

Epilepsy: diagnosis, treatment and healthcare



Epilepsy Action and NHS Tayside –
working together to support
people with epilepsy.

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.

Join us...

You can help us in our vital work by becoming a member. All members receive our magazine *Epilepsy Today*, free cover under our unique personal accident insurance scheme and access to our services and conferences.

“Our vision is to live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction”

Epilepsy Action, vision statement

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Word List

AED - anti-epileptic drug





Introduction

The aim of this booklet is to give you a brief introduction to epilepsy, to tell you how it is diagnosed and how it can be treated. It also talks about healthcare services and what you can do if you are not happy with your treatment.

If you have any further questions about anything to do with epilepsy, you can speak to an adviser on the Epilepsy Helpline, freephone 0808 800 5050. You can also contact your GP, epilepsy specialist, or epilepsy specialist nurse.

Further information on all the topics covered in this booklet is available from Epilepsy Action.

Contact details

There are several organisations mentioned in the booklet. You can find contact details for all of them at the end, on page 33.

About epilepsy and seizures

About epilepsy

About seizures

Seizure types

About epilepsy

If you have epilepsy, you may sometimes have seizures (also called fits). There are many types of epilepsy. Each person will experience epilepsy in a way that is unique to them.

About seizures

Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity in the brain. This is often referred to as epileptic activity. The epileptic activity causes a temporary disruption to the way the brain normally works, so the brain's messages become mixed up. The result is an epileptic seizure.

How seizures affect a person depends on the area of the brain affected by the epileptic activity. For example, some people lose consciousness during a seizure but other people do not. Some people experience strange sensations, or parts of their body might twitch or jerk. Other people fall to the floor and convulse. This is when they jerk violently as their muscles tighten and relax over and over again.

Seizures usually last between a few seconds and several minutes. After a seizure, the person's brain and body will usually return to normal.

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

Seizure types

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

- **Focal seizures** (also called partial or localised seizures)
In focal seizures, epileptic activity is in just part of the brain. You may remain alert during this type of seizure or you may not be aware of what is happening. You may experience movements you can't control or unusual sensations or feelings. Sometimes, onlookers may not be aware that you are having a seizure.
- **Generalised seizures**
Generalised seizures involve epileptic activity in both halves of the brain. You usually lose consciousness during this type of seizure. Sometimes it can be so brief that nobody notices. The muscles in your body may stiffen and/or jerk. You may fall down.

Sometimes, the epileptic activity that starts as a focal seizure can spread to the rest of your brain and become a generalised seizure.

When a doctor is making a diagnosis of epilepsy, it is important that they know what kind of seizures you are having. This helps them to decide on the best treatments for you.



Image illustrating brain cell activity.

What to do if you think you've had a seizure

Visiting your GP

If you think that you've had a seizure, the first person to see is your GP.

If your GP thinks you might have epilepsy, they will usually arrange for you to see an epilepsy specialist at the hospital. This is to make sure you get the right diagnosis and have the best treatment for your epilepsy. The epilepsy specialist is usually a neurologist (for adults) or a paediatrician (for children).

Epilepsy clinics

If there is an epilepsy clinic in your area, your GP will usually refer you there. Epilepsy clinics provide things like 'fast-track' appointments for people who have had their first seizure, and the latest scanning equipment.

Diagnosing epilepsy

How epilepsy is diagnosed

There are a number of medical conditions that can cause symptoms similar to epilepsy. This can make epilepsy difficult to diagnose.

An epilepsy specialist will make a diagnosis based mainly on your symptoms. It can be helpful if somebody who has seen you have a seizure can give a description of what they saw happen. It can also be helpful if you keep a diary of your seizures. You can make a note of dates, times and a description of what happened, and how you were feeling before and after.

The epilepsy specialist may ask you to have some tests at the hospital. These include EEG tests and CT or MRI scans. None of these tests can prove that you do or do not have epilepsy, but they may give useful information. This includes the possible cause of your epilepsy and the type of seizures you have.

Tests used in the diagnosis of epilepsy

EEG (electroencephalogram) tests

An EEG test tells doctors about the electrical activity happening in your brain. An EEG only shows what is happening in your brain at the time the test is being done. It's not able to show what has already happened or what is going to happen in the future. Despite this, an EEG can sometimes be very helpful to doctors when they are diagnosing epilepsy.

