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 how epilepsy is diagnosed and how it can be treated. It also tells you 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 Action 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.
About epilepsy and seizures

About epilepsy
If you have epilepsy, you have had seizures (also called fits) and you may have more. 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(s) 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.

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 one part of the brain. The person might remain alert during this type of seizure or they might not be aware of what is happening. They might experience movements they can’t control or unusual sensations or feelings. Sometimes, onlookers may not be aware that they are having a seizure.

- **Generalised seizures**
  Generalised seizures involve epileptic activity in both halves of the brain. The person loses consciousness during this type of seizure. Sometimes it can be so brief that nobody notices. The muscles in the body may stiffen and/or jerk. They might fall down.

  Sometimes, the epileptic activity that starts as a focal seizure can spread to the rest of the brain and develop into 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 recommend the best treatment for you.
What to do if you think you have had a seizure

Visit your GP

If you think you have had a seizure, the first person to see is your GP. If they think 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

There are a number of medical conditions that can cause symptoms similar to epilepsy, which can make it difficult to diagnose. So, an epilepsy specialist will make a diagnosis based mainly on your symptoms.

You can help the specialist to make a diagnosis by:

• Taking a detailed diary of your seizures to your appointments, with dates, times and a description of what happened, and how you were feeling before and after
• Taking someone who has seen your seizures, or a written description from someone who has seen your seizures, to your appointments
• Taking some video clips of your seizures to the appointment, if this is possible

Tests used in the diagnosis of epilepsy

The epilepsy specialist may arrange for 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. However, they can sometimes give useful information, such as the cause of your epilepsy and the type of seizures you have.
**EEG (electroencephalogram)**

An EEG test measures the electrical activity that is happening in your brain. During the test, an EEG specialist places harmless electrodes on your scalp, using a special glue or sticky tape. The electrodes are connected to the EEG machine, which records the electrical signals in your brain onto a computer.

An EEG only shows what is happening in your brain at the time the test is being done. It is not able to show what has already happened or what is going to happen in the future. So, if there is no epileptic activity in your brain at the time the test is done, the EEG will show clear results. However, EEG tests can sometimes provide useful information to doctors.
CT scans (computerised tomography)

A CT scan is a type of X-ray that shows the physical structure of the brain. During the scan, you’ll usually lie on your back on a flat bed. The CT scanner, which looks like a giant thick ring, will rotate around your head, taking X-rays.

A CT scan doesn’t 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. During the scan, you lie inside the MRI machine, which is a very large tube.

An MRI scanner is more powerful than a CT scanner. It has a higher chance 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 epilepsy. They can also be used to find out if your seizures are not caused by epilepsy, but another medical condition, such as diabetes.
Treatment with epilepsy medicine

The most common way epilepsy is treated is with epilepsy medicines. They do not cure epilepsy, but aim to try and stop seizures happening. Generally, they do this by changing the levels of chemicals in your brain that control the electrical impulses.

Starting treatment

A single seizure is not usually classed as epilepsy. This is why doctors often don’t prescribe epilepsy medicine until you have had two or more seizures. Occasionally, doctors might recommend that you start treatment after just one seizure, if they think you are at risk of having more.

There are many different epilepsy medicines available. Your epilepsy specialist will recommend the most appropriate one for you. They will take various things into consideration, including:

- The type of seizures you have
- Your age and sex
- If you have any other medical conditions
- If you take any other medicines
- Your preferences

Doctors usually try to prescribe just one epilepsy medicine at a time. This is because the more you take, the higher is the risk of having side-effects. However, there may be times when you need to take two or more. One example is if you change from one epilepsy medicine to another. Another example is if the doctor thinks that taking an extra one would give you better seizure control.

Epilepsy Action has a list of epilepsy medicines in the UK.
Free prescriptions
If you have epilepsy and take epilepsy medicines, you are entitled to free prescriptions. The rules about paying for prescriptions are different in England, Northern Ireland, Scotland and Wales, so contact Epilepsy Action for more information.

Taking epilepsy medicine
Most epilepsy medicine is available 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.

Epilepsy medicine is usually taken once or twice a day. Sometimes it is taken three times a day. It is important to take it regularly, as prescribed by your doctor. This is to keep as steady a level of the medicine in your blood as possible. If you miss a dose, this can increase the risk of having a seizure.
It is a good idea to get advice about what you should do if you ever forget to take your epilepsy medicine. You could speak to your epilepsy specialist, GP or epilepsy nurse about this. The advice they give you will depend on which epilepsy medicine you are taking and the dose. They will also consider any other medical conditions you have, or other medicines you are taking, that might affect your epilepsy.

