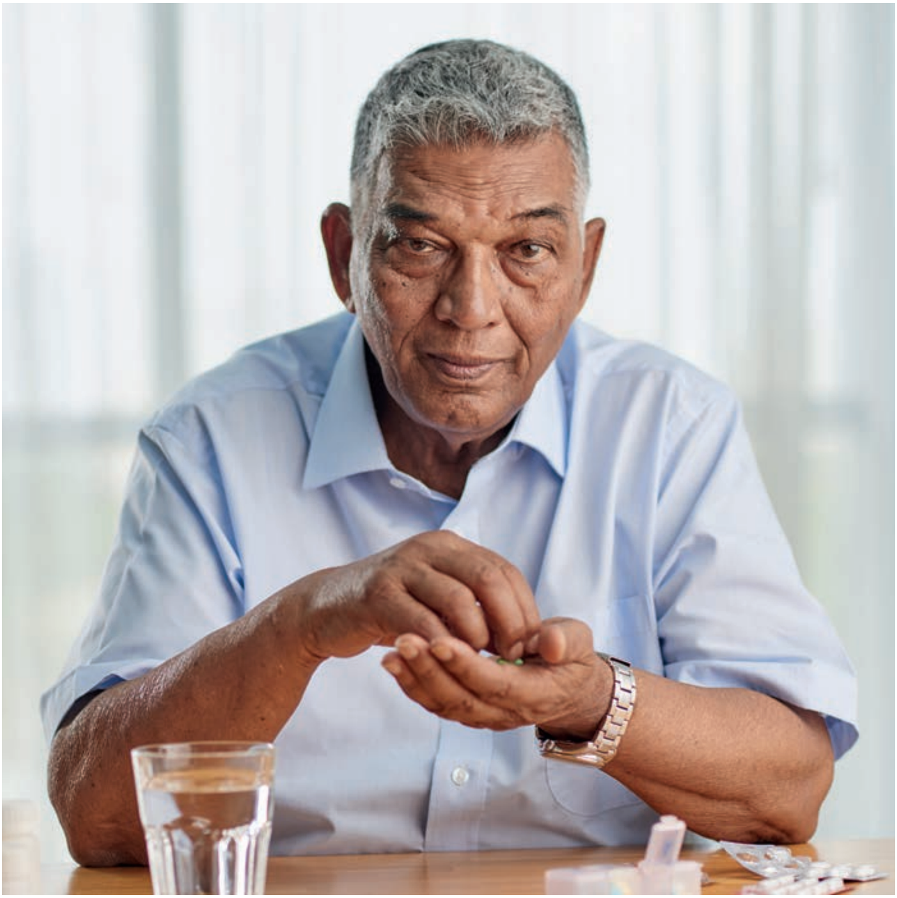
epilepsy action

Epilepsy: diagnosis, treatment and healthcare



epilepsy.org.uk
Epilepsy Action Helpline: 0808 800 5050

Epilepsy Action – together we can change lives

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

Together we can:

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

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

Please donate today.

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

Thank you.

Registered with FUNDRAISING REGULATOR

Contents

Introduction

This booklet tells you what epilepsy is, how it is diagnosed, and what the different types of treatment are. It also tells you what to expect from your epilepsy care.

Throughout the booklet, you'll see web links showing you where you can find more information about that subject on our website. If you have any questions about the information in this booklet, or would like to talk to someone about epilepsy, the Epilepsy Action Helpline is here for you. See page 39 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. Ask your GP, 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. You will usually only be diagnosed with epilepsy if:

- You have had two or more seizures, **or**
- You have had one seizure and your doctor thinks there is a high chance you 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?

