later life
Developing epilepsy after 65
3 what is epilepsy?
4 types of seizures
7 how is epilepsy diagnosed?
10 why have I developed epilepsy now?
11 how is epilepsy treated?
19 will epilepsy affect my life?
23 epilepsy and safety
24 epilepsy and leisure
26 what to do if someone has a seizure
27 other organisations

This symbol means further information is available.

Call us for a large print version

helpline
01494 601 400
Monday and Tuesday 9am to 4pm,
Wednesday 9am to 7.30pm. National call rate.
developing epilepsy after 65

Epilepsy can happen to anyone and 1 in 100 people in the UK has epilepsy. It can start at any age, but tends to be more common in older adults, and in children and teenagers. Epilepsy is most common in people over 65.

This booklet is specifically about developing epilepsy in later life. It has a brief introduction to epilepsy, some of the possible causes for developing epilepsy in later life, and how it is diagnosed. It looks at treatment and who is usually involved in your epilepsy care. It also covers issues that may be important to you if you have epilepsy in later life.

We have more information on these topics, available from our helpline or on our website.

In this booklet we use the terms ‘later life’ and ‘older people’ to refer to people aged 65 or over.

what is epilepsy?

We understand more about epilepsy these days than we used to. We know that many old misunderstandings about epilepsy are not true. Epilepsy is not something you can catch from another person. It is not a mental health problem and it does not cause dementia.

Epilepsy is a neurological condition (affecting the brain and nervous system) where there is a tendency to have repeated seizures that start in the brain.
Why do seizures happen?

The brain has millions of nerve cells which control the way we think, move and feel. The brain sends messages from one cell to the next using electrical signals. If the electrical signals are disrupted, or too many signals are sent at once, this causes a seizure (previously called a ‘fit’ or ‘attack’).

Most seizures happen suddenly, last a few seconds or minutes, and stop by themselves. Some people have seizures in their sleep, others when they are awake, and some people have both.

Some people have episodes that look like seizures but they are not due to epilepsy (see page 9).

In this booklet when we use the word ‘seizure’ we mean an epileptic seizure.

Types of seizures

We often think that seizures are when someone collapses and their body jerks and shakes, but there are also other types of seizures. The type of seizure someone has depends on which area of their brain is affected and what this part of the brain controls.

Seizures are divided into two main types: focal seizures (previously called partial seizures) and generalised seizures.
Focal seizures

Focal seizures start in, and affect, just one part of the brain. Most people who develop epilepsy in later life have focal seizures rather than generalised seizures.

**Focal aware seizures (FAS)** affect only a small part of the brain. You are conscious and aware that something unusual is happening. These seizures may include a rising feeling in the stomach, an unusual smell or taste in the mouth, twitching in one hand or limb, or a sudden intense feeling such as fear. Often they only last for a few seconds, but for some people they may last longer and develop into a focal impaired awareness seizure.

**Focal impaired awareness seizures (FIAS)** affect a larger part of the brain than focal aware seizures. Your consciousness is partly affected, so you may be confused or not fully know what is happening. You may be able to hear what is going on around you but may not be able to fully understand or respond. You may not remember the seizure afterwards. This type of seizure may last a few seconds or a few minutes.

Like a focal aware seizure, what happens during a FIAS depends on which part of the brain is affected. This may include confusion, chewing movements or lip smacking, wandering, fiddling with objects or clothing, or circular or kicking movements of your arms or legs.
Focal to bilateral tonic-clonic seizures start as a focal seizure, but the seizure spreads from one side to both sides of the brain and becomes generalised (see below). Some people call the focal seizure at the start an ‘aura’ or ‘warning’, if they know from experience that another seizure is likely to follow.

Generalised seizures

Generalised seizures affect both sides of the brain at once and happen without warning. There are different types of generalised seizures and they all affect consciousness, apart from myoclonic seizures (see below). A person can have one or more of these types of seizure. Types of generalised seizure include:

Tonic clonic seizures (previously called grand mal). You lose consciousness, collapse and your body stiffens and jerks or shakes.

Absences. You become unconscious for a short time (usually a few seconds) but do not collapse. You may look blank and be unresponsive.

