



epilepsy
society


what is epilepsy?

An introduction



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

 This symbol means further information is available.

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helpline

01494 601 400

Monday and Tuesday 9am to 4pm,
Wednesday 9am to 7.30pm. 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. Other conditions that can look like epilepsy include fainting or very low blood sugar which may happen in people being treated for diabetes.

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 brief change in the way the brain works. This interruption or build up of electrical signals can cause a seizure (sometimes called a 'fit' or 'attack').

epilepsy is common

Anyone can develop epilepsy, at any time of life. It happens in people of all ages, races and social classes. Epilepsy is most commonly diagnosed in children and in people over 65. There are over half a million people with epilepsy in the UK, so around 1 in 100 people.

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 leaflet 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 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 at the types of seizures.



See our leaflet *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.
- 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.

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 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. These include blood tests, an **Electroencephalogram (EEG)** and brain scans such as **Computerised Tomography (CT)** and **Magnetic Resonance Imaging (MRI)**.

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.



See our leaflet *diagnosis* and our factsheet *recording seizures*.

how is epilepsy treated?

Anti-epileptic drugs (AEDs)

Up to 70% of people with epilepsy could have their seizures controlled (they 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 gradually 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 booklet *medication for epilepsy*.

Other treatments for epilepsy

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

- 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, 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 AEDs, and is supervised by trained medical specialists and dietitians. Dietary treatments for adults are available on a limited basis in the UK.



See our factsheets *epilepsy surgery, VNS therapy 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 their prescribed AEDs. Less commonly, seizures can be triggered by flashing lights (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, and your family and friends, to make sense of what is happening.



See our information booklet *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, leisure, or social life.

However epilepsy affects you, or how you feel about it, there is help available.



See our factsheet *what help is available?*

finding 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.

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



See our factsheet *carers*.



further information

Epilepsy Society information

Carers

Diagnosis

Epilepsy surgery

Just diagnosed

Ketogenic diet

Medication for epilepsy

Photosensitive epilepsy

Recording seizures

Seizures

VNS therapy

What help is available?

See our videos 'All about epilepsy' at epilepsysociety.org.uk/epilepsytv



summary of terms

Computerised Tomography (CT) – a special type of x-ray using a scanner and a computer to take pictures of the brain.

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

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

Magnetic Resonance Imaging (MRI) – a type of scan that uses strong magnetic fields and radio waves to produce detailed pictures of the brain or other parts of the body.

Neurofibromatosis – a genetic condition that can cause growths on the nerves.

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 sends mild electrical stimulation to the brain through the vagus nerve (a large nerve in the neck).

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. 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.



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