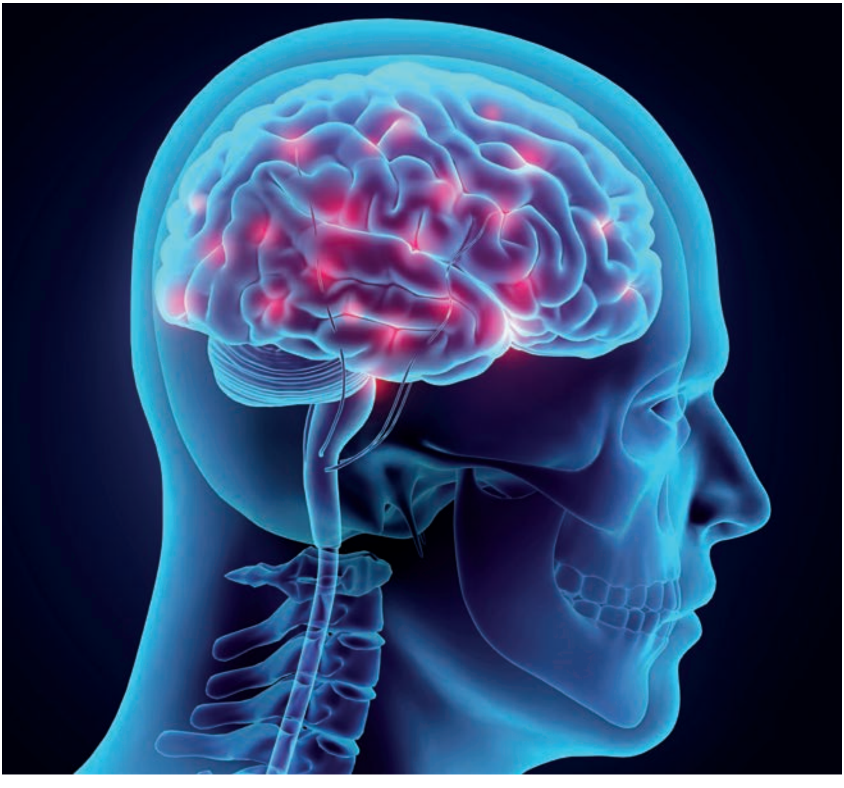
Electrical activity is happening in our brain all the time, as the cells in the brain send messages to each other. A seizure happens when there is a sudden burst of intense electrical activity in the brain. This causes a temporary disruption to the way the brain normally works. The result is an epileptic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

There are many different types of seizure. 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.



Diagnosing epilepsy

If you've had a seizure, your GP or the hospital where you attended A&E should arrange for you to see an epilepsy specialist. For adults, an epilepsy specialist is usually a neurologist. This means a doctor who's an expert in conditions that affect the brain and nerves.

There are a number of conditions that can cause symptoms similar to epilepsy, so it can take a while to diagnose. To help them make a diagnosis, your epilepsy specialist will take a full description of your symptoms. They may also arrange for you to have some tests.

A description of your symptoms

Your specialist will want to know as much as possible about what happens to you during your seizures. You can help them by:

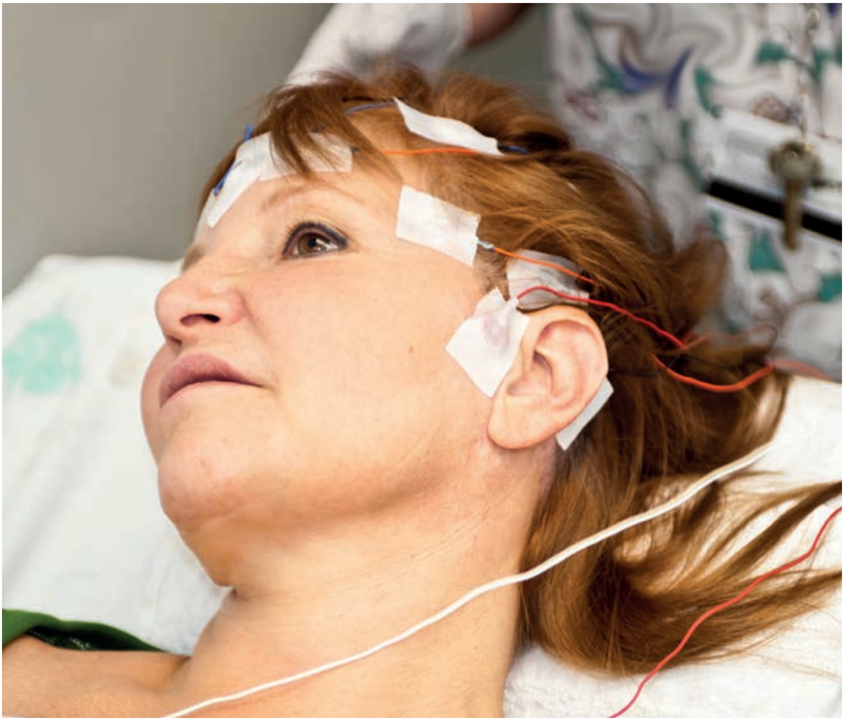
- Taking a detailed diary of your seizures to your appointments. This should show the dates, times and a description of what happened, and how you felt before and after
- Taking someone with you who has seen your seizures. Alternatively, a written description from someone who has seen your seizures would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

Tests used in the diagnosis of epilepsy

There are a range of tests used to help diagnose epilepsy. You might have had some in hospital soon after your seizure, and your specialist may arrange for you to have others if needed.

