptions are free for everyone.

There are many different epilepsy medicines. The one that's best for you will depend on things like:

- The type of seizures you have
- The cause of your epilepsy
- Any potential side effects
- Your age
- Your sex

Your specialist should explain which medicines may be suitable for you and why, and tell you about any possible side effects. If you decide to take medicine, you will usually start on a low dose and increase it step-by-step, until you get to the recommended dose.

If your seizures don't stop after getting to the full dose of medicine, talk to your specialist. They may suggest trying a different medicine instead. Around half of people with epilepsy find their seizures stop with the first medicine they try. But some people need to try a few medicines before they find one that works well for them. And some people need to take two or more epilepsy medicines together.

For some people, medicines are not effective and there are other treatments for epilepsy that they may be able to try. These include different types of epilepsy surgery, and a special diet called the ketogenic diet.

Find out more: epilepsy.org.uk/treatment

Epilepsy specialist nurses

Your GP or specialist might arrange for you to see an epilepsy specialist nurse, if there is one in your area. These are nurses with training and expertise in epilepsy. The nurse can answer questions about your treatment and living with epilepsy. They can also provide a link between you and your specialist.

How can I take control of my epilepsy?

Here are a few things you can do to help you manage your epilepsy. They might help you to have fewer seizures. Or they might help you to feel more confident about living with epilepsy.

Take your medicine regularly

It's important to take your epilepsy medicine regularly, as prescribed by your doctor. Missing a dose can increase your risk of having a seizure. Missing doses is common, so ask your doctor in advance what to do if you forget a dose. You can also get information about what to do if you miss a dose from the leaflet that comes with your medicine, from the NHS website or by calling NHS 111.

Know your rights

There are guidelines about the standard of treatment and care you should get for your epilepsy. This includes how quickly you should get to see a specialist or have tests, and how often you should have a review of your treatment.

Find out more: epilepsy.org.uk/info/treatment/getting-right-treatment-care-for-epilepsy

I've been blessed with a brilliant neurologist, who has found the right balance of medications to get my seizures under control.



Understand your triggers

You might find that certain things make you more likely to have seizures. These are often called triggers. Common triggers include stress, not sleeping well, alcohol and missing doses of epilepsy medicine. A very small number of people have seizures triggered by lights that flash or flicker. Avoiding your triggers and improving your wellbeing can help you to have fewer seizures. However, not everyone is able to identify a trigger for their seizures.

Alcohol and recreational drugs

Some people with epilepsy drink alcohol and some don't. It's up to you to decide if you're going to drink alcohol. But bear in mind that drinking too much alcohol can make seizures more likely.

Recreational drugs can also be a seizure trigger. Alcohol and drug misuse can also increase your risk of sudden unexpected death in epilepsy (SUDEP). See page 17 for information about SUDEP.

If you need support to cut down or stop drinking or using drugs, speak to your GP. You can also contact our helpline for details of support services.

Keep a seizure diary

Many people's seizures follow a specific pattern. For example, if you have periods, you might find you have seizures at a particular time in your menstrual cycle. Keeping a seizure diary can help you and your doctors see if there is a pattern to your seizures. It can also help you to find out if anything triggers your seizures. Some people use an app on their phone, or contact us for a free paper diary.

Read our tips to help with memory problems

Many people with epilepsy have problems with their memory. Seizures can affect memory. And some epilepsy medicines can affect memory. We have information and tips to help.

Find out more: epilepsy.org.uk/memory

Talk to people

Finding out you have epilepsy can be a lot to come to terms with, but talking to friends and family can help. You might also want to talk to other people with epilepsy. Our Talk and Support groups and social media are a great way to connect with others. See page 24 for more details of support from Epilepsy Action.

Don't let it rule or ruin your life, hard to do at first, as I know only too well. But talking it through with family and friends can and will help you to come to terms with it.



Look after your wellbeing

Living with epilepsy can have a big impact on your emotions. This is particularly true if you have just been diagnosed. You might feel stressed, sad, angry, lonely or anxious. Taking steps to improve your wellbeing can help you feel and function better. Our free resources, including an online course and booklet, cover easy steps to help you do just that.

