Epilepsy: an introduction

www.epilepsy.org.uk
Epilepsy Helpline: 0808 800 5050
Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

**Our work...**

- We provide information to anyone with an interest in epilepsy.
- We improve the understanding of epilepsy in schools and raise educational standards.
- We work to give people with epilepsy a fair chance of finding and keeping a job.
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations.
- We promote equality of access to quality care.

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

**Join us...**

You can help us in our vital work by becoming a member. All members receive our magazine Epilepsy Today, free cover under our unique personal accident insurance scheme and access to our services and conferences.
Contents

Introduction 4
  About epilepsy 4
  The causes of epilepsy 5
About epileptic seizures 6
  Seizure types 6
  Things that trigger seizures 7
Diagnosis and treatment of epilepsy 8
  Diagnosis 8
  Treatment 8
  Epilepsy medicine 9
  Paying for your epilepsy medicines 9
Living with epilepsy 10
  Coming to terms with epilepsy 10
  The equality laws 11
  Memory 11
  Depression 12
  Risks of having epilepsy 12
  Safety 13
  Reducing the risk of seizures 14
  Leisure activities 14
  Alcohol and illegal drugs 14
  Driving 15
  Education 15
  Work 16
  Insurance 16
  Help available 16

Epilepsy: an introduction 3
Introduction

This booklet gives some basic facts about living with epilepsy. It looks at what epilepsy is, how it is treated and how to deal with seizures. It also looks at things like going out, driving, and working.

Epilepsy Action has a lot more information about epilepsy. If you would like to know more, please contact us. See page 23 for details.

About epilepsy

In the UK, there are over 600,000 people with epilepsy.

Any one of us can have a one-off epileptic seizure. But if you have epilepsy, it means you have had more than one epileptic seizure. And you could have some more in the future.
Around five people in every 100 will have an epileptic seizure at some time in their life. Out of these five people, around four will go on to develop epilepsy.

There are many types of epilepsy. Some types of epilepsy start when you are very young, and some in later life. Some types last for a short time and other types can last for the whole of your life.

**The causes of epilepsy**

In around six out of 10 people, doctors don't know the cause of their epilepsy. For many of these people, it is just part of how they are made that makes them more likely to have a seizure.

Some people do have a cause for their epilepsy. One cause can be brain damage. There are a number of things that can cause brain damage. These include:
- a difficult birth
- a brain infection, such as meningitis
- a stroke
- a serious brain injury.

There doesn’t have to be damage to your brain for you to have epilepsy. You could have a medical condition in which it is quite common to also have epilepsy. Some of these conditions are tuberous sclerosis and cerebral palsy. In some people with a learning disability, the cause of their learning disability can also cause their epilepsy.
About epileptic seizures

Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity in the brain. In this booklet this intense electrical activity is called ‘epileptic activity’.

Seizure types

There are many different types of seizure. They can be classed by where in the brain the epileptic activity starts.

Focal (partial) seizures – In these seizures, the epileptic activity starts in just a part of your brain. You may stay alert in this type of seizure. Or you may not know what is going on around you.

Image illustrating brain cell activity.
Parts of your body may move and you can’t stop it. Or you may have unusual sensations or feelings. Sometimes, other people may not be aware that you are having a seizure.

Focal seizures can be very brief or last for minutes. Sometimes, epileptic activity starts as a focal seizure, spreads to the rest of your brain and becomes a generalised seizure.

**Generalised seizures** – These seizures involve epileptic activity in both halves of your brain. You lose consciousness during this type of seizure, although sometimes it can be so brief that no one notices. Sometimes it can last for many minutes. The muscles in your body may stiffen and/or jerk. You may fall down.

**Things that trigger seizures**

Some things make seizures more likely for some people with epilepsy. These are often referred to as ‘triggers’. Triggers are things like stress, not sleeping well and drinking too much alcohol. Some people say they have more seizures if they miss meals. Not taking your epilepsy medicine is another common trigger. A very small number of people with epilepsy have seizures triggered by lights that flash or flicker.

Avoiding triggers lowers the risk of having a seizure.
Diagnosis and treatment of epilepsy

Diagnosis

One of the most important parts of getting the right treatment for your seizures is getting the right diagnosis. Doctors base their diagnosis on what they are told about your seizures.

It is very helpful to keep a detailed diary of your seizures. You can show this to your doctor. It is also very helpful for someone who has seen you have a seizure to go with you to see your doctor. They can tell the doctor what it was like.