Electroencephalogram (EEG)

The EEG machine records the electrical signals from your brain on a computer. During the EEG test, 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) brain scan

An MRI scan uses a strong magnetic field to create pictures of tissues, organs and other structures inside the body, on a computer. Some people have epilepsy caused by damage or other problems in their brain, so an MRI scan can check for this.

You can read more about EEG and MRI tests at epilepsy.org.uk/eeg and epilepsy.org.uk/mri

Electrocardiogram (ECG) and blood tests

An ECG is a test to check your heart activity. It's used to check for any heart-related conditions that can cause symptoms that look like a seizure.

You may also be offered blood tests to check your general health and to see if any other conditions may be causing your symptoms. If your specialist thinks you might have a type of genetic epilepsy, they may refer you for genetic testing.

What happens if I'm diagnosed with epilepsy?

If the epilepsy specialist diagnoses you with epilepsy, they should tell you what type of epilepsy you have and the name of your seizures. They should also give you information about your treatment options, and about living with epilepsy, including safety risks and how to reduce them.

Treatment with epilepsy medicine

The main treatment for epilepsy is epilepsy medicines. Some people call them anti-seizure medications (ASMs) or anti-epileptic drugs (AEDs). They don't cure epilepsy, but try to prevent seizures from happening. They do this by changing the levels of chemicals in the brain that control electrical activity.

Whether or not to take medicine for your epilepsy should be a joint decision between you and your specialist. If you need help deciding, the specialist should also involve your family or carer.

Starting treatment

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

There may be a choice of medicines that might work well for you. If this is the case, your specialist should give you information about each one, to help you make a decision.

Doctors usually try to prescribe just one epilepsy medicine at a time. But some people need to take two or more different epilepsy medicines to control their seizures. These are usually medicines that work in different ways, but work well together.

Taking epilepsy medicine

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.

Epilepsy medicine is often available in a number of different forms such as chewable, crushable or dispersible tablets, capsules, liquids and granules. If you find tablets difficult, ask your GP to prescribe you something easier to swallow.

Making treatment with epilepsy medicine easier

Here are some suggestions:

- Ask your doctor or pharmacist for clear instructions on how to take it
- If you find the leaflet that comes with your medicine 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
- If you have lots of medicines to take, ask your pharmacist about a dosette box. These are boxes that show which pills you need to take and when
- Use an app or alarms on your mobile phone to remind you to take your medicine
- 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
- Sign-up for your GP's online service. This allows you to order your repeat prescriptions online. If you like, you can give access to someone else so they can order prescriptions for you
- If you're in England, ask your GP for a form to get a medical exemption certificate. This allows you to get all your prescription medicines for free

How much medicine will I need to take?

Your doctor will tell you how much of your epilepsy medicine you should take, and what time of day you need to take it. Most people start on a low dose and gradually increase it to the maintenance dose. This is the dose that works best for them to prevent seizures and avoid side effects.

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?

For five out of 10 people with epilepsy, the first epilepsy medicine they try will stop their seizures. It's not possible to say how long this will take. But for many people, it happens quickly. For others, it takes longer.

If you've reached the maintenance dose of your medicine but are still having seizures, speak to your specialist. They might recommend trying another medicine.

Around a third of 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.

I’ve tried several epilepsy medicines and I’m still having seizures. What can I do?

If you’ve tried two or more medicines and you’re still having seizures, your specialist should refer to a specialist epilepsy centre. This is sometimes called a tertiary centre or tertiary service.

