

*epilepsy scotland*

Scotland's voice for epilepsy

# Diagnosing epilepsy



**Helpline: 0808 800 2200**

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**[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**

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# I have had a funny turn, faint or seizure – what happens next?

If you have had a seizure, faint or funny turn, you should make an appointment with your doctor. It's important to remember that people can have a seizure or funny turns for many reasons. It doesn't automatically mean you have epilepsy.

The doctor will usually refer you to a hospital to see a consultant if they think it could be epilepsy. The consultant will probably be a neurologist but could be a general doctor who may have a special interest in epilepsy.



# What happens at the hospital?

The consultant will want to know exactly what has happened before, during and after your episode. If you remember anything about your funny turn, write it down before your appointment. It's easy to forget to mention something that could be important. If someone was with you and saw what happened, the consultant will want to speak to them. We call this an 'eye witness account'. If possible, ask that person to go along with you to the hospital appointment, or ask them to be available on the phone.

## **The consultant might ask you questions like:**

- How did you feel and what were you doing before the episode?
- Did anyone see you during it?
- How long did it last?
- What happened after the episode?
- How long was it before you felt ok?
- Was there only one type of episode or was there more than one?
- Has there been any recent illness?
- Does anyone in the family have a history of epilepsy?
- Do you have any other medical problems?

It can help to prepare answers to these questions before you see the consultant.

During the appointment the consultant will give you a physical examination. They will check your balance, eye control and reflexes. They will also test your heart rate and may suggest you have an ECG (electrocardiogram) (see page 7).

The consultant will also carefully look at your previous medical history. Sometimes this can explain why someone develops epilepsy. An earlier brain injury, meningitis or a stroke can, for example, be the reason why some people develop epilepsy. Sometimes, there can be a genetic link. If epilepsy runs in your family, this could be an important clue for the neurologist. However, for many people, there will be no clear reason for their epilepsy.



# Will they do any tests?

There is no single test that will tell the consultant whether you have epilepsy or not. They will make a diagnosis based on:

- your medical history
- what you remember happened, particularly before your seizure
- the description of what happened to you during the seizure, if someone saw you.

There are, however, some tests the consultant can do to find out what could have caused the seizure. These tests can also tell the consultant what type of epilepsy you have, and what the best treatment is.

Epilepsy can sometimes be difficult to diagnose. For example, the tests may not show anything up. Usually, the consultant will want to wait and see if you have another seizure before confirming that you have epilepsy.



# What kind of tests are there?

Remember, you may not need to have all of the following tests. This will depend on many things, such as your age. It may also depend on what the consultant thinks could be the cause.

All of these tests are painless.

## **ECG (Electrocardiogram)**

This test measures the electrical activity of your heart. The test is often done to rule out heart disease, which can sometimes cause a seizure.

## **EEG (Electroencephalogram)**

### **Where is it done?**

This test will be done in the EEG department of a general hospital or special epilepsy clinic by an EEG technician. The test results have to be examined later, so you may have to wait for them for a while.

### **How does it work?**

An EEG machine records the electrical activity of your brain from the millions of nerve cells in the brain. This is shown on a screen or can be printed on paper.

During an epileptic seizure the electrical activity of the brain becomes disrupted. This unusual brainwave pattern is then shown on the recording. Most people will not have a seizure during an EEG but the recording may still pick up small traces of disturbances in your brain waves between seizures. Even if you have no seizure during an EEG, it may still tell the neurologist something important.

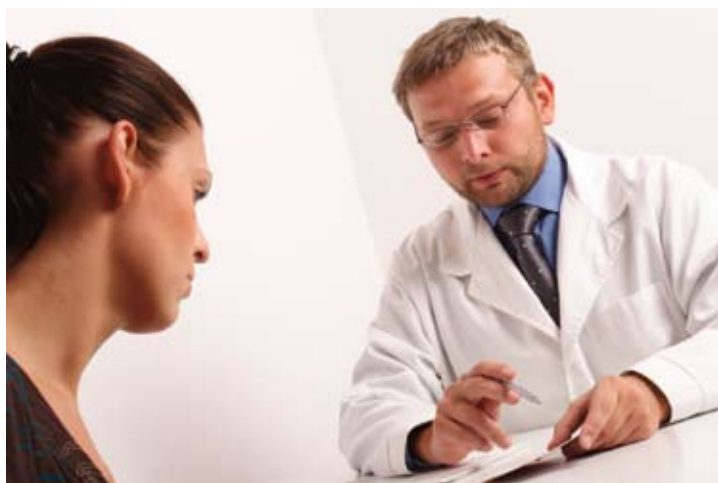
It's worth remembering that some people with epilepsy have normal EEGs and some people who don't have epilepsy can have abnormal EEG readings. An EEG is not a test to diagnose epilepsy. It can, however, confirm that you have epilepsy if your neurologist suspects this.