If your doctor thinks you may have epilepsy, they should arrange for you to see a doctor that specialises in epilepsy. This is usually a neurologist (for adults) or a paediatrician (for children). This doctor will probably suggest you have some tests. These tests may include blood tests, an EEG (recording of your brainwaves), and a brain scan. These tests can help the doctor work out the type and cause of the epilepsy. But there isn’t a single test that can prove if you do or don’t have epilepsy.

Treatment

The main treatment for epilepsy is epilepsy medicine. You may hear these medicines called anti-epileptic drugs or AEDs. The medicine doesn’t cure epilepsy, but helps stop or reduce the number of seizures. Around 40 in every 100 people with epilepsy have their seizures stopped with the first epilepsy medicine they try.
There are also other ways to treat epilepsy. These include different types of epilepsy surgery, and a special diet sometimes used for children with epilepsy – the ketogenic diet.

**Epilepsy medicine**

There are many different medicines for epilepsy. Your epilepsy specialist will recommend the best one for you. They should let you know how it works and what its possible side-effects are. It’s usual to start the medicine at a low dose and increase it step-by-step, until it’s at a dose that is going to work best for you. This slow increase helps to reduce any side-effects.

Everyone is different, and some people find they don’t get on with a particular medicine, even at a low dose. If this happens to you, you and your doctor could see if a different medicine would be better for you.

A list of medicines for epilepsy in the UK is available from Epilepsy Action.

**Paying for your epilepsy medicines**

In the UK, if you have epilepsy, you don’t have to pay for your epilepsy medicine. If you live in England you will need to get an exemption certificate from your doctor. All prescriptions in Scotland, Wales and Northern Ireland are free of charge.
Living with epilepsy

Coming to terms with epilepsy

If you have just found out that you have epilepsy, you may need some time to come to terms with it. Having epilepsy can change things. It’s likely that you won’t be able to drive for some time. And you will have to think about some of the things you do, to make sure you are as safe as possible. But with the right treatment, you could be one of the seven out of 10 people that could have their seizures fully controlled.
You might want to talk to some other people with epilepsy. This could be at an Epilepsy Action local meeting. Or you could become a member of our online community, forum4e. This is a safe and friendly place to talk about your epilepsy. Go to www.forum4e.com

If you are finding it really hard to come to terms with your epilepsy, or it is making you anxious or worried, talk to your doctor.

**The equality laws**

In the UK there are laws that say everyone has the right to be treated fairly at work or when using services. The Equality Act covers people in England, Scotland and Wales. The Disability Discrimination Act covers people in Northern Ireland.

The equality laws are there to protect you if you have epilepsy, even if you are seizure-free. It doesn’t matter whether or not you take epilepsy medicine. And they protect you if you have had epilepsy in the past.

**Memory**

Finding it hard to remember things seems to be a common problem for people with epilepsy. Epileptic seizures can affect memory. If there is damage to the brain that causes the epilepsy, this can also cause memory problems. And some epilepsy medicine can affect memory. Epilepsy Action has information on things you can do to help with memory problems.
Depression

Depression is common in people with epilepsy. There can be many reasons for depression. Sometimes it is linked to epilepsy or epilepsy medicines. If you have just found out you have epilepsy, you might have had to change things about your life that you don’t want to. Or other people might be treating you differently because of your epilepsy. If you think you are depressed, talk to your doctor as depression can be treated.

Risks of having epilepsy

Many people with epilepsy lead full lives. Their seizures are brief and don’t cause them any particular problems. They just get on with life. But it’s important to know that there is a small risk of dying because of epilepsy. People can die as a result of a seizure.
Or they can die as a result of an accident that happens because of a seizure. Sometimes, the cause of the epilepsy may be to blame. For example, someone may have damage to their brain. In some cases, there is no clear reason why a person with epilepsy has died. When this is the case, it is called sudden unexpected death in epilepsy (SUDEP).

Taking your epilepsy medicine regularly, and talking to your doctor about any concerns you have about your epilepsy, can help to reduce the risks. Epilepsy Action has more information about ways to reduce the risks of SUDEP.

**Safety**

It’s a good idea to think about things you can do to make life with epilepsy as safe as possible. Because most things carry some risk, it’s impossible to live a risk-free life. But there are usually ways to lower risks. Sometimes it’s just a matter of taking a few extra steps to make an activity safer.

How you lead your life is your decision. But if your epilepsy is not controlled – even if you only have one seizure a year – you need to think carefully about risk. For example, having a seizure in the bath would put you at risk of drowning. You can reduce this risk by having a shower instead.

If you think there are things you can do to make your home safer if you had a seizure, you may be entitled to some help. Your local social work office will be able to tell you more.
Reducing the risk of seizures

One good way of making life safer is to do everything you can to not have seizures.