Making treatment with epilepsy medicine easier

Here are some suggestions:

• Ask the pharmacist for clear instructions on how to take it
• If you find the patient information leaflet difficult to read, 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 help you to make sure that you 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 to give you prescriptions for enough medicine to last two or three months
Doses of epilepsy medicine

Your doctor will tell you how much of your epilepsy medicine you should take. It is usual to start taking a low dose and gradually increase it to the maintenance dose. This is the amount of medicine which 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 (mg) each day. For zonisamide it is between 300 and 500 mg 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 the 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 control of your seizures, or to reduce the risk of side-effects.

How long it takes for epilepsy medicine to work

Many people with newly-diagnosed epilepsy respond well to epilepsy medicine and they have fewer seizures, or the seizures stop altogether. It is not possible to say how long this will take. For many people, it happens quickly, but for others it can take a lot longer.

About 30 in every 100 people with epilepsy have seizures that do not respond well to epilepsy medicine. They continue to have a number of seizures, even though they have tried two or more different ones.
**Side-effects**

All medicines can cause side-effects. These are effects that a medicine has on your body, in addition to the job they are supposed to do. Side-effects are usually unwanted and common ones include headaches, feeling sick, dizziness, drowsiness and mood changes.

The risk that you will have side-effects from your epilepsy medicine depends on a number of things, including which one(s) you take and any other medicines you take.

When you collect your prescription, there should, by law, be a patient-information leaflet (PIL) which lists the possible side-effects. You could get any of those listed, but 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 epilepsy medicine. Once your body has had a few days or weeks to get used to taking it, they should lessen or disappear completely. If they don’t, talk to your GP or epilepsy specialist. They might make changes to your epilepsy medicine to lessen the side-effects.

**The Yellow Card Scheme**

If you think that you are getting side-effects from your epilepsy medicine, talk to your GP. They can report them to the Medicines and Healthcare products Regulatory Agency (MHRA).
You can also report side-effects yourself by completing a Yellow Card. These are available from your GP, pharmacist or the Yellow Card scheme:
Tel: 0808 100 3352 Website: yellowcard.mhra.gov.uk

Changes in how well epilepsy medicine works

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

• Not taking your epilepsy medicine regularly
• Your epilepsy may have changed
• The cause of your epilepsy may have changed
• Your body may have got used to the epilepsy medicine, so the medicine no longer works
• Gaining or losing weight

The National Institute for Health and Care Excellence (NICE) is an independent organisation. They provide guidelines for treatment and care for people using the NHS in England, Northern Ireland and Wales. NICE recommends that if your epilepsy medicine is not stopping or reducing your seizures, your GP should arrange for you to see an epilepsy specialist. The specialist might suggest changes to your treatment, to try and get better seizure control.

It is very important that you do not make any changes to your epilepsy medicine yourself. This could cause you to have more seizures.

Further information about NICE can be found on page 35.
Changing epilepsy medicine

If you have been taking an epilepsy medicine for a while, and are still having seizures or side-effects, talk to your GP or epilepsy specialist. They might suggest that you try taking a different one.

The usual way to change epilepsy medicine 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.

If you change your epilepsy medicine, you are at risk of having more seizures than usual. There is a small risk of having withdrawal seizures from stopping the old medicine, or the new medicine might not work well for you. Because of this, your doctor might advise you to stop driving for a period of time. You may also decide to avoid activities such as some sports, until you and your doctor feel sure that you have good seizure control.
Interactions between epilepsy medicines

If you take more than one epilepsy medicine, one of them may raise or lower the amount of another in your blood. This could cause you to have more seizures.

So, if you take more than one epilepsy medicine, and your doctor changes the dose of one, they might also change the dose of other ones you are taking. This is to make sure that they still work well together.

Drug level monitoring

Drug level monitoring involves having regular blood tests to check how much of a medicine (or drug) is in a person’s blood.