Myoclonic seizures. These are muscle jerks, causing a limb or part of the body to jerk or spasm. Myoclonic seizures are usually very brief, and you stay conscious. You may have just one jerk or several jerks together. Myoclonic seizures often happen just after waking up. You may have other types of seizures as well.

See our leaflet seizures.
After a seizure

It may take some time for you to recover after a seizure. You may have a headache or feel very tired and want to sleep. You may be confused, sometimes called ‘post-ictal’ (after seizure) confusion or lose some memory for a while. Very rarely, some people have some numbness, or paralysis, in a part of their body for a while (called Todd’s paralysis). You may feel back to normal again after a short time, or it may take you hours or days to feel fully recovered.

See page 26 for what to do if someone has a seizure.

how is epilepsy diagnosed?

Epilepsy is a tendency to have repeated seizures, so a single one-off seizure is not usually classed as epilepsy. However, it is recommended that any single suspected seizure is investigated by a doctor, as there may be various possible causes.

If you have had one or more seizures, your GP should refer you to a specialist. This will usually be a neurologist (a doctor who specialises in conditions of the brain and nervous system) or a geriatrician (a doctor who specialises in the medical care of older people). Ideally this will be someone who also specialises in epilepsy.

Visit nice.org.uk/guidance/cg137
What will the specialist ask about?

A diagnosis of epilepsy is usually based on what happens during the unusual events you have had, so your specialist may ask you to describe in detail what happened before, during and after the event.

If you can’t remember what happened, someone else who saw what happened may be able to give a description. This person could either come with you to the appointment or write down the description for you to take with you. It may be possible for the specialist to speak to the person on the phone during your appointment.

See our factsheet recording seizures.

The specialist may ask you the following.

- How were you feeling before the seizure? Did you feel tired? Had you eaten or drunk anything? Had you been unwell? Had you been stressed or worried about anything?
- What happened during the seizure itself? Did you feel strange? Did you move in an unusual way? How long did the seizure last?
- How did you feel afterwards? Were you confused? Were you tired? Did you have a headache, muscle aches, or need to sleep?

If neither you nor anyone else can describe your seizure, your specialist may suggest a short stay in hospital for investigation.
Tests to help diagnose epilepsy

There are tests that can help to diagnose epilepsy. The tests alone cannot confirm or rule out epilepsy, but they can give extra information to help find out why you are having seizures.

The tests you have may include an Electroencephalogram (EEG) to look at your brain’s electrical activity, a brain scan, such as Computerised Tomography (CT) or Magnetic Resonance Imaging (MRI), to look at the structure of your brain.

See our leaflet diagnosis.

Epilepsy or something else?

Not all ‘funny turns’ are due to epilepsy. Some other medical conditions may look like epileptic seizures. Also seizures themselves can vary. For these reasons, epilepsy can sometimes be hard to diagnose.

Other conditions that can look like epileptic seizures include fainting (syncope – which has many possible causes including a drop in blood pressure), or very low blood sugar (hypoglycaemia) which may happen in people with diabetes. Problems with blood circulation and the heart can also look like epilepsy. The symptoms of a transient ischaemic attack (TIA or ‘mini stroke’) may sometimes be confused with a seizure, because they may affect one side of the body, or the person may be temporarily unable to speak.
Your specialist may therefore try to rule out causes other than epilepsy. They may ask you to have blood tests, an Electrocardiogram (ECG), or other tests to check how your heart is working. If another condition is found at an early stage, this may help you and your doctors to manage it.

**why have I developed epilepsy now?**

There are many possible causes of epilepsy but some causes are more common in later life.

As we get older the blood vessels that supply blood to the brain may become narrower and harder, which can affect the flow of blood, and therefore oxygen, to the brain. The most common causes of seizures starting in later life are cerebrovascular, where there are changes or damage to the blood vessels around the brain.

Some people who have had a stroke may have one or more seizures. However this does not necessarily happen, and, in many cases, seizures are not linked with strokes.

Your doctor or specialist may be able to tell you what has caused your epilepsy, although the cause cannot always be found. Finding out what type of seizures you have is useful for both you and your doctors. This is because decisions about treatment are partly based on the type of seizures someone has.
how is epilepsy treated?