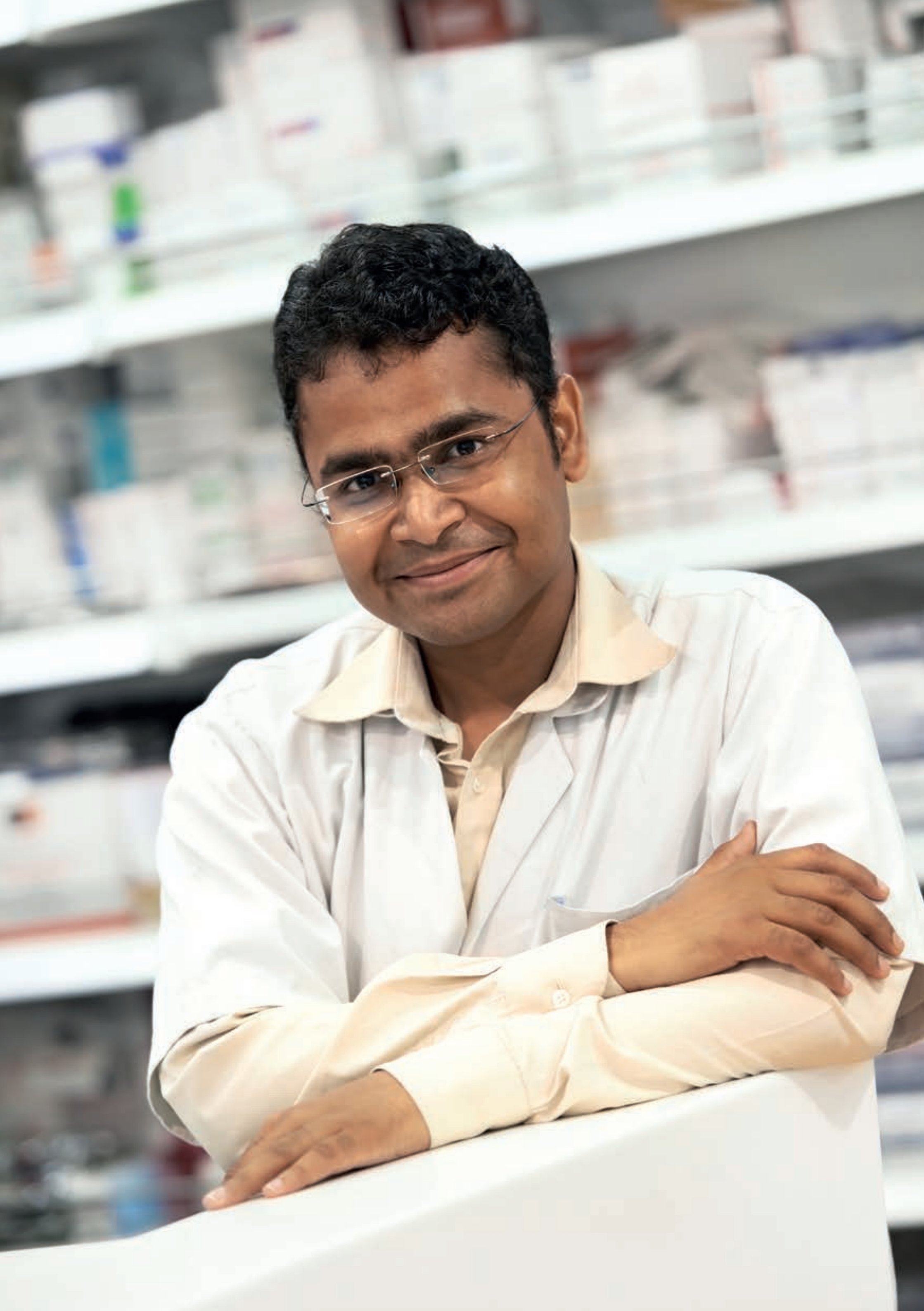
Doctors at a specialist epilepsy centre should review your epilepsy and treatment to try to get you better seizure control. They might also talk to you about other treatments for epilepsy. See page 25 for other ways of treating epilepsy.

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?

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. This means 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 reduce your epilepsy medicine, your doctor should give you clear instructions about how to do this. 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.

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 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

- **The cause of your epilepsy** – if your epilepsy is caused by damage or other problems in your brain, there is a higher risk your seizures will return

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 6 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.