Here are some ways to keep seizures to a minimum.
• If you know there are things that trigger your seizures, try to avoid them.
• Find ways to deal with stress, when you can’t avoid it altogether.
• Try to have regular sleeping patterns.
• Don’t forget to take your epilepsy medicine.
• Never run out of your epilepsy medicine.

Leisure activities

If there are things you like to do in your spare time, having epilepsy shouldn’t usually stop you. If you have seizures, you might need to take some extra safety measures. For example, if you go swimming, take someone with you who knows what to do if you have a seizure in the water.

Alcohol and illegal drugs

Some people with epilepsy drink alcohol and some people don’t. It’s up to you to decide if you’re going to drink alcohol. But bear in mind that for some people, alcohol can make seizures more likely.

There is no control over what goes into illegal drugs. They can be dangerous and they can trigger seizures.
Driving

There are laws about driving if you have a one-off seizure, or if you have epilepsy. You may have to stop driving for a time. These laws are there to make sure that all road users are as safe as possible. Contact Epilepsy Action for up-to-date information on the driving laws.

Education

You should have the same choice of school or college as any other student. Education is covered by the equality laws, which means you should not be discriminated against because of your epilepsy. You should also have access to extra support at school and college if you need it.
**Work**

All jobs, except the armed forces, are open to people with epilepsy. There may be some jobs you can’t do if your seizures mean you or others would be put at risk. Examples are police officer, fire fighter and working at heights.

The equality laws mean it is against the law for someone to treat you unfairly at work because of your epilepsy.

If you can’t drive because of your epilepsy, you might find it difficult to get to work. If you are not able to use the bus or train, the Access to Work scheme (through Jobcentre Plus) may help with the costs of taxi travel. Go to www.direct.gov.uk

**Insurance**

If you are taking out insurance, you may be asked questions about your health. If you are, you will need to be honest about your epilepsy. If you’re not, you may not be fully insured. There are special rules for insurance under the equality laws. Insurers can charge more for an insurance policy, if they think there is a higher risk of someone making a claim. They can even refuse to insure someone. But they must look at each case individually.

**Help available**

If you have epilepsy you can get free prescriptions. You may also be able to get cheaper, or free, bus and rail fares. If your epilepsy affects your everyday life, you may be able to get some benefits.
About this publication

This booklet is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the booklet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

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First aid for tonic-clonic seizures

The person goes stiff, loses consciousness and falls to the floor.

Do...
• Protect the person from injury (remove harmful objects from nearby)
• Cushion their head
• Aid breathing by gently placing the person in the recovery position when the seizure has finished (see the pictures)
• Stay with them until recovery is complete
• Be calmly reassuring

Don’t...
• Restrain the person’s movements
• Put anything in their mouth
• Try to move them unless they are in danger
• Give them anything to eat or drink until they are fully recovered
• Attempt to bring them round

Call 999 for an ambulance if...
• You know it is the person’s first seizure
• The seizure continues for more than five minutes
• One seizure follows another without the person regaining consciousness between seizures
• The person is injured
• You believe the person needs urgent medical attention
First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

Do...

• Guide the person away from danger
• Stay with the person until recovery is complete
• Be calmly reassuring
• Explain anything that they may have missed

Don’t...

• Restrain the person
• Act in a way that could frighten them, such as making abrupt movements or shouting at them
• Assume the person is aware of what is happening, or what has happened
• Give them anything to eat or drink until they are fully recovered
• Attempt to bring them round

Call 999 for an ambulance if...

• You know it is the person’s first seizure
• The seizure continues for more than five minutes
• The person is injured
• You believe the person needs urgent medical attention
Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books, videos and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue.

Epilepsy Action’s support services

Local meetings: a number of local branches offer support across England, Northern Ireland and Wales.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at www.forum4e.com

Epilepsy awareness: Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.
Epilepsy: an introduction

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How useful have you found this publication?
☐ Very useful ☐ Useful
☐ Quite useful ☐ Not at all useful

Is the language clear and easy to understand?
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Registered charity in England (No. 234343)
How to contact the Epilepsy Helpline

Telephone the Epilepsy Helpline freephone 0808 800 5050
Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm
Our helpline staff are Text Relay trained

Write to us free of charge at
FREEPOST LS0995, Leeds LS19 7YY
Email us at helpline@epilepsy.org.uk or visit our website:
www.epilepsy.org.uk Text your enquiry to 0753 741 0044
Send a Tweet to @epilepsyadvice

About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people’s cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative, about our services.

To ensure the quality of our services we may monitor calls to the helpline.
Epilepsy Helpline:
freephone 0808 800 5050
www.epilepsy.org.uk

Environmental statement
All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from sustainable forests.