Doctors do not usually do drug level monitoring for people taking epilepsy medicine, unless there is a specific reason to do so. Here are some of those reasons.
• To make sure that a person is taking the right dose of the epilepsy medicine phenytoin
• To see if a person is taking their epilepsy medicine regularly
• To find out if the reason a person is getting side-effects is because the dose of their epilepsy medicine is too high
• To find out if levels of certain epilepsy medicines have changed during pregnancy
Stopping treatment

If you have been seizure-free for at least two years, your epilepsy specialist might discuss with you the risks and benefits of continuing or stopping your epilepsy medicine. They will suggest this if they think that the risk of your seizures coming back is low. Here are some of the things they will consider to make this decision:

- **How long you have been seizure-free** – the longer you have been seizure-free, the lower is the risk that you will have another seizure
- **How many epilepsy medicines you take** – if you needed more than one epilepsy medicine to control your seizures, there is a higher risk that your seizures will return if you stop taking medicine
- **How many seizures you had before they were stopped with epilepsy medicine** – the more you had, the higher is the risk that your seizures will return
- **The type and cause of your epilepsy** – 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 are 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 this. It could take a few months to stop taking it altogether. If you stop taking epilepsy medicine too quickly, it could cause you to have more frequent and severe seizures.
Possible effects of epilepsy medicine on other things

**Your bones**

Some epilepsy medicines may cause your bones to become thinner and more brittle, which means you are more at risk of breaking them. These are:

- Carbamazepine
- Primidone
- Phenytoin
- Sodium valproate

If you are concerned that you may be at risk of having weaker bones, 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.
Contraception

If you are a woman with epilepsy, it is advisable to plan any pregnancy if you can. This is to make sure that the pregnancy is as healthy as possible for both you and your baby. So, it is important to use a type of contraception that works well for you.

Some epilepsy medicines make some types of contraception work less well than they should. This could lead to an unplanned pregnancy.

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

Epilepsy medicines which may interact with some types of contraception include:

• Carbamazepine
• Lamotrigine
• Phenobarbital
• Primidone
• Topiramate
• Eslicarbazepine acetate
• Oxcarbazepine
• Phenytoin
• Rufinamide

If you take epilepsy medicine and you are planning to use contraception, speak to your GP, or your local sexual health clinic (details in your local Phone Book).

Epilepsy Action has more information about contraception and planning a baby if you have epilepsy.
Possible effects of other things on epilepsy medicine

Prescribed medicines

Some medicines used to treat conditions other than epilepsy can increase your risk of having seizures. They might lower your resistance to seizures, or interact with your epilepsy medicine, making it work less well.

Some of these include some antidepressants, some types of antihistamines, some antibiotics and some anti-malaria treatments.

If you are going to take a prescribed medicine, always check with your GP or pharmacist if they could affect your epilepsy or epilepsy medicine.

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 name 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 stays the same.

Here are the generic and some brand names of some commonly used epilepsy medicines.

<table>
<thead>
<tr>
<th>Generic name</th>
<th>Brand names</th>
</tr>
</thead>
<tbody>
<tr>
<td>carbamazepine</td>
<td>Tegretol</td>
</tr>
<tr>
<td></td>
<td>Carbagen</td>
</tr>
<tr>
<td>lamotrigine</td>
<td>Lamictal</td>
</tr>
<tr>
<td>levetiracetam</td>
<td>Keppra</td>
</tr>
<tr>
<td>sodium valproate</td>
<td>Epilim</td>
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<td></td>
<td>Episenta</td>
</tr>
<tr>
<td></td>
<td>Epival</td>
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<tr>
<td>topiramate</td>
<td>Topamax</td>
</tr>
</tbody>
</table>
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 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. Some chemists in the UK carry supplies of Tegretol from all three countries. So, if a pharmacist gives you Tegretol, it could have been made in any of those countries.

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.
The problem 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. Some people have also experienced side-effects that they have not had before.

For this reason, 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. However, not all doctors agree with this.

Advice for people who prescribe epilepsy medicine

The National Institute for Health and Care Excellence (NICE) is an independent organisation. They provide guidelines for treatment and care for people using the NHS in England, Northern Ireland and Wales.

NICE’s advice about prescribing epilepsy medicines

Consistent supply to the child, young person or adult with epilepsy of a particular manufacturer’s AED (epilepsy medicine) preparation is recommended, unless the prescriber, in consultation with the child, young person, adult and their family and/or carers as appropriate, considers that this is not a concern.
The Medicines and Healthcare Products Regulatory Agency (MHRA) also gives guidance to people who prescribe medicine and to pharmacists. It is not official policy that must be followed, and Epilepsy Action does have some concerns about it.