CT scans (computerised tomography)

A CT scan is a type of X-ray that shows the physical structure of the brain. It does not show if you have epilepsy. However it may show if there is anything in your brain, such as a scar, or damaged area, that could cause epilepsy. Not everyone will need to have a CT scan.



MRI scans (magnetic resonance imaging)

An MRI scanner uses radio waves and a magnetic field to show the physical structure of the brain. An MRI scanner is more powerful than a CT scanner. An MRI scan has a higher chance than a CT scan of showing something in your brain that could cause epilepsy. Not everyone will need to have an MRI scan.

Blood tests

These are used to check your general health, and to look for any medical conditions that might be causing your epilepsy. They can also be used to find out if your seizures are not caused by epilepsy, but another medical condition. An example of this is diabetes.

Anti-epileptic drug treatment

- Introduction to anti-epileptic drugs
- Starting treatment with anti-epileptic drugs
- Taking your anti-epileptic drugs
- Doses of anti-epileptic drugs
- How long it takes for anti-epileptic drugs to work
- Side-effects of anti-epileptic drugs
- Anti-epileptic drugs and your bones
- Anti-epileptic drugs and contraception
- The Yellow Card Scheme
- Changes in how well anti-epileptic drugs work
- Changing anti-epileptic drugs
- Interactions between anti-epileptic drugs
- Drug level monitoring
- Stopping anti-epileptic drug treatment

Introduction to anti-epileptic drugs

The most common way epilepsy is treated is with anti-epileptic drugs (AEDs). AEDs do not cure epilepsy, but aim to try and stop seizures happening. AEDs are taken at regular times each day.

Starting treatment with anti-epileptic drugs

There are many different AEDs available. Your epilepsy specialist will recommend the most appropriate one for you. To choose the AED, the specialist will look at things like the type of seizures you have, and if you have any other medical conditions.

Doctors usually try to avoid prescribing more than one AED at a time. This is because the more drugs you take, the higher the risk of having side-effects. There may be times, however, when you need to take two or more AEDs. For example, when you change from one AED to another.



Or, if the doctor thinks that having an additional AED would help to control your seizures better.

A list of AEDs in the UK is available from Epilepsy Action.

Taking your anti-epileptic drugs

Most AEDs come as tablets, capsules, liquids and chewable or crushable tablets. If you find tablets difficult, you can ask your GP to prescribe you something that you would find easier to swallow.

AEDs are usually taken once or twice a day. Sometimes they are taken three times a day. It's important to take your AEDs regularly, as prescribed by your doctor. This is to keep as steady a level of the drug in your blood as possible. If you miss taking your AEDs this can sometimes trigger a seizure.

It's a good idea to get advice about what you should do if you ever forget to take your AEDs. You could speak to your epilepsy specialist, GP or epilepsy nurse about this. The advice they give you will depend on which AED you are taking and the dose. They will also consider any other medical conditions you have, or medicines you are taking, that might affect your epilepsy.

Doses of anti-epileptic drugs

Your doctor will tell you how much of your AED you should take. It's usual to start an AED at a low dose and gradually increase it to the maintenance dose. The maintenance dose is the amount of drug which is thought to work well at controlling your seizures.

Each AED has a different usual maintenance dose. For example, the recommended maintenance dose for carbamazepine is between 800 and 1,200 milligrams (mg). For zonisamide it is between 300 and 500 mg.

It may take a few weeks or months to get to the maintenance dose of your AED. By starting the drug at a lower dose and gradually increasing it, this allows your body to slowly get used to the drug. This lowers the risk of getting side-effects.

Sometimes, your doctor may suggest that you take a higher or lower dose than the usual maintenance dose. This might be to get better control of your seizures or reduce the risk of side-effects.

How long it takes for anti-epileptic drugs to work

Many people with newly-diagnosed epilepsy respond well to AEDs. This means that they have fewer seizures, or the seizures stop altogether. It's not possible to say how long this will take. Many people find the right AED and dose very quickly. For some people it can take a lot longer.



About 30 in every 100 people with epilepsy have seizures that do not respond well to AEDs. They continue to have a number of seizures, even though they have tried two or more AEDs.

Side-effects of anti-epileptic drugs

Like most drugs, AEDs can cause side-effects. The risk that you will have side-effects depends on a number of things, including which AED you take and any other medicines you take.

When you start taking an AED, your doctor or pharmacist should give you a patient-information leaflet (PIL), by law. The PIL lists all the possible side-effects of that drug. Although you could get any of those side-effects, most people get few or mild side-effects. Some people do not get any side-effects at all.



