epilepsy society

epilepsysociety.org.uk

Epilepsy Awareness & Seizure Management Training

CPD
The CPD Certification Service

Course content

Epilepsy awareness and seizure management:

- an introduction to epilepsy
- causes and diagnosis
- different types of seizures (including seizure management and first aid)
- status epilepticus
- treatment options – medication and side effects
- risk management and support needs

COURSE OBJECTIVES – After this training you will be able to explain:

- how epilepsy can affect a person physically
- how epilepsy can affect a person socially and psychologically
- how epilepsy is diagnosed and treated
- how to help during and after a seizure

Epilepsy Society
Chesham Lane,
Chalfont St Peter,
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What is epilepsy?

Epilepsy - an introduction

Epilepsy is a neurological condition where there is a tendency to have seizures that start in the brain.

Not all seizures are due to epilepsy. Other conditions that can look like epilepsy include fainting, or when people with diabetes have low blood sugar and have a diabetic seizure.

In this information when we use the term 'seizure' we mean epileptic seizure.

How seizures start

The brain has millions of nerve cells which control the way we think, move, and feel. The brain uses electrical signals to send messages from one nerve cell to another.

If the messages are interrupted, or the electrical signals do not switch off when they are no longer needed, this can cause a brief change in the way the brain works. This interruption, or build up, of electrical signals can cause a seizure.

Epilepsy is common

Anyone can develop epilepsy, at any time of life. It happens in people of all ages. There are over 600,000 people with epilepsy in the UK.

There are many different 'epilepsies'

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.

Just knowing that a person 'has epilepsy' does not tell you much about their epilepsy, or the type of seizures they have. However, in this information we use the term 'epilepsy' as it is a familiar term for many people.

How epilepsy is described

You may see epilepsy described in two ways. The *type of epilepsy* describes what has caused the seizures to start, and which part of the brain is affected during a seizure. For example, in the term 'genetic generalised epilepsy', 'genetic' refers to the likely cause (see below), and 'generalised' means that both sides of the brain are affected during a seizure.

Another way to describe epilepsy is to talk about the *type of seizures* a person has.
Visit epilepsysociety.org.uk/epileptic-seizures

What causes epilepsy?

Different epilepsies are due to many different underlying causes. The causes can be complex, and sometimes hard to identify. A person might start having seizures because they have one or more of the following:

- a genetic tendency, passed down from one or both parents (inherited);
- a genetic tendency that is not inherited, but is a new change in the person's genes;
- a structural (sometimes called 'symptomatic') change in the brain, such as the brain not developing properly, or damage caused by a brain injury, infections like meningitis, a stroke, or a tumour. A brain scan, such as Magnetic Resonance Imaging (MRI), may show this; or
- structural changes due to genetic conditions such as tuberous sclerosis or neurofibromatosis, which can cause growths affecting the brain.

Some researchers now believe that the chance of developing epilepsy is probably always genetic to some extent, in that any person who starts having seizures has always had some level of genetic likelihood to do so. This level can range from high to low and anywhere in between.

Epilepsy varies greatly and affects everyone differently. If you or someone you know has epilepsy, you may find it helpful to learn more. Here are some basic facts about epilepsy and where to get more information.

Helpline 01494 601400
Confidential, national call rate.
Information and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

Even if seizures start after a brain injury or other structural change, this may be due to *both* the structural change *and* the person's genetic tendency to have seizures, combined. This makes sense if we consider that many people might have a similar brain injury, but not all of them develop epilepsy afterwards.

Seizure thresholds

Part of the genetic likelihood of developing seizures is called a seizure threshold. This is our individual level of resistance to seizures.

Any of us could have a seizure under certain circumstances but, for most people, their natural resistance to having seizures is high enough to stop that happening.

Our seizure threshold is one part of our genetic makeup which can be passed from parent to child. So the chance of you having seizures may depend partly on whether either, or both, of your parents has epilepsy. If you have a *low seizure threshold*, your brain is less resistant to seizures. So you are more likely to suddenly start having seizures for no obvious reason than someone with a high seizure threshold.

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

How is epilepsy diagnosed?

Diagnosing epilepsy can be difficult. Unless someone is having a seizure, there is often no obvious sign that they have epilepsy.

Many people will have a one-off seizure at some point in their lives, but a diagnosis of epilepsy is usually made after a person has had more than one seizure.

The person who has the seizure may not remember what happened. So it can be very helpful to have a description of what happened, from someone who saw the seizure, to pass on to the specialist.

A number of investigations may give more detailed information that can help with a diagnosis, including:

- blood tests;
- an electroencephalogram (EEG), a test where electrodes are used to record brain activity;
- a brain scan called Computerised Tomography (CT scan), which is a special type of x-ray using a scanner and a computer to take pictures of the brain; and
- Magnetic Resonance Imaging (MRI). This is a type of scan that uses strong magnetic fields and radio waves to produce detailed pictures of the brain.

However, these tests alone cannot confirm or rule out a diagnosis of epilepsy. Often it is a combination of test results, a person's medical history, and information from those who saw the seizure, that is used to reach a diagnosis.

Visit epilepsysociety.org.uk/diagnosis

How is epilepsy treated?

Anti-seizure medication (ASM)

Up to 70% of people with epilepsy could have their seizures controlled (they stop having seizures), with the right medication. ASM is taken regularly to prevent seizures from happening, by reducing the brain's excessive electrical activity.

ASM is not used during a seizure to stop it, and it does not cure epilepsy. There are different ASMs, and the ASM that someone is prescribed depends partly on the type of seizures they have.

Some people's epilepsy goes into 'spontaneous remission' and they stop having seizures. When this happens they may be able to gradually stop taking their ASM, with guidance from their neurologist.

Other people need to carry on taking ASM for the long term to keep their seizures under control. This may be the case if the underlying cause of the seizures is still there, for example a scar on the brain.

Visit epilepsysociety.org.uk/anti-seizure-medication

Other treatments for epilepsy

For some people whose epilepsy does not respond to ASM, other treatments may be possible:

- Epilepsy surgery (also called neurosurgery) may be possible for some people if tests are able to show where in the brain the seizures are starting.
- VNS (Vagus nerve stimulation) therapy aims to help regulate the brain's normal electrical activity to reduce the number or severity of seizures.

It is a form of treatment that sends mild electrical stimulation to the brain through the vagus nerve (a large nerve in the neck). It is normally used alongside ASM.

- For some children and adults, the ketogenic diet may help to reduce the number or severity of their seizures. The diet is a medical treatment, often started alongside ASM, and is supervised by trained medical specialists and dietitians. Dietary treatments for adults are available on a limited basis in the UK.

Visit epilepsysociety.org.uk/epilepsy-surgery
epilepsysociety.org.uk/vagus-nerve-stimulation
epilepsysociety.org.uk/ketogenic-diet

Seizure triggers

For some people, certain situations can trigger (set off) a seizure. Triggers don't cause epilepsy but they can make seizures more likely for a person with epilepsy. Possible seizure triggers include:

- lack of sleep;
- stress;
- alcohol and drugs;
- not taking ASM as prescribed;
- flashing lights or moving patterns (called photosensitive epilepsy);
- periods;
- a high temperature due to an infection or illness. This may be a common trigger for some children;
- some foods and drinks or not eating properly; and
- some essential oils used in complementary therapies.

Not everyone will have the same triggers. But if is possible to identity what the triggers are for your seizures, it may be possible to avoid them.
Visit epilepsysociety.org.uk/seizure-triggers

Will epilepsy affect my life?

Developing epilepsy may affect you in different ways. Some people may feel relieved to be given a name and treatment for their condition.

Sometimes a diagnosis can be hard to come to terms with. Talking about any worries you may have, asking questions, and sharing information may help you, and your family and friends, to make sense of what is happening for you.
Visit epilepsysociety.org.uk/just-diagnosed

Some people find that their epilepsy does not affect their life much, especially if their seizures are controlled with treatment that suits them. For other people, epilepsy may affect different areas of life, such as work or home life, lifestyle, travel and holidays, leisure, or social life.
Visit epilepsysociety.org.uk/work-employment-and-epilepsy
epilepsysociety.org.uk/travel-and-holidays
epilepsysociety.org.uk/exercise-and-sport
epilepsysociety.org.uk/wellbeing
However epilepsy affects you, or how you feel about it, there is help available.
Visit epilepsysociety.org.uk/what-help-available

There can be a lot of information about the condition to come to terms with. It is important to remember that epilepsy is a very individual condition and affects people differently.
Visit epilepsysociety.org.uk

Support available

Epilepsy Society helpline
Our confidential helpline provides emotional support and information for anyone wanting to know more about epilepsy.
You can contact our helpline by phone, email, or webchat (see page 1).

How to help

Would you know what to do if you saw someone having a seizure? Remember **Calm, Cushion, Call**:

Calm: stay calm and take control of the situation.

Cushion: cushion their head with something soft.

Call: call an ambulance.

Visit epilepsysociety.org.uk/ccc or visit epilepsysociety.org.uk/seizure-first-aid

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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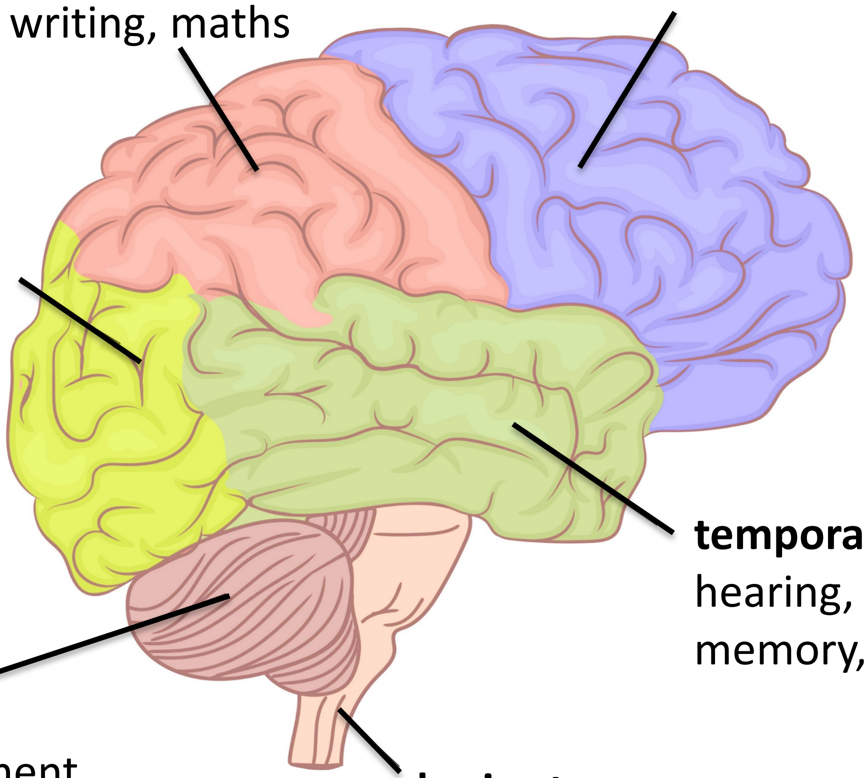
Diagram of the brain



Parietal lobe
sensation, perception,
reading, writing, maths

frontal lobe
movement, problem solving
decision making, behaviour

occipital lobe
vision

temporal lobe
hearing, speech
memory, emotions

cerebellum
muscle control,
balance, movement,
language processing,
memory.

brain stem
sends signals from the brain
to the rest of your body

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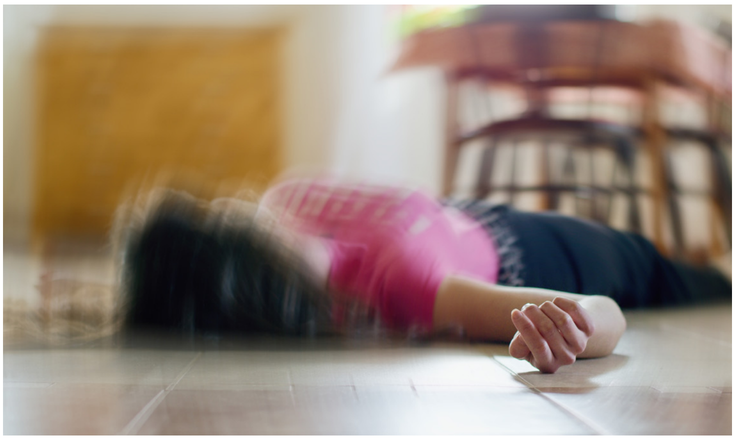
Seizures

An introduction to epileptic seizures



This information covers different types of epileptic seizures and what they can look like.
Visit epilepsysociety.org.uk/what-epilepsy

Whether you, or someone you know, has had a single seizure or has been diagnosed with epilepsy, it may help to identify the type of seizures that are relevant to you, and how they affect you. Also, page 5 has information on what to do if someone has a seizure.
Call our helpline for information or time to talk. See below for details.

Are all seizures the same?

Epileptic seizures start in the brain. There are other types of seizures which may look like epileptic seizures but they do not start in the brain.

Some seizures are caused by conditions such as low blood sugar (hypoglycaemia) or a change to the way the heart is working.

Some very young children have 'febrile convulsions' (jerking movements) when they have a high temperature. These are not the same as epileptic seizures.

In this information when we use the word 'seizure' we mean an epileptic seizure.

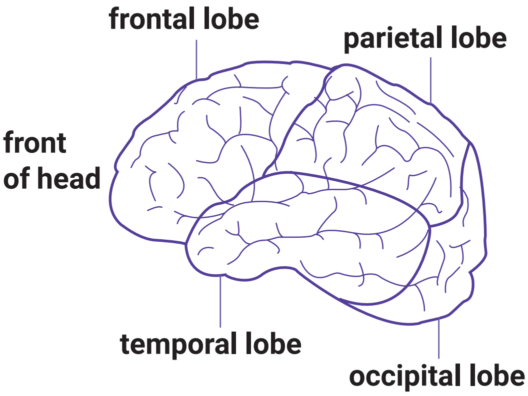
Why do epileptic seizures happen?

The brain has millions of nerve cells which control the way we think, move, and feel. The nerve cells do this by passing electrical signals to each other. If these signals are disrupted, or too many signals are sent at once, this causes a seizure.

The brain has many different functions. Mood, memory, movement, consciousness, and our senses are all controlled by the brain, and any of these can be affected if someone has a seizure. They may feel strange or confused, behave in an unusual way, or lose some or all awareness during the seizure.

