



# Diagnosis

How epilepsy is diagnosed.

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## How epilepsy is diagnosed

Diagnosing epilepsy usually involves collecting information from different tests, finding out what happens before, during, and after your seizures, and speaking to someone else who might have seen your seizures. With all the collected information the most likely cause of your seizures may be found.

Epileptic seizures are caused by a disturbance in the electrical activity of the brain **(and so they always start in the brain)**.

You may be diagnosed with epilepsy if you have:

- two or more seizures that happen more than 24 hours apart; or
- a single seizure, with a high risk of having further seizures.

Getting a diagnosis is not always easy because there is no single test that can diagnose epilepsy.

This leaflet explains the tests that are usually done and what the tests might show about the seizures you are having.

## What is epilepsy?

Anyone can have a single seizure at some point in their life. This is not the same as having epilepsy, which is a tendency to have repeated seizures that start in the brain.

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## **What are epileptic seizures?**

The brain has millions of nerve cells which control how 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 an epileptic seizure (previously called a 'fit' or 'attack').

Mood, memory, movement, consciousness, and our senses are all controlled by the brain and can all be affected if someone has an epileptic seizure. Epileptic seizures can be different for each person.

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## **Diagnosing epilepsy**

The National Institute for Health and Care Excellence (NICE) produces guidelines for treating specific health conditions in England and Wales. If there is a possibility that you have epilepsy, NICE recommends that you are referred to a specialist (a doctor who is trained in diagnosing and treating epilepsy) within two weeks.

Your diagnosis is based on finding out what happened to you before, during, and after your seizures. For example, some types of faints can look like epileptic seizures, and often before fainting a person feels cold and clammy, and their vision goes blurry. But epileptic seizures happen very suddenly, and a person may have no warning that a seizure is about to happen.

If you have a seizure, you may not remember what has happened. It can be helpful to have a description of what happened from someone who saw your seizure, to pass on to your GP or specialist.

Here are some questions that may help you, or someone who witnessed your seizure, to record information about what happened.

### **Before the seizure**

- Did anything trigger (set off) the seizure, for example, did you feel tired, hungry, or unwell?
- Did you have any warning that the seizure was going to happen?
- Did your mood change, for example, were you excited, anxious or quiet?
- Did you make any sound, such as crying out or mumbling?
- Did you notice any unusual sensations, such as an odd smell or taste, or a rising feeling in your stomach?
- Where were you, and what were you doing before the seizure?

### **During the seizure**

- Did you appear to be 'blank' or stare into space?
- Did you lose consciousness or did you become confused?
- Did you do anything unusual, such as mumbling, wandering about, or fiddling with your clothing?

- Did your colour change (become pale or flushed) and if so, where (face or lips)?
- Did your breathing change (for example, become noisy or look difficult)?
- Did a part of your body move, jerk, or twitch?
- Did you fall down, or go stiff, or floppy?
- Did you wet yourself?
- Did you bite your tongue or cheek?

### **After the seizure**

- How did you feel after the seizure – did you feel tired, worn out, or need to sleep?
- How long was it before you were able to carry on as normal?
- Did you notice anything else?

[Visit \*\*epilepsysociety.org.uk/recording-information-seizures\*\*](https://www.epilepsysociety.org.uk/recording-information-seizures)

### **Looking at your medical history**

Apart from the description of the seizure, there are other things that can help to explain why your seizures have happened. Your medical history and any other medical conditions will also be considered as part of your diagnosis.

Sometimes the cause of someone's epilepsy can be found, for example, following a head injury, a brain infection (such as meningitis), or a stroke. Some inherited conditions (passed from parent to child), such as tuberous sclerosis, can cause epilepsy.

However, for many people there are no clear reasons why they have epilepsy.

## **What tests might I have?**

Your neurologist or specialist may ask you to have some tests to get extra information about your seizures. The tests are usually done by a technician (a person who is trained to do them).

The results from the tests are then passed back to the neurologist to see what they show. The results may indicate that you have epilepsy and may also show a cause for your epilepsy. There are a number of tests that can help rule out other causes for your seizures. These include the following.

### **Blood tests**

A sample of blood will usually be taken from your arm, with a syringe. The sample is used to check your general health and to rule out other possible causes for your seizures, such as low blood sugar levels or diabetes.

### **Electrocardiogram (ECG)**

An ECG is used to record the electrical activity of the heart. This is done by sticking electrodes (a bit like plasters) to the arms, legs, and chest. These electrodes pick up the electrical signals from the heart.

An ECG does not give out electrical signals, so having one doesn't hurt. An ECG can help to rule out the cause of seizures being due to the way the heart is working.

## Tests to diagnose epilepsy

No test can say for certain that you do or do not have epilepsy. But when the information from the tests is added to the description of what happens during your seizures, this builds up a clearer picture of what happened. This can help with the diagnosis and when choosing treatment.

### Electroencephalogram (EEG)

An EEG is used to record the electrical activity of the brain by picking up electrical signals from the brain cells. These signals are picked up by electrodes on the head and are recorded on a computer.



The recording shows how the brain is working. Like an ECG, the electrodes only record electrical activity – they do not give out electrical signals and they do not hurt.



Before the test, the technician measures your head to work out where to place the electrodes. Each electrode is held in place using a sticky paste. Once the electrodes are attached they are connected to the recording machine.

The test lasts about 30 minutes and you will probably be sitting or lying down.

### **What does an EEG show?**

An EEG gives information about the electrical activity of the brain during the time the test is happening.