There is more risk that you will get side-effects in the early days of taking an AED. Once your body has had a few days or weeks to get used to the AED, these side-effects should lessen or disappear completely. If they don't, talk to your GP or epilepsy specialist. They may be able to make changes to your AEDs to lessen the side-effects.

Anti-epileptic drugs and your bones

The AEDs carbamazepine, phenobarbital, phenytoin and sodium valproate may cause your bones to become thinner and more brittle. This means you are more at risk of breaking them.

If you are concerned that you may be at risk of having weaker bones, it's a good idea to talk to your GP. They can suggest ways you can look after your bones, such as taking vitamin supplements and exercising, if this is suitable for you.

Anti-epileptic drugs and contraception

If you are a woman with epilepsy, it is advisable to plan any pregnancy very carefully. This is to make sure that the pregnancy is as healthy as possible for both you and your baby. Some AEDs make the contraceptive pill work less well. This could lead to an unplanned pregnancy. These AEDs include carbamazepine, eslicarbazepine acetate, lamotrigine, oxcarbazepine, phenobarbital, phenytoin, primidone, rufinamide and topiramate.

The contraceptive pill can also interact with the AED lamotrigine and cause the amount of lamotrigine in your blood to drop. This can increase the risk of seizures.

More information about contraception, planning a baby and epilepsy is available from Epilepsy Action.

The Yellow Card Scheme

If you think that you are getting side-effects from your AEDs, it's advisable to talk to your GP. Your GP may report the side-effects to the Medicines and Healthcare products Regulatory Agency (MHRA). Alternatively, you can report side-effects yourself by completing a Yellow Card. These are available from your GP or pharmacist or through NHS Direct or the Yellow Card website and hotline (contact details at the back of this booklet).

Changes in how well anti-epileptic drugs work

A small number of people with epilepsy may find that their AED stops working as well as it once did. There can be a number of reasons for this.

- The person may not be taking their AED regularly.
- The person's epilepsy itself may have changed.
- The cause of the person's epilepsy may have changed.
- The person's body may have got used to the AED, so it no longer works.



The National Institute for Health and Clinical Excellence (NICE) recommends that if your AEDs are not stopping or reducing your seizures, your GP should arrange for you to have an appointment with an epilepsy specialist. The specialist may be able to suggest changes to your treatment to try and get better control of your seizures.

If you have to wait a long time to see your epilepsy specialist, it's important that you do not make any changes to your AEDs yourself. This could cause you to have more seizures. You could ask your GP or epilepsy specialist nurse for advice about taking your AEDs while you are waiting to see your epilepsy specialist.

Further information about NICE can be found on page 29.

Changing anti-epileptic drugs

If you have been taking an AED for a while and you are still having seizures, or experiencing side-effects, talk to your GP or epilepsy specialist. They may suggest that you try a new AED.

The recommended way to change to a different AED is to start taking a new AED as well as your old AED. Once you are taking the right dose of the new AED, the old AED is gradually reduced. This way of changing AEDs is to make sure that there is always enough medicine in your body to control seizures.

It's important to bear in mind that when changing AEDs there is a risk that you could have more seizures than usual. This could be because the new drug does not work well for you. Because of this, your doctor may advise you to stop driving for a period of time. If you live in England, Scotland or Wales you may need to stop driving for up to six months. If you live in Northern Ireland, you will have to stop driving for at least six months. You may also decide to avoid activities such as some sports, until you and your doctor feel sure that the new AED is working well.

More information about epilepsy and driving is available from Epilepsy Action

Interactions between anti-epileptic drugs

If you take more than one AED, it's possible for one AED to raise or lower the amount of a different AED in your blood. For example, carbamazepine (Tegretol) may reduce the amount of sodium valproate (Epilim) in your blood. This could cause you to have more seizures.

If you take more than one AED, and your doctor suggests that you change the dose of one of them, they may also advise you to change the dose of the other.



Drug level monitoring

Drug level monitoring involves having regular blood tests to check how much of a drug is in a person's blood.

It's not usual for doctors to do drug level monitoring for AEDs. This is because the tests do not usually provide helpful information about most AEDs. The exception to this is phenytoin. Blood tests can help doctors make sure that a person is taking the right dose of this particular AED.