The brain has two sides called hemispheres. Each hemisphere has four parts called lobes. Each lobe is responsible for different things such as vision, speech, and emotions.

One hemisphere of the brain (side-view)



Any of us could potentially have a single seizure at some point in our lives. This is not the same as having epilepsy, which is a *tendency* to have seizures that start in the brain.

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

Some facts about seizures

- Most seizures happen suddenly without warning, last a short time (a few seconds or minutes), and stop by themselves.
- Seizures can be different for each person.
- Just knowing that someone has epilepsy does not tell you what their epilepsy is like, or what type of seizures they have.
- Calling seizures 'major' or 'minor' does not tell you what happens to the person during a seizure. The names of seizures used in this information describe what happens in a seizure.
- Some people have more than one type of seizure, or their seizures may not fit clearly into the types described here. But even if someone's seizures are unique, they usually follow the same pattern each time they happen.
- Not all seizures involve jerking or shaking movements. Some people seem vacant, wander around, or are confused during a seizure.
- Some people have seizures when they are awake, called 'awake seizures'. Some people have seizures while they are asleep, called 'asleep seizures' (or 'nocturnal seizures'). The names 'awake' and 'asleep' do not explain the type of seizures, only when they happen.
- Injuries can happen during seizures, but many people don't hurt themselves, and don't need to go to hospital or see a doctor.

Visit epilepsysociety.org.uk/first-aid

Types of seizures

In March 2017 the International League Against Epilepsy (ILAE), a group of the world's leading epilepsy professionals, introduced a new method to group seizures, which they called a 'classification'. This gives doctors a more accurate way to describe a person's seizures, and helps them to prescribe the most appropriate treatments.

In April 2025 they updated their classification.
Visit ilae.org/updated-classification-epileptic-seizures-2025

Seizures are divided into groups depending on:
- how much of the brain is affected;
- whether or not a person loses consciousness; and
- whether or not seizures involve other symptoms, that you can see or hear.

Depending on where they start, seizures are described as focal, generalised, unknown, or unclassified.

Some seizures involve symptoms that you can see or hear, such as movement, noises, or looking flushed. ILAE calls these 'observable manifestations'.

Other seizures involve symptoms that can't be seen or heard, such as unusual feelings or sensations. These are described as 'without observable manifestations'.

What are focal seizures?

Focal seizures start in, and affect, just one part of the brain, sometimes called the 'focus' of the seizures. They might affect a large part of one hemisphere or just a small area in one of the lobes.

Sometimes a focal seizure can spread to both sides of the brain (bilateral). Some people view this focal seizure as a warning, that another seizure will happen (see focal to bilateral tonic-clonic seizures, page 3).

Levels of consciousness

Focal seizures are also described depending on a person's consciousness during their seizures – whether or not they are aware of what is happening around them and if they are able to respond.

Focal preserved consciousness seizures

In focal preserved consciousness (previously called focal aware seizures) the person is conscious, will usually know that something is happening and can respond and will remember the seizure afterwards.

Some people find it hard to put their focal preserved consciousness seizures into words. During the seizure, they may feel 'strange' but not be able to describe the feeling afterwards. This may be upsetting or frustrating for them.

Focal impaired consciousness seizures

Focal impaired consciousness seizures (previously called focal impaired awareness seizures) affect a bigger part of one hemisphere (side) of the brain than focal preserved consciousness seizures.

The person's consciousness is affected and they may be confused. They might be able to hear you, but not fully understand what you say or be able to respond to you. They may not react as they would normally. If you speak loudly to them, they may think you are being aggressive, and so they may react aggressively towards you.

Focal impaired consciousness seizures often happen in the temporal lobes but can happen in other parts of the brain.

After the seizure, the person may be confused for a while. This is sometimes called 'post-ictal' (after-seizure) confusion.

It may be hard to tell when the seizure has ended. The person might be tired, and want to rest. They may not remember the seizure afterwards.

What happens during focal seizures?

This depends on where in the brain the seizure happens and what that part of the brain normally does.

Seizures with observable manifestations can involve:

- making lip-smacking or chewing movements, repeatedly picking up objects or pulling at clothes;
- suddenly losing muscle tone and limbs going limp or floppy, or limbs suddenly becoming stiff;
- repetitive jerking movements that affect one or both sides of the body;
- stiffness or twitching in part of the body, (such as an arm or hand);
- making a loud cry or scream; or
- making strange postures or repetitive movements such as cycling or kicking.

Seizures without observable manifestations can involve:

- a 'rising' feeling in the stomach or déjà vu (feeling like you've 'been here before');
- getting an unusual smell or taste;
- a sudden intense feeling of fear or joy;
- a strange feeling like a 'wave' going through the head;
- a feeling of numbness or tingling;
- a sensation that an arm or leg feels bigger or smaller than it actually is; or
- visual disturbances such as coloured or flashing lights or hallucinations (seeing something that isn't actually there).

Focal to bilateral tonic-clonic seizures

Sometimes focal seizures spread from one side to both sides of the brain. This is called a focal to bilateral tonic-clonic seizure (previously called a secondarily generalised tonic clonic seizure).

When this happens the person becomes unconscious and will usually have a tonic clonic (jerking or shaking) seizure.

When focal seizures spread very quickly, the person may not be aware that it started as a focal seizure.

What are generalised seizures?

Generalised seizures affect both sides of the brain at once and happen without warning. The person will be unconscious (except in myoclonic seizures), even if just for a few seconds, and afterwards will not remember what happened during the seizure.

Tonic clonic seizures

These are the seizures most people think of as epilepsy.

At the start of the seizure:

- the person becomes unconscious;
- their body goes stiff, and if they are standing up they usually fall backwards;
- they may cry out; and
- they may bite their tongue or cheek.

During the seizure:

- they jerk and shake as their muscles relax and tighten rhythmically;
- their breathing might be affected and become difficult or sound noisy;
- their skin may change colour and become very pale or bluish; and
- they may wet themselves.

After the seizure (once the jerking stops):

- breathing and colour usually returns to normal; and
- they may feel tired, confused, have a headache, or want to sleep.

A person's seizures usually last the same length of time each time they happen, and stop by themselves.

However, sometimes seizures do not stop, or one seizure follows another without the person recovering in between. If this goes on for five minutes or more it is called status epilepticus, or 'status'.

Status is not common, but can happen in any type of seizure and the person may need to see a doctor.

Status in a tonic clonic seizure is a medical emergency, and the person will need urgent medical help.

It is important to call for an ambulance. See page 5 for what to do if someone has a seizure.

Visit epilepsysociety.org.uk/first-aid

Clonic seizures

Clonic seizures involve repeated rhythmical jerking movements of one side or part of the body or both sides (the whole body) depending on where the seizure starts. Seizures can start in one part of the brain (focal with observable manifestations) or affect both sides of the brain (generalised clonic).

Tonic and atonic seizures

In a **tonic** seizure the person's muscles suddenly become stiff. If they are standing they often fall, usually backwards, and may injure the back of their head. Tonic seizures tend to be brief and happen without warning.

In an **atonic** seizure (or 'drop attack') the person's muscles suddenly relax, and they become floppy. If they are standing they often fall, usually forwards, and may injure the front of their head or face. Like tonic seizures, atonic seizures tend to be brief and happen without warning.

With both tonic and atonic seizures people usually recover quickly, apart from possible injuries.

Myoclonic seizures

Myoclonic means 'muscle jerk'. Muscle jerks are not always due to epilepsy (for example, some people have them as they fall asleep).

Myoclonic seizures are brief but can happen in clusters (many happening close together in time), and often happen shortly after waking.

In myoclonic seizures the person is conscious, but they can be classified as focal or as generalised seizures. This is because they may be followed by a generalised seizure (such as a tonic clonic seizure).

Negative myoclonic seizures

In this type of seizure, the person briefly loses muscle tone and may lose their balance and fall or struggle to regain their balance. They may lose their grip on objects and drop them.

Negative myoclonic seizures can sometimes be a symptom of an epilepsy syndrome.

Visit epilepsysociety.org.uk/epilepsy-syndromes

Absence seizures

Absence seizures are more common in children than in adults, and can happen very frequently.

Typical absences

During a typical absence the person becomes blank and unresponsive for a few seconds. They may appear to be 'daydreaming'. The seizures may not be noticed because they are brief.

The person may stop what they are doing, look blank and stare, or their eyelids might blink or flutter. They will not respond to what is happening around them. If they are walking they may carry on walking, but will not be aware of what they are doing.

Atypical absences

Atypical absences are similar to typical absences (see above) but they start and end more slowly, and last a bit longer than typical absences. As they also include a change in muscle tone, where the limbs go limp or floppy, some people may fall.

What are unknown seizures?

This term is sometimes used to describe a seizure if doctors are not sure where in the brain the seizure starts. This may happen if the person was asleep, alone, or the seizure was not witnessed.

What are unclassified seizures?

If there is not enough information about a person's seizure, or if it is unusual, doctors may call it an unclassified seizure.
Visit epilepsysociety.org.uk/recording-information-seizures

What should I do if someone has a seizure?

How you can help someone during a seizure will depend on the type of seizures they have, and how much you know about their epilepsy. If you don't know the person follow our basic first aid message:

1. Calm
Stay calm and take control of the situation

2. Cushion
Cushion their head with something soft

3. Call
Call an ambulance

Visit epilepsysociety.org.uk/ccc

If they seem confused, stay with them, talk calmly and quietly, and gently guide them away from any danger.
For more detailed information visit epilepsysociety.org.uk/first-aid

Trusted Information Creator
Patient Information Forum

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.

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Anti-seizure medication

epilepsy society

An introduction to anti-seizure medication

For most people with epilepsy, the main type of treatment is anti-seizure medication (ASM), previously called anti-epileptic drugs or AEDs. Up to 70% (7 in 10) of people could stop having seizures with the right medication.

About anti-seizure medication

What is anti-seizure medication and what does it do?

ASM is a type of medication that aims to stop seizures from happening. It does not stop a seizure once it has started and it cannot cure epilepsy.

Some medications are taken as a 'course of treatment' to cure a condition, for example, taking a course of antibiotics for an infection.

ASM is different: it is a preventative medication taken every day to try and stop seizures from happening. It does this by reducing the excessive electrical activity in the brain that causes seizures. The way it works is not completely understood, and it is likely that different ASMs work in slightly different ways.

What is the aim of treatment with ASM?

The aim of treatment is 'optimal therapy'. This means taking the fewest types of ASMs, at the lowest dose, in order to get the best seizure control possible, with the fewest side effects.

If optimal therapy cannot be found with one particular ASM there are usually several others that can be tried alone or combined.

When is treatment usually started?

Epilepsy is the tendency to have repeated seizures that start in the brain. Treatment is usually only considered after a diagnosis of epilepsy has been made. This is usually after someone has had repeated seizures.
Visit epilepsysociety.org.uk/diagnosis

In some rare situations treatment might be considered straightaway, after just a single seizure. This is usually only when a doctor thinks that it is very likely that you will have further seizures.

Who will be involved with my epilepsy care?

If you or your child have been diagnosed with epilepsy, it is likely that you will have seen a specialist – a neurologist for adults, or a paediatrician or paediatric neurologist for children. The specialist should have expertise in epilepsy. You may already have discussed treatment options with them. They will usually prescribe your ASM and arrange follow-up appointments to see how you are getting on.

The day-to-day management of your epilepsy might be under the care of your GP. For example, they might write your prescriptions. They should also have a copy of your treatment plan (see page 6).

You might also see an epilepsy specialist nurse (ESN). ESNs work alongside the specialist and GP to help you manage your epilepsy. Not all hospitals have an ESN but you can ask about this at your local hospital. In the longer term, if your seizures become controlled, you might only see your GP to review your epilepsy each year.

How is ASM chosen?

There are about 30 ASMs and each has a particular type or types of seizures that it works for. The choice of ASM firstly depends on the type of seizures you have, and which ASM works for these seizures.

The National Institute for Health and Care Excellence (NICE) has recommendations about which ASMs should be used for different types of epilepsy and seizures.
Visit nice.org.uk/guidance/NG217

This information is for both adults and children with epilepsy and answers some questions you might have about anti-seizure medication. Where we talk about controlling seizures or 'seizure control' we mean stopping seizures from happening.

Helpline 01494 601400
Confidential, national call rate.
Information and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

When an ASM is chosen, your specialist will take into account any other conditions you have, or medication you take. As you may be on ASM for a number of years, they will consider not just what is right for you now but also for the future. For example, when a girl is first prescribed ASM they will think about when she becomes an adult and may want to start a family, as some ASMs can affect an unborn baby (see page 4).

Although ASM recommendations are largely the same for men, women and children, there are some reasons why a particular ASM might be chosen or avoided for a particular person. This may be due to possible side effects (see below).

Starting treatment

You are entitled to free prescriptions for your ASM and any other prescribed medication.

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

Treatment is usually started with a ‘first line’ ASM. This is an ASM that is tried first and taken on its own, sometimes called monotherapy. Once the most appropriate ASM for you has been identified and discussed with you, you will usually start on a very low dose. This helps your body get used to the medication, and makes side effects less likely.

The dose is then increased slowly over a number of weeks until it stops your seizures. The right dose for you may be different to what is right for someone else. This is sometimes referred to as your ‘individual therapeutic concentration’.

Therapeutic drug monitoring (TDM) uses blood levels to individualise epilepsy treatment to get the best seizure control with the least side effects. TDM can be very useful when starting medication, although not everyone is offered TDM.

Visit epilepsysociety.org.uk/monitoring-your-medication

How the body absorbs, uses and removes medication changes with age. For children, ASM doses are based on their body weight and so the dose increases as they get older (up to around 12 years of age). For adults, doses are not based on body weight.

For most people, once the right ASM for them is found, it will stop their seizures. Although for some people it can take time to get this right, the aim is to stop your seizures by just taking one ASM.

However, if your seizures do not stop when the dose is increased, or you start to have side effects, you may want to talk to your doctor about changing to a different ASM.

Because different ASMs work in different ways, if one does not control your seizures, it doesn’t mean that other ASMs won’t work. If you change from one ASM to another, the second ASM is usually added and slowly increased to a dose which is likely to work, and the original drug is slowly reduced.

If your seizures are not controlled with a single ASM you may take a combination of ASMs. This is called polytherapy. Some ASMs added to a first line ASM are called ‘second line’ ASMs. This is slightly different for children because ASMs are not split into first and second line for treating children age 12 and under.

Some people continue to have seizures despite taking ASM. In this case they may continue to take ASM to reduce their seizures as much as possible and consider trying other types of treatment (see page 7).

