

Epilepsy: diagnosis, treatment and healthcare



Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work...

- We provide information to anyone with an interest in epilepsy
- We improve the understanding of epilepsy in schools and raise educational standards
- We work to give people with epilepsy a fair chance of finding and keeping a job
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations
- We promote equality of access to quality care

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Your support

We hope you find this booklet helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action.

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.



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Introduction

This booklet tells you what epilepsy is, how it is diagnosed, and what the different types of treatment are.

We asked some people with epilepsy about how they felt when they were diagnosed with epilepsy and how they got on with their treatment. Read what two of them say later in the booklet.

If you would like to know more about any of the information in the booklet, or would like to talk to someone about epilepsy, the Epilepsy Action Helpline is here for you. See page 43 for ways to contact us.

Did you know?

In the UK, if you have epilepsy and take epilepsy medicines, you can get all your prescription medicines for free. Speak to your doctor, pharmacist or Epilepsy Action for more details.

About epilepsy and seizures

What is epilepsy?

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

Anyone can have a one-off seizure, but this doesn't always mean they have epilepsy. Epilepsy is usually only diagnosed if someone has had two or more seizures. But sometimes it is diagnosed when a person has had only one unprovoked seizure and doctors think it is likely they could have more.

Epilepsy can start at any age and there are many different types. Some types of epilepsy last for a limited time and the person eventually stops having seizures. But for many people, once their seizures start, they have them for life.

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 someone during a seizure depends on which part of their brain is affected. In some types of seizure the person may stay alert and be aware of what's going on around them. In other types they may lose awareness. Some people have unusual sensations, feelings or movements. Or they may go stiff, fall to the floor and jerk.

Seizures usually last between a few seconds and several minutes. After recovering from a seizure, the person's brain and body will usually return to how they were before the seizure started.

Some people only ever have seizures when they are awake, and some only when they are asleep. Other people have a mixture of both.

What are the different types of seizure?

The different types of seizure are classed by which part or parts of the brain the epileptic activity is in.



Focal seizures (also called partial seizures)

When a person has a focal seizure, they have epileptic activity in just one part of the brain. They may still be alert or they may be unaware of what is going on around them. They might have movements they can't control, or unusual sensations or feelings. People around them might not know that they are having a seizure.

This is what Vanessa says about her focal seizures:

“During a focal seizure, I would get very confused, I'd maybe rock, and I wouldn't be aware of what I'd said or done after I'd come out of them. They'd vary in length – they'd probably only be one or two minutes long actually – I'd get very confused and I'd talk gibberish. I'd be very confused when I was coming out of my fit.”

Generalised seizures

Generalised seizures involve epileptic activity in both halves of the brain. A person having a generalised seizure will lose consciousness. Sometimes it can be so brief that nobody notices. Their muscles may stiffen and/or jerk. They might fall down.

Sometimes, the epileptic activity starts as a focal seizure but then develops into a generalised seizure.

For a video and information about different types of seizure, go to: [epilepsy.org.uk/first aid](http://epilepsy.org.uk/first-aid)

Diagnosing epilepsy

Some other medical conditions can cause symptoms similar to epilepsy. This can make it difficult to diagnose. So an epilepsy specialist will make a diagnosis mainly on your symptoms.

You can help the specialist to make a diagnosis by:

- Taking a detailed diary of your seizures to your appointments. This should show the dates, times and a description of what happened, and how you felt before and after
- Taking someone with you who has seen your seizures. Alternatively, a written description from someone who has seen your seizures would be really helpful
- Taking some video clips of your seizures to the appointment, if possible

If you are diagnosed with epilepsy, the specialist should classify it by seizure type and syndrome. A syndrome is a group of signs and symptoms that, added together, suggest a particular medical condition. The specialist and your GP should agree a care plan with you that looks at lifestyle as well as medical issues.

Tests used in the diagnosis of epilepsy

The epilepsy specialist may arrange for you to have some tests at the hospital. These are likely to include EEG tests and possibly an MRI scan. The results of these tests can sometimes give useful information, such as a possible cause of your epilepsy and the types of seizure you have.