Occasionally, doctors may do blood tests to see if a person is taking their AEDs regularly. They may also do a blood test if they think a person is getting side-effects because the dose of their AED is too high. Blood tests may also be done for people who take AEDs who are going to have surgery, or for pregnant women.



Stopping anti-epileptic drug treatment

Some people have to take AEDs for the rest of their life, even if they no longer have seizures. Other people can stop taking AEDs when they have been seizure-free for a few years. It's important not to stop taking your AEDs without getting advice from your epilepsy specialist.

If you want to try and stop taking your AEDs, you and your epilepsy specialist will need to consider a number of things. These include whether there is a physical cause for your epilepsy and how long it took for your seizures to stop. This information can help your specialist decide what the risks of your seizures coming back would be if you didn't take AEDs.

If your epilepsy specialist recommends that stopping AEDs is right for you, they will usually advise you to stop taking them very gradually. This may take a few months. If you suddenly stop taking them, this could cause you to have more frequent and severe seizures.

Getting the same version of your anti-epileptic drugs every time

Generic prescribing

Nearly all AEDs have a generic name and a brand name. The generic name is the name of the main ingredient. The brand name is given by the drug company.

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

When a doctor prescribes a drug by its generic name, a pharmacist can dispense any brand of that drug. This is called generic prescribing.

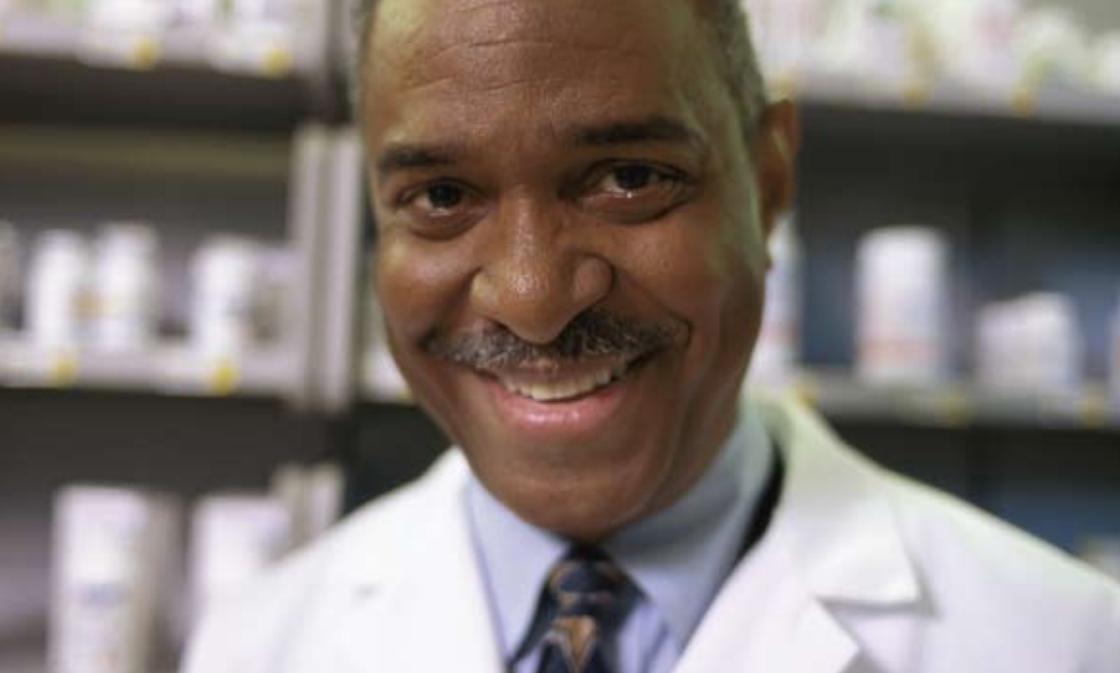
Parallel imports

Some drug companies make the same drug at factories in the UK and in several other countries. An example of this is the AED Tegretol. This is made in Italy and the Netherlands, as well as the UK. Some UK pharmacists may carry supplies of Tegretol made in factories outside the UK, even though the same drug is available from UK factories. When drugs that are made in the UK are also imported into the UK from other countries, they are called parallel imports.

The problem with generic prescribing and parallel imports

Generic prescribing and parallel imports mean there can be many different versions of one drug. Some people, who have switched to a different version of their AED, have noticed that their seizure pattern has changed. Some people have also experienced new side-effects.