<table>
<thead>
<tr>
<th>The MHRA’s guidelines about prescribing epilepsy medicines</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category 1 – Phenytoin, carbamazepine, phenobarbital, primidone</strong></td>
</tr>
<tr>
<td>For these drugs, doctors are advised to ensure that their patient is maintained on a specific manufacturer’s product.</td>
</tr>
<tr>
<td><strong>Category 2 – Valproate, lamotrigine, perampanel, retigabine, rufinamide, clobazam, clonazepam, oxcarbazepine, eslicarbazepine acetate, zonisamide, topiramate</strong></td>
</tr>
<tr>
<td>For these drugs the need for continued supply of a particular manufacturer’s product should be based on clinical judgement and consultation with patient and/or carer taking into account factors such as seizure frequency and treatment history.</td>
</tr>
<tr>
<td><strong>Category 3 – Levetiracetam, lacosamide, tiagabine, gabapentin, pregabalin, ethosuximide, vigabatrin</strong></td>
</tr>
<tr>
<td>For these drugs it is usually unnecessary to ensure that patients are maintained on a specific manufacturer’s product unless there are specific concerns such as patient anxiety, and risk of confusion or dosing errors.</td>
</tr>
</tbody>
</table>
How to get the same version of your epilepsy medicine

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

If you take an epilepsy medicine that is in category 2 or 3 of the MHRA guidelines, your doctor might not want to prescribe you the same brand. However, you could ask your doctor if you could stay on the same brand if:
• The thought of changing makes you feel anxious or confused and/or
• You think you have had side-effects or seizures because you have been prescribed a different version of your epilepsy medicine

You can ask your doctor to write ‘no parallel imports’ (see page 24) on your prescription, but the pharmacist doesn’t have to take any notice of this. However, you can insist that your epilepsy medicine is given to you with a Patient Information Leaflet and packaging that is written in English.

If your epilepsy medicine is not made in the UK, it may be impossible to get exactly the same version every time. It is advisable to discuss this with your GP.
Other ways of treating epilepsy

Most people with epilepsy take epilepsy medicine, which can be very effective in reducing or stopping seizures. But if it does not work well for you, there are other treatments that may help.

_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 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 epilepsy medicines, 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 neck at regular times throughout the day. This sends impulses to the brain, which helps to prevent electrical activity that causes seizures.

It can take from a couple of months to two years after the VNS is implanted to notice a difference in seizure control. Sometimes, it doesn’t work at all. The benefits of having the VNS can include the following:
- Fewer seizures
- Less severe seizures
- Improved quality of life
The ketogenic diet

The ketogenic diet is sometimes used to try and help children whose seizures cannot be reduced or stopped with epilepsy medicine. 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.

Some children become seizure free as a result of the diet. Other children have fewer seizures. However, the diet does not work for every child, and it is not possible to predict who it 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

Complementary treatments include acupuncture, herbal treatments, homoeopathy, and aromatherapy. 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.

There is no scientific evidence to suggest that any type of complementary treatment can reduce or stop seizures. If you are thinking about trying any, talk to your GP or epilepsy specialist first. They can let you know if they are aware of any reason why the treatment might cause any problems for your epilepsy or epilepsy medicine.
If you do decide to use any complementary treatments, you should continue to take your epilepsy medicine as usual. It is also advisable to check that the person who provides the treatment (the therapist) or who advises you on the treatment 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 library.

**Herbal medicines, supplements and essential oils**

Some herbal medicines and supplements can increase the risk of seizures if you have epilepsy. Some examples are ephedra, ginkgo biloba, pennyroyal, star anise and St John’s wort, but there are many more.

Some essential oils can also increase the risk of seizures if you have epilepsy. These are:
- Fennel
- Rosemary
- Sage

If you are thinking about using any kind of herbal medicine, supplement, or essential oil, always check with your pharmacist or GP. They can let you know if there are any reasons why they might affect your epilepsy or epilepsy medicine.
Sudden unexpected death in epilepsy

About sudden unexpected death in epilepsy

Epilepsy Action believes that it is very important for people with epilepsy and their families to be aware of the risks associated with epilepsy. This information is about one significant risk, and that is sudden unexpected death in epilepsy (SUDEP).

It is estimated that SUDEP happens to one in every 1,000 people with epilepsy. There is no way of predicting who will be affected by SUDEP. However, some people with epilepsy have a higher risk than others. One of the most important risk factors is uncontrolled generalised tonic-clonic seizures.

The risk of SUDEP is thought to be higher, the more seizures you have. The risk of SUDEP if you are seizure-free is very, very low. And, SUDEP is rare in people who are newly diagnosed with epilepsy.

Risk factors for SUDEP

Any of the following things are thought to increase a person’s risk of SUDEP:

• Having uncontrolled generalised tonic-clonic seizures
• Not taking epilepsy medicine as prescribed
• Having seizures that are not controlled by epilepsy medicine
• Having frequent changes to epilepsy medicine
• Being a young adult (in particular male)
• Having sleep seizures
• Having seizures when alone
• Regularly drinking large amounts of alcohol
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 your seizures are not controlled, here are some ways that you can manage your epilepsy, to try and reduce them.