Side effects and interactions

As with all medications, ASM can cause side effects, and possible side effects vary from one ASM to another. Whether you will have side effects or not depends on how you react to the drug (as people can respond differently to the same drug). How important side effects are depends on how important they are to you.

Information about side effects is included in the patient information leaflet (PIL) that comes with the packaging for each medication. The list of side effects can be long and off-putting. But listed side effects are only *possible* side effects. They do not always happen.

They are often listed by how frequently they occur, such as ‘common’ and ‘rare’.These terms are the same for all drugs and they show how likely it is that a side effect will happen (how many people will have it). Knowing what these terms mean may help to put side effects into perspective, and help you to make decisions about taking medication or not.

The possible side effects of ASM may affect the choice of ASM. For example, medication that causes extreme sleepiness might be avoided for a student who needs to be alert in class. There are also particular issues around ASM for women and girls who are, or may become, pregnant (see page 4).

If you are having side effects that are causing you concern you can talk to your specialist, ESN, or GP.

Types of side effects

- Allergic reactions are rare and usually happen very quickly after starting an ASM. An itchy skin rash is often the first sign of an allergic reaction. If you have an allergic reaction, it is important that you speak to your specialist, a GP, or pharmacist as soon as possible about what to do. Allergic reactions can be very serious.
- Dose-related side effects happen when the dose of a drug is too high, and usually go away if the dose is reduced. This is why medication is usually started at a low dose and increased slowly.
- Long term (or chronic) side effects happen when a drug is taken for a long time, usually many years.

Side effects can be difficult to recognise in babies, children, and people with learning disabilities as they may not be able to say how they are feeling. If your child is taking ASM and feels unwell, you might notice a change in their behaviour.

If you have a side effect which isn't listed in the PIL, you can report this to the Medicines and Healthcare Products Regulatory Agency (MHRA), the agency responsible for the safety of medicines in the UK, via their yellow card scheme.

Visit epilepsysociety.org.uk/yellow-card-scheme

What are drug interactions?

Some drugs can affect, and be affected by, other drugs. This is called a 'drug interaction'. When two drugs interact, how one or both drugs work will be affected. Interactions can result in one or both drugs:

- working better (being more effective); or
- working less well, for example, if one prevents the other from working or speeds up how quickly it is eliminated (got rid of) from the body, so it has less time to work.

Drug interactions can happen between different ASMs, and between ASM and other types of drugs including non-prescription (or 'over the counter') medications, complementary therapies, and herbal remedies. For this reason, it is helpful to say if you are taking other drugs before starting ASM, or that you are taking ASM before starting any other drugs.

Usually, there is no interaction between ASM and frequently used pain relief medications such as those containing paracetamol or ibuprofen.

ASM and alcohol

Alcohol can affect how well ASM works and can also trigger seizures for some people. This depends on the ASM, how much the person drinks, and how they react to alcohol. Drinking alcohol when taking ASM is a personal choice and the PIL, or your specialist, will be able to tell you more about drinking alcohol with that medication.

When should I take my ASM?

ASM works best when it is taken regularly and at about the same time every day. For most ASMs it does not matter when in the day you take them, only that you try to stick to the same time each day. If you take it more than once a day it is useful to try to take it evenly spread out.

It is important to take ASM regularly because this helps to keep the levels in your body 'topped up', to stop seizures from happening.

If you are unsure about when to take your ASM you could talk to your specialist or pharmacist. The aim of taking ASM is to make your treatment as simple and convenient as possible so that it fits into your daily routine.

How long will I have to take ASM for?

How long you need to take ASM for depends on your epilepsy, your seizures, and how you respond to the ASM. Most people will take ASM for at least several years and sometimes for life.

- For some people, seizures stop or go away on their on their own (called spontaneous remission). In this case, they might come off their medication with help from their neurologist (with medical supervision).
- Some children have an epilepsy syndrome where their seizures stop at a particular age and so they may be able to stop taking their ASM at that point.

Are all ASMs the same?

Most ASMs have two names: a generic name (for example carbamazepine) and a brand or trade name given by the manufacturer (for example Tegretol). The generic name refers to the active ingredient in the drug (which works to control, or treat, the condition it is taken for).

Some ASMs have more than one generic form, each of which has the same active ingredient, and each can be given its own name. For some ASMs different forms may use different ingredients, such as binding or colouring agents, which can affect how they are absorbed and used in the body.

Swapping between different forms of ASM could affect seizure control or cause side effects. So it is often recommended that, once you have found a form of ASM to control your seizures, you take the same form of this ASM all the time (with every prescription) whether it is generic or branded. This is called 'consistency of supply'.

It is a good idea to check that you have the right form of ASM before leaving the pharmacy as they may not be able to change it once you have left.

Visit epilepsysociety.org.uk/generic-and-branded-ASMs

Some drugs are made abroad and brought into the UK. Other drugs are made in the UK, exported, and brought back to the UK. These are called 'parallel imports'. They are sometimes labelled in a different language or have different packaging from usual.

If you are concerned about your medication, you can ask your doctor to write 'no parallel imports' on your prescription.

My child has epilepsy – will ASM affect their behaviour or learning?

The aim of medication is to stop seizures without side effects or impact on behaviour. However, some children may have side effects that affect their behaviour, although these may go away after a few weeks. Some changes in behaviour could be due to the seizures themselves or other things, such as how the child feels about their epilepsy and how other people react, or they may just be a part of growing up.

Many people find that their epilepsy and medication does not impact on their learning. However, for other children it might have an effect, for example, due to seizures disrupting their lessons or medication affecting their concentration.

If you are concerned about whether ASM is affecting your child, you can talk to their paediatrician.

Visit epilepsysociety.org.uk/information-parents

Are there any special issues for girls and women?

Some ASM can affect periods and some types of contraception, and some types of contraception are less effective for girls and women taking particular ASMs. This depends on the individual, which ASM they take, and the type of contraception they use. Some girls and women have catamenial epilepsy – where their seizures happen at a particular time during their menstrual cycle. They may be prescribed an extra ASM, alongside their regular ASM, to take when seizures are likely to happen.

Visit epilepsysociety.org.uk/women-and-girls

ASM and birth defects

Taking some ASMs may affect a developing baby. However, these risks need to be carefully considered for each person and balanced against the possibility of seizures happening during pregnancy which may also affect a developing baby, or the safety of the mother.

Different ASMs vary in the risk they pose, and the risk of birth defects rises with higher doses of the drug. Taking more than one ASM also increases the risk. Sodium Valproate (including Epilim, Depakote, Episenta, Epival, Kentlim, Syonell, Valpal, Belvo, Convulex, Dyzantil and Orlept) and Topiramate (Topamax) have greater risks in pregnancy than other ASM. The MHRA has issued guidance and information on the risks of taking Sodium Valproate and Topiramate during pregnancy.

Visit epilepsysociety.org.uk/are-there-risks-my-baby
Visit gov.uk/guidance/valproate-use-by-women-and-girls
and epilepsysociety.org.uk/news/new-safety-measures-topiramate-during-pregnancy

There is also evolving information about potential risks from taking sodium valproate for men.

Visit epilepsysociety.org.uk/about-epilepsy/sodium-valproate

If you are thinking of starting a family, it is essential that you talk to your neurologist about planning your epilepsy treatment for pregnancy, and for when the baby arrives.

Visit epilepsysociety.org.uk/pregnancy-and-epilepsy

New to epilepsy treatment

Should I start treatment?

Your specialist may recommend that you start treatment but the choice is ultimately yours and will depend on your situation. To help you make a decision the following things may be useful.

- Understanding your condition and how it affects you.
- Understanding what treatment is being suggested and why.
- Understanding how this treatment might affect your life as well as your epilepsy.
- Having enough information to decide what you want to do and being able to discuss this with your specialist.
- Having an agreed treatment plan and being able to follow it.

To help you decide about taking medication, for you or your child, it can be important to be aware of, and think through, the benefits and risks of taking, or not taking ASM. This may depend on how your seizures affect you and how often they happen.

If you need more information to help you to make a decision, you can talk to your specialist, ESN, or GP. You can also talk it through with our epilepsy helpline (see page one).

How serious can the risks be?

For most people with epilepsy, seizures last for a short time and stop on their own. Although there is a risk of accident and injury, seizures themselves do not usually cause any lasting harm. However, for some people their seizures can cause serious harm.

Status epilepticus

Status epilepticus (or 'status') is where a seizure continues without stopping, or a series of seizures happen without the person recovering in between, for five minutes or more. This can happen with any seizure type. When status happens in a tonic clonic seizure, this is life threatening and needs urgent treatment.

Status can affect the person's oxygen levels and blood pressure, their heart, and lungs. This can cause permanent brain damage and can be fatal. So it is important to seek medical help if a seizure is prolonged or repeated.

Visit epilepsysociety.org.uk/first-aid-epileptic-seizures

The two emergency medications used to prevent status in the community (not in hospital) are midazolam and diazepam.

Visit epilepsysociety.org.uk/emergency-medication

It is important that everyone who is prescribed emergency medication has a current written plan (or protocol) for being given it. Specialist training is needed to give emergency medication. Epilepsy Society can provide this training.

Visit epilepsysociety.org.uk/training-courses-epilepsy

Seizures that last longer than usual, or an increased number of seizures, often happen before status. For some people, missing doses of ASM can cause status.

SUDEP

On rare occasions people die suddenly for no clear reason. When this happens to someone with epilepsy it may be called sudden unexpected death in epilepsy (SUDEP). SUDEP is when a person with epilepsy dies and no other cause of death can be found.

SUDEP usually happens when the person is asleep and so it can be hard to know why it has happened, but it is thought to be related to having a seizure and the person stops breathing and their heart stops.

The number of people who die from SUDEP is relatively low (around 600 per year in the UK) and an individual's level of risk will depend on how their epilepsy affects them.

As SUDEP is thought to be related to having seizures, a key way to reduce the risk is to try to get the best seizure control possible. This is usually through taking ASM. If you are worried about status or SUDEP, you can talk to your specialist or you could call our confidential helpline (see page one).

Visit epilepsysociety.org.uk/SUDEP

If you are taking medication

For anti-seizure medication to work at its best, it needs to be taken regularly at around the same time or times each day.

However, it is not uncommon for people to forget to take medication or accidentally miss a dose.
Some people with epilepsy have memory problems related to their epilepsy which can make remembering to take medication difficult.

Some people may also take too much medication if they forget that they have already taken a dose.

For most people, missing one dose on a rare occasion is unlikely to cause a seizure. If you miss a dose, or take too much medication, the patient information leaflet may tell you what to do.

In general, if a dose is missed and the ASM is usually taken:

- once a day - take the forgotten dose as soon as you remember it; or
- twice a day - take the forgotten dose, if you remember, within six hours after it was due. Otherwise don't take the forgotten dose and just take the next dose at the due time.

It is important that, if you miss a dose, you do not take twice as much at the next dose time. Taking a larger dose than normal could cause side effects. If you find that you regularly forget your medication, there are memory aids and techniques that may help.
Visit epilepsysociety.org.uk/memory

I find it difficult to take my ASM - are alternative forms available?

Your specialist or pharmacist can tell you whether there are alternative forms for your ASM. Some ASMs come as tablets, and capsules, liquids and syrups, sprinkles and granules (which can be added to food), and suppositories. Some ASMs are available as 'slow release' forms which release their active ingredient more slowly in your body than non-slow release forms.

For babies, some medication can be dissolved in water. Giving it this way means you can check that they have taken all of it. You can ask your pharmacist about how medication can be taken.

It is difficult to get to the pharmacy to collect my medication, or to my GP for a repeat prescription - what might help me?

Some surgeries and pharmacies offer services that might help, such as repeat prescriptions and home deliveries.
Visit epilepsysociety.org.uk/making-most-your-pharmacist

Should I take another dose if I'm sick?

If you have been sick or have diarrhoea, this can affect how well your medication will work.
Whether you should take the dose of medication again may depend on how soon after taking your medication you were sick. In general the following applies.

- If you are sick within one hour of taking medication, take another dose.
- If you are sick more than one hour after taking medication, wait until your next dose is due before taking it.

The PIL for your medication may have more information or you could talk to your pharmacist about what to do.

Managing your treatment

Care and treatment plans

A care plan is an overview of your epilepsy and its treatment and management. It includes information about your epilepsy and seizures, and other issues that may be important to you, such as education, work, driving, and starting a family.

You should be offered a care plan, particularly if your epilepsy is recently diagnosed. This might be part of the letter that your specialist will write following an appointment. If you are not offered a care plan you can ask for one.

Part of a care plan includes a treatment (or medication) plan. This sets out how your epilepsy will be treated and usually includes how to start and increase your medication, and what to do if it does not work or you have side effects.

Your care plan is made by you and your specialist, or epilepsy nurse, together. You should be given a copy of the plan which is usually also given to your GP. It should be reviewed and updated when needed.

How do I know if treatment is working?

Often the best way to measure how well treatment is working is to look at whether your seizures have stopped or if you are having fewer seizures.

Keeping a seizure diary can help to record how many seizures you are having, when they happen, if anything triggers them, and if your medication is reducing or stopping them.
Visit epilepsysociety.org.uk/seizure-diaries

Monitoring epilepsy

Epilepsy reviews

You may be offered regular reviews of your epilepsy. If you are still having seizures, a review should be annually with your specialist but, if your seizures become well controlled, you might have annual reviews with your GP.
Visit epilepsysociety.org.uk/your-appointment-or-review

ASM and osteoporosis

Some ASMs affect bone density in some people. If you have osteoporosis or a family history of osteoporosis, you may be offered a bone density test, and to have your calcium and vitamin D levels checked.
Visit epilepsysociety.org.uk/osteoporosis-and-epilepsy

What is drug resistant epilepsy?

Most people's seizures (around 7 in 10) are controlled with medication. That is why medication is usually the type of treatment that is tried first. But if you have tried two or more anti-seizure medications and you continue to have seizures, this is sometimes called drug resistant epilepsy, uncontrolled epilepsy, intractable epilepsy, or refractory epilepsy. It affects around 3 in 10 people with epilepsy. There are other types of treatment that might be considered. This might be instead of, or alongside, ASM. Rather than waiting until you have tried lots of different ASMs, your specialist might talk to you about alternatives if two or three ASMs have not worked for you.