People with epilepsy are at more risk of having mental health problems than people without epilepsy. If anxiety or low mood are affecting your daily life, talk to your GP. They can suggest treatments or sources of support to help.



Can I have children?

If you want to have children, your epilepsy should not stop you. Most women with epilepsy have healthy pregnancies and give birth to healthy babies. If you are a woman and want to have children at some point, talk to your doctor or epilepsy specialist nurse. This is because there is a risk that having seizures, or taking epilepsy medicine during pregnancy, can affect the health of you or your baby. The doctor or epilepsy specialist nurse can help you plan any pregnancies and suggest changes to your medicines to make sure you and your baby will be as safe and healthy as possible.

If you do get pregnant unexpectedly, don't stop taking your medicine. Instead, talk to your doctor as soon as possible, so they can get you the help and advice you need.

Parents with epilepsy

If you are a parent, you might be worried about how to explain your epilepsy to your children. Or you might want to know how to keep them safe if you have a seizure while caring for them. Read our tips at [epilepsy.org.uk/info/caring-children](https://www.epilepsy.org.uk/info/caring-children)



How can I stay safe?

Seizures can put you at risk of having accidents, so if your seizures are not completely controlled it's important to think about safety. You may just need to make a few simple changes to make your normal activities safer. For example, you could drown if you had a seizure in the bath and there was no-one there to make you safe, so you might choose to have showers instead. And if you go swimming, take someone with you who knows what to do if you have a seizure in the water.

You can still lead an absolutely normal life with it, you can still continue to do what you used to. Don't let it stop you from doing new things either.



Can I die because of my epilepsy?

Having epilepsy comes with certain risks. One small but important risk to know about is the risk of dying from epilepsy. Knowing about it means you can take steps to reduce your risk.

Rarely, people can die from very long seizures, lasting hours, or from accidents caused by a seizure. But in many cases there's no clear reason why a person with epilepsy has died. When this happens, it's called sudden unexpected death in epilepsy (SUDEP). SUDEP happens in around 1 in every 1,000 people with epilepsy per year.

Although no-one knows the exact cause of SUDEP, research has shown there are some things that make you more at risk. The biggest risk factor is having frequent tonic-clonic seizures. These are where you lose consciousness and your body shakes. People who have other types of seizure, and people who have very few seizures, are less at risk. Your doctor should talk to you about your individual level of risk, and ways to reduce it.

The main way to reduce your risk of both SUDEP and dying from seizures or accidents is to have as few seizures as possible. Taking your epilepsy medicine as prescribed, not drinking too much alcohol and asking your doctor for regular epilepsy reviews, if you still have seizures, can all help. If you have sleep seizures, sharing a bedroom or using a monitor to alert someone in your home if you have a seizure may reduce your risk of SUDEP.

Find out more: epilepsy.org.uk/sudep

Can I drive?

The law says if you have a seizure you must stop driving and inform the driving agency. This is to protect you and others on the road.

You will usually have to be seizure free for 12 months before you can get your driving licence back, but there are different rules depending on the type of seizures you have.

Find out more: epilepsy.org.uk/driving

I don't drive now, so I cycle instead. But I see all the wonderful things around me that I missed whilst rushing around in the car.



Did you know? – If you are not allowed to drive because of your epilepsy, you may be able to get free or reduced price bus travel. If you work, you may also be able to get help with work-related travel costs through the Access to Work scheme. Find out more at: epilepsy.org.uk/benefits

Will having epilepsy stop me doing certain jobs?

All jobs, except the armed forces, are open to people with epilepsy. Legally, employers can't use your epilepsy as a reason not to employ you, or to dismiss you, unless they have very good reason. They could legally refuse to give you a job if you are still having seizures and this would put you or others at risk (for example, working at heights).

If your epilepsy makes it difficult for you to do your job, your employer may be able to make changes at work to help. This is called making reasonable adjustments.

Find out more: [epilepsy.org.uk/work](https://www.epilepsy.org.uk/work)

What are my legal rights?

The equality laws in the UK protect disabled people from being treated unfairly because of their disability. You are considered disabled under the equality laws if your epilepsy has a substantial effect on your day-to-day activities, or would do so if you were not taking epilepsy medicine. The laws cover work, education and access to services. If you would like more information about the equality laws and epilepsy, contact Epilepsy Action.

