

Epilepsy

Introduction

Epilepsy is a condition that affects the brain and causes repeated seizures, also known as fits.

1 in 100 people has the condition. Epilepsy usually begins during childhood, although it can start at any age.

Seizures

Seizures are the most common symptom of epilepsy, although many people can have a seizure during their lifetime without developing epilepsy.

The cells in the brain, known as neurones, communicate with each other using electrical impulses. During a seizure, the electrical impulses are disrupted, which can cause the brain and body to behave strangely.

The severity of the seizures can differ from person to person. Some people simply experience a 'trance-like' state for a few seconds or minutes, while others lose consciousness and have convulsions (uncontrollable shaking of the body).

Why does epilepsy happen?

Epilepsy can happen for many different reasons, although usually it is the result of some kind of brain damage.

Epilepsy can be defined as being one of three types, depending on what caused the condition. These are:

Symptomatic epilepsy – when the symptoms of epilepsy are due to damage or disruption to the brain.

Cryptogenic epilepsy – when no evidence of damage to the brain can be found, but other symptoms, such as learning difficulties, suggest that damage to the brain has occurred.

Idiopathic epilepsy – when no obvious cause for epilepsy can be found.

Diagnosing epilepsy

Epilepsy is most often diagnosed after you have had more than one seizure. This is because many people have a one-off epileptic seizure during their lifetime.

The most important information needed by a DOCTOR or neurologist is a description of your seizures. This is how most cases of epilepsy are diagnosed.

Some scans may also be used to help determine which areas of your brain are affected by epilepsy, but these alone cannot be used for a diagnosis.

How is epilepsy treated?

While medication cannot cure epilepsy, it is often used to control seizures. These medicines are known as anti-epileptic drugs (AEDs). In around 70% of cases, seizures are successfully controlled by AEDS.

It can take some time to find the right type and correct dose of AED before your seizures can be controlled.

In some cases, surgery may be used to remove the area of the brain affected or to install an electrical device that can help control seizures.

Living with epilepsy

While epilepsy is different for everyone, there are some general rules that can help making living with the condition easier.

It is important to stay healthy through regular exercise, a balanced diet and avoiding excessive drinking.

You may have to think about your epilepsy before you undertake things such as driving, using contraception and getting pregnant.

Advice is available from your DOCTOR or support groups to help you adjust to life with epilepsy.

Sudden unexpected death in epilepsy (SUDEP), while rare, is one of the main dangers associated with epilepsy. Every year between 500 and 1,000 people die as a result of SUDEP, this is less than 1% of people with epilepsy.

Although the cause of SUDEP is unknown, a clear understanding of your epilepsy and good management of your seizures can reduce the risk.

Symptoms of epilepsy

The main symptoms of epilepsy are repeated seizures. There are many different types of seizure, depending on the area of the brain affected.

People with epilepsy can experience any variety of seizure, although most people follow a consistent pattern of symptoms known as an epilepsy syndrome.

Seizures can occur when you are awake or asleep (nocturnal seizures).

Doctors classify seizures by how much of the brain is affected. There are:

partial seizures – where only a small part of the brain is affected

generalised seizures – where most or all of the brain is affected

Some seizures do not fit into these categories and are known as unclassified seizures.

Partial seizures

There are two types of partial seizure:

simple partial seizure – where you remain fully conscious throughout

complex partial seizure – where you lose your sense of awareness and can't remember what happened after the seizure has passed

Symptoms of a simple partial seizure include:

changes in the way things look, smell, feel, taste or sound

an intense feeling that events have happened before (déjà vu)
a tingling sensation, or 'pins and needles', in your arms and legs
a sudden intense emotion, such as fear or joy
the muscles in your arms, legs and face may become stiff
you may experience twitching on one side of your body

The symptoms of a complex partial seizure normally involve apparently strange and random bodily behaviour, such as:

smacking your lips
rubbing your hands
making random noises
moving your arms around
picking at clothes
fiddling with objects
adopting an unusual posture
chewing or swallowing

During a complex partial seizure, you will not be able to respond to anyone else, and you will have no memory of the event.

Complex partial seizures are quite common and account for 2 in 10 of all seizures experienced by people with epilepsy.

Generalised seizures

In most cases, a person having a generalised seizure will be completely unconscious.

