


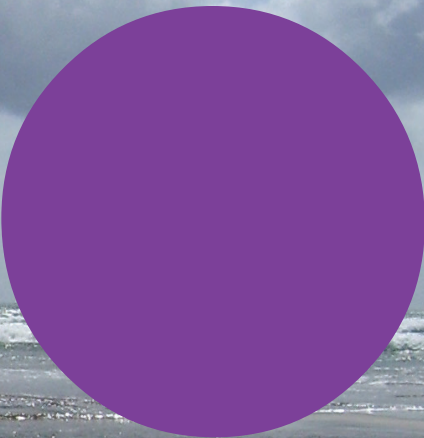




epilepsy
society

what is epilepsy?


An introduction



epilepsy society

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Words set in **black bold** within the text are explained on page 11.

 When you see this symbol, it means further information is available.

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helpline

01494 601 400

Monday to Friday 10am to 4pm
(national call rate)

an introduction

Epilepsy varies greatly and affects everyone differently. If you or someone you know has epilepsy, you may find it helpful to learn more. This leaflet gives some basic facts about epilepsy, and points out where you can get more detailed information and help.

epilepsy

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. Seizures can happen for many different reasons, such as diabetes or a heart condition.

In this leaflet 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 change in the way the brain works for a short time. This interruption or build up of electrical signals can cause a seizure (sometimes called a 'fit' or 'attack').

epilepsy is common

Epilepsy is a common serious neurological condition. More than half a million people in the UK have epilepsy, which is around 1 in 100 people.

Anyone can develop epilepsy: it happens in all ages, races and social classes. Epilepsy is most commonly diagnosed in children and people over 65.

There are different types of epilepsy

There are over 40 types of epilepsy, often called 'the epilepsies'. Just knowing that a person 'has epilepsy' does not tell you very much about their epilepsy and the type of seizures they have.

How epilepsy is described

You may see epilepsy described in two ways. One way is to describe the *type of epilepsy* which is about the cause of the epilepsy and which part of the brain is affected during a seizure. For example, in the term 'idiopathic generalised epilepsy', 'idiopathic' refers to the likely cause (see page 5), 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. In this leaflet we look at the types of epilepsy and not the types of seizures.



See our leaflet *seizures*.

causes of epilepsy

Epilepsy is due to an underlying cause but the cause can be complex. There are many possible causes and they may not always be found. The causes of epilepsy can be put into three main groups: symptomatic, idiopathic, or cryptogenic epilepsy.

Symptomatic epilepsy

This is where there is a known cause for a person's epilepsy, such as a head injury, infections like meningitis, the brain not developing properly, a stroke, a scar or a tumour. A scan, such as Magnetic Resonance Imaging (MRI), may show the cause.

Some symptomatic epilepsies may happen because of a genetic condition such as **Tuberous Sclerosis**, which causes structural abnormalities in the brain and other organs.

Idiopathic epilepsy

This is when the epilepsy is likely to be due to a **genetic** tendency, that could have been **inherited** from one or both parents, or it may be from a change that happens in the person's genes before they are born.

Part of a genetic tendency to have seizures is called a **seizure threshold** (see page 6).

Cryptogenic epilepsy

This is when the cause for a person's epilepsy has not yet been found, despite investigations.

seizure thresholds

A person's seizure threshold often plays a key role in whether they will develop epilepsy.

A seizure threshold is our individual level of resistance to seizures. We all have a seizure threshold and any one of us has the potential to have a seizure. However some people will be more likely to have a seizure than others.

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 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.
- If you have a *high seizure threshold* you are less likely to have a seizure. However, damage to the brain (for example from a severe head injury or an infection) could lower your seizure threshold; making a seizure more likely.

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 is



usually made after a person has had more than one seizure. When someone has a seizure they may not remember what has 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, including blood tests, an **Electroencephalogram (EEG)** and brain scans such as Computerised Tomography (CT) or Magnetic Resonance Imaging (MRI) may give more detailed information that can help with a diagnosis.

However, these tests 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.

 **See our leaflet *diagnosis*.**

how is epilepsy treated?

Anti-epileptic drugs (AEDs)

Up to 70% of people with epilepsy could have their seizures controlled (they could stop having seizures), with the right medication. AEDs are taken regularly to prevent seizures from happening by reducing the brain's excessive electrical activity. AEDs are not used during a seizure to stop it, and they do not cure epilepsy. There are different AEDs, and the AED 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 stop taking their AEDs, with guidance from their neurologist. Other people need to carry on taking AEDs 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.



See our leaflets *medication for adults or medication for children.*

Other treatments for epilepsy

For some people whose epilepsy does not respond to AEDs, there may be other possible treatment options.

- Epilepsy surgery (also called neurosurgery) may be possible for some people if tests 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 normally used alongside AEDs.
- For some children, the ketogenic diet may help to reduce the number or severity of their seizures. The diet is a medical treatment, often started alongside AEDs, and is supervised by trained medical specialists and dietitians. Dietary treatments for adults are developing on a limited basis in the UK.



See our factsheets *epilepsy surgery, VNS and ketogenic diet.*

seizure triggers

For some people certain situations can trigger (set off) a seizure. Common triggers include lack of sleep, stress, alcohol and not taking medication. Less commonly, seizures can be triggered by flashing lights. This is called **photosensitive epilepsy**. It may be possible to avoid triggers if they can be identified.



See our factsheet *photosensitive epilepsy*.

will epilepsy affect my life?

Developing epilepsy may affect you in different ways. Some people 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, asking questions and sharing information may help you, or your family and friends, to make sense of what is happening.

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, leisure, or social life.

However epilepsy affects you, or how you feel about it, there is help available. See page 10 for further ways we can support you.



See our factsheet *what help is available?*

getting support

Epilepsy Society helpline

If you want to know more, or talk to someone about epilepsy, our confidential helpline offers information and emotional support.

 **See back cover for contact details.**

Epilepsy Society forum

If you want to talk online to other people affected by epilepsy, then you can visit our forum. The forum is free and open to anyone, with dedicated sections for carers and parents.

 **Visit www.epilepsysociety.org.uk/forum**

If you support someone with epilepsy, there is information and support for you if you need it.

 **See our factsheet *carers* or visit www.epilepsysociety.org.uk/carers**

further information

Epilepsy Society information

Carers

Diagnosis

Epilepsy surgery

Ketogenic diet

Medication for adults

Medication for children

Photosensitive epilepsy

Seizures

VNS

What help is available?





summary of terms

Electroencephalogram (EEG) – a test where electrodes are used to record brain activity.

Genetic – the information in your DNA that determines your characteristics, for example hair colour, sex and height.

Inherited – characteristics that are passed on to you from your parents.

Neurological – to do with the brain, nerves and the nervous system.

Photosensitive epilepsy – where seizures are triggered by flashing lights or moving patterns.

Seizure threshold – the brain's natural level of resistance to having seizures.

Spontaneous remission – when seizures stop happening of their own accord.

Tuberous Sclerosis – a rare condition that causes growths in organs including the brain.

VNS (Vagus nerve stimulation) therapy – a form of treatment that uses mild electrical stimulation of the left vagus nerve (a large nerve in the neck).

Every effort is made to ensure that all information is correct. Please note that information may change after printing. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

www.epilepsysociety.org.uk

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