Electroencephalogram (EEG)/video telemetry

The EEG machine records the electrical signals from your brain on a computer. During the EEG, an EEG specialist places harmless electrodes on your scalp, using a special glue or sticky tape. The electrodes are then connected to the EEG machine, which records the electrical signals onto a computer.

Magnetic resonance imaging (MRI scan)

An MRI scan uses a strong magnetic field and radio waves to create pictures of tissues, organs and other structures inside the body on a computer. It can show if there's a structural cause for someone's epilepsy.



The MRI scan isn't painful, but it can be very noisy. And some people find it very uncomfortable being in a confined space. The radiographer who does the scan might need to inject you in your hand or arm, with a harmless dye. This is to make the tissue and blood vessels show up as clearly as possible. A few people have had allergies to the dye, so the radiographer will ask if you have any allergies first.

You need to keep still while you are being scanned, otherwise the scan picture may be blurred.

The MRI scan can take up to an hour.

To see a video of someone having an MRI scan on the Epilepsy Action website go to: epilepsy.org.uk/mri

Blood tests

You might be asked to have a blood test. This is to check your general health, and to look for any medical conditions that might be causing epilepsy. They can also be used to find out if your seizures could be caused by another medical condition, such as diabetes, rather than epilepsy.

Treatment with epilepsy medicine

Epilepsy is usually treated with epilepsy medicines. They don't cure the epilepsy, but try and stop the seizures happening. They do this by changing the levels of chemicals in the brain that control electrical activity.

Starting treatment

A single seizure is not always classed as epilepsy, so wouldn't always need treating with epilepsy medicines. However, if you are considered to be at a high risk for further seizures, your specialist might suggest prescribing epilepsy medicines after a single seizure.

There are many different epilepsy medicines available. When the specialist is deciding which one will best suit you, they will consider things like:

- The types of seizure you have, as some medicines are only effective for certain types of seizure
- Your age and sex
- Your lifestyle
- Any other medical conditions you have
- Any other medicines you take
- Which medicine you would prefer

Doctors usually try to prescribe just one epilepsy medicine at a time. This is because the more you take, the higher the risk of having side-effects. For five out of 10 people with epilepsy, the first epilepsy medicine they try will stop their seizures. But

some people need to take two or more different epilepsy medicines. These are usually medicines that work in different ways, but work well together. And some people continue having seizures, even though they have tried a number of different epilepsy medicines, in different combinations.

This is what Sarah says about being diagnosed with epilepsy:

“Epilepsy shouldn’t stop your life being what you want it to be. You don’t come to terms with being diagnosed with epilepsy overnight. Still, with time your body adjusts and you adapt. At first the medication can make your brain feel really groggy, but that gets better too.”

For a video of Ian and his mum talking about his epilepsy diagnosis go to: epilepsy.org.uk/ian

Epilepsy Action has a list of epilepsy medicines available in the UK.

Taking epilepsy medicine

Epilepsy medicine is usually available as tablets, capsules, liquids and chewable or crushable tablets. If you find tablets difficult, ask your GP to prescribe you something easier to swallow.

Epilepsy medicine is usually taken once or twice each day. Sometimes it is taken three times a day. It’s important to take it regularly, as prescribed by your doctor, because missing a dose can increase the risk of having a seizure.

Once you are prescribed epilepsy medicine, it's a good idea to get advice about what to do if you ever forget to take it. You could speak to your epilepsy specialist, GP or epilepsy nurse about this. They can also tell you what to do if you have sickness or diarrhoea. The advice they give you will depend on which epilepsy medicine you are taking, and the dose.