Anti-epileptic drugs (AEDs)

Most people with epilepsy are prescribed anti-epileptic drugs (AEDs). The aim of AEDs is to prevent seizures from happening. AEDs do not stop seizures while they are happening, and they do not cure epilepsy. Most people stop having seizures once they are on a drug that suits them. However, for some people, their seizures will not stop completely, so the aim is then to reduce their seizures as much as possible, while avoiding unwanted side effects.

Like all drugs, AEDs can cause side effects in some people. Some side effects go away as the body gets used to the medication, or if the dose is adjusted.

Although your doctor or specialist may recommend you start taking medication, you can discuss with them the possible risks and benefits of taking medication.

Starting treatment

AEDs are normally started at a low dose to allow your body to get used to them. The dose is gradually increased until it reaches a level that controls your seizures (stops them from happening). The dose at which an AED will control seizures varies from one person to another, and will depend on the type of seizures you have and how your body responds to the drug.
Will my treatment work immediately?

For many people, the first AED they try will work well, once they are on the right dose. The aim is to stop seizures without the AED affecting your everyday life. This can sometimes be a difficult balance. It can take time to find the right AED at the right dose. Sometimes it is necessary to try different AEDs, or different combinations, to get the best seizure control.

What side effects might the drugs have?

Like all drugs, AEDs can cause side effects for some people, depending on their individual reaction to the drug, and the dose they are taking. Many people do not have side effects, because they are on the right dose of a drug that suits them. Possible side effects vary between different AEDs, and for each person.

Because AEDs work in the brain to prevent seizures, some may affect memory and your ability to think quickly. Some AEDs may make you feel sleepy, which may also affect your memory. However, if your memory is affected by seizures, your memory may be improved by taking AEDs if they are controlling your seizures.

A list of possible side effects is included on the patient information leaflet (PIL) that comes with your AEDs. If you need a large print PIL you can ask your pharmacist.

See our booklet medication for epilepsy or visit medicines.org.uk/emc/browse-medicines
If you are having side effects, your specialist may suggest adjusting the dose or trying a different AED.

The Yellow Card scheme is a way of reporting side effects to the Medicines and Healthcare products Regulatory Agency (MHRA), which regulates the safety of medicines in the UK. Reporting side effects helps to identify potential problems with a drug.

Yellow Card forms are available from pharmacies, hospitals or your GP. Or call the Yellow Card Hotline on 0800 731 6789 or visit yellowcard.mhra.gov.uk

Are AEDs taken every day?

To work best, AEDs need to be taken regularly every day. Some drugs are taken once a day and others are taken twice or three times a day, although the aim is to keep the routine of taking drugs as simple as possible. Some AEDs are available in a slow-release form, called ‘chrono’ or ‘prolonged release’. In a slow-release form, the drug is released into your system gradually so that there is a steady level of the drug in your body over time. This means you take fewer doses per day of a slow-release drug, than a drug that is not slow-release.

Missing an occasional AED dose does not usually cause a seizure. But if AEDs are not taken at regular intervals the level in the body varies and you are more likely to have a seizure. AEDs are likely to work best if you follow the instructions on the label and ask your doctor or pharmacist if you have any concerns.
How long will I have to take AEDs for?

For some people their epilepsy stops on its own, but it may not be possible to say if this will happen for you. Because AEDs do not ‘cure’ epilepsy, if you stop taking them, your seizures may come back. So, many people take AEDs for life to stop seizures happening and for peace of mind. If you have had no seizures for two or more years, it may be worth discussing with your doctor the risks and benefits of gradually stopping your AEDs.

AEDs and other medication

Sometimes AEDs can affect other medication, and other medication can affect AEDs, so it is important to tell your specialist about all the medication you take. They can then see which AEDs will suit you best, to avoid the different medications affecting each other and how well they work.

What might help me to take my medication?

Taking medication regularly can be easier if your treatment plan is easy to follow and suits your lifestyle. For example, taking your AEDs at a regular time in your existing routine, such as with a morning drink.