There are six main types of generalised seizure:

Absences

Absence seizures, sometimes called petit mal, mainly affect children. They cause the child to lose awareness of their surroundings for up to 20 seconds. The child will seem to stare vacantly into space, although some children will flutter their eyes or smack their lips. The child will have no memory of the seizure.

Absences can occur several times a day. Although they are not dangerous, they may affect the child's performance at school.

Myoclonic jerks

These types of seizures cause your arms, legs or upper body to jerk or twitch, much like if you have received an electric shock. They often only last for a fraction of a second, and you should remain conscious during this time.

Myoclonic jerks often happen in the first few hours after waking up and can occur in combination with other types of generalised seizures.

Clonic seizure

This causes the same sort of twitching as myoclonic jerks, except the symptoms will last longer, normally up to two minutes. Loss of consciousness may occur.

Atonic seizure

Atonic seizures cause all your muscles to suddenly relax, so there is a chance you will fall to the ground. Facial injuries are common with this type of seizure.

Tonic seizure

Unlike an atonic seizure, tonic seizures cause all the muscles to suddenly become stiff. You can lose balance and fall over, so injuries to the back of the head are common.

Tonic-clonic seizure

A tonic-clonic seizure, sometimes known as grand mal, has two stages. Your body will become stiff and then your arms and legs will begin twitching. You will lose consciousness and some people will wet themselves. The seizure normally lasts between one and three minutes, but they can last longer.

This is the most common type of seizure, and about 60% of all seizures experienced by people with epilepsy are tonic-clonic seizures.

Tonic-clonic seizures are what most people think of as an epileptic fit.

Auras

People who have epilepsy often get a distinctive feeling or warning sign that a seizure is on its way. These warning signs are known as auras, but they are actually simple partial seizures.

Auras differ from person to person, but some common auras include:

noticing a strange smell or taste

having a feeling of déjà vu

feeling that the outside world has suddenly become unreal or dreamlike

experiencing a sense of fear or anxiety

your body suddenly feeling strange

Although this warning cannot prevent the seizure, it can give you time to warn people around you and make sure you are in a safe place.

Status epilepticus

Status epilepticus is a seizure that lasts longer than 30 minutes or a series of seizures where the person does not regain consciousness in between. If a seizure lasts longer than five minutes, call for an ambulance.

Prolonged seizures can be treated with diazepam given as an injection or through someone's rectum. However, if seizures continue because they are not quickly brought under control in this way, it is very important that the patient be transferred to hospital. In hospital, the airways will need to be closely monitored and a high level of sedation may be required to control the seizures.

An alternative treatment is a medication called buccal midazolam. This comes in liquid form and is administered by trickling the liquid onto the inside of your cheek. It is then absorbed into your bloodstream.

You do not have to be a healthcare professional to do this, but you do need the correct training as well as permission from the person who has epilepsy. If you care for someone with epilepsy, you can be trained to administer rectal diazepam or buccal midazolam in case status epilepticus occurs.

Causes of epilepsy

In most cases of epilepsy, a cause cannot be found. If there is an identifiable cause, it usually involves some form of brain damage.

The brain is a delicate mix of neurons (brain cells), electrical impulses and chemicals, known as neurotransmitters. Any damage has the potential to disrupt the workings of the brain and cause seizures.

There are three main categories of epilepsy:

Symptomatic epilepsy – there is a known cause for a person's epilepsy, such as a head injury.

Idiopathic epilepsy – despite investigation, no apparent cause for epilepsy can be found.

Cryptogenic epilepsy – like idiopathic epilepsy, no apparent cause can be found. However, there is strong evidence that this type of epilepsy may be the result of brain damage.

Symptomatic epilepsy

Causes of symptomatic epilepsy include:

conditions that affect the structure of the brain, such as cerebral palsy

drugs and alcohol misuse

birth defects

problems during birth which cause a baby to be deprived of oxygen, such as the umbilical cord getting twisted or compressed during labour

infectious conditions that can damage the brain, such as meningitis

head injuries

strokes

brain tumours

Idiopathic epilepsy

In around 60% of cases, no cause of epilepsy is found. This may be because medical equipment is not advanced enough to spot some types of damage or because the epilepsy has a genetic cause.