Making treatment with epilepsy medicine easier

- Ask the pharmacist for clear instructions on how to take it
- If you find the package leaflet difficult to read because the type is too small, ask for one in large print
- If the packaging is difficult for you to open or handle, ask the pharmacist to change it
- Ask the pharmacist if they sell dosette boxes or something similar. These keep your medicines organised and may help you to take the right ones at the right time
- Contact the Disabled Living Foundation for information about other special pill containers or alarms that you can buy. These can be used to remind you to take your medicine
Tel: 0300 999 0004
Website: dlf.org.uk
- Once your dose is stabilised, ask your GP if they would be prepared to give you prescriptions for enough medicine to last two or three months

- If your GP and pharmacist use the Electronic Prescription Service (EPS), they may be able to arrange for your prescriptions to go directly to your pharmacist. This means you no longer have to remember to order your prescriptions. The pharmacist will automatically do that for you. And some pharmacists offer a delivery service too. See NHS Choices for more information. Go to: [NHS.org.uk](https://www.nhs.org.uk)

What are the usual doses of epilepsy medicine?

Your doctor will tell you how much of your epilepsy medicine you should take, and what time of day you need to take it. It's usual to start on a low dose and gradually increase it to the maintenance dose. This is the amount that is thought to work well at controlling seizures.

Each epilepsy medicine has a different maintenance dose. For example, for carbamazepine it is between 800 and 1,200 milligrams (mgs) each day. For zonisamide it is between 300 and 500 mgs each day.

It can take a few weeks or months to reach the maintenance dose. Starting at a lower dose, then gradually increasing it, allows your body to slowly get used to the medicine. This reduces your risk of side-effects.

Sometimes, your doctor might advise you to take a higher or lower dose than the recommended maintenance dose. This could be to get better seizure control or to reduce your risk of side-effects.



How long will it take for my medicine to work?

Many people with newly-diagnosed epilepsy respond well to epilepsy medicine and have fewer seizures. It's not possible to say how long this will take. But for many people, it happens quickly. For others, it takes longer.

About three in 10 people with epilepsy have seizures that don't respond well to epilepsy medicine. They continue to have seizures even though they have tried two or more different medicines.

Side-effects

When you get your prescription, it should, by law include a package leaflet which lists the possible side-effects. Side-effects are unwanted symptoms caused by medicines. All medicines can cause side-effects, including epilepsy medicines. The risk of getting side-effects varies from person to person.

Some people have told us that their side-effects have lessened over time, as their body has got used to taking their epilepsy medicines.

What should I do if I get side-effects?

If you have side-effects that continue, talk to your GP or epilepsy specialist. They might make changes to your epilepsy medicine to reduce the side-effects.

If you are driving or working with machinery, check the package leaflet to see if certain side-effects could make this unsafe for you.

The Yellow Card Scheme

Either you or your GP can report your side-effects to the Medicines and Healthcare products Regulatory Agency (MHRA). You can do this by:

- Picking up a Yellow Card from your GP surgery or local pharmacy
- Filling in a Yellow Card online: mhra.gov.uk
- Calling the Yellow Card freephone hotline: 0808 100 3352

Reporting side-effects to the MHRA can help make sure that medicines are made safer in the future.

My medicine isn't working as well as it did

A small number of people find that their epilepsy medicine stops working as well as it did. If this happens to you, there could be a number of reasons:

- You haven't taken your epilepsy medicine regularly
- You have been given a different version of your epilepsy medicine
- Your epilepsy has changed
- The cause of your epilepsy has changed
- Your body has got used to your epilepsy medicine, so it no longer works
- You have gained or lost a lot of weight
- You have started, or stopped, using or taking something else that has an effect on your epilepsy medicine

I've tried several epilepsy medicines and none works. What can I do?

If your epilepsy medicine is not stopping or reducing your seizures, your GP should arrange for you to see an epilepsy specialist. This is recommended by the National Institute for Health and Care Excellence (NICE). NICE is an independent organisation that provides guidelines for treatment and care for people in the NHS in England, Northern Ireland and Wales. The Scottish Intercollegiate Guidelines Network (SIGN) provides guidelines for Scotland.



When you see the epilepsy specialist, they will review your epilepsy and treatment to try to get you better seizure control. They might also talk to you about other treatments for epilepsy.

For more information about other treatment for epilepsy, see page 30.