Not all healthcare providers believe that taking a different version of AEDs can affect someone's epilepsy. However, the National Institute of



Health and Clinical Excellence (NICE) and Epilepsy Action recommend that people with epilepsy always get the same version of their AED wherever possible.

How to get the same version of your anti-epileptic drugs

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

Although you can ask your doctor to write ‘no parallel imports’ on your prescription, your pharmacist doesn’t have to take any notice of this. However, many pharmacies will do their best to help their customers, so it may still be worth asking your doctor to do this.

If your AEDs are not made in the UK, it may be impossible to get exactly the same version every time. It would be advisable to discuss this with your GP.

Other ways of treating epilepsy

Introduction

Brain surgery

Vagus nerve stimulation

The ketogenic diet

Complementary treatments

Introduction

Most people with epilepsy take AEDs and these can be very effective in reducing or stopping seizures. If AEDs do not work well for you, there are some other treatments that may be helpful.

Brain surgery

A small number of people with epilepsy can have brain surgery to try and stop their seizures. Doctors will usually only consider surgery for you if there is an obvious cause in your brain for your epilepsy, such as scar tissue. You will also have to have tried a few different AEDs, but still be having seizures. You and your doctor will need to weigh up the benefits and risks of having brain surgery.

Vagus nerve stimulation

Vagus nerve stimulation (VNS) is a treatment for epilepsy where a small device is implanted under the skin below the left collar bone. This device, similar to a pace-maker, is called a generator. The generator is connected to a thin wire, which stimulates the vagus nerve in the person's neck at regular times throughout the day. This sends impulses to the person's brain, which helps to prevent electrical activity that causes seizures. The aim of VNS is to reduce how many seizures you have, how long they last and how severe they are.

VNS does not work straight away. It can take anything from a couple of months to two years to see an improvement in seizures. It is rare for a



person to become seizure free as a result of VNS. However, many people have fewer or less severe seizures and report a better quality of life overall. Some people, however, experience no change in their seizures.

The ketogenic diet

The ketogenic diet is sometimes used to try and help children whose seizures cannot be reduced or stopped with AEDs. The diet is higher in fats and lower in carbohydrates than a typical diet.

The ketogenic diet should only be used under the supervision of a dietician who is an expert in the diet. This is because the balance of the diet needs to be carefully worked out for each child. Some children find the diet unpleasant and difficult to follow. Other children manage the diet very well.

Research suggests that for some children the diet can work well and reduce or stop seizures. The diet does not work for every child, and it is not possible to predict who the diet will help.

At present, the ketogenic diet is not used for adults with epilepsy in the UK. However, doctors are doing some research to see if this would be possible in the future.



Complementary treatments

Some people with epilepsy use complementary treatments to try and lower the number of seizures they have. Or they use them to improve their quality of life. Complementary treatments include acupuncture, herbal treatments, homeopathy, and aromatherapy. Some aromatherapy oils have been shown to be helpful for people with epilepsy. These include ylang ylang, camomile and lavender.

There is no scientific evidence to suggest that any type of complementary treatment can reduce or stop a person's seizures. For this reason, it's advisable for you to continue taking your AEDs as usual, even if you are using complementary treatments.

If you are thinking about trying a complementary treatment, it's a good idea to talk to your GP or epilepsy specialist about it first. It's also advisable to check that the person providing the treatment (the therapist) is registered. Complementary therapy organisations can give you names of registered therapists, and advice about what to look for in a good therapist. You can find details of complementary therapy organisations on the internet or at your local library.

Effects of other things on epilepsy treatment

Prescribed medicines

Some medicines used for other things than epilepsy may increase your risk of having seizures. These medicines include many of the antidepressants, some types of antihistamines, some antibiotics and some anti-malaria treatments. This increased risk of seizures could be because the drugs interact with your AEDs. Or it could be because they lower your resistance to seizures.

Over-the-counter medicines, supplements and essential oils

Many herbal medicines and supplements can increase the risk of seizures if you have epilepsy. Some examples are ephedra, evening primrose oil, ginkgo biloba, pennyroyal, wormwood, Saint John's Wort, shankhpushpi and shoseiryuto.

Some essential oils can also increase the risk of seizures if you have epilepsy. Some examples are sage, rosemary, wormwood, fennel and hyssop.

If you are thinking about using any kind of over-the-counter medicine, supplement, or essential oil, it's advisable to check them out with your pharmacist or GP. They can let you know if there are any reasons why they might affect your epilepsy.