Many researchers have suggested that small genetic changes in the brain could be the cause of epilepsy. Current research is looking for defects in certain genes that may affect electrical transmission in the brain.

While a number of studies have been carried out, no strong association has been found between any particular genes and the development of epilepsy.

Cryptogenic epilepsy

The term cryptogenic epilepsy is used when no definite cause for epilepsy can be found but there is strong evidence that symptoms are due to damage or disruption to the brain.

Evidence that suggests a person has cryptogenic epilepsy includes:

they have learning difficulties

they have a developmental condition, such as autistic spectrum disorder

they have unusual electroencephalogram (EEG) readings (an EEG is a device that measures the electrical activities of the brain)

Triggers

Many people with epilepsy find certain circumstances or substances can trigger a seizure. These triggers include:

stress

lack of sleep

alcohol, particularly binge drinking and during a hangover

illegal drugs such as cocaine, amphetamines, ecstasy, and any opiate-based drugs such as heroin, methadone or codeine

health conditions that cause a high temperature (fever)

flashing lights (this is an uncommon trigger that affects only 5% of people with epilepsy, and is known as photosensitive epilepsy)

Some women may be more prone to seizures just before, during or after their period. This is because hormones released by the body during that time can affect chemicals in the brain, making seizures more likely.

Seizure threshold

Most people with epilepsy have a seizure threshold. This is the point at which the brain's natural resistance to seizures is passed, triggering a seizure.

People with a low seizure threshold have frequent seizures, whereas people with a high seizure threshold experience less frequent seizures and triggers will have less effect on them.

Diagnosing epilepsy

Epilepsy is usually difficult to diagnose quickly. In most cases, it cannot be confirmed until you have had more than one seizure.

It can be difficult to diagnose because many other conditions, such as migraines and panic attacks, can cause similar symptoms.

If you have had a seizure, you will be referred to a specialist in epilepsy, normally a neurologist (a doctor who specialises in conditions that affect the nervous system).

Describing your seizures

Some of the most important pieces of information needed to diagnose epilepsy are the details about your seizure or seizures.

The doctor will ask you what you can remember and any symptoms you may have had before it happened, such as feeling strange before the seizure or experiencing any warning signs. It may be useful to talk to anyone who witnessed your seizure and ask them exactly what they saw, especially if you cannot remember the seizure.

The doctor will also ask about your medical and personal history and whether you use any medicines, drugs or alcohol.

The doctor may be able to make a diagnosis of epilepsy from the information you give, but they might run further tests.

You may need an electroencephalogram (EEG), which can detect unusual brain activity associated with epilepsy. Or you may have a magnetic resonance imaging (MRI) scan, which can spot any defects in the structure of your brain.

However, even if these tests don't show anything, it is still possible that you have epilepsy.

Electroencephalogram (EEG)

An EEG test measures the electrical activity of your brain through electrodes placed on your scalp. During the test, you may be asked to breathe deeply or close your eyes, as these actions could reveal unusual brain activity associated with epilepsy.

You may also be asked to look at a flashing light, but the test will be stopped immediately if it looks like the flashing light could trigger a seizure. Read more about electroencephalograms.

Magnetic resonance imaging (MRI) scan

An MRI scan can often detect possible causes of epilepsy, such as defects in the structure of your brain or the presence of a brain tumour. Read more about MRI scans.

Treating epilepsy

Treatment for epilepsy is generally used to control seizures, although not everyone with the condition will need to be treated.

If seizures are not intrusive and only last for a short while, treatment may not be necessary.

Also, it may be possible to control your epilepsy by avoiding things that trigger your seizures, such as sleep deprivation and alcohol.

While some people may need to be treated for the rest of their lives, this is not always the case. Sometimes people have epileptic seizures at one stage in their life, only for them to become less frequent or disappear as they get older. This is more common if seizures first occur in childhood or early-adulthood.

Good epilepsy care

The National Institute for Health and Clinical Excellence (NICE) has published guidelines on the diagnosis and care of children and adults with epilepsy.

The guidelines give comprehensive and objective information on the benefits and limitations of the various ways of diagnosing, treating and caring for people with epilepsy. They can help health professionals and patients decide on the most appropriate treatment.

Treatment overview

Anti-epileptic drugs (AEDs) are usually the first choice of treatment. About 70% of people with epilepsy have their seizures controlled with AEDs.

