Just diagnosed

How epilepsy might affect you

There can be a lot of misunderstanding about epilepsy and seizures, but it is a common condition. About one in a hundred people has epilepsy and there are 79 new epilepsy diagnoses made each day, so you may already know people with the condition.

People respond to a diagnosis of epilepsy in different ways, and it can take time to get used to. For some people it's a relief, especially if they have been waiting for a diagnosis for a long time. For others, it may be a shock. It can be a difficult time, with many challenges. You might be experiencing lots of different, and changing, emotions.

Giving yourself time to work out how your epilepsy affects you and what choices to make, can be helpful. There may be people close to you who may support you, and they might like to see this information too.

This information was created with the help of people with epilepsy. It includes topics people told us they would have found helpful to know about when they were diagnosed with epilepsy. People with epilepsy told us that support and information can really help when newly diagnosed.

Although some people want information and support straight away, others want to wait for a while until they feel ready to start finding out more. If you are looking for more information, emotional support, or time to talk, you might like to contact our confidential helpline (see details below).

About epilepsy

Anyone can develop epilepsy, at any time of their life. Epilepsy is not just one condition, but a group of many different 'epilepsies' with one thing in common: a tendency to have seizures which start in the brain.

Epilepsy is a neurological condition, which means it affects the brain and the nervous system.

Epileptic seizures are usually sudden, last a short time, and stop by themselves. They can start when you are awake or asleep and can cause a change in awareness of what you are doing, your behaviour, or your feelings.

There are many different types of seizure and the type of seizure you have depends on which part of your brain is affected and what that part of your brain controls.

Some people have seizures where they lose consciousness, may fall down, and shake. Other people might go 'blank' and stare for a few seconds, or become confused, wander around, or behave in an unusual way.

Some people have seizures that other people don't notice, but which affect their senses or how they feel. Some people have more than one type of seizure.

The type of seizure, and how long they last for, is usually fairly constant for each person, but can change over time. Learning what type of seizures (and ideally, what type of epilepsy) you have can help you and your doctors decide what treatment is likely to suit you best.

Your neurologist, GP, or nurse may be able to tell you more about your epilepsy. You can also get information about epilepsy from us when you are ready for it.

Visit epilepsysociety.org.uk/what-epilepsy
epilepsysociety.org.uk/epileptic-seizures

This information aims to help you learn more about epilepsy, to understand how it might affect you, and answer some questions you might have about living with the condition.

Helpline 0300 102 0024
Confidential, information, and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

Who will I see about my epilepsy?

You may see different people to help you manage your epilepsy. This might include the following people:

- During your diagnosis you will probably have seen a neurologist, who may specialise in epilepsy. It is the neurologist who will generally diagnose epilepsy and prescribe and start any treatment, such as medication. You might continue to see a neurologist while trying to get your seizures controlled, and you might also have ongoing regular reviews of your epilepsy with a neurologist. NICE (the National Institute for Health and Care Excellence) produces guidelines, and recommends that anyone who has a first seizure is seen urgently (within two weeks).
- You might see an epilepsy specialist nurse (ESN), who can be a good link between you, the neurologist, and your GP. Specialist nurses might be involved in your treatment, and they may support you in other ways, such as talking to you about your epilepsy and how you are getting on.
- Your GP might also be involved in your epilepsy management. They are usually responsible for prescribing any ongoing treatment, and they are generally the first person you go to if you have any questions or concerns. Some GPs have a specialist interest in epilepsy.
- You might also see other people about your epilepsy, depending on how things are for you. This could include an occupational therapist, community nurse, mental health support, or social worker.

Visit epilepsysociety.org.uk/epilepsy-care-pathway
Visit nice.org.uk/guidance/ng217

Why am I having seizures?

Your brain controls the way you function. Inside your brain millions of nerve cells pass messages via electrical signals to each other. During a seizure these electrical signals are disrupted, and this affects how you feel or what you do while the seizure is happening.

Sometimes there is a clear cause for seizures, for example, if someone has damage to their brain from a difficult birth, an infection such as meningitis, a stroke, or a head injury.

Epilepsy can be passed down from one or both parents (inherited), but in some cases it may be from a change that happens only in the person's own genes. Some researchers now believe that the chance of developing epilepsy is probably always genetic to some extent.