Grapefruit juice and pomegranate juice

Grapefruit juice and pomegranate juice can make the AEDs carbamazepine, diazepam and midazolam work less well than they should. If you take any of these AEDs, it is advisable to not drink grapefruit juice or pomegranate juice. It is only the juice that affects AEDs, not the fruits themselves.

Sudden unexpected death in epilepsy

Many people with epilepsy live full and active lives. However, there is a slightly higher risk of death than in people who do not have epilepsy. This may be due to accidents, suicide and any medical conditions that caused the epilepsy. Sometimes, death appears to be directly related to epilepsy itself. This is referred to as sudden unexpected death in epilepsy (SUDEP).

Epilepsy Action believes that it is very important for people with epilepsy and their families to be aware of the risks of SUDEP. This gives people the opportunity to make lifestyle choices, which can help to reduce the risk of SUDEP. Taking your AEDs and making sure that you are getting the best possible treatment for your epilepsy are important ways of reducing the risk of SUDEP.

In the UK, there are around half a million people with epilepsy. It's estimated that about 500 people die of SUDEP each year. Although there is no way of predicting who will be affected by SUDEP, the risk is thought to be higher, the more seizures you have. The risk of SUDEP in people who are seizure-free is very low.

Risk factors for SUDEP

Here are some factors that may increase a person's risk of SUDEP.

- Having tonic-clonic seizures (sometimes called grand-mal seizures)
- Not taking AEDs as prescribed by a doctor
- Having seizures that are not reduced or stopped by AEDs
- Having sudden and frequent changes to AEDs
- Being a young adult (in particular male)
- Having sleep seizures
- Having seizures when alone



Managing your epilepsy to reduce the risks of SUDEP

The most effective way to reduce the risk of SUDEP is to have as few seizures as possible. If you still have seizures, even though you take AEDs, there are things you can do to try and reduce them.

- Always take your AEDs as prescribed by your doctor.
- Never stop taking your AEDs, or make changes to them, without talking to your GP or epilepsy specialist first.
-
- Make sure that you never run out of your AEDs.
- Ask your epilepsy specialist, or epilepsy specialist nurse, what you should do if you ever forget to take your AEDs at your usual time.



- If your seizures continue, ask to be referred to an epilepsy specialist for a review of your epilepsy. They may suggest changes to your AEDs, or other treatment options, such as brain surgery or vagus nerve stimulation.
- Keep a diary of your seizures. This can help doctors when they are considering the best treatment for you.
- Avoid things that may trigger your seizures. Common triggers include forgetting to take AEDs, lack of sleep, stress, lack of food, and too much alcohol.
- If your epilepsy is very difficult to control, ask your doctor about going to a specialist epilepsy centre. Contact Epilepsy Action for more information about specialist epilepsy centres.

Getting healthcare

About the National Institute for Health and Clinical Excellence (NICE)

About the Scottish Intercollegiate Guidelines Network (SIGN)

NICE and SIGN Guidelines

Epilepsy specialist nurses

Seeing an epilepsy specialist privately

About the National Institute for Health and Clinical Excellence (NICE)

NICE is an independent organisation that provides guidelines for treatment and care for people using the NHS in England, Northern Ireland and Wales. The guidelines are for healthcare professionals, patients and their carers to help them make decisions about treatment and healthcare.

About the Scottish Intercollegiate Guidelines Network (SIGN)

SIGN aims to improve the quality of healthcare for patients in Scotland by providing guidelines for treatment and care. The guidelines are for healthcare professionals, patients and their carers, to help them make decisions about treatment and healthcare.

NICE and SIGN Guidelines

The NICE and SIGN Guidelines recommend that everyone with epilepsy should have their own care plan. This should be agreed between you, your family and/or carers (if appropriate), your GP and your epilepsy specialist.

The guidelines also recommend that you should have a review with a medical professional responsible for your epilepsy care, at least once a year. This is advisable even if you are not experiencing any particular problems. The review is an opportunity to make sure that you are still getting the best treatment for your epilepsy.



Epilepsy specialist nurses

Epilepsy specialist nurses can spend time with you discussing your epilepsy, your treatment and any problems you may have, that are related to your epilepsy. As well as seeing you at an epilepsy 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.

Seeing an epilepsy specialist privately

Some epilepsy specialists only work within the NHS and do not take private referrals. If you wish to see a specialist privately, you will need to ask your GP to refer you for a private appointment.