AEDs come in different forms, including tablets that you swallow; tablets that can be crushed or mixed with water; granules that can be sprinkled onto food; or in syrup form. You can ask your specialist or pharmacist which forms your AED comes in.
A pill box or drug wallet can help remind you which tablets to take and when. These have compartments for each day of the week, divided into morning, afternoon and evening. Some types of pill box also have an alarm. These are available from pharmacies.

**What happens if my AEDs don’t help?**

If your AEDs don’t help to control your seizures, your doctor may look at your diagnosis again to check that you do have epilepsy, and to find out as much as possible about your seizures. They may also look at whether other medications you take affect your AEDs.

Your doctor may also check that your treatment plan is easy to follow, and that it suits your lifestyle. They may ask you if you find it easy to remember to take your medication, and about other things that could affect your seizures, such as alcohol or lack of sleep.

Therapeutic drug monitoring (TDM) – measuring the level of AED in the blood – may be useful for some people whose seizures are not responding to AEDs. The way drugs are broken down and absorbed by the body can change as we get older, and TDM may help to see if this is why seizures are still happening. TDM can also look at how your different medications interact, and help work out the best dose to avoid side effects.

See our factsheet *monitoring epilepsy* and our booklet *medication for epilepsy*.
Who will be involved in managing my epilepsy?

Those involved in your epilepsy care may include a neurologist or geriatrician who may have a special interest in epilepsy. Between appointments with these specialists, your GP is responsible for your prescriptions and general medical care. You can tell your GP if you have concerns about your epilepsy or treatment. They may be able to help you with your drugs or refer you back to the specialist if necessary.

You may see other medical professionals such as an epilepsy specialist nurse (ESN). ESNs can talk to you about your epilepsy, liaise with your specialist or GP, and answer any questions you have. Your specialist will know if there is an ESN working at your clinic.

Other professionals who can provide help or support may include a community nurse, an occupational therapist, or a social worker.

Managing epilepsy includes looking at whether your epilepsy could affect, or be affected by, other conditions or medication for other conditions. For example, osteoporosis (where bones become fragile and are more likely to break) is common in later life, due to many factors. Epilepsy and taking AEDs may contribute to the risk of developing osteoporosis, but how much they contribute to this risk is not clear, and will vary from person to person. Osteoporosis can be diagnosed with a bone density scan, and can be treated.
Working with your doctors

Doctors often encourage people to become involved in their own healthcare. They understand that you might have questions about your epilepsy, how it affects you, and how it is treated. Learning more about your epilepsy can help you to make informed decisions about your health and your treatment options.

Before you see any professional involved in your care, you may find it useful to write a list of what you want to talk about. Appointments can be short, so it can help to focus on what is most important to you.

The following are just suggestions. You may have other questions that are specific to your situation.

To ask yourself before the appointment:

• What do I need most from this appointment?
• Is anything about my epilepsy or my treatment worrying me at the moment?
• Is anything about my epilepsy affecting my life? For example, sleeping badly or feeling isolated.
• How can the doctor help the appointment go well? For example, they could repeat key information at the end, or give you more time to ask questions.
• How do I feel about my epilepsy?

Visit epilepsysociety.org.uk/your-appointment
To ask at the appointment (if necessary):

- How and when should I take this medication?
- How do I know if this medication is helping?
- How long will I need to take it?
- Why do I need to still take it if I am seizure-free?
- What if I stopped taking it, or took a lower dose?
- Can I drink alcohol with this medication?
- Can this medication affect my other medication?
- Will this medication affect me if I’m on it for a long time (many years)?
- What can help to remind me to take my medication?
- What should I do if I miss a dose, or take too much?

What are epilepsy reviews?

It is recommended that you have a review of your epilepsy every 6 or 12 months with someone who has an expert knowledge of your epilepsy. This may be your GP or specialist. You can also ask for a review at any point if you would like one. Your review looks at how well your seizures are controlled by your AEDs, whether you are having any side effects, how you feel generally, and any concerns you may have.

Some pharmacies also offer a free Medicines Use Review to look at any concerns you have about your AEDs and any other medication you take.

See our factsheets epilepsy review checklist and making the most of your pharmacist.
will epilepsy affect my life?

Reacting to a diagnosis

If you are diagnosed with epilepsy, you may have many emotions. The experience of epilepsy is different for everyone, and it may affect your life in various different ways, or not at all. You may feel shocked, angry, numb or disbelieving. You may even feel relieved: what’s been happening to you has a name and a treatment.