## What happens during an EEG test?

Small discs, called electrodes, are placed on your head with special glue or paste. Sometimes a cap is used, particularly for children, to keep the electrodes in place. These electrodes are connected to the EEG machine by wires. The machine will record any activity that is taking place in your brain. It will not cause anything to happen. The test is not painful and lasts approximately 45 – 60 minutes. Sometimes, with your permission, a video will also be taken during the test (see video-telemetry on Page 10).

The EEG technician will ask you to keep very still because any movement can affect the results. They may also ask you to do simple tasks, such as:

- opening and closing your eyes several times
- taking deep breaths for approximately three minutes
- looking at a flashing light called a stroboscope.





## **Other types of EEG tests**

Sometimes, you will be asked to come back for more EEG tests or a slightly different kind of EEG test. This could be because the first test did not give the neurologist much useful information. These different EEG tests can be:

**Sleep deprived EEG:** Your neurologist may ask you to stay awake the night before an EEG. Depriving you of sleep can intensify some changes in the electrical activity of your brain, which may suggest that you have epilepsy. These can also be recorded during the EEG and can provide the doctors with important information.

**Sleep EEG:** If your normal EEG test has not shown anything, your doctor may want to do an EEG test while you are asleep. When you sleep, your brain waves change. If there is any disturbance in your brainwaves, this can become more obvious during sleep. This can sometimes give the doctor additional information which may help with your diagnosis.

**Ambulatory EEG:** You can walk around and carry on with your normal life during this test. The EEG technician will again fit electrodes to your scalp with special glue. You will also wear a small box which records the electrical activity of your brain. You may have to carry this box with you for at least 24 hours. Sometimes, your doctor wants to see a recording taken over several days as this will collect a lot of useful information. They want to see what happens to your brain's activity in your every-day life.

**Video-telemetry:** Sometimes it can be useful for the doctor to see what happens to you during a seizure. This can be done with a camera that is linked to the EEG machine. When you have a seizure, the machine will record your brain's electrical activities. A camera records your seizure. This test is often done over several days to increase the chance of recording one of your seizures. This gives the doctor an opportunity to watch your seizures and check these with any activity on the EEG recording. All of this will help your doctor find out if you have epilepsy and also what type of epilepsy you have. It can also tell your doctor if there is a cause for your seizures other than epilepsy.

## Brain scans

Brain scans show the structure and function of the brain. This will allow a doctor to see if there is anything in the brain that could be causing your seizures. It does not show if you have epilepsy. The things they are looking for are, for example, scarring from a head injury.

There are two main types of brain scan which look at the structure of your brain:

**CT (Computed tomography) scan:** This is sometimes also called a CAT scan. Your consultant will use X-rays to record images of your brain. During a CT scan you have to lie very still on a platform. Your head will be at the centre of a scanning machine. The scanner turns internally and pictures are taken from different positions. This is then made into images. The CT scan lasts about 15-20 minutes.

**MRI (Magnetic resonance imaging) scan:** This type of scan uses magnetism instead of X-rays. It is much more detailed than CT scanning. It is often used with children and people who are being considered for surgery. An MRI scan is usually not done if your seizures start in both sides of the brain (generalised seizure). This is because a generalised seizure is normally not caused by structural damage to your brain. An MRI scan is very similar to a CT scan. The difference is that the scanner does not turn. You are also completely enclosed. This can sometimes make people feel claustrophobic. Some people like listening to music during the scan to take their mind off the scan and to help them relax. The MRI lasts around 25 - 35 minutes.

Your doctor may want to repeat the scans if they find something that could be of interest. Sometimes, they will inject a special dye. This will give them a more detailed picture.

There are other types of brain scans, such as **Diffusion Tensor Imaging (DTI)**. This measures the movement of water in the brain. It can detect those areas where the normal flow of water is disrupted. This can tell the consultant where there may be an abnormality in the brain which could cause seizures. DTI is a new testing method and there are currently only a few of these scanners in the UK.