Usually, AED treatment will not begin until after you have had a second seizure. This is because a single seizure is not a reliable indicator that you have epilepsy. In some cases, treatment will begin after a first seizure if:

An electroencephalogram (EEG) test shows brain activity associated with epilepsy.

A magnetic resonance imaging (MRI) scan shows damage to the brain.

You have a condition that has damaged the brain, such as a stroke.

For some people, surgery may be an option. However, this is only the case if removing the area of the brain where epileptic activity starts would not cause damage or disability. If successful, there is a chance your epilepsy will be cured.

If surgery is not an option, an alternative may be to implant a small device under the skin of the chest. The device sends electrical messages to the brain. This is called vagus nerve stimulation (see below).

Sometimes, a special diet is used for children whose seizures are difficult to control and do not respond to drug treatment.

Anti-epileptic drugs (AEDs)

Most people with epilepsy can be successfully treated with medicines known as anti-epileptic drugs (AEDs). AEDs do not cure epilepsy, but can prevent seizures from occurring.

There are many different AEDs. Generally, they work by changing the levels of the chemicals in your brain that conduct electrical impulses. This reduces the chance of a seizure.

The drugs used to treat epilepsy are often referred to as first-line and second-line drugs. This does not mean that one type of drug is better than the other, but it refers to when the drugs were first introduced. First-line drugs are older and have treated epilepsy for decades. Second-line drugs are much newer.

The type of drug prescribed depends largely on the kind of seizures that you have.

The older first-line AEDs include sodium valproate, carbamazepine, phenytoin and phenobarbital.

Newer second-line AEDs are recommended if there is a reason why you cannot take AEDs, if there is concern about an older AED interacting with other drugs (such as the contraceptive pill), or if you are thinking of having a baby.

Newer AEDs include gabapentin, lamotrigine, levetiracetam, oxcarbazepine, tiagabine, topamax and vigabatrin. Levetiracetam is not recommended for children, but the others are recommended if older AEDs do not benefit children with epilepsy.

Your specialist will start you on a low dose of the AED, then gradually increase it within safe limits until your seizures stop. If one AED does not control seizures, another will be tried by gradually introducing the new drug and slowly reducing the dose of the old drug.

The aim is to achieve maximum seizure control with minimum side effects, using the lowest possible dose of a single drug. Trying a different type of AED is preferable to taking more than one AED, although a combination of drugs may be necessary to control seizures.

Follow your specialist's advice as switching brands or formulations could lead to seizures.

Side effects are common when starting treatment with AEDs. However, they are short term and usually pass in a few days. Side effects include:

nausea

abdominal pain

drowsiness

dizziness

irritability

mood changes

Some side effects, which produce symptoms similar to being drunk, occur when the dose of AEDs is too high. They include:

unsteadiness

poor concentration

drowsiness

vomiting

double vision

If you experience any of these symptoms, contact your DOCTOR or epilepsy specialist immediately so that your dosage can be revised.

It is important you follow any advice about when to take AEDs and how much to take. Never suddenly stop taking an AED because doing so could cause a seizure.

While taking AEDs, do not take any other medicines, including over-the-counter medicines or complementary medicines such as St John's Wort, without first speaking to your DOCTOR or epilepsy specialist. Other medicines could have a dangerous interaction with your AEDs and cause a seizure.

If you do not have a seizure for more than two years, it may be possible to stop taking your AEDs. Your epilepsy specialist can discuss with you the best way to safely stop taking your AEDs.

Vagus nerve stimulation (VNS)

If, after you have tried various types of AED, your epilepsy is still poorly controlled, vagus nerve stimulation (VNS) therapy may be recommended. This involves surgically implanting a small electrical device, similar to a pacemaker, under your skin, near your collarbone.

The device has a lead that is wrapped around one of the nerves in the left side of your neck, known as the vagus nerve. The device passes a regular dose of

electricity to the nerve to stimulate it. This can help reduce the frequency and severity of seizures.

If you feel the warning sign of a seizure coming on, you can activate an extra 'burst' of stimulation, which can often prevent the seizure from occurring.

How and why VNS works is not fully understood, but it is thought that stimulating the vagus nerve alters the chemical transmissions in the brain.