Emergency medicine

Most people with epilepsy have seizures that last a short time and stop by themselves. But some people are at risk of having seizures that do not stop on their own and last too long. This is called status epilepticus, and can be dangerous.

If your doctor thinks you are at risk of status epilepticus, they might prescribe you emergency medicine. This is medicine to stop your seizure if it lasts longer than usual. Emergency medicine can be given to you by a family member, carer, teacher or colleague, as long as they've been trained how to use it.

If your doctor prescribes you emergency medicine, they should make sure you have an emergency care plan explaining when and how to use it.

Side effects and interactions

Side effects

When you get your medicine it will include a patient information leaflet that 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 find their side effects lessen over time, as their body gets 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 form from your GP surgery or local pharmacy
- Filling in a Yellow Card online at yellowcard.mhra.gov.uk
- Calling the Yellow Card freephone hotline: 0800 731 6789

Reporting side effects to the MHRA can help them identify any new side effects or safety issues they might not have known about.

Bone health

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 newer 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.

Contraception

Some epilepsy medicines make some types of hormonal contraception, such as the pill, work less well than they should. This could mean you have an unplanned pregnancy.

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

If you are considering which type of contraception to use, speak with your GP, epilepsy specialist nurse or your local family planning clinic. They can help you choose a form of contraception that will work with your epilepsy medicine and suit your lifestyle.

To check which types of contraception may work with your epilepsy medicine, go to epilepsy.org.uk/contraception

Medicines to treat other conditions

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, over-the-counter medicine or herbal remedy, always check with your GP or pharmacist first. This is to make sure they won't affect your epilepsy or treatment.

Grapefruit

It's important to avoid eating grapefruit or drinking grapefruit juice when taking some epilepsy medicines. This is because a chemical that is naturally found in grapefruit can increase the levels of these medicines in your body. This could increase your chance of having side effects.

The epilepsy 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. These medicines are called by the generic name and are sometimes cheaper than the branded version.

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

Generic name	**Original brand name**
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 company's version of that medicine. This is called generic prescribing.

Are there any problems with generic prescribing?

Many people can switch between different versions of their medicine without any problems. But 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) has looked at this issue and given advice to doctors prescribing epilepsy medicine. It says that for some epilepsy medicines, there is a risk that switching between versions could affect seizure control or side effects. If you are taking one of these medicines, your doctor should try to make sure you get the same version all the time. For some other epilepsy medicines, the MHRA says the risk of seizures or side effects from switching versions is very low.

To read what the MHRA says about different epilepsy medicines go to epilepsy.org.uk/generic-prescribing

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. If the brand is written on your prescription, the pharmacist must give it to you.

If you want to stay on a particular manufacturer's generic version, your doctor can write the generic name and the name of the manufacturer on your prescription. Your pharmacist should always try to give you the version your doctor has written on your prescription.

What if I can't get the version of epilepsy medicine I usually have?

Sometimes there can be a shortage of supplies or a company may stop making a medicine. Unfortunately, where this is the case, there may be no choice but to take a different version. The doctor who prescribes your epilepsy medicine should be able to advise you what to do if this happens.

Other ways of treating epilepsy

Most 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

Brain surgery for epilepsy involves:
- Removing a small part of your brain that is causing your seizures, **or**
- Separating the part of the brain causing your seizures from the rest of your brain

The aim of epilepsy brain surgery is to stop your seizures, reduce the number of seizures you have, or make them less severe. Brain surgery isn't suitable for all types of epilepsy.

Find out more at epilepsy.org.uk/surgery

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.

Only some people with epilepsy are able to have VNS therapy on the NHS.

You might be offered VNS if epilepsy medicines have not controlled your seizures. You must also be unsuitable for epilepsy brain surgery, or you have had brain surgery but are still having seizures.