If medication doesn't work

Most people's seizures are controlled with medication. That is why medication is usually the type of treatment that is tried first. But if medication doesn't stop all your seizures, or only stops some of them, there are other types of treatment that might be considered. This might be instead of, or alongside, ASM. Rather than waiting until you have tried lots of different ASMs, your specialist might talk to you about alternatives if two or three ASMs have not worked for you.
Visit epilepsysociety.org.uk/epilepsy-and-brain-surgery
epilepsysociety.org.uk/vagus-nerve-stimulation
epilepsysociety.org.uk/ketogenic-diet

If your seizures are not controlled with medication, your specialist may want to review your diagnosis, the type of epilepsy or seizures you have, and the treatment you have had so far.
They may refer you to a tertiary service (a specialist hospital or unit that focuses on specific care for different conditions) if they feel that more specialist treatment, other than ASM, would be appropriate for you. Specialists at the tertiary centre would review your epilepsy and treatment to try to get you better seizure control.

Visit epilepsysociety.org.uk/about-epilepsy/care-and-treatment/referral-tertiary-care

Coming off anti-seizure medication

Some people may need to take ASM for a long time. If someone has not had a seizure for two or more years then they may think about withdrawing (coming off) their ASM.

If you are thinking of coming off ASM it is important to get advice from your specialist. Suddenly stopping treatment can cause seizures to start again or happen more often and last longer than before. With your specialist, you can plan how to come off the medication slowly and decide what to do if your seizures start again. If seizures do start again, taking the same ASM straightaway usually gives the same seizure control as before. However, sometimes the ASM may not work as well as before.

Most people do not have symptoms if a drug is withdrawn slowly.

However, ASMs that might cause withdrawal symptoms include phenobarbital, diazepam, clonazepam, clobazam, and phenytoin. Thinking about the impact on your life if your seizures start again, such as the effect on driving, work, and leisure, can be an important part of deciding whether to come off your ASM.

If you are considering coming off ASM, the Driver and Vehicle Licensing Agency (DVLA) has specific guidelines on this. If you drive against your doctor's advice, you will be driving illegally.
Visit epilepsysociety.org.uk/what-driving-regulations-mean-you

Medication shortages

Epilepsy Society often hears from people with epilepsy and their families about medicines shortages. Always try to get your prescription to your pharmacy in good time – up to seven days before you need it. This will enable the pharmacist to source other supplies if they are out of stock.

If you are experiencing difficulties accessing your medication, try contacting the customer service desk listed on the patient information leaflet that comes with your medication. Alternatively, you can ask your pharmacist to contact the manufacturer to see which wholesalers have supply.

If you are still having problems getting your medication, you can try taking a paper prescription to a different pharmacist.

Or, if you haven't got a paper prescription or can't get one in time, The Human Medicines Regulations 2012 say you can request an emergency supply of your medication from any pharmacy without a prescription.

Who can I talk to?

You might want to talk to your specialist, ESN, GP, or pharmacist about your epilepsy and your medication. Or you can call our confidential helpline (see page 1).

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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Ketogenic diet

What is the ketogenic diet?

The ketogenic diet is a very high fat, very low carbohydrate, controlled protein diet that has been used since the 1920s to treat epilepsy.

The diet is a medical treatment, and is usually only considered when at least two suitable medications have been tried and not worked. The ketogenic diet is an established treatment option for children with hard to control epilepsy. However, adults may also benefit from dietary treatments.

Dietary treatments for epilepsy must only be followed with the support of an experienced epilepsy specialist and dietitian (food specialist).

How does the diet work?

Usually the body uses glucose (a form of sugar) from carbohydrates, found in foods like sugar, bread or pasta, for its energy source. Chemicals called ketones are made when the body uses fat for energy - this is called ketosis. With the ketogenic diet, the body mostly uses ketones instead of glucose for its energy source.

It is not clear exactly how the diet helps reduce seizures in some people. Research has shown that a particular fatty acid called decanoic acid, may be involved in the way the diet works.

Who is the diet suitable for?

The diet may not work for everyone but it is suitable for many different seizure types and epilepsy syndromes.

If you, or your child, has severe feeding problems, or has a condition where a high fat diet would cause problems, the diet may not be suitable.

The ketogenic diet can be adapted to diets from all different cultures, as well as for people with allergies or those on modified texture diets. The dietitian will calculate the diet and try to include foods you or your child likes. The diet can be used in children and adults of any age, although infants need close monitoring.

What sort of food is eaten on the diet?

There are different forms of the ketogenic diet. The types of foods eaten and how each diet is calculated are slightly different, but all forms have shown effectiveness, in randomised controlled trials, in reducing seizures for some people.

Classical ketogenic diet

In this diet, most of the fat comes from cream, butter, oil, and other naturally fatty foods. The classical diet includes very little carbohydrate and protein. Each meal includes a strictly measured ratio of fat to carbohydrate and protein.

Medium chain triglyceride (MCT) ketogenic diet

MCTs are certain types of fat. This diet allows for more carbohydrates, so may offer more variety. It includes some fat from naturally fatty foods, as well as some fat from a supplement of MCT oil or emulsion. This can be mixed into food or milk and is only available on prescription. Unlike the classical diet's strict ratio of fats to carbohydrate and protein, the MCT diet is calculated by the percentage of energy (calories) provided by these particular types of fat.

The following types of ketogenic diets are more flexible, and may suit older children, adolescents, or adults.

Modified Atkins diet and modified ketogenic diet

The Modified Atkins diet and modified ketogenic diet (sometimes called 'modified ketogenic therapy') use a high proportion of fats and a strict control of carbohydrates. These are often considered more flexible than the classical or MCT ketogenic diets, as more protein can be eaten, and approximate portion sizes may be used in place of weighed recipes.

Low glycaemic index treatment (LGIT)

This diet focuses on how carbohydrates affect the level of glucose in the blood (the glycaemic index), as well as

The ketogenic diet may help reduce seizures and have other positive effects. Dietary treatments for epilepsy are specialised, and need to be supervised by trained medical specialists.

Helpline 01494 601400
Confidential, national call rate.
Information and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

the amount of carbohydrate eaten. Approximate portion sizes are used rather than food being weighed.

Is this a healthy way to eat?

To make sure the diet is nutritionally balanced, an experienced dietitian works out exactly how much of which foods the person can eat each day. To help with this, people have individual recipes, are given support on how to plan meals, and are guided on which foods should be avoided. As the diet can be quite restrictive, the dietitian will recommend any vitamin and mineral supplements that are needed.

How is a person's health monitored?

Regular follow-ups with the dietitian, and medical team, will monitor your or your child's growth (height and weight, if applicable), health, epilepsy, and if there is a need for any change to anti-seizure medication (ASM), such as changing to sugar-free versions. If the diet is followed carefully, individuals do not put on weight, or lose weight inappropriately.

You may be given a diary to record the number and type of seizures you or your child has while on the diet. As food can affect how we feel or act, you may be asked to note any changes in your or your child's mood, alertness and overall behaviour. It usually takes at least three months to see whether the diet is effective.

The length of time the diet is followed may vary, but if an individual remains seizure-free, has fewer seizures, or maintains other benefits, such as improved quality of life, they may consider (with their medical team) slowly coming off the diet after two years.

How is the diet monitored?

To check that the diet is producing ketones, ketone levels are checked using a blood test, or a urine analysis stick, which is dipped into a container of your or your child's urine. The blood test involves a small pin prick on the finger (similar to monitoring diabetes). You can decide with your doctor which method to use.

Does the diet have side effects and does it work?

Constipation is common, partly due to a lack of fibre. This can easily be treated. Hunger, vomiting and lack of energy are also common at the start of treatment, but these tend to decrease with time and may be avoided with careful monitoring.Many people report an increase in energy and feeling more alert once they are used to the diet.

A clinical trial at Great Ormond Street Hospital in 2008 showed that around 4 in 10 children (38%) who started a ketogenic diet had reduced seizures and were able to reduce their anti-seizure medication. Although not all children had better seizure control, some had other benefits such as increased alertness, awareness, and responsiveness. This was the first trial of the ketogenic diet for children with epilepsy. There are now other high-quality trials showing the diet to be effective in infants and adults with epilepsy.

You can discuss the option of starting the diet with your GP or paediatrician/neurologist.

K.Vita® supplement

K.Vita® is a supplement made from MCT fats, designed as an alternative treatment to the ketogenic diet for children and adults with epilepsy. It is taken alongside a 'healthy' diet, and not restricted in carbohydrates, although some ketogenic centres also use it as part of a ketogenic diet. Your neurologist can request a prescription for K.Vita® from your GP.

Further information

Great Ormond Street Hospital (GOSH)
gosh.nhs.uk
Enter 'ketogenic diet' in the search box for information.

Matthew's Friends
01342 836 571
matthewsfriends.org
Information and support for patients and families considering the ketogenic diet.

The Daisy Garland
01803 847 999
thedaisygarland.org.uk
Provides help and support for families and funding for ketogenic dietitians.

Epilepsy Society is grateful to Dr Natasha Schoeler, Senior Research Fellow at UCL Great Ormond Street Institute of Child Health, and Specialist Ketogenic Dietitian at Great Ormond Street Hospital for Children, who reviewed this information.

For a printed copy of this information contact our helpline.

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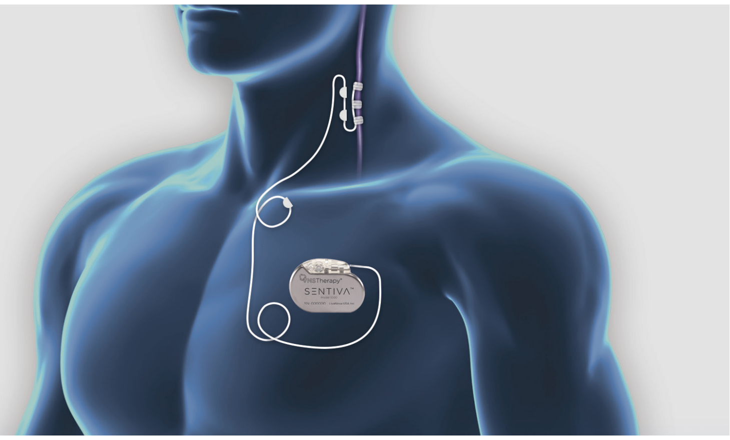
VNS Therapy™

epilepsy society

What are the vagus nerves?



The vagus nerves are a pair of nerves that start in the brain and run through the body. They carry messages between the brain and the body.

What is VNS Therapy and how does it work?

Vagus nerve stimulation (VNS Therapy) is a treatment for drug-resistant epilepsy that involves a stimulator (or 'pulse generator') which is connected, inside the body, to the left vagus nerve in the neck. The stimulator sends regular, mild electrical stimulations through this nerve to help calm down the irregular electrical brain activity that leads to seizures.

What is the aim of VNS Therapy?

VNS Therapy aims to reduce the number, length, and severity of seizures. For some people, their seizures become much less frequent, for some it may reduce their seizures a little, and for others it has no effect. VNS Therapy may reduce the length or intensity of seizures, but this does not happen for everyone. It may also reduce the time it takes to recover after a seizure. It is possible to completely stop some seizures but it does not 'cure' epilepsy.

The effect of VNS Therapy may not happen straightaway; it can take up to a year for it to have an effect on someone's seizures. It is used alongside anti-seizure medications (ASMs) not instead of them. However, if VNS therapy works, it may be possible to reduce a person's ASMs over time.

Can I be considered for VNS therapy?

VNS therapy is usually considered if you have tried a number of ASMs which have not fully controlled your seizures, and if you are not suitable for, or do not want to have, brain surgery.

People who are considering VNS therapy will usually be given more information about it from their neurologist or epilepsy specialist nurse.

What is the stimulator like?

The stimulator is a bit like a heart pacemaker. It measures approximately 4 x 2 cm and is implanted (placed) under the skin in the upper chest (under the left collar bone) during a small operation under general anaesthetic. The operation lasts around one and a half hours.

Because of the operation, there will be a small scar where it is put in. A lead connects the stimulator in the chest to the vagus nerve in the left side of the neck. Because the electrodes are coiled around the nerve in the neck, there will also be a small scar where they are inserted, usually in the fold of the neck.

How does the stimulator work?

The stimulator is usually switched on within two weeks of it being implanted. The neurologist or nurse will programme the stimulator and set the amount (strength and length) of the electrical stimulation given.

The amount of stimulation varies from person to person, but is usually started at a low level and slowly increased to a suitable level for each person. Usually it is set at 30 seconds of stimulation every five minutes through the day and night.The stimulator has a battery inside it, which can last approximately five years. When the battery is low, the stimulator needs to be replaced with a shorter operation to just replace the generator/stimulator (usually lasting 45 minutes).

Vagus nerve stimulation (VNS Therapy) is a form of treatment for people with epilepsy whose seizures are not controlled with medication.

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

What can VNS Therapy do if I have a seizure?

Some people have a warning or aura, which is a focal preserved consciousness seizure, that tells them that they may have a further seizure.

When this happens, the VNS Therapy magnet can be passed over the stimulator to give stronger stimulation for a slightly longer period of time. This may stop the aura from developing into another seizure, or may reduce how long it takes the person to recover after a seizure.

The magnet can be worn on the wrist like a watch, on a belt, or attached to a wheelchair. For people who have no warning before a seizure, someone else could use the magnet for them when a seizure happens. This may help stop or shorten the seizure. The magnet can also be swiped over the VNS after a seizure and it may help with post seizure recovery.

Some people may experience an increase in heart rate during their seizures. The Aspire SR® and SenTiva® devices can detect these changes and give automatic stimulation in a similar way to magnet stimulation. This can help stop seizures before they spread across the brain.

Does VNS Therapy have any side effects?

VNS therapy can cause side effects but usually only during the time that the VNS is being increased to reach the suitable level for the individual, and when the VNS is delivering the current. Side effects may not happen for everyone but can include discomfort in the throat, a cough, and sometimes a hoarse voice.

Side effects usually reduce over time and do not usually mean that the stimulator has to be switched off. If side effects are a problem, the neurologist or nurse can adjust the settings, or the magnet can be held over the stimulator for a few seconds to briefly stop the stimulation. VNS therapy does not affect, and is not affected by, anti-seizure medication.

What about any other positive effects?

Many people feel that VNS therapy improves their mood, memory, or alertness. It may also help reduce depression and have a positive effect on their quality of life (overall wellbeing).

What happens if it does not work?

VNS Therapy does not work for everyone. If there is no benefit from VNS Therapy, you and your specialist may consider having it switched off or removed. Even if VNS Therapy has no effect on the seizures, it might have other positive effects (see previous question).