See our booklet just diagnosed.

Coming to terms with epilepsy

Many people have a full life with epilepsy. However, some find it hard to come to terms with their diagnosis. They may avoid doing the things they would normally do, in case they have a seizure. They may feel isolated or depressed if they feel life has changed since developing epilepsy. These feelings can affect self-confidence and quality of life. This may or may not be true for you, and your feelings about epilepsy may change over time.

See our booklet the bigger picture about mood.

Self management UK runs free courses for anyone with a long-term health condition. Courses cover issues such as relaxation and coping with tiredness, and may help you feel more in control of how epilepsy affects you.

Visit selfmanagementuk.org or call 0800 988 5560.
If you are worried about seizures happening, there may be ways to adapt your lifestyle while still being able to do the things you would normally do. Many activities can be made safer by having someone with you who knows how to help if you have a seizure. Keeping mentally and physically active may help make epilepsy just part of your life and not the most important part.

See our leaflets safety and risk and factsheets exercise and diet and nutrition.

Driving and travel

If you drive, often the first impact of having seizures is that you have to stop driving and notify the Driver and Vehicle Licensing Agency (DVLA). If your seizures are controlled and you are seizure-free for one year, you can apply to get a new driving licence.

See our leaflet driving and travel for driving regulations.

If you are not able to drive, you may be eligible for free or discounted travel. The Disabled Persons Railcard gives you, and someone travelling with you, up to a third off most train fares.

Visit disabledpersons-railcard.co.uk or call 0345 605 0525.

A National Bus Pass is free for people over 60 and people with disabilities. Contact your local council for information and an application form.

See our factsheet what help is available for more about discounted public transport.
**Financial help**

Anyone over 60 can get free NHS prescriptions. You may also be able to claim help with travel costs to hospital appointments, as well as some disability benefits. This depends on how your epilepsy affects you.

If another person gives you care and support for at least 35 hours a week, they may be entitled to benefits.

See our factsheet *what help is available* and our benefits guides at epilepsysociety.org.uk/benefits
Visit gov.uk/disability-benefits-helpline or your local Citizens Advice Bureau for more information.

**How might my family and friends react?**

If you are diagnosed with epilepsy, the reaction of family and friends can vary. They may be concerned and want to offer support. Some people may not understand epilepsy, or may become overprotective.

Epilepsy in itself should not affect your ability to make your own decisions. If your family and friends understand how your epilepsy affects your life, they may more easily support you in making decisions.

**Will I need more support or care?**

Some people with epilepsy need support or care from others around them. This may depend on whether they are having seizures and if seizures or other medical conditions affect their independence or safety.
Support from others may include giving first aid, noting any trigger or pattern to your seizures, listening and emotional support, providing transport, household tasks, or helping you to adapt your home or lifestyle.

You may also be aware that others who support you have their own health or social needs. They may feel isolated, tired, or under pressure. There is information and support available for anyone in a caring role.

See our factsheet *carers and first aid*.

**Will I need to change my home environment?**

The majority of older people with epilepsy live in their own homes, and many live on their own. For most people, having epilepsy does not mean they are less able to look after themselves than other people without epilepsy, or that their living arrangements need to change.

Depending on their situation, some people may choose to move to somewhere with extra support, such as sheltered housing. In most cases, this is not likely to be just because they have developed epilepsy. Before making big decisions about your home, it may help to give yourself time to see how your epilepsy will affect you in the long term, especially if your medication reduces your seizures or stops them completely.

Whatever your home situation, there may be support available or safety ideas that can help you live as independently as possible (see next page).
epilepsy and safety

Some simple safety measures can make accidents and injuries less likely if you have a seizure. For example, using a microwave or having a guard on your cooker hob so that you can avoid touching hot surfaces; having a shower rather than a bath; and having a shower when someone else is around so they can help you if needed.

If you feel you need help or support at home, you can ask your local social services for a ‘social care needs assessment’. This involves an occupational therapist visiting you at home to see what might help you, for example safety equipment. You can also ask your GP for help. They may arrange for a community nurse to visit you or find out about other support or services in your community.