- Always take your epilepsy medicine as prescribed
- Never stop taking your epilepsy medicine, or make changes to it, without talking to your doctor first
- Make sure that you never run out of your epilepsy medicine
- Ask your epilepsy specialist or epilepsy nurse in advance what you should do if you ever forget to take your epilepsy medicine
- If your seizures continue, ask to be referred to an epilepsy specialist for a review of your epilepsy – they may be able to suggest changes to your epilepsy medicine, or other treatment options
- Keep a diary of your seizures – this can help you and your doctors identify any patterns to your seizures or seizure triggers
- Avoid situations which may trigger your seizures – common triggers include not taking epilepsy medicine as prescribed, lack of sleep, stress and too much alcohol
- If your epilepsy is very difficult to control, ask your specialist if you could be referred to a specialist epilepsy centre for treatment. Contact Epilepsy Action for more information about this
Getting healthcare

About the National Institute for Health and Care 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.

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.

NICE and SIGN guidelines

The aim of NICE and SIGN guidelines is to help healthcare professionals, patients and their carers to make decisions about treatment and healthcare.

Both sets of 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 be having, 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**

If you wish to see a specialist privately, you can ask your GP to refer you for a private appointment. Be aware that some epilepsy specialists only work within the NHS and do not take private referrals.

**Choose and Book and epilepsy services**

In England, where it is available, the Choose and Book service lets you choose and book your first appointment with a consultant-led epilepsy specialist team. Choose and Book gives you some choice about the place, time and date of your appointment.

Epilepsy Action has more information about getting healthcare.
Organisations who give advice about healthcare

**Care Quality Commission (England)**

The Care Quality Commission (CQC) regulates all health and adult social care services in England. They make sure that essential standards of quality and safety are being met, wherever care is provided. These include hospitals and GP services.

The CQC listens to what people say about the services they have received, and involves the public about any decisions they need to make. They also provide information online about how the services in your area measure up to the national standards. You can tell the CQC about any concerns you have about your care.

Tel: 03000 616161
Website: cqc.org.uk

**Health and Social Care (Northern Ireland)**

This is a gateway to Health and Social Care Services in Northern Ireland. It contains links to the Acute and Community Services provided by the five Health Trusts, General Practitioner Surgeries and Clinics, Health Boards and Agencies and central government healthcare services.

Website: hscni.net

**NHS Choices (England)**

NHS Choices provides health advice and information services for people in England.

Website: nhs.uk
**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.
Tel: 08454 242 424  
Website: nhs24.com

**NHS Direct Wales – Galw Iechyd Cymru**

This is the NHS Direct service for people in Wales. It provides health advice and information in English and Welsh. They also provide advice and information through their website.
Tel: 0845 46 47  
Website: nhsdirect.wales.nhs.uk

**Patient and Client Council (Northern Ireland)**

The Patient and Client Council (PCC) provides an independent voice for patients, service users, 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.
Tel: 0800 917 0222  
Website: patientclientcouncil.hscni.net
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 exists to make sure that the NHS listens to patients, their families, carers and friends. It can provide you with information about the NHS and help you with any other health-related enquiry. PALS also helps to resolve complaints about healthcare. PALS is currently available in England.

To find your nearest PALS, contact your local hospital, your GP practice or Epilepsy Action.

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 Choices, 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 Choices, NHS 24, NHS Direct Wales or Care Quality Commission can give you advice.

Your local Citizens Advice Bureau can provide advice and support if you want to complain about the NHS.
Tel: Find the number in your local Phone book
Website: adviceguide.org.uk
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 Choices, NHS 24, NHS Direct Wales, Patient and Client Council or Care Quality Commission can give you more advice about making a complaint.

Alternatively, your local Citizens Advice Bureau can provide advice and support if you want to complain about the NHS.
Tel: Find the number in your local Phone book
Website: adviceguide.org.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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This booklet was reprinted in June 2016 with a change to the information about grapefruit and epilepsy medicines. See page 22 for details.

Acknowledgements

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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, e-books, 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 aged 16 years or over. Join at 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.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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<td>I feel more informed about issues to do with epilepsy</td>
<td></td>
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<tr>
<td>I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse/other (cross out those that don’t apply)</td>
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<td>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</td>
<td></td>
</tr>
<tr>
<td>I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline, support groups or forum4e</td>
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Please tell us how you think we can improve this information

________________________________________________________________________________________
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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.
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

Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
tel 0113 210 8800  email epilepsy@epilepsy.org.uk

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All Epilepsy Action booklets are printed on environmentally friendly,
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