Most people who undergo VNS still need to take AEDs.

Some mild to moderate side effects of VNS have been reported, including:

temporary hoarseness and a change in voice tone when the device is being used (this normally occurs every five minutes and lasts for 30 seconds)

sore throat

shortness of breath

coughing

Ketogenic diet

A ketogenic diet was one of the treatments used before AEDs were available, but is no longer recommended for adults with epilepsy. A ketogenic diet is high in fats and low in carbohydrates and protein, and may make seizures less likely by altering the chemical composition of the brain. However, a high-fat diet is linked to serious health conditions, such as diabetes and cardiovascular disease, so is not generally recommended.

A ketogenic diet is sometimes advised for children with seizures that are difficult to control and have not responded to AEDs. The diet has been shown to reduce the number of seizures in some children. It should only be used under the supervision of an epilepsy specialist with the help of a dietitian.

Surgery

If your epilepsy is still poorly controlled after two years of treatment, you may be referred to a specialist epilepsy centre to see if you are suitable for brain surgery.

This involves having various types of brain scans to find out where the epilepsy is focused. Memory and psychological tests are also conducted to gauge how you are likely to cope with the stress of surgery and how it might affect you.

Surgery is only recommended when:

A single area of only one side of the brain is causing seizures.

Removing that part of the brain would not cause any significant loss of brain function.

As with all types of surgery, this procedure carries a risk. About 1 in 100 patients has a stroke after surgery, and about 5 in 100 experience memory problems. However, around 70% of people who have epilepsy surgery become completely free of seizures.

Before having the procedure, your surgeon will explain to you the benefits and risks of the surgery.

Most people normally recover from the effects of surgery after a few days, but it could be two to three months before you are fully fit and able to return to work.

Deep brain stimulation (DBS) therapy is also a surgical treatment for epilepsy. It is used to treat people with epilepsy that is difficult to control or cannot have a part of their brain removed.

DBS involves implanting electrodes into specific areas of the brain to control seizures. The electrodes are controlled by an external device called a neurostimulator.

Complementary therapies

There are several complementary therapies that some people say work for them. However, none has been shown conclusively in a study to reduce seizures. Withdrawing anti-epileptic medication without medical specialist supervision may result in seizures. Treat with caution any advice from therapists to reduce or stop taking your anti-epileptic medication.

Herbal remedies should be used cautiously because some of their ingredients can interact with anti-epilepsy drugs. St John's Wort, a herbal remedy used for mild depression, is not recommended for people with epilepsy because it can

affect the blood levels of anti-epilepsy drugs and may affect seizure control. Ayurvedic herbal medicines are also not recommended.

For some people with epilepsy, stress can trigger seizures. Stress-relieving and relaxation therapies such as exercise, yoga and meditation may help.

Living with epilepsy

There are no rigid guidelines for living with epilepsy, as everyone's condition is different. However, there are some general points that can help.

Know your triggers

The more you know about the things that trigger your seizures and how to avoid them, the less debilitating your epilepsy will be. Keep a seizure diary to help you work out if you have any triggers.

Take your medication

Anti-epilepsy medication controls seizures in around 70% of people. Working with your specialist to find the medication that suits you best, and taking it exactly as prescribed, is probably the most effective way to live well with epilepsy.

Regular reviews

You will have regular reviews of your epilepsy and treatment. This is usually carried out by your DOCTOR, but sometimes by your neurologist and their team. If your epilepsy is not well controlled, you may have more frequent reviews.

Self-care

Self-care is an integral part of daily life. It involves taking responsibility for your health and wellbeing with support from those involved in your care. Self-care includes what you do every day to stay fit and maintain good physical and mental health, prevent illness or accidents and care more effectively for minor

ailments and long-term conditions. People with long-term conditions can benefit enormously from being supported to self care. They can live longer, experience less pain, anxiety, depression and fatigue, have a better quality of life and be more active and independent.

Healthy living

Regular exercise and a healthy diet are recommended for everyone, not just people with epilepsy. They can help prevent many conditions, including heart disease and many forms of cancer. Try to eat a balanced diet, containing all the food groups, to give your body the nutrition it needs. Exercising regularly can increase the strength of your bones, relieve stress and reduce fatigue.