Your doctor or neurologist may be able to tell you what has caused your epilepsy, but this is not always possible. Research continues into understanding more about why seizures happen in some people and not in others.

Visit epilepsysociety.org.uk/what-epilepsy

What triggers seizures?

For some people certain situations can 'trigger' a seizure (make a seizure more likely to happen). Triggers are not the same as underlying causes.

Triggers vary but include lack of sleep, stress, excitement, alcohol, and not taking your medication as prescribed.

Flashing or flickering lights or certain visual patterns can be a trigger for some people. This is called photosensitive epilepsy and it affects around 3% of people with epilepsy. You may have had a test for photosensitive epilepsy if you had an electroencephalogram (EEG – a test which records the electrical activity of the brain) during your diagnosis.

Visit epilepsysociety.org.uk/seizure-triggers

What treatment options are there?

Epilepsy is sometimes referred to as a long-term condition, as people often live with it for many years or for life. Although generally, epilepsy cannot be 'cured', for most people, seizures can be 'controlled' (stopped), so that epilepsy has little or no impact on their lives. So treatment is often about managing seizures in the long-term.

Visit epilepsysociety.org.uk/about-epilepsy/epilepsy-care-your-rights

Medication

Most people with epilepsy take anti-seizure medication (ASM) to stop their seizures from happening. However, there may be other treatment options for people whose seizures are not controlled by ASM.

Visit epilepsysociety.org.uk/treatment

ASM and birth abnormalities

Some ASMs have a higher risk of causing birth abnormalities. Different ASMs vary in the risk they pose.

The Medicines and Healthcare products Regulatory Agency (MHRA) has issued guidance on prescribing Topiramate to women, and Sodium Valproate to women and men under the age of 55.
Visit epilepsysociety.org.uk/living-epilepsy/starting-a-family

Free prescriptions
People with epilepsy are entitled to free prescriptions for their ASM and any other prescribed medication. This is called medical exemption. To apply for free prescriptions in England, you can fill in form FP92A, available from your doctor's surgery.

It is important to carry your medical exemption card with you when you collect your prescription. In Scotland, Wales, and Northern Ireland all prescriptions are currently free.

Other treatments
Managing medication can often be a balance between preventing seizures and keeping side effects to a minimum. For most people, ASM helps to control their seizures, but for others, despite trying different types, the ASMs do not stop their seizures completely.

In some cases, looking at other treatment options may be helpful. For example, someone may be considered for epilepsy surgery, VNS (vagus nerve stimulation) therapy, Epicranial Application of Stimulation Electrodes for Epilepsy (EASEE), or a specialist medical dietary treatment, alongside their ASM. For most people, these are considered only after several medications have not worked.
Visit epilepsysociety.org.uk/epilepsy-surgery
epilepsysociety.org.uk/vagus-nerve-stimulation
epilepsysociety.org.uk/easee-device
epilepsysociety.org.uk/ketogenic-diet

Do I need to tell other people?

Whether to tell other people about your epilepsy, who to tell, and when, is your choice. There might be some people around you who it may be useful to tell, so they can offer support.

It might depend on how you are feeling about your diagnosis, and whether you are ready to talk to other people about it. Making decisions about who to tell at your own pace, may help you to feel more in control of what is happening.

Some people don't know much about epilepsy, and may expect you to explain. It might be helpful to have some information that you could give to them to help them understand. You could give them your ID card or show them this information.

Some people you talk to may already have their own ideas about epilepsy. They might not understand that there are different types of seizures.

Thinking about what you want people to know about your epilepsy might help you to feel prepared if they ask you questions. Giving them something practical to do might help them to feel that they are helping you. Perhaps saying something like "I have epilepsy and it would really help me if you could…" might help them to respond to you in a way that you would find helpful.

How can I manage my epilepsy?

Taking an active role in managing your epilepsy ('self-management') can be an important part of helping to reduce your seizures and feeling in control.

Learning about how your epilepsy affects you, and being involved and able to make informed choices about managing your treatment, is all part of this.

Having a good relationship with your healthcare professionals and your pharmacist can also help.
Visit epilepsysociety.org.uk/anti-seizure-medication

Some people have triggers for their seizures (see page 2) such as stress or lack of sleep. Triggers can vary from one person to another, and not everyone will have triggers. If you can identify any triggers, you might be able to reduce the number of seizures you have by avoiding these triggers.