Can I have an MRI scan if I have VNS therapy?

If you have VNS therapy and need an MRI, it is important that everyone involved with the scan is aware, so that they can decide if the scan can be done safely.
VNS therapy is 'MRI conditional' meaning that, as long as certain precautions are followed, an MRI scan is possible on some areas of the body.
Visit vnstherapy.co.uk for more information

X-rays and CT scans do not affect, and are not affected by, VNS therapy. This is because they do not produce enough radiation to cause damage to the stimulator. However, extra care may be needed, or the stimulator may need to be switched off for the scan, and turned back on again afterwards.

Can I use an induction hob?

VNS devices may be affected by the magnet in an induction hob. However, you would have to be leaning your chest over the induction hob for it to affect the VNS. In addition, the magnet in the induction hob would only disable the VNS for the period of time it is held over the device – so usually relatively short time periods.
It stops the usual stimulation from working temporarily, restarting once the magnet is not close to the VNS device.

Can I go through airport security?

At the airport, you can provide security officers with your VNS Therapy ID card, which explains that you have an implanted medical device. You can request a pat-down check instead.

Further information

vnstherapy.co.uk
For more information about VNS Therapy for patients and carers, and for medical professionals.
LivaNova (are the manufacturers of the VNS Therapy system)

Trusted Information Creator

Patient Information Forum

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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Epilepsy surgery

What is epilepsy surgery?

Epilepsy surgery is carried out on the brain to treat epilepsy. This may involve removing a specific area of the brain which might have caused the epilepsy. In this information, we use the word 'surgery' to mean epilepsy surgery.

What types of surgery are there?

Resective surgery
This is the most common epilepsy surgery. The surgeon removes a small portion of brain tissue from the area of the brain where seizures occur. Resective surgery is usually performed on one of the temporal lobes, an area of the brain that controls emotions, verbal memory, visual memory, and understanding language.

Disconnection surgery
This is where the surgeon disconnects one part of the brain from another part to stop the seizure from spreading. This is done either by cutting the connections between the two halves (hemispheres) of the brain. Or it can be done by cutting the nerve fibres in the outer layers of the brain.

Laser Interstitial Thermal Therapy (LITT)
This is also known as laser beam therapy. It is different from the other surgeries as the wound left afterwards is very small, which means that, often, you can go home the next day. With LITT a laser is used to pinpoint and destroy a small part of the brain that is causing the seizures. It is carried out in a Magnetic Resonance Imaging (MRI) scanner.
Visit england.nhs.uk/2024/05/nhs-patients-to-access-world-leading-laser-beam-surgery-to-prevent-epileptic-seizures/ and epilepsysociety.org.uk/news/new-laser-beam-therapy

When would someone have surgery?

For some people surgery can stop or reduce the number of seizures they have. Surgery might be considered if:

- you have tried several anti-seizure medications (ASMs) and none of them have stopped or significantly reduced your seizures; and
- a cause for your epilepsy can be found in a specific area of your brain, where surgery is possible. This is called the 'epileptogenic lesion'.

Whether you are suitable for surgery is something that you may like to talk about with your GP or neurologist. If you meet the criteria and are considered for surgery, you will need to have further tests before you can have the surgery.

Tests used before surgery

If you are referred for surgery assessment you will probably go to a specialist centre for tests. There are many different pre-surgical tests you might have before you can be given the go-ahead for surgery.

These can include MRI scans, an EEG (electroencephalogram) and video telemetry (an EEG while also being filmed). Other types of scan may also be done, which trace a chemical injected into the body. This can show detailed information about where seizures start in the brain.

Memory and psychological tests are also used to see how your memory and lifestyle might be affected after the surgery. These types of tests also help the doctors to see how you are likely to cope with the impact of having this type of surgery.

Epilepsy surgery is carried out on the brain to treat epilepsy. This may involve removing a specific area of the brain which might have caused the epilepsy.

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

The tests will confirm whether:

- the surgeons can reach the epileptogenic lesion during surgery and can remove it safely without causing new problems;
- other parts of your brain could be affected by the surgery, for example the parts that control your speech, sight, movement, memory, or hearing;
- you have a good chance of having your seizures stopped by the surgery and better quality of life; and
- you have any other medical conditions that would stop you from having this kind of surgery.

The results from the pre-surgical tests will help you and your neurologist decide whether surgery is an option for you, and what the result of the surgery might be. Your specialist will also talk with you about the possible risks and benefits of having surgery.

For many people the results show that surgery is not an option. The majority of people who are recommended for surgery, and have these tests carried out, are unable to have surgery.

Deciding whether to have surgery

Having any kind of surgery on the brain is a big decision, and you may have lots of questions or concerns that you want to discuss before you are able to make up your mind. The doctors will be used to this because it is an important part of deciding about, and preparing for, surgery.

To give you the full picture when deciding about having surgery, your doctor will explain to you about the potential risks of the kind of surgery you are having. Although your doctor can give you information and advice, the final decision is yours. To give you time to talk about how you are feeling about surgery, you may be offered some form of pre-surgical counselling.

Visit epilepsysociety.org.uk/what-we-do/research/neuroimaging/neuroimaging-case-studies

What are the possible risks of surgery?

For any type of surgery, there are possible risks relating to how the person responds to anaesthetic, or to any complications that happen during the operation.

Risks for epilepsy surgery will vary depending on what type of surgery a person has. The most common type of epilepsy surgery is removal of part of the temporal lobe. Possible risks of this type of surgery include problems with memory, a partial loss of sight, depression, or other mood problems.

These risks will vary from person to person, and may be only temporary in some cases. For some people, their memory and mood could improve after epilepsy surgery. So the chance to ask your medical team questions before surgery is very important, to help you understand what the specific possible risks are for you.

Can I change my mind?

You may feel very excited about the surgery or you might be feeling nervous about it. This is absolutely normal. You might also feel that you've changed your mind about having surgery, for whatever reason. This is OK – it is a big decision, and you have the right to say no to the surgery if you don't want to have it.

After surgery

Immediately after the surgery your doctors will monitor your recovery. For the first few days you may feel very tired and need to sleep, as it can take a while for the anaesthetic to completely wear off.

Some people who have brain surgery will have seizures within the first week of surgery – but this does not mean the surgery has not been successful. Seizures after surgery can happen because of the direct stress the brain experiences in surgery.

How long you may need to spend in hospital will depend on the type of surgery you have had and how you are recovering. Generally your doctors might expect you to be back to your normal activities about six weeks after your surgery, but this is very individual.

Reviews after surgery

Following surgery most people will have reviews with their doctors about their recovery and any seizure activity. How often you will need a review will be something you and your doctors will decide together.

How will I know if my surgery has worked?

Before your surgery, your medical team will have talked with you about the aims of your surgery and how successful they expect the surgery to be. This may mean completely stopping all seizures, or it may mean reducing the number or severity of seizures.

Usually it takes two years after surgery to fully measure how successful your surgery has been.

How successful is epilepsy surgery?

The chances of becoming seizure free after surgery varies from person to person. Among other things it depends on the type of surgery and what your scans and tests show.

In a recent study in London, of 1,024 people who had epilepsy surgery, 69% did not have seizures with impaired consciousness at 1 year after the surgery, 45% at 10 years, 41% at 20 years, and 38% at 30 years.

A greater than 50% reduction in seizure days was achieved by 96% of people at 1 year, 88% at 10 years, and remained stable at 82% from 26 years onwards.

Most of these people will still take their ASM for some time.

You can talk to your neurologist about when you might be able to start slowly coming off ASM.

Further information

Brain Buddy
brainbuddy.co.uk
Brain Buddy UK is a patient self-help group that brings together people with a lived experience of epilepsy surgery.

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First aid for epileptic seizures

What to do if someone has a seizure

Knowing how to help someone during and after a seizure may mean you feel more confident if a seizure happens. How you can best help someone depends on the type of seizure they have and what happens to them when they have a seizure.

This factsheet gives some simple steps on what to do during and after a seizure. If it is someone you know, they may have told you how you can help them, or you might like to ask them what they would like you to do.

If it is someone you don't know, or you don't know about their epilepsy, follow our basic first aid message: Calm, Cushion, Call (CCC).
Visit epilepsysociety.org.uk/ccc

Are all seizures the same?

There are different types of epileptic seizures. How a seizure affects one person might be different from how it affects someone else.

- Some people have seizures while they are awake ('awake' seizures). Some have seizures while they are asleep ('asleep' or 'nocturnal' seizures). These names do not describe the type of seizure, just when they happen.
- Some people have more than one type of seizure.
- Most seizures happen suddenly and without warning, last a short time (seconds or minutes), and stop by themselves.
- Although people can be injured during a seizure, most people don't hurt themselves and don't usually need to go to hospital or see a doctor. See page 3 for when to call for an ambulance.
- There are different types of seizure, and details are below.

Visit epilepsysociety.org.uk/epileptic-seizures
The following information describes different types of seizures and what you can do to help.

Focal seizures

Focal seizures start in, and affect, part of the brain: either a large part or just one small area. What happens during the seizure depends on where in the brain the seizure happens and what that part of the brain normally does.

Focal preserved consciousness seizures (FPC)

During a focal preserved consciousness seizure the person is conscious (aware and alert) and usually knows that the seizure is happening. This seizure could be an unusual smell or taste, a twitching of an arm or hand, a strange 'rising' feeling in the stomach, or a sudden feeling of intense joy or fear.
How to help

- As the person might feel strange or be upset, reassuring them might be helpful.

Focal impaired consciousness seizures (FIC)

Focal impaired consciousness seizures affect more of the brain than focal preserved consciousness seizures. The person's consciousness is affected, and they may be confused and not know what they are doing. They may wander around, behave strangely, pick up objects, or make chewing movements with their mouth.

Afterwards they may be confused for a while, or need to sleep. These seizures can last a few seconds or a few minutes.
How to help

- Do not restrain the person as this might upset or confuse them.
- Gently guide them away from any danger, for example from walking into the road.
- Speak gently and calmly as they may be confused. If you speak loudly or grab them, they might not understand and may get upset or respond in an aggressive way.

Managing seizures is often simple: keeping the person safe from harm and staying with them as they fully recover afterwards.

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

After the seizure

- They may feel tired and want to sleep. It might be helpful to remind them of where they are.
- Stay with them until they fully recover and can safely return to what they had been doing before the seizure.
- Some people recover quickly, but others may take longer to feel back to normal again.

Focal to bilateral tonic clonic seizures

Sometimes focal seizures spread from one side to both sides of the brain. This is called a focal to bilateral tonic clonic seizure. Some people call the focal seizure an 'aura' or 'warning', as it warns them that a tonic clonic seizure may follow (see below).

How to help

- If you or the person is aware of the warning, they may need help to get to a safe place before the tonic clonic seizure happens.

Generalised seizures

Generalised seizures affect both sides of the brain at once and happen without warning. The person usually becomes unconscious and will not remember the seizure afterwards.

Absence seizures

During an absence seizure the person becomes unconscious for a short time. They may look blank and stare and will not respond to what is happening around them. If they are walking, they may carry on walking but will not be aware of what they are doing.

How to help

- Stay with the person, and gently guide them away from any danger.

Tonic and atonic seizures

In a tonic seizure the person's muscles suddenly become stiff. If they are standing, they often fall, usually backwards, and may injure the back of their head.

In an atonic seizure (or 'drop attack') the person's muscles suddenly relax and become floppy. If they are standing, they often fall, usually forwards, and may injure their head or face.

Both seizures are brief and happen without warning. Most people usually recover quickly.

How to help

- Reassuring them may be helpful. If they are injured, they may need medical help.

Myoclonic seizures

Myoclonic means 'muscle jerk', and these seizures involve jerking of a limb or part of a limb. They often happen shortly after waking up, are brief, and can happen in clusters (many happening close together in time).

How to help

- You don't need to do anything to help during the seizure other than make sure that the person has not hurt themselves.

Tonic clonic and clonic seizures

During a tonic clonic seizure the person goes stiff ('tonic' phase), usually falls to the ground, and shakes or has jerking movements ('clonic' phase). Their breathing may be affected, and they may go pale or blue, particularly around their mouth. They may also bite their tongue or cheek.

Some people have clonic seizures without going stiff to start with. Although it can be frightening to see, this is not usually a medical emergency. Usually, once the movements have stopped, the person recovers and their breathing goes back to normal.

How to help

- Try to stay calm.
- Check the time to see how long the seizure lasts (see below for why this is important).
- Only move the person if they are in a dangerous place, for example in the road. Instead, move any objects (such as furniture) away from them so they don't hurt themselves.
- Put something soft (such as a jumper) under their head, or cup their head in your hands, to stop it hitting the ground.
- Look for medical jewellery or an ID card for information about what to do.
- Do not hold them down – allow the seizure to happen.
- Do not put anything in their mouth – they will not swallow their tongue.
- Try to stop other people crowding around.

After the seizure

- Gently roll them on to their side into the recovery position (see page 4).
- If their breathing sounds difficult or noisy, gently open their mouth to check that nothing is blocking their airway.
- Wipe away any spit from their mouth.
- Try to minimise any embarrassment. If they have wet themselves, deal with this as privately as possible (for example, put a coat over them).

- Stay with them until they have completely recovered. They may need gentle reassurance.
- Do not give them anything to eat or drink until you are sure that they have fully recovered.

When to call an ambulance

Usually, when a person has a seizure, there is no need to call 999 for an ambulance. However, **always do** call an ambulance if:

- you know it is the person's first seizure;
- they have injured themselves badly;
- they have trouble breathing after the seizure has stopped;
- one seizure immediately follows another with no recovery in between;
- the seizure lasts two minutes longer than is usual for them; or
- you do not know how long their seizures last.

For someone you do not know, follow our basic first aid message: Calm, Cushion, Call.
Visit epilepsysociety.org.uk/ccc

Some people recover quickly from a tonic clonic seizure, but often they will be very tired, want to sleep, and may not feel back to normal for several hours or sometimes days.

Status epilepticus

A person's seizures usually last the same length of time each time they happen and stop by themselves. However, sometimes seizures do not stop, or one follows another without the person recovering in-between.

If this goes on for five minutes or more, it is called 'status epilepticus', or 'status'. Status is not common, but can happen in any type of seizure and the person may need to see a doctor. **Status in a tonic clonic seizure is a medical emergency** and the person will need urgent medical help. Status can cause brain damage or even death. It is important to call for an ambulance.
See above for when to call an ambulance.

Some people are prescribed emergency medication, either buccal midazolam or rectal diazepam, to stop their seizures.