Other brain scans look at how well the brain is working. There are mainly two types, a SPECT and a PET scan. These tend to be done if you are being assessed for brain surgery:

**A SPECT (Single Photon Emission Computed Tomography)** will help the doctor find out where in your brain the epilepsy starts. A slightly radioactive (but safe) substance is injected into a vein around the time of a seizure. The scan picks this up as it passes through the brain. When you have a seizure, a great deal of energy is being used up in the area of your brain which is affected. Because of the increase in energy, the amount of blood flowing through this area of the brain is also increased. The SPECT scan will be able to detect this change in blood flow.

**A PET (Positron emission tomography)** scan is usually not used to diagnose epilepsy. Very few people need this test. Similar to a SPECT scan, this scan also involves injecting a slightly radioactive (but safe) substance. This substance will measure the amount of oxygen and glucose (sugar) used by the various areas of your brain. Like any part of our body, the brain needs oxygen and glucose to function. When you have epilepsy, your brain will use up different amounts of energy. Those areas of your brain which are affected by the epilepsy use less energy between seizures and this is shown up on the scan. This will allow a consultant to identify the exact area of brain tissue which can be removed by surgery.

## Blood tests

Most people will not need a blood test. However, from time to time your doctor may take a blood sample. This is usually taken from your arm with a syringe. The doctor will want to check the level of anti-epileptic drug in your blood.

## Genetic testing

There is no routine blood test for a suspected genetic (inherited) link. Limited progress has, however, been made with some genetic forms of epilepsy in children. Yorkhill Children's Hospital in Glasgow runs the UK's first paediatric genetic epilepsy service. As a result, children with some genetic forms of epilepsy can be tested at an early stage. An early diagnosis could mean better drug treatment and better seizure control. Your doctor will tell you if this test is suitable for your child. There is no such test for adults at the moment.



# What happens after I have been diagnosed with epilepsy?

Once you have a diagnosis of epilepsy, your consultant will tell you what type of seizures you have. They will also discuss treatment options with you. The most common treatment is taking anti-epileptic drugs (AEDs).

Most epilepsy clinics have epilepsy specialist nurses. Your consultant will normally refer you to one. If not, ask to be referred to one. They are an excellent source of information and advice. A lot of people want to know, for example, how epilepsy will affect their work, driving or safety. If you are a woman you may worry about how your epilepsy may affect your contraception or starting a family.

It can be a shock to be told you have epilepsy. However, epilepsy is the most common neurological condition, and some 40,000 people in Scotland have it. You can speak to someone in confidence on our freephone Helpline **0808 800 2200**. We can give you emotional support to help you cope with a new diagnosis. Our trained staff will be happy to answer questions you may have about your epilepsy and give you practical advice on many aspects of living with epilepsy.

Our publications have lots of useful information on epilepsy. There is a list at the end of this booklet. If you can't find what you are looking for, phone us.

Finally, you can also contact us via our Helpline text service on **07786 209 501**, email us on **enquiries@epilepsyscotland.org.uk**, or visit our website **www.epilepsyscotland.org.uk** for more information.

# Further information

## We currently have the following information:

<ul style="list-style-type: none"><li>• A guide to epilepsy — what you need to know</li><li>• A woman's guide to epilepsy</li><li>• A parent's guide to epilepsy</li><li>• An employer's guide to epilepsy</li><li>• Caring for people with epilepsy and learning difficulties</li><li>• Diagnosing epilepsy</li><li>• Emotional wellbeing</li><li>• Epilepsy — a guide for teachers</li><li>• Epilepsy and driving</li><li>• Epilepsy and employment</li></ul>	<ul style="list-style-type: none"><li>• Epilepsy and leisure</li><li>• Epilepsy and memory</li><li>• Epilepsy and treatment</li><li>• Epilepsy in later life</li><li>• First aid for seizures</li><li>• Men and epilepsy</li><li>• Photosensitive epilepsy</li><li>• Seizures explained</li><li>• Staying safe with epilepsy</li><li>• SUDEP (Sudden unexpected death in epilepsy) — jointly published with Epilepsy Bereaved)</li></ul>
<p><b>We also have information leaflets designed for people with mild to moderate learning difficulties. These are:</b></p>	<ul style="list-style-type: none"><li>• All about epilepsy</li><li>• Safety and epilepsy</li><li>• Living with epilepsy</li></ul>

We are constantly updating and adding more information. Phone us for the latest information or a free copy of any of our publications.

If you have questions after reading this leaflet, please call our Helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format, large print, or a different language, please call **0808 800 2200**.

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