What if I need to change my epilepsy medicine?

If you need to change from one epilepsy medicine to another, your doctor should give you clear instructions about how to do this. The usual way is to start taking the new one at a low dose, alongside your existing one. The dose is gradually increased until you reach the maintenance dose, then the old epilepsy medicine is gradually reduced. This can take weeks or months to do.

Will my new medicines affect my original one?

During the changeover you will be taking two different epilepsy medicines. Although your doctor will try to keep the risk as low as possible, if you take more than one epilepsy medicine, they may interact with one another. One might raise or lower the amount of another in your blood. This could cause you to have more seizures, or develop side-effects. To try to stop this happening, your doctor might have to regularly adjust the dose of one, or both of them. This is to make sure they still work well together.

What if I need to reduce my epilepsy medicine?

If you need to reduce your epilepsy medicine, your doctor should give you clear instructions about how to do this. And during this time, you could be at risk of having seizures. For this reason, your doctor might advise you to stop driving for a period of time. You might also decide to avoid some sporting activities until you and your doctor feel sure that you have good seizure control.

Do I need regular blood tests?

You will only usually need to have blood tests to monitor your epilepsy medicine if, for example:

- Your doctor wants to make sure you are taking the right dose of your epilepsy medicine
- You are having side-effects from your epilepsy medicine that could be related to too high a dose
- You are pregnant, or have recently given birth, and there is concern that your medicine level may be too low, or too high
- You are going to start, or stop taking another epilepsy medicine that could interact with your epilepsy medicine
- You are taking a medicine for another condition that could interact with your epilepsy medicine

You may also be offered blood tests to check your general health.

Will I ever be able to stop taking epilepsy medicine?

If you have been seizure free for at least two years, your epilepsy specialist might talk to you about the benefits and risks of continuing, or stopping your epilepsy medicine. They will only suggest this if they think your risk of having seizures in the future is low. Here are some of the things they will consider before making this decision:

- **How long you have been seizure-free** – the longer you have been seizure free, the less likely you are to have another seizure
- **How many epilepsy medicines you take** – if you needed more than one epilepsy medicine to control your seizures, you are at a higher risk of having seizures if you stop taking your medicine
- **The number of seizures you had before they were stopped with epilepsy medicine** – the more seizures you had, the higher the risk that your seizures will return
- **The type of your epilepsy or syndrome** – some types of epilepsy, such as juvenile myoclonic epilepsy, will usually return if you stop taking medicine
- **How old you were when your seizures started** – some types of epilepsy that begin in childhood go away when you become an adult

If you do stop taking epilepsy medicine, you will usually do it very gradually. Your epilepsy specialist will advise you how to do it. It could take a few months to stop completely.

If you drive, the driving agencies recommend that for safety, you should stop driving during the period of medicine withdrawal, and for six months after withdrawal is complete. Your doctor will tell you if you can start driving again earlier than this. You don't need to tell the driving agency or return your licence, unless you have a seizure.



Possible effects of epilepsy medicine on other things

Your bones

In 2009, the Medicines and Healthcare products Regulatory Agency (MHRA) advised that people taking the following older epilepsy medicines long-term were at risk of osteoporosis or broken bones:

- Carbamazepine Phenytoin
- Primidone Sodium valproate
- Phenobarbital

There isn't enough information yet to say whether other epilepsy medicines, such as oxcarbazepine, levetiracetam and gabapentin affect bone health.

If you are concerned about your epilepsy medicines affecting your bone health, speak to your doctor.

[Epilepsy Action has more information about epilepsy and osteoporosis.](#)

Contraception

Some epilepsy medicines make some types of contraception work less well than they should. This could mean you have an unplanned pregnancy. These drugs are:

- Carbamazepine
- Eslicarbazepine acetate
- Lamotrigine
- Oxcarbazepine
- Phenobarbital
- Phenytoin
- Primidone
- Rufinamide
- Topiramate if you take 200 mgs or more
- Perampanel if you take 12 mgs or more

Some types of contraception make lamotrigine work less effectively. This could lead to an increase in your seizures.