Carers need training in giving emergency medication. It is important for the person to have their own written protocol (plan) about when to give it, for the carer to follow.
For more information on our training, email es.training@epilepsysociety.org.uk or visit epilepsysociety.org.uk/epilepsy-training

Seizures and dental injuries

Although most people do not usually hurt themselves during a seizure, sometimes seizures can cause injuries. If someone falls in a seizure, they may loosen or crack a tooth and will probably need to see a dentist quickly so the tooth can be repositioned or repaired.

If someone knocks out a tooth, and you feel confident to help, some quick action may mean that the tooth can be saved and replaced.

Only do this if the person is otherwise well enough after the seizure.

How to help

- Try to find the tooth. Pick it up by the crown, and **do not touch the root**.
- If the tooth is dirty, clean it by rinsing it in milk or running it under water. **Do not scrub it**.
- Put the tooth back into the socket as quickly as possible.
- Ask the person to bite down on a clean tissue or handkerchief to keep the tooth in place. The person should see a dentist as soon as possible.
- If you are not able to put the tooth back in its socket, try to keep it wet, if possible by putting it in some milk.

Visit nhs.uk/conditions/knocked-out-tooth

If someone uses a wheelchair

Usually, a person with epilepsy will have a care plan. The care plan will advise how to help the person if they use a wheelchair and have a seizure, and how to help once the seizure has stopped.

If you can't find the care plan, here is some general information about what to do if someone has a seizure while using their wheelchair.

How to help

- Put the wheelchair brakes on.
- Do not try to restrain them or put anything in their mouth.
- Do not try to move them, unless their care plan says to do so. Moving them could cause injury to either you, or the person having the seizure.
- Let them stay sitting in the wheelchair and, if they are wearing a harness or seatbelt, keep it fastened.

If they are not wearing a harness or seatbelt, try to gently support them in the wheelchair to avoid them falling.

- Try to support or cushion the person's head, perhaps with a rolled up jumper or a head rest if there is one.
- Do not try to bring them round or give them anything to eat or drink until you are sure that they have completely recovered.

If someone is in water

Focal and absence seizures

How to help

- Hold their head above water level or guide them away from deep water. Once they have recovered, they may feel confused or need to rest.

Tonic clonic seizures

How to help

- If possible, keep the person's face out of the water by gently tilting their head.
- Call out to the lifeguard for help and try to move the person to more shallow water.
- Once they are out of the water, try to cushion their head.
- Do not restrain them or put anything in their mouth. They will not swallow their tongue.
- When the seizure has stopped, place them in the recovery position and keep them warm.
- Stay with them until they have fully recovered.

When to call an ambulance

- see page 3; or if they have swallowed/inhaled water.

The recovery position

- Kneel on the floor to one side of the person. If the person is pregnant, kneel on their left so you can roll them onto their left side. This protects the blood flow to the baby.
- Place the arm nearest you at a right angle to their body, with the palm facing upwards. This will help to keep it out of the way when you roll them over.
- Gently pick up their other hand with your palm against theirs (palm to palm). Turn any rings inwards to avoid scratching their face. Now place the back of their hand under their opposite cheek (for example, against their left cheek if it is their right hand). Keep your hand there to guide and support their head as you roll them.
- Use your other arm to reach across to the person's knee that is furthest from you, and pull it up so that their leg is bent, and their foot is flat on the floor.
- Gently pull their knee towards you so that they roll over onto their side, facing you. Their body weight should help them to roll over quite easily.
- Move the bent leg that is nearest to you, in front of their body so that it is resting on the floor. This position will help to balance them.
- Gently raise their chin to tilt their head back slightly, as this will open up their airway and help them to breathe. Check that nothing is blocking their airway. If there is an obstruction, such as food in their mouth, remove this if you can do so safely. Stay with them, giving reassurance, until they have fully recovered.
- If you are not happy with how they are recovering, or are concerned for any reason, call 999 for an ambulance.

Visit epilepsysociety.org.uk/recovery-position

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.

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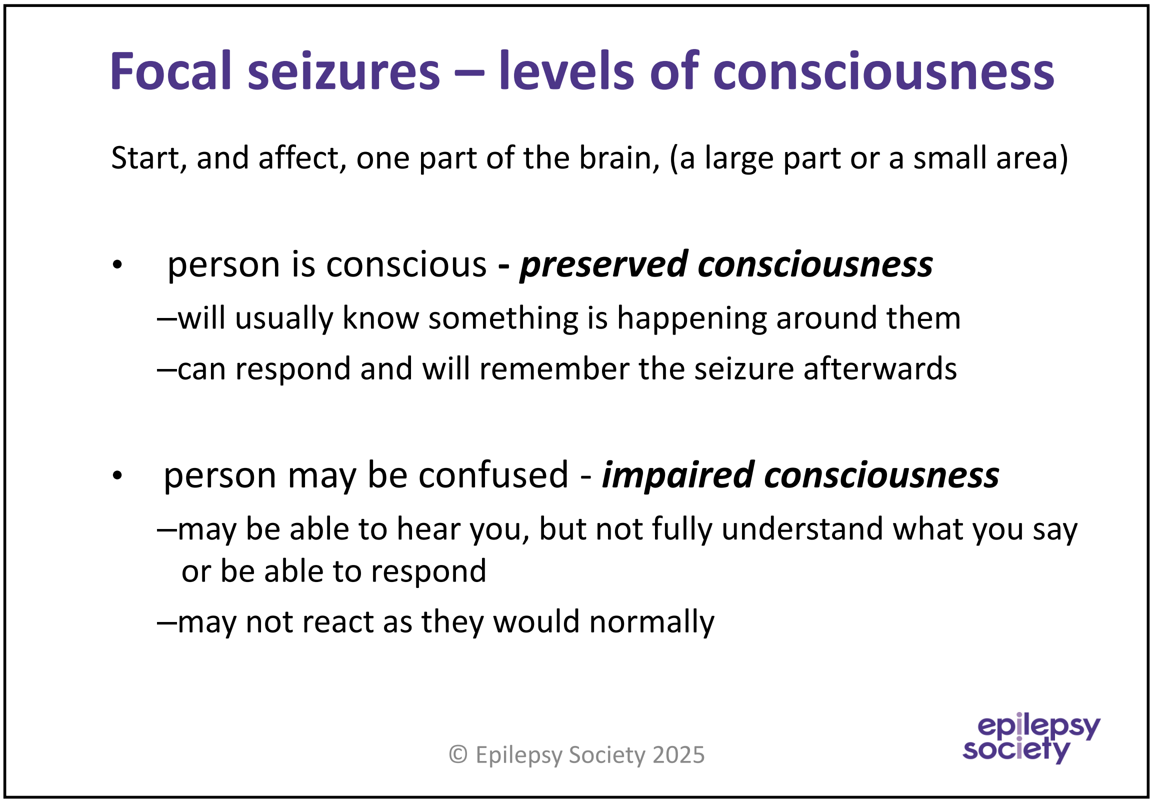

Focal seizures – levels of consciousness

Start, and affect, one part of the brain, (a large part or a small area)

- person is conscious **- *preserved consciousness***
  - –will usually know something is happening around them
  - –can respond and will remember the seizure afterwards
- person may be confused - ***impaired consciousness***
  - –may be able to hear you, but not fully understand what you say or be able to respond
  - –may not react as they would normally

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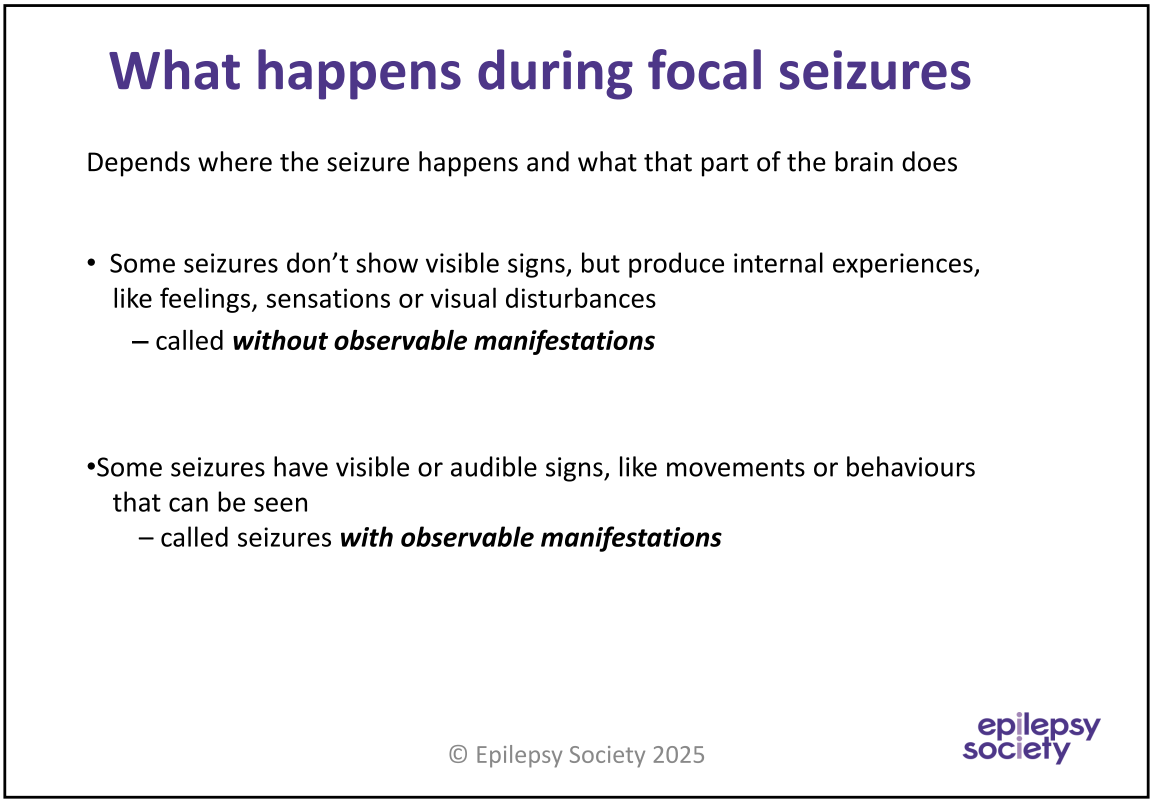
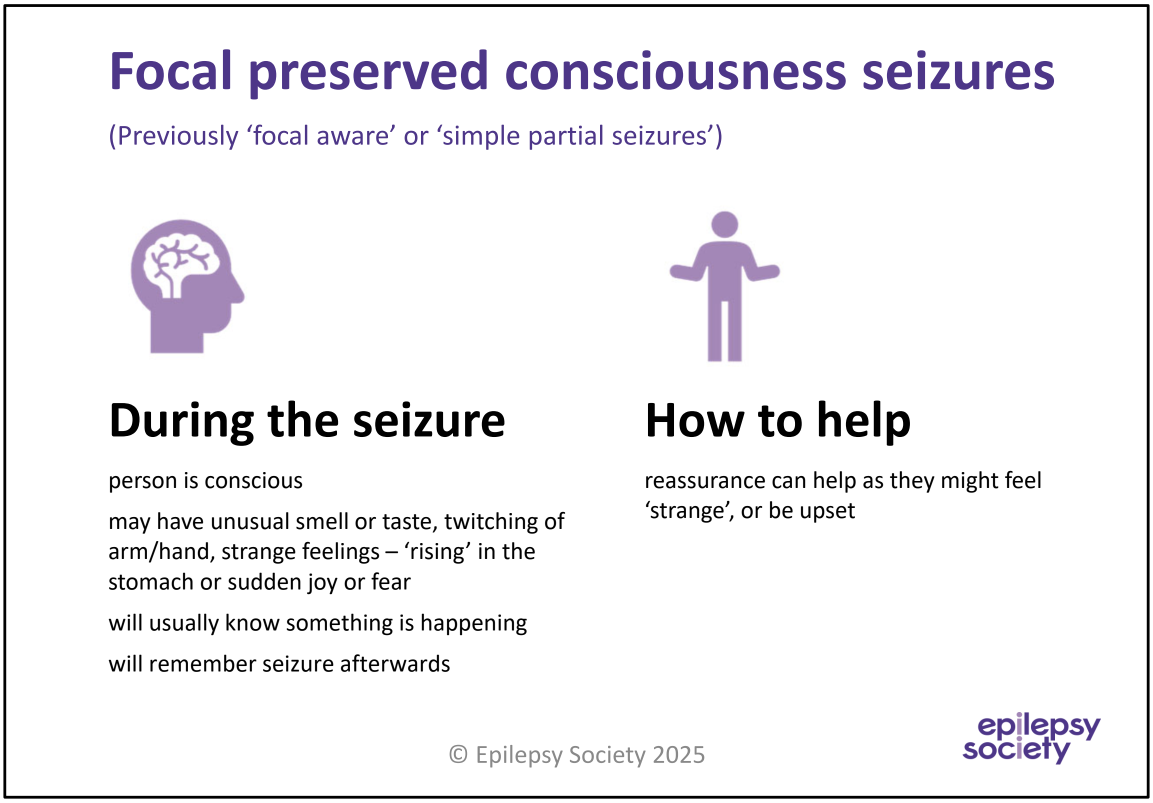


What happens during focal seizures

Depends where the seizure happens and what that part of the brain does

- Some seizures don’t show visible signs, but produce internal experiences, like feelings, sensations or visual disturbances
  – called ***without observable manifestations***

- Some seizures have visible or audible signs, like movements or behaviours that can be seen
  – called seizures ***with observable manifestations***



Focal preserved consciousness seizures

(Previously ‘focal aware’ or ‘simple partial seizures’)