Some people choose to keep a diary of when their seizures happen, any triggers, any side effects, and how they feel.
Contact our helpline for a free seizure diary. Or download a pdf from our website.

Improving your overall wellbeing may also help to reduce the number of seizures you have. This could include having a balanced diet, keeping physically active, sleeping well, and finding ways to relax and manage any stress. Some people find complementary or psychological therapies help with their overall wellbeing. For some, just talking to someone who understands can help too.
Visit epilepsysociety.org.uk/wellbeing-and-epilepsy

Will my epilepsy go away?
Many people need to take ASM, or other treatment, for the long-term to keep their seizures under control. However, for some people, their epilepsy goes into 'spontaneous remission' and seizures stop happening. This can depend on the underlying cause of seizures.

If this happens, you and your specialist may decide together to gradually stop your treatment, and they can help you do this safely. **You should never stop taking your ASM without medical supervision.**

How might epilepsy affect my life?

Having a diagnosis of epilepsy may have an impact on various aspects of your life, depending on how your seizures affect you.

Can I drive if I have epilepsy?
If you have a driving licence and you have a seizure, the DVLA regulations say that you must stop driving. For many people this can have a big impact and can be very difficult or upsetting.

By law you are responsible for telling the DVLA about your epilepsy and returning your licence to them. This is the case whatever type of seizures you have had, whether you lost consciousness or not, and whether or not you are taking ASM.

You can apply for a new Group 1 licence (cars, motorbikes, and mopeds) after one year of having no seizures, whether you are prescribed ASM or not.

If your seizures only happen in your sleep, or they do not affect your consciousness, nor cause any functional impairment, the regulations are different.

To get a new Group 2 licence (buses and lorries) you need to have had no seizures for 10 years and not be prescribed ASM.

Suddenly losing your licence, even if it is only temporarily, may have a big impact on you practically and emotionally.

If you can't drive due to your epilepsy, you can get free or discounted travel on buses, trains, and tube. If you can't get to work using public transport, you may be able to get financial help through the Access to Work Scheme. Contact your local Jobcentre Plus office.
Visit epilepsysociety.org.uk/driving and epilepsysociety.org.uk/living-epilepsy/what-help-available

Can epilepsy affect my work?
Whether epilepsy will affect your work depends on how your epilepsy affects you and what your job involves. For example, jobs which involve driving, working with machinery, near open water, or at heights could be affected.

Although you do not legally have to tell an employer about your epilepsy, it may be important for them to know so that they can keep you safe at work and treat you fairly.

To keep you and other employees safe at work, your employer may need to do a risk assessment of your work environment and the tasks involved in your job. They may also ask how you would like to be supported if you have a seizure at work.

To treat you fairly alongside other employees, your employer needs to know how your epilepsy affects you so that they can consider any 'reasonable adjustments' you may need to help you do your job. This is because epilepsy is covered as a disability under the Equality Act 2010, even if you do not consider your epilepsy to be a disability. If you feel that you might be discriminated against in employment because of your epilepsy, there is support and more information available about the Equality Act.
Visit epilepsysociety.org.uk/work-employment-and-epilepsy

Whether or not you work, you may be entitled to claim benefits or other financial help. This will depend on how your epilepsy affects you. Your local benefits agency or Jobcentre Plus can look at your individual situation to see what you may be entitled to. You can also talk to a disability benefits helpline or your local Citizens Advice.
Visit epilepsysociety.org.uk/benefits epilepsysociety.org.uk/what-help-available or turn2us.org.uk for help with benefits or citizensadvice.org.uk

Epilepsy and safety
Keeping safe, while having a full life, can be about balancing what is most important to you with what will keep you safe.

If your seizures become controlled, your epilepsy may have little effect on what you do.

Some activities, including some sports and leisure activities, carry more risk of accidents or injury if you have seizures. But they may be made safer with simple measures and by thinking about how your seizures affect you.
Visit epilepsysociety.org.uk/exercise-and-sport

If during your seizures you become confused or do things that you don't remember, you may want to think about what would help to keep you safe.

Some people get a 'warning' or 'aura' (when they know a seizure is starting to happen). This may give them enough time to get to a safe place before the seizure develops further.