If you take epilepsy medicine and are planning to use contraception, contact Epilepsy Action for more information. You could also speak with your family doctor, epilepsy specialist nurse or your local family planning clinic. They can help you choose a form of contraception that will work for you and suit your lifestyle.

Possible effects of other things on epilepsy medicines

Some medicines used to treat conditions other than epilepsy can increase the risk of having seizures. They might lower your resistance to seizures. Or they may interact with your epilepsy medicines, making them work less well, or causing more side-effects. If you are going to take any prescribed medicine or over-the-counter medicine, always check with your GP or pharmacist first. This is to make sure they won't affect your epilepsy or treatment.

Below are some examples of these medicines, but there are others.

- Antidepressants
- Benzodiazepines
- Antipsychotics
- Painkillers
- Steroids

Grapefruit

Some research suggests that eating grapefruit or drinking grapefruit juice could increase your chances of having unwanted side-effects from some epilepsy medicines. This is because a chemical that is naturally found in grapefruit can cause you to have higher levels of these medicines in your body. If you have any concerns about this, talk to your GP or pharmacist.

The medicines that can be affected by grapefruit are:

- Carbamazepine
- Diazepam
- Midazolam

Getting the same version of your epilepsy medicine every time

Generic prescribing

Nearly all medicines have a generic and a brand name. The generic name is usually the name of the main ingredient. The brand name is given by the company that makes the medicine.

In the first years that a medicine is available for patients, it is under licence. This means that only the company that developed it can sell it. They will give it their own brand name. Once the licence runs out, any company can make the medicine, giving it a different brand name. The generic name always stays the same.



These are the generic and some brand names of some commonly used epilepsy medicines:

Generic name	Brand names
carbamazepine	Tegretol
lamotrigine	Lamictal
levetiracetam	Keppra
sodium valproate	Epilim
topiramate	Topamax

If a doctor writes the generic name of your medicine on your prescription, a pharmacist can give you any brand of that medicine. This is called generic prescribing. To keep costs down, a pharmacist may choose to give you a cheaper version of a medicine.

Parallel imports

Some companies make the same medicine at their factories in the UK and in several other countries. An example of this is the epilepsy medicine Tegretol, which is made in Italy and the Netherlands, as well as in the UK.

When medicines that are made in the UK are also imported from other countries for use in the UK they are called parallel imports. There are a number of signs that your epilepsy medicine is a parallel import. For example, the packet may look different, or have wording in another language.

Are there any problems with generic prescribing and parallel imports?

Generic prescribing and parallel imports mean there can be many different versions of one medicine.

Some people who have switched to a different version of their epilepsy medicine have noticed that they have had more, or different seizures. And some people have had side-effects that they have not had before.

The Medicines and Healthcare products Regulatory Agency (MHRA) gives guidance to people who prescribe medicine, and to pharmacists. MHRA says that for some epilepsy medicines, the same brand does not have to be dispensed every time.

However, Epilepsy Action believes that people with epilepsy should always get the same version of their epilepsy medicine, wherever possible. This is called consistency of supply. Not all doctors agree with this.

Contact Epilepsy Action for more information about consistency of supply.

How can I get the same version of my epilepsy medicine each time?

The most reliable way to get the same version is to ask your doctor to write the brand name on your prescription. It is the law that if the brand is written on your prescription, the pharmacist must give it to you.

You can ask your doctor to write 'no parallel imports' (see page 27) on your prescription, but the pharmacist doesn't have to take any notice of this. However, you can insist that you have your epilepsy medicine with the package leaflet and label in English.

If your epilepsy medicine is not made in the UK at all, it may be impossible to get exactly the same version every time. This is something you could discuss with your GP.



Other ways of treating epilepsy

Many people with epilepsy have their seizures reduced or stopped with epilepsy medicines. But if this isn't the case for you, there are other treatments that might help.