During the seizure

person is conscious

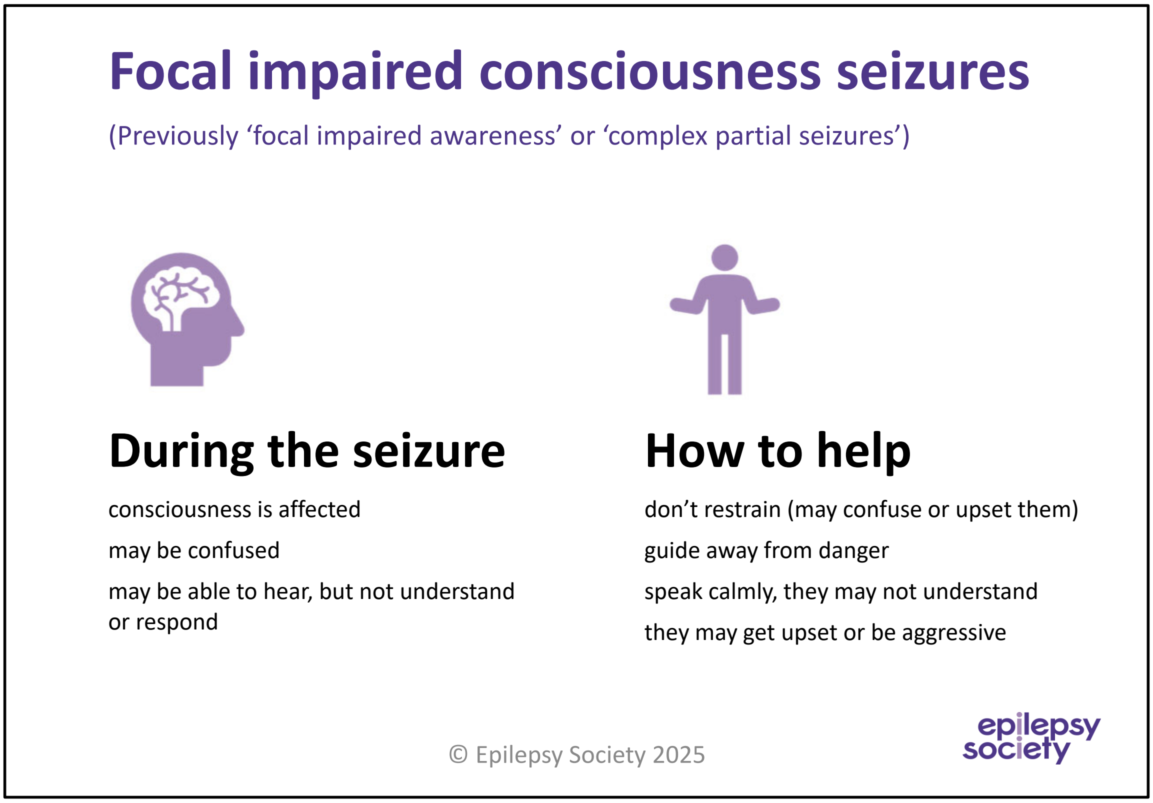
may have unusual smell or taste, twitching of arm/hand, strange feelings – ‘rising’ in the stomach or sudden joy or fear

will usually know something is happening

will remember seizure afterwards

How to help

reassurance can help as they might feel ‘strange’, or be upset



Focal impaired consciousness seizures

(Previously ‘focal impaired awareness’ or ‘complex partial seizures’)

During the seizure

consciousness is affected

may be confused

may be able to hear, but not understand or respond

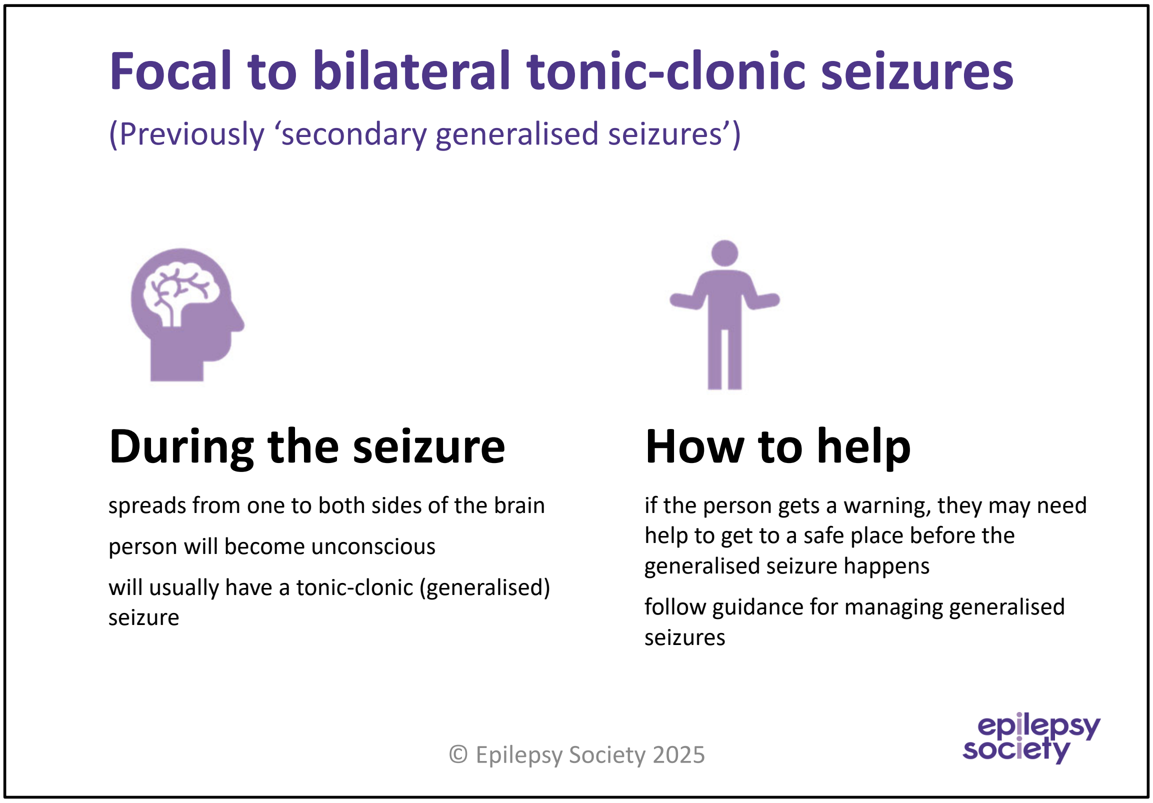
How to help

don’t restrain (may confuse or upset them)

guide away from danger

speak calmly, they may not understand

they may get upset or be aggressive



Focal to bilateral tonic-clonic seizures

(Previously ‘secondary generalised seizures’)

During the seizure

spreads from one to both sides of the brain

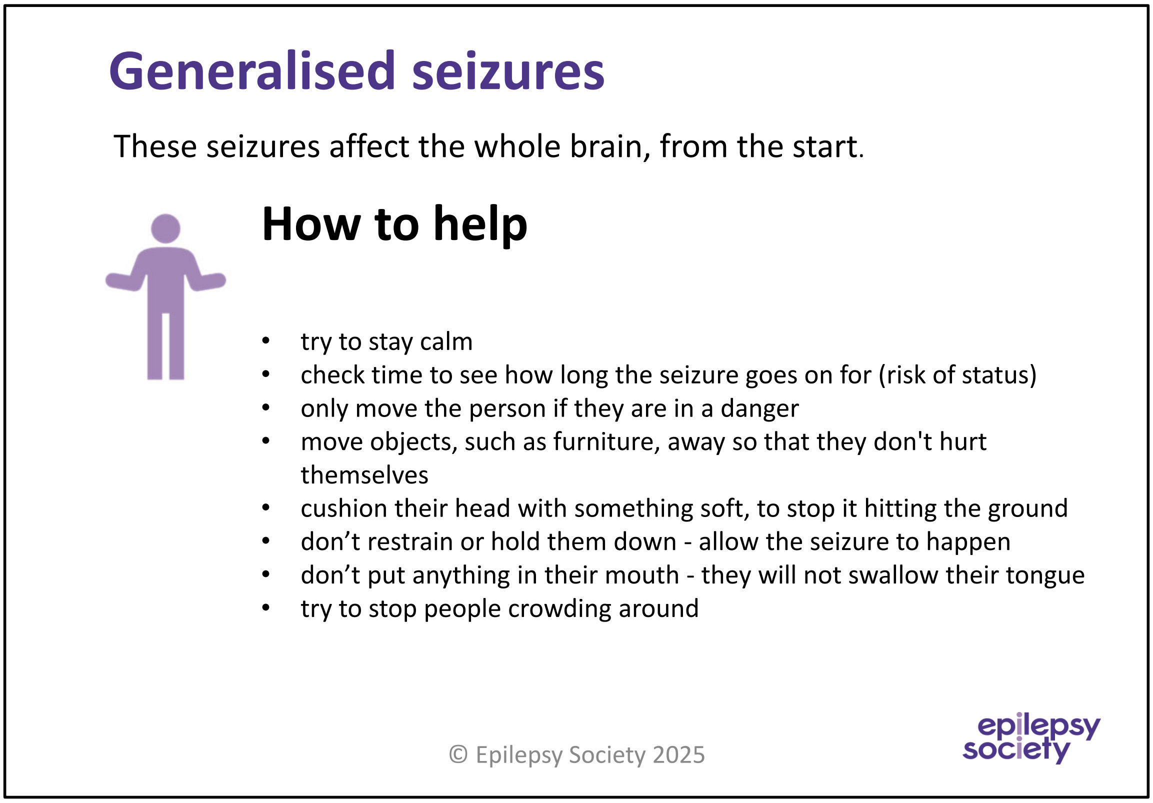
person will become unconscious

will usually have a tonic-clonic (generalised) seizure

How to help

if the person gets a warning, they may need help to get to a safe place before the generalised seizure happens

follow guidance for managing generalised seizures

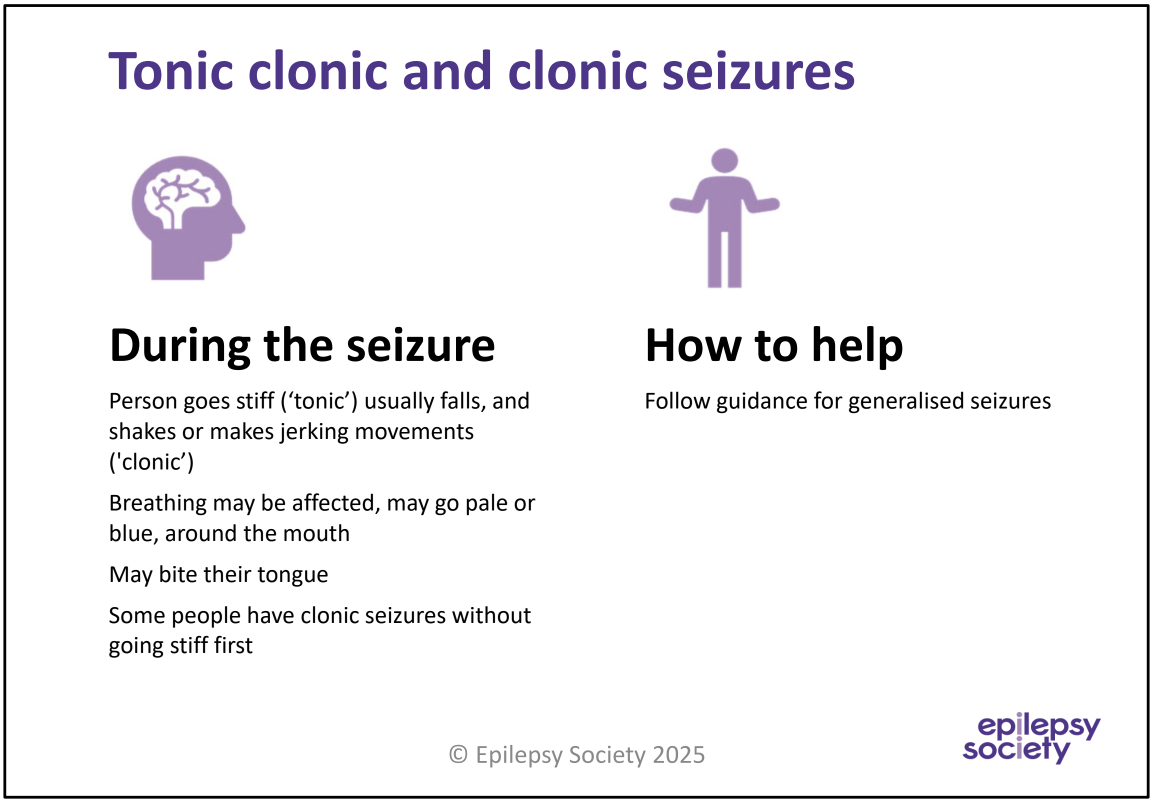


Generalised seizures

These seizures affect the whole brain, from the start.

How to help

- try to stay calm
- check time to see how long the seizure goes on for (risk of status)
- only move the person if they are in a danger
- move objects, such as furniture, away so that they don't hurt themselves
- cushion their head with something soft, to stop it hitting the ground
- don’t restrain or hold them down - allow the seizure to happen
- don’t put anything in their mouth - they will not swallow their tongue
- try to stop people crowding around



Tonic clonic and clonic seizures

During the seizure

Person goes stiff (‘tonic’) usually falls, and shakes or makes jerking movements ('clonic’)

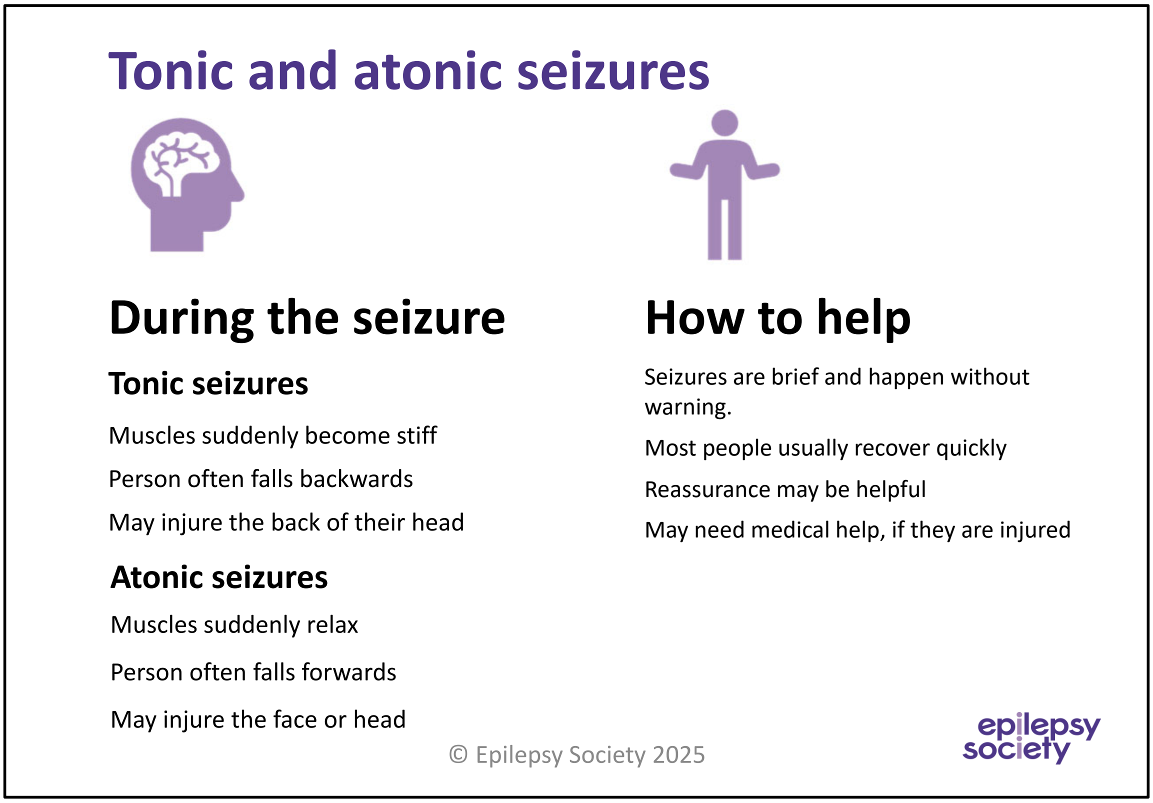
Breathing may be affected, may go pale or blue, around the mouth

May bite their tongue

Some people have clonic seizures without going stiff first

How to help

Follow guidance for generalised seizures



Tonic and atonic seizures

During the seizure

Tonic seizures

Muscles suddenly become stiff

Person often falls backwards

May injure the back of their head

Atonic seizures

Muscles suddenly relax

Person often falls forwards

May injure the face or head

How to help

Seizures are brief and happen without warning.