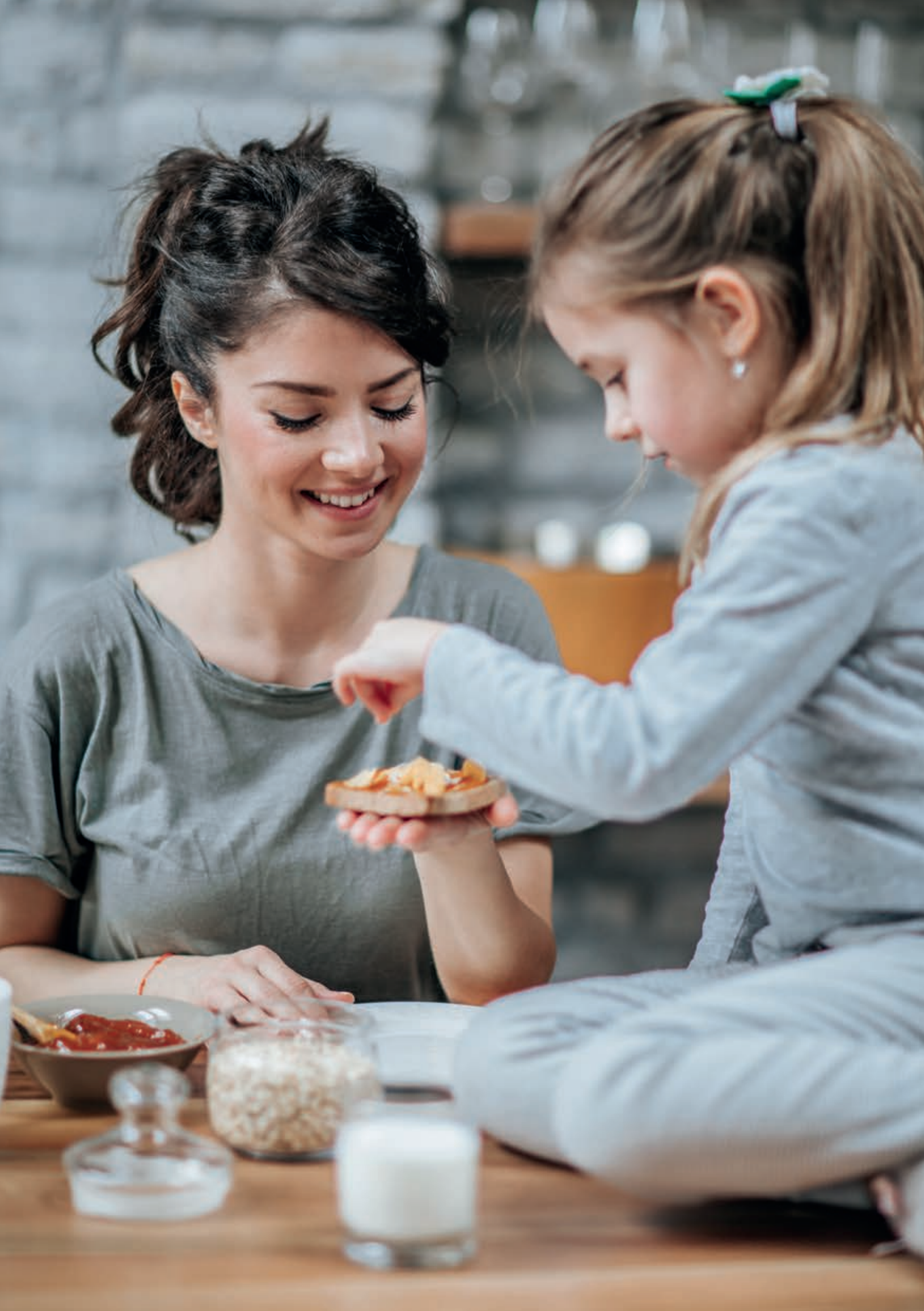
Find out more at epilepsy.org.uk/vns

The ketogenic diet

The ketogenic diet (also called ketogenic therapy) is a specialist medical diet that can help to control seizures for some people. It's much higher in fats and lower in carbohydrates than a typical diet.

The ketogenic diet is recommended as an option on the NHS for people with some rare and severe types of epilepsy. It may also be an option for people whose seizures have not stopped with epilepsy medicine, and where brain surgery and VNS have not worked or are not suitable.

Find out more at epilepsy.org.uk/ketogenic



Sudden unexpected death in epilepsy

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

People can die from a seizure itself, or from an accident caused by a seizure. But in some cases there's no clear reason why a person with epilepsy has died. When this happens, it's called sudden unexpected death in epilepsy (SUDEP).

Am I at risk of SUDEP?