Epilepsy brain surgery

Epilepsy surgery is done to:

- Try to stop your seizures **or**
- Reduce the number of seizures you have **or**
- Make your seizures less severe

Overall, the aim is to improve your quality of life. Epilepsy surgery isn't suitable for all types of epilepsy, but it can be very effective.

Sean had epilepsy brain surgery. You can listen to his story at: epilepsy.org.uk/sean

Vagus nerve stimulation (VNS)

VNS therapy involves a small electrical device, like a pacemaker, which is implanted under the skin of your chest. The device sends electrical impulses to your brain through a nerve in your neck called the vagus nerve. The aim is to reduce the number of seizures you have and make them less severe.

VNS therapy uses the VNS system, which is made up of three parts:

- A small pacemaker-like device, called a generator
- A thin, flexible wire, called a lead
- A hand-held magnet

The vagus nerve sends messages between the brain and other parts of the body. In VNS therapy, a generator is connected to the vagus nerve by a lead. The generator is programmed to send electrical impulses to the vagus nerve at regular intervals, all day, every day. These impulses are then carried by the vagus nerve to the brain.

The ketogenic diet/modified Atkins diet

The ketogenic diet is higher in fats and lower in carbohydrates than a typical diet. It has been used for many years to help children whose seizures can't be reduced or stopped with epilepsy medicine. The modified Atkins diet is less strict than the ketogenic diet. Around three to four adults in every 10, who have used these diets, have had their seizures reduced.

There are currently only three centres in the UK that treat adults with these diets. But if your seizures are difficult to control, you might want to discuss this treatment option with your epilepsy specialist.

Sudden unexpected death in epilepsy

What is sudden unexpected death in epilepsy?

If someone with epilepsy dies suddenly and unexpectedly, and no obvious cause of death can be found, it is called sudden unexpected death in epilepsy (SUDEP).

SUDEP has been shown to be connected with seizures, particularly tonic-clonic (convulsive) seizures. The exact cause is not known and there may be no single explanation. However, it is thought that seizure activity in the brain may sometimes cause changes in the person's heartbeat or breathing. This could cause the person to stop breathing or their heart to stop beating.

What is my risk of SUDEP?

- If you have epilepsy, your risk is 1 in 1,000
- If you have frequent tonic-clonic seizures, you have an increased risk, particularly if they happen during sleep
- If you have a drug or alcohol problem, your risk is higher than someone who doesn't have these problems
- If you have very few seizures, you are at a lower risk, but still at risk
- If you have absence or myoclonic seizures, you are not known to be at increased risk

How can I reduce my risk of SUDEP?

The most effective way to reduce the risk of SUDEP is to have as few seizures as possible. Also important is to take the smallest effective dose and number of epilepsy medicines.

If your seizures are not controlled, here are some ways to manage your epilepsy:

- Always take your epilepsy medicines exactly as prescribed
- Never stop taking your epilepsy medicines, or make changes to them, without talking to your doctor first
- Make sure you never run out of your epilepsy medicines
- Ask your epilepsy specialist or epilepsy nurse in advance what you should do if you ever forget to take your epilepsy medicines
- Ask to be referred to an epilepsy specialist for a review of your epilepsy. They may be able to suggest changes to your epilepsy medicines, or other treatment options, which may include surgery
- Try not to sleep on your stomach as recent research suggests that people with epilepsy who sleep on their stomach may be at higher risk of SUDEP

If you would like to speak to one of our advisers about SUDEP, please contact the Epilepsy Action Helpline.

Annual Review

You should have a review of your epilepsy and treatment every year. If you are an adult and you are no longer in the care of an epilepsy specialist, the review could be with your GP. But if you are still in the care of an epilepsy specialist, it could be with them or an epilepsy specialist nurse.

If you are currently under the care of an epilepsy specialist and your epilepsy is still difficult to control, you may be offered a referral to a specialist centre. You should be referred to a specialist centre if:

- The doctors are not sure what type of epilepsy syndrome or seizures you have
- Your seizures are not controlled with epilepsy medicines within two years of starting them
- You have tried two different types of epilepsy medicines, but these have not worked
- You have, or are at risk of having, severe side-effects from epilepsy medicine
- You have a psychological or psychiatric condition
- There is something abnormal in your brain

This specialist service should include a team of professionals who are experienced in assessing people with complex epilepsy. They should have access to investigations and medical and surgical treatment.