Most people usually recover quickly

Reassurance may be helpful

May need medical help, if they are injured

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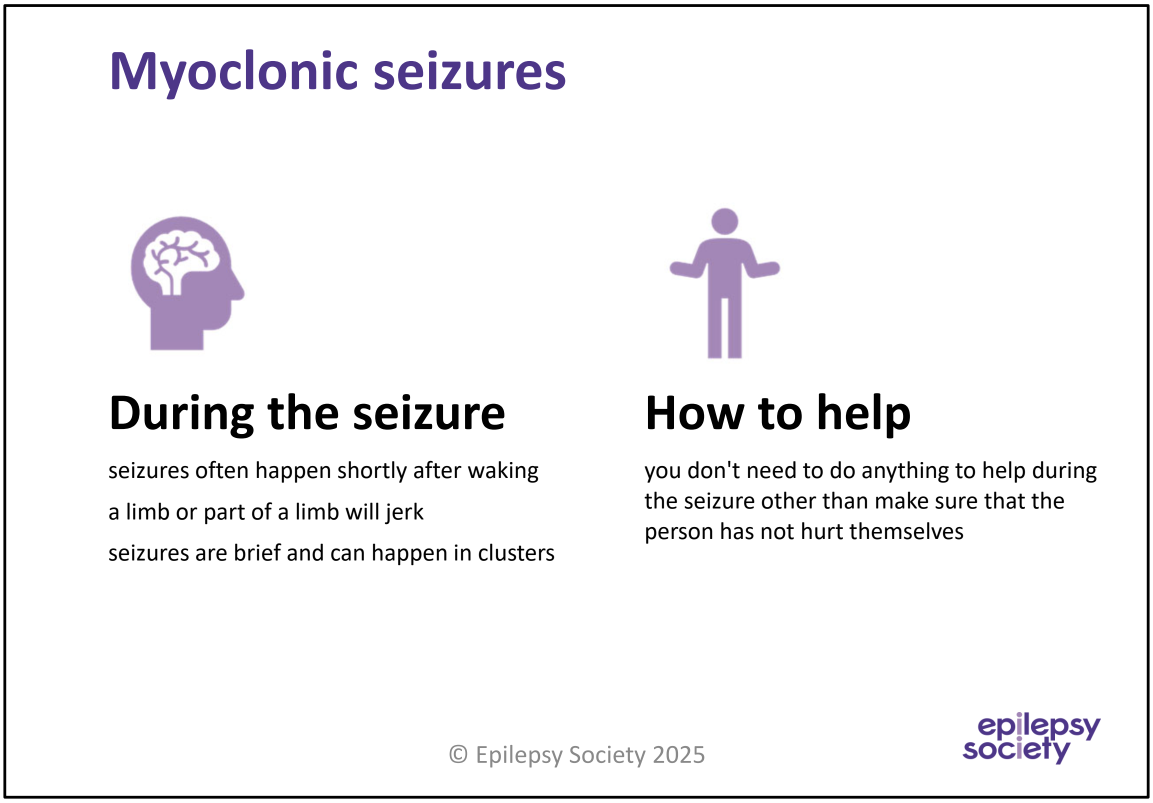


Myoclonic seizures

During the seizure

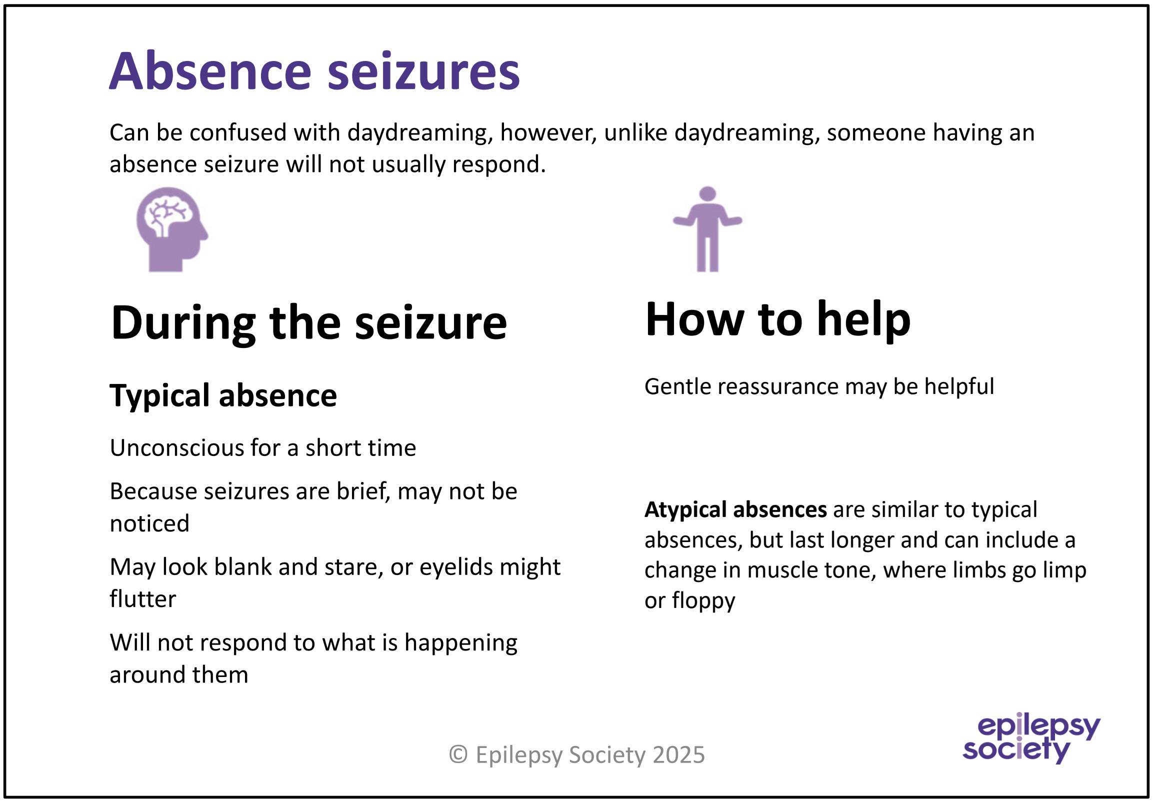
seizures often happen shortly after waking

a limb or part of a limb will jerk

seizures are brief and can happen in clusters

How to help

you don't need to do anything to help during the seizure other than make sure that the person has not hurt themselves



Absence seizures

Can be confused with daydreaming, however, unlike daydreaming, someone having an absence seizure will not usually respond.

During the seizure

Typical absence

Unconscious for a short time

Because seizures are brief, may not be noticed

May look blank and stare, or eyelids might flutter

Will not respond to what is happening around them

How to help

Gentle reassurance may be helpful

Atypical absences are similar to typical absences, but last longer and can include a change in muscle tone, where limbs go limp or floppy

Recording seizures

epilepsy society

Some people cannot remember what happened to them during a seizure and may not be aware that they have even had one. This can make it difficult for them to describe their seizures to their specialist. If you have witnessed a seizure, the questions below may be helpful for the person to share with the specialist.

How did the seizure start?

If known, when the seizure started, was the person awake ☐ or asleep? ☐

Was the person restless or did they cry out before the seizure started?

Was there any trigger for the seizure (such as feeling tired, stressed, excited, or unwell)?

What position were they in when the seizure happened or when they were found?

Standing ☐ lying on front ☐ lying on back ☐ lying on side ☐ sitting ☐ other ☐

Did they appear to have any warning beforehand? If so, what did you notice?

Did they have any unusual sensations, such as a taste or smell, a rising feeling in the stomach, numbness, or pins and needles? When did they experience this?

Was there any change in muscle tone (did they become stiff or floppy)?

Did they fall down and, if so, forwards or backwards?

Did they lose awareness, appear dazed or confused or lose consciousness?

Was there any change in their breathing pattern? Did they have difficulty breathing?

This factsheet lists what can be useful to know about someone's epilepsy, and what to look out for and note, before, during, and after a seizure. This may help a doctor to confirm a diagnosis or identify the type of seizures someone is having.

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

Did their face change colour? Did they become pale, blue around the mouth, or flushed?

Were their eyes open or closed during the seizure? If open, were their eyes turned to one side (which side)?

Was there any movement, such as jerking or twitching? If so, was this rhythmical? Was it on both sides of the body or on one side only and, if so, which side? Was it symmetrical (the same on both sides) or not symmetrical?

Were there any automatisms (automatic behaviours) such as wandering around, chewing or lip-smacking, making strange movements or postures with their limbs, picking up objects for no reason, or fiddling with clothing?

Did they make any noises, such as mumbling, not making sense, or repeating words or phrases?

How long did the seizure last?

Were they incontinent (did they wet themselves)?

Did they bite the inside of their cheek or their tongue?

How were they afterwards? Were they confused or sleepy? If they slept afterwards, for how long? Or were they immediately back to their normal selves?

How long did it take for them to fully recover and return to normal activities?

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.

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For a printed copy of this information contact our helpline.

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Chesham Lane,
Chalfont St Peter,
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The recovery position

1. Kneel on the floor to one side of the person. If the person is pregnant, kneel on their left so you can roll them onto their left side. This protects the blood flow to the baby.

2. Place the person's arm that is nearest to you at a right angle to their body, so that it is bent at the elbow with the palm facing upwards. This will keep it out of the way when you roll them over.

3. Gently pick up their other hand with your palm against theirs (palm to palm). Turn any rings inward to avoid scratching their face. Now place the back of their hand onto their opposite cheek (for example, against their left cheek if it is their right hand). Keep your hand there to guide and support their head as you roll them over.

4. Use your other arm to reach across to the person's knee that is furthest from you, and pull it up so that their leg is bent and their foot is flat on the floor.

See next page for steps 5 to 7.

The recovery position can help someone recover after a tonic clonic seizure. These steps should be followed once the shaking has stopped.

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

5. Gently pull their knee towards you so that they roll over onto their side, facing you. Their body weight should help them to roll over quite easily.

6. Move their bent leg that is nearest to you, in front of their body so that it is resting on the floor. This position will help to balance them.

7. Gently raise their chin to tilt their head back slightly, as this will open up their airway and help them to breathe. Check that nothing is blocking their airway. If there is an obstruction, such as food in their mouth, remove this if you can do so safely. Stay with them, giving reassurance, until they have fully recovered.

For our video of how to put someone into the recovery position visit epilepsysociety.org.uk/recovery-position

For more information on first aid for epileptic seizures visit epilepsysociety.org.uk/firstaid

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Call for an ambulance if:

- you know it is the person’s first seizure;
- they have injured themselves badly;
- they have trouble breathing after the seizure has stopped;
- one seizure immediately follows another with no recovery in between;
- the seizure lasts two minutes longer than is usual for them; or
- you do not know how long their seizures last.

For a printed copy of this information contact our helpline (details above).

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Resources and further information

A wide range of information is available from Epilepsy Society - visit **epilepsysociety.org.uk**
Contact our Helpline on **0300 102 0024** or email **helpline@epilepsysociety.org.uk**

ESNA - Epilepsy Specialist Nurses Association
esna-online.org

NICE - National Institute for Health and Care Excellence - Epilepsies in children, young people and adults
nice.org.uk/guidance/ng217

ILAE – International League Against Epilepsy
ilae.org
ilae.org/files/dmfile/updated-classification-of-epileptic-seizures-2025.pdf

FNDAction
fndaction.org.uk

Matthew's Friends
matthewsfriends.org

NHS
england.nhs.uk/personalisedcare/pcsp

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Tell us what you think

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We really welcome your feedback on today's course, so we can make sure future courses are as informative and helpful as possible for all who attend. **Please take a few moments to complete this form and hand it to your trainer before you leave.** **Thank you.**

Date.. **Trainer** ....

Please rate the following statements:	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Training objectives were clearly described.	☐	☐	☐	☐	☐
Interaction and participation were encouraged.	☐	☐	☐	☐	☐
Topics covered were relevant to me.	☐	☐	☐	☐	☐
The content of the course was easy to follow.	☐	☐	☐	☐	☐
The delegate pack and handouts were helpful.	☐	☐	☐	☐	☐
The training will be useful for me.	☐	☐	☐	☐	☐
The trainer was knowledgeable.	☐	☐	☐	☐	☐
The trainer was well prepared.	☐	☐	☐	☐	☐
Training objectives were met.	☐	☐	☐	☐	☐
Sufficient time was allowed for Q&A.	☐	☐	☐	☐	☐

What have you learnt from attending this training?

What will you do differently as a result of this training?

What could be done to improve this training? Please give examples if possible.

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Epilepsy awareness follow-up questions

Your name: .... Date:..

1. Give two examples of how epilepsy can affect a person physically.

2. Give two examples of how epilepsy can affect a person socially and psychologically.

3. How is epilepsy diagnosed?

4. Name some of the treatments for epilepsy.

5. List three actions you would take to support an individual experiencing a seizure.

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