Drinking

Heavy drinking can cause seizures, as well as interact with anti-epileptic drugs (AEDs), making them less effective. AEDs can heighten the effects of alcohol, while alcohol can make the side effects of AEDs worse.

Heavy drinking is also associated with disrupted sleep patterns, and this can increase the risk of having a seizure. Drinking no more than the recommended daily limits will reduce any potential side effects.

The recommended daily limits for alcohol are three to four units for men and two to three units for women. A unit of alcohol is equal to about half a pint of normal strength lager, a small glass of wine or a pub measure (25ml) of spirits.

Women and epilepsy

Contraception

Some anti-epileptic drugs (AEDs) can reduce the effectiveness of some types of contraception, including:

contraceptive injections

contraceptive patches

the combined oral contraceptive pill – often known as 'the pill'

the progesterone-only pill (POP) or mini pill

contraceptive implants

If you are sexually active and want to avoid pregnancy, ask your DOCTOR or epilepsy specialist whether your AEDs could affect any of these methods of contraception.

You may need to use another form of contraception such as a condom or coil.

Some AEDs have also been known to make the emergency contraceptive pill less effective. If you require emergency contraception, you may need an intrauterine device (IUD). Your DOCTOR, family planning clinic or pharmacist should be able to advise you.

Pregnancy

There is no reason why women with epilepsy cannot have a healthy pregnancy. However, it is always preferable if the pregnancy is planned. This is because there is a slightly higher risk of complications developing during pregnancy. However, with forward planning, these risks can be minimised.

The main risk is that some AEDs are known to increase the chances of a serious birth defect occurring, such as spina bifida, cleft lip or a hole in the heart. The risks depend on the type of AED and the dosage you are taking.

The UK Epilepsy and Pregnancy Register can provide more information and advice about the use of AEDs during pregnancy.

If you are planning a pregnancy, talk to your epilepsy specialist. It may be possible to change the AED you are taking to minimise risks. Taking 5mg of a folic acid supplement each day can also help reduce risks of birth defects.

If you discover you are pregnant, do not stop taking your medicine. The risks to your baby from uncontrolled seizures are far higher than any risks associated with your medicines.

There are no risks associated with breastfeeding while taking an AED.

Children and epilepsy

Many children with well-controlled epilepsy can learn and participate in their school's activities completely unaffected by their condition. Others may need extra support to get the most out of their time at school. Make sure your child's teachers know about their condition and the medication they need to control it.

Epilepsy is more common among children with learning disabilities and special educational needs. These children are entitled to extra help to overcome their difficulties. Each school will have at least one member of staff with responsibility for children with special educational needs. The law says that all state schools must do their best to meet special educational needs, sometimes with the help of outside specialists.

If your child needs a lot of extra help, the local education authority may carry out an assessment. This will outline the help your child needs, set a number of long-term goals, and ensure your child is regularly reviewed.

Talk to others

If you have any questions, your DOCTOR or nurse may be able to reassure you. You may also find it helpful to talk to a trained counsellor or psychologist, or to someone at a specialist helpline. Your DOCTOR surgery will have information on these.

Some people find it helpful to talk to other people who have epilepsy, either at a local support group or in an internet chat room.

Driving

If you have a seizure, you have a legal responsibility to inform the respective government authority.

Sudden unexpected death in epilepsy (SUDEP)

When somebody with epilepsy dies and no apparent cause can be found, it is known as sudden unexpected death in epilepsy (SUDEP).

Although the risk of SUDEP for someone with epilepsy is low, SUDEPs are estimated to cause between 500 and 1000 deaths in the UK every year.

The exact causes of SUDEPs are unknown, and it is not possible to predict who will be affected. One theory is that seizures could affect the person's breathing

and heartbeat. More recently, it has been suggested that there may be a genetic cause.

Things that may lead to SUDEP include:

having seizures which cause loss of consciousness and the body to go stiff and start jerking (generalised tonic-clonic seizures)

poorly controlled epilepsy, such as not using anti-epileptic drugs (AEDs) as prescribed or to control seizures

having sudden and frequent changes to AEDs

being a young adult (in particular male)

having sleep seizures

having seizures when alone

drinking large amounts of alcohol

If you are worried that your epilepsy is poorly controlled, contact your epilepsy specialist. It may be possible to refer you to a specialist epilepsy centre for further treatment.