If your epilepsy is not difficult to control but you have concerns about issues such as pregnancy, you should also have access to the specialist service.

Epilepsy specialist nurses

There may be epilepsy specialist nurses in your area. These nurses can usually spend time with you discussing your epilepsy, treatment and any epilepsy-related problems. As well as seeing you at an epilepsy specialist clinic, they may be able to talk to you over the phone, or visit you at home.

If you would like to find out if there is an epilepsy specialist nurse in your area, contact your GP, your epilepsy specialist, or Epilepsy Action.

Debbie is an epilepsy specialist nurse who also has epilepsy. You can see her video where she talks about diagnosing epilepsy at epilepsy.org.uk/debbie



If you are unhappy with your care or treatment

GP

If you are not happy with your care or treatment from your GP, talk to the GP or practice manager. You could also consider seeing a different GP, or changing to another practice. NHS Choices, NHS Scotland, NHS Direct Wales or Health and Social Care Online Northern Ireland can tell you how to do this.

Hospital

If you are not happy with your care or treatment from your hospital, talk to your epilepsy specialist or specialist nurse. They may be able to look at the problem, and make sure it doesn't happen again.

If you are still unhappy, talk to your GP about your concerns and ask about other options. This could include getting an opinion from a different epilepsy specialist. You have a right to ask for this. And your GP can arrange it, if they feel it is in your best interest.

If you wish to make a complaint about your care or treatment from the hospital, contact PALS, or the NHS Trust responsible for the hospital. NHS Choices, NHS Scotland, NHS Direct Wales or Health and Social Care Online Northern Ireland can tell you how to do this. Alternatively, your local Citizens Advice Bureau can provide advice and support, if you want to make a complaint.

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 you would like to say about the booklet, please contact us.

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.

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First aid for tonic-clonic seizures

The person goes stiff, loses consciousness and falls to the floor.

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) when the seizure has finished (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 injured **or**
- You believe the person needs urgent medical attention

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**
- The person is injured **or**
- You believe the person needs urgent medical attention

Further information

If you have any questions about epilepsy, please contact the Epilepsy Action Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue. Or download a copy at epilepsy.org.uk/catalogue

Epilepsy Action's support services

Local meetings: a number of local branches offer support across England, Northern Ireland and Wales.

Coffee and chat groups: these give people living with epilepsy the chance to meet new people, share experiences and learn more about life with epilepsy.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. You have to be aged 16 or over to join. Go to forum.epilepsy.org.uk

Epilepsy awareness: Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.

Epilepsy: diagnosis, treatment and healthcare

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, support groups or forum4e

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

Thank you.

epilepsy *action*

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

Registered charity in England (No. 234343)

Ways to contact the Epilepsy Action Helpline



Telephone: freephone 0808 800 5050

We are usually open 8.30am to 5.30pm, Monday to Friday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.



Email: helpline@epilepsy.org.uk

Email us your question about epilepsy. We aim to reply within 48 hours (on work days)



Text: 0753 741 0044

Text us and we aim to send a text reply back to your phone within 24 hours (on work days)



Twitter: @epilepsyadvice

Tweet us with your question and we will tweet back (on work days)



Post: New Anstey House, Gateway Drive, Leeds, LS19 7XY

Write to us and we aim to reply within seven working days

About the Epilepsy Action Helpline

We do:

- Provide confidential advice and information about epilepsy to anyone
- Give general medical information
- Give general information on legal and welfare benefit issues related to epilepsy

We do not:

- Tell people what to do
- Offer a medical diagnosis or suggest treatment
- Take up people's legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

We welcome feedback, both positive and negative, about our services.

Epilepsy Action Helpline:

freephone 0808 800 5050

epilepsy.org.uk



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Environmental statement

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