See our leaflets safety and risk.

Safety alarms

Some people with epilepsy choose to have an alarm that is set off if they have a seizure. Some alarms work by pressing a button if you feel a seizure coming on. Others sound automatically if you fall with no warning. Some alarm systems go through to a call centre, while other systems alert someone you have chosen, such as a family member or neighbour.

Visit livingmadeeasy.org.uk
Medical ID cards and jewellery

You may choose to wear or carry with you something that says you have epilepsy. This means that if you have a seizure, people around you and medical staff will know that you have epilepsy.

Call our helpline for an ID card.

epilepsy and leisure

Alcohol

How alcohol affects someone with epilepsy depends on the individual, whether they are taking AEDs, and how much alcohol they drink. Alcohol can be a trigger for seizures for some people, particularly in the hangover period. Alcohol can also disrupt sleep patterns, which can make seizures more likely. It is often recommended that someone with epilepsy has no more than 1 – 2 units of alcohol per day.

If you take AEDs, the patient information leaflet that comes with your AEDs may say whether you can drink alcohol with that medication. Your doctor may also be able to advise you.

Computers, TV and cinema

Most people with epilepsy have no problems with using computers, watching TV, or going to the theatre or cinema. Photosensitive epilepsy, where seizures can
be triggered by flashing lights or contrasting patterns, affects around 3% of people with epilepsy. It is rare in later life, but it is usually tested, with your consent, during a routine EEG test (see page 9).

Exercise and keeping active

Many activities can be made safer with simple safety measures. For example, cycling with a helmet to help prevent head injuries, and cycling with someone who knows what to do to help if you have a seizure. Swimming with a friend, and telling the lifeguards at the pool what your seizures are like, means they can help you quickly if you have a seizure in the water.

Gardening and DIY

Gardening or home improvements may be made safer by thinking about the type and frequency of your seizures, as well as the tools you may be using for each job, and the space you will be working in.

Travel

Most people with epilepsy travel with no problems, especially if they are with someone who knows what to do if they have a seizure. Informing airlines or other travel representatives that you have epilepsy can be useful for them and for your peace of mind.

See our leaflet leisure.
what to do if someone has a seizure

If the person seems blank or confused, stay with them, speak calmly, and gently guide them away from danger.

**Tonic clonic seizures**

- try to stay calm;
- check the time to see how long the seizure lasts;
- move objects away from them so they don’t hurt themselves;
- put something soft under their head to protect it;
- don’t hold them down or put anything in their mouth;
- don’t move them, unless they are in direct danger;
- after the shaking stops put them into the recovery position. Check that nothing is blocking their airway such as food or dentures; and
- stay with them until they have recovered.

**Call 999 for an ambulance if:**

- it is the person’s first seizure;
- they have injured themselves badly;
- they have trouble breathing after the seizure stops;
- they have one seizure after another without recovering in between;
- the seizure lasts **two minutes** longer than is usual for them; or
- the seizure lasts for more than **five minutes**.

See our factsheet *the recovery position* or visit epilepsy-society.org.uk/step-step-recovery-position
further information

Epilepsy Society information
Benefits (series of guides) Making the most of your pharmacist
Carers Medication for epilepsy
Diagnosis Monitoring epilepsy
Diet and nutrition Recording seizures
Driving and travel Risk
Epilepsy review checklist Safety
Exercise Seizures
First aid The bigger picture
‘I have epilepsy’ ID card The recovery position
Just diagnosed What help is available?
Leisure Your appointment

other organisations

Age UK – Working to improve the lives of older people.
0800 169 6565 ageuk.org.uk

Independent Age – Advice and support for older people.
0800 319 6789 independentage.org

The Silver Line – helpline for older people.
0800 4 70 80 90 thesilverline.org.uk

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epilepsysociety.org.uk

A full life for everyone affected by epilepsy.

**research**
Pioneering medical research.

**treatment and care**
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**information**
Website, leaflets, factsheets – call 01494 601 392.

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**helpline** 01494 601 400
Monday and Tuesday 9am to 4pm, Wednesday 9am to 7.30pm.
Confidential, national call rate.
Information and emotional support.

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Registered charity no. 206186