After a first seizure

Having a first suspected seizure

Anyone can have a single seizure at some point in their life. For some people this can be a frightening and upsetting event. Sometimes it can take a while to find out what caused the seizure. This can be an uncertain time and it can be difficult to know what to do.

Having one seizure does not necessarily mean you have epilepsy. Epilepsy is a tendency to have repeated seizures that start in the brain.
Visit epilepsysociety.org.uk/what-epilepsy

There are a number of other conditions that can cause seizures that may look similar to epileptic seizures. For example, some kinds of faints can look like an epileptic seizure. There is no single test that can diagnose epilepsy. So getting a diagnosis is not always straightforward or easy.

If you went to hospital at the time of your seizure, they may have done some tests to see what caused the seizure. For example, heart or blood tests, a CT scan (computerised tomography) or an MRI scan (magnetic resonance imaging). They may refer you to see a specialist if they think you may have epilepsy, or to a different type of specialist if they think it could be something else.

What happens next?

If you did not go to hospital, or if they did not refer you to a specialist, you should see your GP. If they think you might have epilepsy, they will refer you to see an epilepsy specialist – a neurologist (for adults), or a paediatrician (for children).
Visit epilepsysociety.org.uk/about-epilepsy/epilepsy-care-pathway

You should be seen by the specialist within two weeks. The two week referral is a guide and it can take much longer. Sometimes you may be able to get an earlier appointment if you let the hospital know if you are able to accept a cancellation appointment at late notice.
Visit epilepsysociety.org.uk/about-epilepsy/epilepsy-care-your-rights

Your specialist appointment

At your first appointment with the specialist they will want to know as much as possible about what happened to you before, during, and after your seizure.

You may not remember what happened to you, so it can be helpful to have a description of what happened from someone who saw your seizure, or to take them with you to the appointment. If you have a recording of the seizure on a phone this can also be useful.

The specialist may refer you for some tests, usually an MRI scan and an Electroencephalogram (EEG). If they do, these tests should be done within six weeks, although it can take much longer.
Visit epilepsysociety.org.uk/diagnosis

Information for you
At your first appointment, your specialist should assess your risk of having another seizure. You should be given information about first aid, safety, how to minimise any further risk, how to recognise another seizure, and what to do if another seizure happens.

Having a single seizure does not necessarily mean you have epilepsy. It can be a difficult and uncertain time when you haven't yet had a diagnosis. Here we suggest some things to do and think about after a first seizure.

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

What do I need to do?

There are a number of things you may want to consider doing, or may have to do, after a first seizure.

Stop driving

If you have had a first seizure of any kind, you must stop driving and notify the Driver and Vehicle Licensing Agency (DVLA). How long you have to stop driving for depends on what type of seizure you had and whether you have another one.

For some people, stopping driving can have a big impact on their lives and can be difficult or upsetting. If you would like to talk things through with someone, you can call our confidential helpline (see page 1).

There is support and help available with travel costs. For example, you may be eligible for a free bus pass or discounted rail travel, or for help with the cost of getting to medical appointments. The government's Access to Work scheme may be able to help with the cost of getting to and from work.

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

You should also tell your motor insurance company about your seizure.

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

Employment

You do not have to tell your employer about the seizure. But if you do, they can carry out a risk assessment and put things in place to keep you safe at work. The Equality Act 2010 makes it illegal for an employer to discriminate against a person due to a health condition. However, employers also have to keep everyone safe so they will need to consider how they do this.

Visit epilepsysociety.org.uk/employment

Education

If your child has had a first seizure, you may want to talk to their nursery, school, or college about what has happened and what you would like them to do if your child has another seizure.

University students may want to let their university, tutors, or friends know. Students may also want to get in touch with the university disability support team.

Visit epilepsysociety.org.uk/children
Visit epilepsysociety.org.uk/university-and-epilepsy

Safety and risk

Risks from seizures vary from one person to another. Looking at ways of managing risk may help you do the things you enjoy and be as independent as possible while still keeping safe. For example, it may be safer to shower rather than taking a bath, in case you have another seizure.

When you see the specialist, they should give you information about your own individual risk of another seizure, and about safety, and minimising risk. In the meantime, you may want to visit our website for general information about risk and staying safe.

Visit epilepsysociety.org.uk/safety-and-risk

Like some other medical conditions, epilepsy can be a cause of death in some individuals. This is called Sudden Unexpected Death in Epilepsy (or SUDEP).

SUDEP is rare and everyone's level of risk is individual to them. It can be worrying to think about but knowing a little about SUDEP and the risks around having seizures might help you to work out what risks apply to you, and how to reduce them so you can feel more in control.

Visit epilepsysociety.org.uk/SUDEP

Looking after yourself, and having a healthy lifestyle may help you minimise risk: eating regularly and healthily, good rest and sleep, avoiding recreational drugs and alcohol, and reducing stress if possible, may help.

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

First aid

You may want to talk to friends, family, and colleagues about how to help if you have another seizure. We have information on our website about first aid for different types of seizures but, for a tonic clonic seizure, our **'Calm, Cushion, Call'** message may be helpful:

- **Calm. Stay calm and take control of the situation.**
- **Cushion. Cushion their head with something soft.**
- **Call. Call an ambulance.**

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

Every effort is made to ensure that all information is correct at the time of publishing. 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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Welfare Benefits
Having a seizure does not automatically mean you can claim benefits. This depends on how your seizure affected you and, sometimes, on your financial situation.
Visit epilepsysociety.org.uk/benefits

What if I have another seizure?

If you have already seen a specialist, they should have told you what to look out for and what to do if you have another seizure. If you haven't seen your specialist yet, you may want to let your GP know if you have another seizure. They may be able to ask for a more urgent appointment with the specialist.

There are many different seizure types and some can be quite subtle. If you notice anything unusual or different for you, note down as much detail as possible about what happened to tell the specialist.
Visit epilepsysociety.org.uk/epileptic-seizures

Treatment

For most people with a diagnosis of epilepsy, the main type of treatment is anti-seizure medication (ASM). ASM is usually only considered after a diagnosis of epilepsy has been made. This is normally after someone has had two or more seizures.

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

Who can I talk to?

Some people find it helpful to talk to friends or family about what has happened. Or you may want to talk to our confidential helpline (see page 1). If you are diagnosed with epilepsy, further information and support is available from your specialist and epilepsy specialist nurse, if you have one, and our helpline.
Visit epilepsysociety.org.uk/just-diagnosed

Further information

NICE (National Institute for Health and Care Excellence)
nice.org.uk/Guidance/cg137
NICE provides guidance on the diagnosis and treatment of epilepsy.

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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