When someone has an epileptic seizure their brain activity changes. This change, known as epileptiform brain activity, can sometimes be seen on an EEG recording. Some people can have epileptiform brain activity even when they do not appear to be having a seizure, so an EEG can be particularly useful for them.

Epileptiform activity can sometimes be provoked (brought on) by deep breathing. The test may include deep breathing to see if epileptiform activity can be provoked and recorded.

### **Flashing lights during the EEG**

Some people with epilepsy have seizures that are started, or 'triggered', by flashing lights. This is called photosensitive epilepsy and affects about 3% of people with epilepsy. An EEG will usually include testing for photosensitive epilepsy.

This involves looking at a light which will flash at different speeds. If you are worried about this you can talk to the technician.

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\*\*photosensitive-epilepsy\*\*](http://epilepsysociety.org.uk/photosensitive-epilepsy)

## **Sleep-deprived EEG**

For most people there is more chance of irregular brain activity showing when they are tired or when they are going to sleep.

Having a sleep-deprived EEG might help to get a more useful reading. This test is done in the same way as a normal EEG but you sleep during the test. To help you sleep you may be asked to stay awake for some, or all, of the night before.

In some cases you may be given a mild sedative to help you to sleep.

## **Ambulatory EEG**

An ambulatory EEG works in the same way as a normal EEG but is portable. It is a small machine that is worn on a belt around your waist. Because it is portable you can move around and carry on with your normal day-to-day routine while the recording happens.

This type of EEG allows brain activity to be recorded for several hours. Because brain activity is recorded for longer, there is more chance of a seizure being recorded than during the normal 30 minute test.

## **Video telemetry**

Video telemetry happens in hospital, usually over a few days. During your stay you will have your own room. A video camera, often mounted on the wall, will record what you are doing. At the same time you will wear a portable EEG so that you are able to move around your room.

Being videoed while wearing an EEG means that, if you have a seizure, your doctors can compare the electrical activity of your brain with what is happening to your body.

## **What do my results mean?**

An EEG can usually show if you are having a seizure at the time of the test, but it can't show what happens to your brain at other times. So even if your test results do not show any unusual activity, it does not rule out having epilepsy. Some types of epilepsy are very difficult to identify with an EEG.

People who do not have epilepsy can sometimes have irregular activity on their EEG. So a result where there is irregular activity does not necessarily mean that the person has epilepsy.

## **Brain scans**

A brain scan may help to find the cause of your seizures. The scan produces pictures of the brain which might show a physical cause for epilepsy, such as a scar on the brain.

But for many people a brain scan does not show up a cause for their seizures, and even if no physical cause is seen, the person may still have epilepsy.

The two common types of brain scan are Magnetic Resonance Imaging (MRI) and Computerised Axial Tomography (CT or CAT).

### **Magnetic Resonance Imaging (MRI) scan**

An MRI scan looks at the structure of the brain and may help to find the cause of your epilepsy. During the scan, detailed pictures are produced using strong magnetic fields. Because of the magnetic fields, metal objects in or near the machine can affect, or be affected by, the machine.

Before having an MRI scan you will need to remove any metal objects such as jewellery, hearing aids, coins, or keys. If you have a heart pacemaker or any surgical implant that contains metal you may not be able to have an MRI scan.

The scanner makes a loud knocking noise, so before it starts you will be given earplugs to wear. You will also be given a buzzer to hold so you can let the technician know if you are uncomfortable or feeling unwell during the scan.

The technician is usually on the other side of a window in another room during the scan, but an intercom means you can talk to them.

There is also a mirror inside the scanner so you can see the technician during the scan.

You may be able to have someone in the room with you during the scan.



Having an MRI scan to help diagnose epilepsy usually takes about 30 minutes. During the scan you will lie on a platform which slides inside the scanner (a bit like going into a tunnel).

Lying still during the scan is important so that the machine can take clear pictures of your brain. An MRI scan is usually a series of short scans with breaks in between, rather than one long scan.

Between each scan the technician might use the intercom to check that you are ok.

## **Computerised Axial Tomography (CT or CAT) scan**

Some people may have a CT scan if they are not able to have an MRI scan (for example, if they have a heart pacemaker, if they might need to have an anaesthetic to have an MRI, or if information about what might be causing their seizures is needed quickly).

CT scans use X-rays to take images of the brain. (CT scans are not suitable if you are pregnant because the X-rays could affect an unborn baby.)

Images from a CT scan are less detailed than those from MRI scans. During a CT scan you lie on a couch which slides into the scanner. Unlike MRI scanners, CT scanners do not make a loud noise.

## **Treatment for epilepsy**

Epilepsy is usually treated with anti-seizure medication (ASM – previously called anti-epileptic drugs or AEDs). ASM aims to prevent seizures from happening but doesn't cure epilepsy. Up to 70% (7 in 10) of people with epilepsy could have their seizures completely stopped with ASM.

ASM does not stop seizures happening for everyone, so other types of treatment may be considered, such as vagus nerve stimulation (VNS) therapy or epilepsy surgery.

**Visit [epilepsysociety.org.uk/treatment](https://www.epilepsysociety.org.uk/treatment)**

## Reacting to a diagnosis

A diagnosis of epilepsy can affect people in different ways. Getting information about epilepsy and asking questions can be helpful for some people.

**Our free *just diagnosed* booklet covers the topics that people with epilepsy have told us are helpful when you are newly diagnosed. To download a pdf of the booklet visit [epilepsysociety.org.uk/diagnosis](http://epilepsysociety.org.uk/diagnosis)**

Our confidential helpline provides emotional support and information for anyone wanting to know more about epilepsy.

**Call our helpline (see back cover).**

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