Am I entitled to any benefits because of my epilepsy?

Some benefits you may be entitled to include:

- Free prescriptions (if you take medicine to treat your epilepsy)
- Free or reduced price bus and rail travel (if you can't drive because of your epilepsy)

If your epilepsy limits your ability to work or means you need extra care and support, you may also be entitled to certain extra government benefits and grants.

Find out more: [epilepsy.org.uk/benefits](https://www.epilepsy.org.uk/benefits)

Don't let it hold you back from doing anything and be open about it. The more people talk about epilepsy the more awareness there will be.



About this publication

This booklet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything else you would like to say about this booklet, please contact us.

Epilepsy Action is proud to be a member of PIF Tick, the quality mark for health information. Find out more at piftick.org.uk

The quotes in this booklet are real comments from people with epilepsy. The pictures have been posed by models.

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Disclaimer

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

First aid for tonic-clonic seizures

The person goes stiff, loses consciousness, falls to the floor and begins to jerk or convulse.

Do...

- Protect the person from injury (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing the person on their side (in the recovery position) once the jerking has stopped (see picture)
- Stay with them until recovery is complete
- Be calmly reassuring



Don't...

- Restrain the person's movements
- Put anything in their mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure **or**
- The seizure continues for more than five minutes **or**
- One seizure follows another without the person regaining consciousness between seizures **or**
- The person is seriously injured **or**
- They have trouble breathing after the seizure has stopped

First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

Do...

- Guide the person away from danger
- Stay with the person until recovery is complete
- Be calmly reassuring
- Explain anything that they may have missed

Don't...

- Restrain the person
- Act in a way that could frighten them, such as making abrupt movements or shouting at them
- Assume the person is aware of what is happening, or what has happened
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure **or**
- The seizure continues for more than five minutes **or**
- One seizure follows another without the person regaining awareness between seizures **or**
- The person is seriously injured

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair.

Epilepsy Action's support services



helpline

Our friendly helpline team offer confidential advice and information to anyone affected by epilepsy:

Freephone 0808 800 5050

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 5 minutes.

Email helpline@epilepsy.org.uk

Send us your question about epilepsy. We aim to reply within 48 hours (on workdays).

To see our opening hours and find out more about the support we offer visit: epilepsy.org.uk/helpline



talk and support

Our Talk and Support groups offer an opportunity to connect with others affected by epilepsy. You can join a group which meets face-to-face or online.



befriending

Our befriending service links people who are affected by epilepsy to a volunteer befriender. Your befriender can listen if you are going through a difficult time and could also help you take steps towards positive change.

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Epilepsy: an introduction

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

Yes	No	
		I feel more informed about issues to do with epilepsy
		I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse/other (cross out those that don't apply)
		I have talked to my employer/colleague/teacher/family/ other (cross out those that don't apply) and they have improved how well they support me
		I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline or support groups

Please tell us how you think we can improve this information

Please return the completed form to:

**FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action,
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY**

You can also give us feedback online. Visit [epilepsy.org.uk/feedback](https://www.epilepsy.org.uk/feedback)

Thank you.

**FREEPOST RTGS-LEYK-XGCK,
Epilepsy Action
New Anstey House,
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Leeds LS19 7XY**

Registered charity in England and Wales (No. 234343)



counselling

Our counselling service is available to adults living in Northern Ireland and Wales who are affected by epilepsy, caring for someone affected by epilepsy, or the parent of someone affected by epilepsy.



**family support
Northern Ireland**

Our family support services offer support to families and carers of people affected by epilepsy in Northern Ireland and Wales.

**To find out more about the services we offer, including ways to get in touch and how to apply, visit:
epilepsy.org.uk/support-for-you.**

Information about epilepsy

Epilepsy Action has a wide range of information on our website about many different aspects of epilepsy. You can also download our information as a factsheet.

If you would like our information printed in large text, you can order this by contacting the Epilepsy Action Helpline.

Epilepsy Action Helpline:

freephone 0808 800 5050

epilepsy.org.uk



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Environmental statement

All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from well-managed forests.