Getting help if you are unhappy with your care or treatment

NHS Direct (England)

NHS 24 (Scotland)

NHS Direct Wales (Galw Iechyd Cymru)

Patient and Client Council (Northern Ireland)

Patient Advice and Liaison Service (England)

If you are unhappy with care or treatment from your GP

If you are unhappy with care or treatment from your hospital

NHS Direct (England)

NHS Direct is a 24 hour telephone health advice and information service for people in England. They also provide advice and information through their website.

NHS 24 (Scotland)

NHS 24 is a 24 hour telephone health advice and information service for people in Scotland. They also provide advice and information through their website.

NHS Direct Wales - Galw Iechyd Cymru

This is the NHS Direct service for people in Wales. It provides information in English and Welsh. They also provide advice and information through their website.

Patient and Client Council (Northern Ireland)

The Patient and Client Council (PCC) provides an independent voice for patients, clients, carers, and communities on health and social care issues in Northern Ireland. They help people make complaints and provide advice and information about health and social care services. They have local offices throughout Northern Ireland.

Patient Advice and Liaison Service – PALS (England)

If you are unhappy with your medical care and treatment from the NHS, the Patient Advice and Liaison Service (PALS) can help you. PALS exist to make sure that the NHS listens to patients, their families, carers and friends. They can provide you with information about the NHS and help you with any other health-related enquiry. PALS also help to resolve complaints about healthcare. PALS is currently available in England.

If you are unhappy with care or treatment from your GP

If you are unhappy with the care or treatment from your GP, talk to your GP or the practice manager. You could also consider seeing a different GP, or changing to another practice. NHS Direct, NHS 24 and NHS Direct Wales can tell you how to do this.

If you want to make a complaint, PALS, Patient and Client Council, NHS Direct, NHS 24 or NHS Direct Wales can give you advice.

If you are unhappy with care or treatment from your hospital

If you are unhappy with your care or treatment from your hospital, it would be a good idea to talk to somebody there. This could be your epilepsy specialist or epilepsy nurse. They may be able to reassure you, or make sure that the problem doesn't happen again.

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

If you wish to make a complaint about your care and treatment from your hospital, contact PALS or the NHS Trust responsible for that hospital. NHS Direct, NHS 24, NHS Direct Wales and Patient and Client Council can give you more advice about making a complaint.

Contact details

NHS Direct (England): 0845 46 47; www.nhsdirect.nhs.uk

NHS 24 (Scotland): 08454 242 424; www.nhs24.com

NHS Direct Wales: 0845 46 47; www.nhsdirect.wales.nhs.uk

PALS: www.pals.nhs.uk

Patient and Client Council: 0800 917 0222;

www.patientclientcouncil.hscni.net

The Patients Association: 0845 608 4455;

www.patients-association.com

Yellow Card hotline: 0808 100 3352; www.yellowcard.gov.uk

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 in the recovery position when the seizure has finished (see the pictures)
- 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
- The seizure continues for more than five minutes
- One seizure follows another without the person regaining consciousness between seizures
- The person is injured
- You believe the person needs urgent medical attention

First aid for focal seizures

The person is not aware of their surroundings or of what they are doing

Some common symptoms

- Plucking at their clothes
- Smacking their lips
- Swallowing repeatedly
- Wandering 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 the person 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
- The seizure continues for more than five minutes
- The person is injured during the seizure
- You believe the person needs urgent medical attention

Further information

If you have any questions about epilepsy, please contact the Epilepsy 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, videos and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue.

Epilepsy Action's support services

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

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at www.forum4e.com

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 the condition. 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

Please complete this form to tell us what you think of this publication.

How useful have you found this publication?

- Very useful Useful Quite useful Not at all useful

Is the language clear and easy to understand?

- Very clear and easy to understand
 Clear and easy to understand
 Quite clear and easy to understand
 Not at all clear or easy to understand

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How to contact the Epilepsy Helpline

Telephone the Epilepsy Helpline freephone **0808 800 5050**

Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm

Our helpline staff are Typetalk trained

Write to us free of charge at **FREEPOST LS0995, Leeds, LS19 7YY**

Email us at **helpline@epilepsy.org.uk** or visit our website:

www.epilepsy.org.uk

Text your enquiry to **07797 805 390**

Send a Tweet to **@epilepsyadvice**

About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people's cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

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

To ensure the quality of our services we may monitor calls to the helpline.

Epilepsy Helpline: freephone 0808 800 5050

www.epilepsy.org.uk



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