Some safety issues are important to consider early on in your diagnosis. For example having a shower can be safer than having a bath because the water drains away and there is less chance of you slipping under the water during a seizure. Using an 'engaged' sign on the door, instead of locking it, means that someone can help you if you need it.

There may be ways to adapt the way you cook or do jobs around the house, or to adapt your daily and leisure activities, to help keep you safe during a seizure.

Having someone with you, who knows what to do if you have a seizure, may help to keep you safe during some activities.

If you live alone, there are ways to get help or contact someone for support through alarm systems or mobile phones. Medical ID cards or jewellery can let other people know how to help if you have a seizure when out and about.
Visit epilepsysociety.org.uk/safety-and-risk or contact our helpline for a free ID card or download the card at epilepsysociety.org.uk/medical-id-cards-and-jewellery

Alcohol and drugs

Whether to drink alcohol or take recreational drugs is a personal choice, but it is worth knowing the possible effects they could have on your epilepsy.

Alcohol is a common trigger for seizures. It also disrupts sleep patterns which can be a trigger for seizures.

Alcohol can make epilepsy medication less effective or make the side effects of medication worse. The Patient Information Leaflet (PIL) that comes with your ASM may say whether you can drink alcohol with it. However, the effect alcohol has on your seizures is individual.

Recreational drugs can trigger seizures or increase the frequency of seizures for some people and can also interact with medication. Taking recreational drugs increases the risk of seizures and of mental and physical health problems, which in turn may make seizures more likely.

Learning more about your own epilepsy and treatment means you can make informed choices about your lifestyle.
Visit epilepsysociety.org.uk/alcohol-drugs-and-epilepsy

What are the risks around epilepsy?

Risks of injury are not always easy to avoid, and can be worrying to think about. But being aware of risks, and how you might be able to reduce them, might help you feel more in control of your epilepsy.

For some people, seizures may carry risks of injury. Although seizures are usually short (a few seconds or minutes) and stop on their own, for some people their seizures do not stop and this is called status epilepticus (status) and they might need emergency medical help to stop them.

For a small number of people, there is a risk of dying due to seizures (called SUDEP or sudden unexpected death in epilepsy).

These serious risks can be frightening to read about but they are rare. A key way to reduce risks is to prevent seizures from happening, by taking your ASM as prescribed and having regular reviews.

It is important to stay healthy, and avoiding, where possible, any known trigger for you.
Visit epilepsysociety.org.uk/SUDEP

Relationships and sex

Some people are concerned about relationships and sex when they are diagnosed with epilepsy. Some worry that their relationships will change, or about how people will react to their diagnosis.

Some may worry that they might have a seizure during sex or feel that having epilepsy might affect their sex drive (their interest in sex). Generally, seizures are no more likely to happen during sex than at any other time.

And although some people do notice a lower sex drive, which could be for a number of reasons related to their epilepsy, having epilepsy will not necessarily affect your interest in sex.

If you are concerned that your epilepsy is affecting you in this way, talking about this with your doctor might be helpful.

Those close to someone diagnosed with epilepsy often feel concerned for them, but can also be going through different emotions themselves, such as guilt, uncertainty, fear, or relief. Being able to talk openly about any needs, worries, or concerns may help some people to find ways of helping, supporting, and understanding each other.

Sometimes epilepsy does change a relationship. Some people might need to rely more on those around them, both practically and emotionally. Relationships can change, as epilepsy can impact on the individual and those close to them. These changes can be positive – many people with epilepsy find that their relationships with partners, family, and friends can grow, be stronger, and become more supportive and encouraging.

Visit epilepsysociety.org.uk/relationships-and-sex

Specific issues for women and girls

For some women and girls with epilepsy, hormone level changes affect when their epilepsy starts, how often seizures happen, and whether their epilepsy goes away. Hormone levels change during puberty, through the menstrual cycle, during pregnancy, and during the menopause.

Some types of contraception can be affected by ASM, making it less effective in preventing pregnancy. Some types of contraceptive can affect the way ASM works. Talking this through with your doctor is important to help you decide on the right contraception for you.

If you are thinking of starting a family, it is essential to talk to your neurologist about your epilepsy treatment for your pregnancy and for when your baby arrives. Getting specialist advice, or preconception counselling, before you become pregnant can help to keep you and your baby safe.

Although the vast majority of women with epilepsy will have a healthy baby, some ASM can affect the development of an unborn baby.