SUDEP is rare, affecting around one in every 1,000 adults with epilepsy each year. This figure is for people with epilepsy in general. Your own level of risk will depend on what type of seizures you have and how well-controlled they are. No one can say exactly who will be affected by SUDEP, but research has shown there are some things that can put you at increased risk:

- **Tonic-clonic seizures:** The biggest risk factor for SUDEP is having uncontrolled tonic-clonic seizures. The more frequent your seizures, the more you are at risk of SUDEP
- **Sleep seizures:** SUDEP often happens at night. This suggests that you may be at more risk of SUDEP if you have seizures during sleep
- **Not taking epilepsy medicine regularly:** There's some evidence that people who don't take their epilepsy medicine regularly, as prescribed by their doctor, have an increased risk of SUDEP

If you have other types of seizure, for example focal or myoclonic seizures, your risk of SUDEP is much lower than someone who has frequent tonic-clonic seizures. However, if you take epilepsy medicine to control your seizures, it's important to keep taking it as prescribed. This is because for some people, not taking their medicine could put them at risk of having tonic-clonic seizures.

How can I reduce my risk of SUDEP?

The most effective way to reduce your risk of SUDEP is to have as few seizures as possible, especially if you have tonic-clonic seizures.

Here are some suggestions to help you have as few seizures as possible:
- Take your epilepsy medicines every day, exactly as they've been prescribed. If you don't like your medicine or have side effects, talk to your epilepsy specialist so they can make changes
- Find out in advance what to do if you miss a dose of medicine, or have vomiting or diarrhoea after taking it
- Try to avoid situations which may trigger your seizures. Common triggers include missing a dose of epilepsy medicines, lack of sleep, stress and drinking too much alcohol
- If your seizures are not fully controlled, 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

Find out more about SUDEP at epilepsy.org.uk/sudep

Treatment reviews

Guidelines in England, Northern Ireland and Wales say you should have a regular review of your epilepsy with a healthcare professional at least once a year if any of these things apply:

- You are a child or young person
- You have a learning disability
- You have tried two or more epilepsy medicines and are still having seizures
- You are at high risk of sudden unexpected death in epilepsy (SUDEP)
- You have another serious health problem alongside your epilepsy, such as a complex mental health problem
- You are taking epilepsy medicine that has a high risk of long-term side effects or interactions with other medicines
- You are able to get pregnant and are taking sodium valproate or another medicine that has a high risk of causing problems if taken during pregnancy

Even if none of these things apply to you, you can still ask for a review of your epilepsy if you have any concerns.

Guidelines in Scotland say everyone with epilepsy should have a review at least once a year.

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.

Guidelines in England, Northern Ireland and Wales say that if you are still having seizures, you should get an appointment with an epilepsy specialist nurse twice a year. You should also be offered an appointment with one after any visits to A&E for your seizures.

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.

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.

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.

How do I make a complaint?

You have the right to complain about any aspect of NHS care or treatment, and to have your complaint dealt with properly. There are different organisations that can help with complaints, depending on which part of the UK you live in. Contact Epilepsy Action for more information.

About this publication

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

To find out why you can trust Epilepsy Action's information, please contact us or visit epilepsy.org.uk/trust

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Disclaimer

First aid for tonic-clonic seizures

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

Do...

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

Don't...

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

Call 999 for an ambulance if...

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

First aid for focal (partial) seizures

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

Do...

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

Don't...

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

Call 999 for an ambulance if...

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

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

Epilepsy Action's support services

helpline

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

Freephone 0808 800 5050
Staff are text relay trained and able to offer advice and information in 150 languages, via an interpreting service.

Live chat
Visit epilepsy.org.uk to chat with a member of the helpline team. We usually reply to chat requests within 5 minutes.

Email helpline@epilepsy.org.uk
Send us your question about epilepsy. We aim to reply within 48 hours (on workdays).

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

talk and support

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

befriending

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

Continued on page 39

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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 or support groups

Please tell us how you think we can improve this information

Please return the completed form to:
FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action,
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY

You can also give us feedback online. Visit epilepsy.org.uk/feedback

Thank you.

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

counselling

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

family support Northern Ireland

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

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

Information about epilepsy

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

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

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Epilepsy Action Helpline:

freephone 0808 800 5050
epilepsy.org.uk

Epilepsy Action
Information you can trust

Find out more
epilepsy.org.uk/trust

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