Risks depend on the type of ASM prescribed, the dose, and each individual situation, and they need to be balanced with seizure control. These issues will be considered when deciding whether to start treatment, and what treatment would be suitable. If you start taking ASM, your neurologist should plan for the possibility of you taking ASM long-term, even if you are not thinking about becoming pregnant at the moment.

Visit epilepsysociety.org.uk/women-and-girls and epilepsysociety.org.uk/starting-a-family

Developing epilepsy in later life

There are many causes of epilepsy but some causes are more common in later life. As we age, 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 cause 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 often, seizures are not linked with strokes.

When epilepsy is a long-term condition

Epilepsy is very individual. Some people will have seizures all their life, but for others they might have epilepsy just for a period of their life, and their epilepsy may go away. This is called ‘spontaneous remission’.

For most people, seizures become well controlled (they still have epilepsy but the medication stops the seizures) and so it has little impact on them.

For others, seizures may take longer to be controlled or may not respond to treatment. Epilepsy might have a greater impact on them, and they may need support and help with work or daily life. For some, epilepsy is a long-term condition, which they live with for many years.

Epilepsy is sometimes classed as a disability. While some people find the term ‘disability’ negative or a ‘label’ that doesn’t feel right, it can be useful to know what this term means and how it might help you to find support.

The Equality Act 2010 is a law that aims to ensure that people are treated fairly and are not discriminated against. This applies to employment, education, and accessing services (such as using shops, health or leisure services).

Epilepsy is considered a disability when it greatly affects someone’s ability to do everyday activities (such as concentrating or remembering things), over a long period.

Epilepsy is sometimes described as a hidden disability because it is not always obvious that someone has epilepsy unless they have a seizure.

Whether you feel that you have a disability or not, you are protected by the Equality Act if your epilepsy affects you in this way. Depending on how your epilepsy affects you, there may be help available, such as benefits or support at home.

Visit epilepsysociety.org.uk/what-help-available

How you may be feeling

People can react differently to a diagnosis. You might feel lots of different emotions. It may not be possible to think or feel positively, or you may feel fine one minute and upset or angry the next. Or you may feel relieved that what has been happening to you has a name and a treatment.

A diagnosis of epilepsy can be hard to accept. Some people find it difficult to come to terms with, or feel worried, down, or anxious. Or you might have your own ideas about what might help you feel better.

There is no right or wrong way to feel. What do you think would make you feel better? Is there anything you can think of that you would like to do right now? Who could you talk to? What feels achievable?

Having a diagnosis of epilepsy may change some things in your life but not necessarily forever.

You might be feeling a sense of loss. It may be helpful to know that these feelings are all common. And to remind yourself that you are still the same person you were before the diagnosis and that support is available if you want it.

Connecting with other people

The way family or friends react to your diagnosis may be just what you need, or you may find some reactions hurtful or unhelpful.

People around you may also feel shocked, frightened, worried, angry, or helpless about your diagnosis. They may not know very much about epilepsy. They may also need time to adjust and work out how they feel.

Visit epilepsysociety.org.uk/mental-health-epilepsy

What you need from them may also change over time. Family and friends can best support you if you are able to tell them clearly what you find helpful.

Many people who contact us say that having someone to talk to, who either has epilepsy, or knows about it, can be really helpful. For some, it can be an important part of coming to terms with a diagnosis of epilepsy.

You might already have people around you who can help and support you. If you would like to, there are various ways in which you can make contact with other people.

Social media

Many people appreciate finding a supportive online community, to share experiences. You can connect with other people affected by epilepsy, and receive information and updates about our work, through our social media channels:
Facebook: facebook.com/epilepsysociety
Instagram: @epilepsysociety
X: @epilepsysociety

Support groups

Some people find face-to-face or online support through meeting other people with epilepsy helpful. You could ask your GP or hospital if they know of any support groups locally, or contact our helpline.

Epilepsy Society's helpline

You, or your friends and family, can talk to our confidential helpline about what is happening and how you are feeling. They can give you time and space to talk things through and think about what you want to do.

Epilepsy Society is grateful to Dr F J Rugg-Gunn, Consultant Neurologist & Honorary Associate Professor, Clinical Lead, Chalfont Centre for Epilepsy, who reviewed this information.

For a printed copy of this information contact our helpline.

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