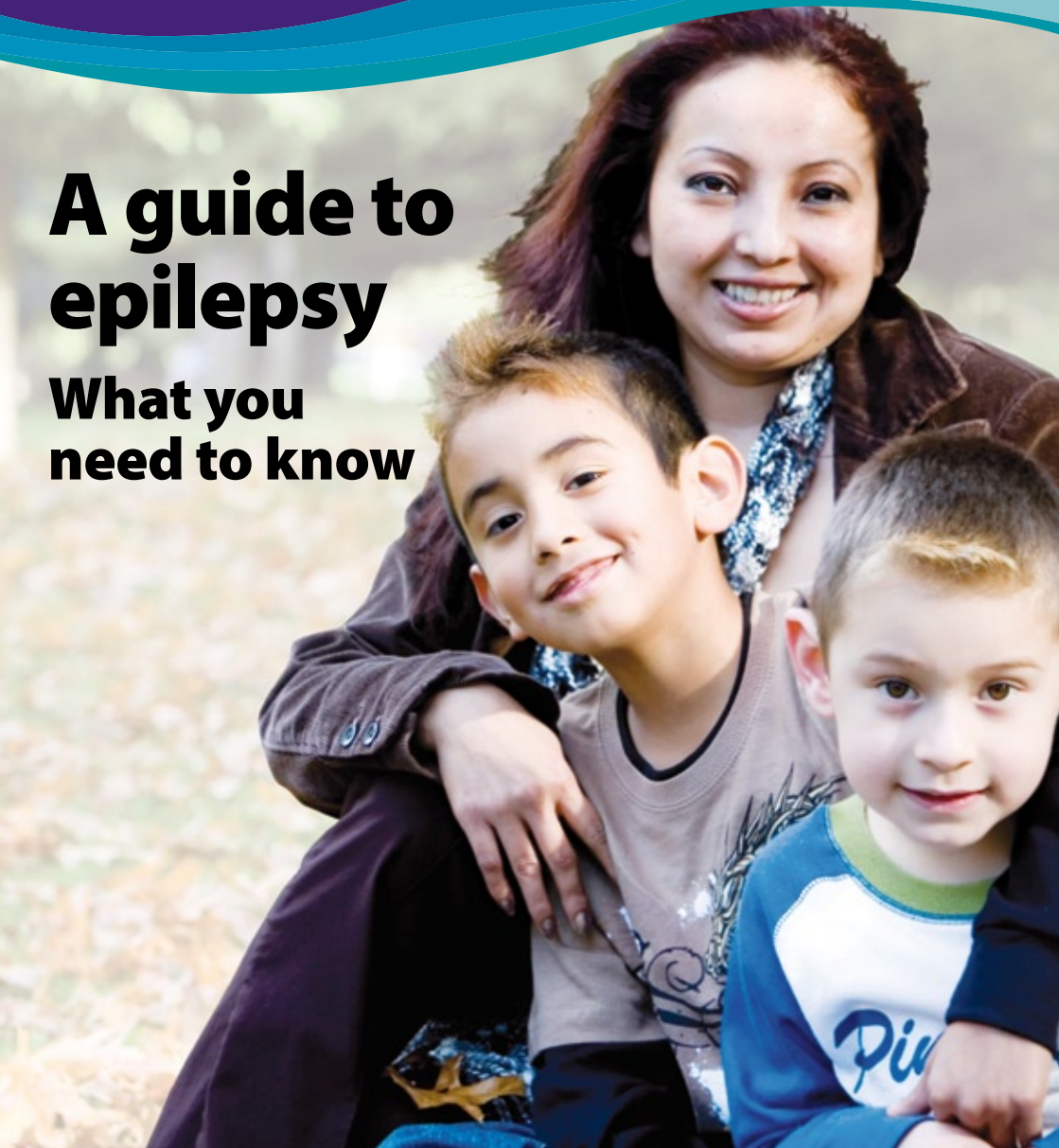


*epilepsy scotland*

Scotland's voice for epilepsy

# **A guide to epilepsy**

## **What you need to know**



**Helpline: 0808 800 2200**

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

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# Introduction

This leaflet is about epilepsy. It is for anyone who wants to know more. It can be a shock to find out that you have epilepsy. But you are not alone.

Epilepsy is not always talked about. This can mean you feel isolated but lots of people have the condition. You may already know someone who does. Call our Helpline on **0808 800 2200** if you have any questions about epilepsy or would like to talk to someone.

Anyone can have a seizure. In fact one in 20 people do. This does not mean they all have epilepsy. Seizures can happen for other reasons, like a high temperature or a head injury. People with epilepsy tend to have repeated seizures. These start in the brain.

Forty thousand people in Scotland have epilepsy. That's one in 130. You can develop epilepsy at any age. It doesn't matter if you are a man or a woman or what your background is. It is more common in children and older people. Older people can develop epilepsy for reasons like dementia or after a stroke. For most people there is no known cause for their epilepsy.

Epilepsy affects people in different ways. This leaflet has general information. If you want to find out more about your own epilepsy and how it affects you, talk to your doctor or epilepsy nurse.



## What is epilepsy?

People with epilepsy tend to have repeated seizures. Most seizures are controlled with the right epilepsy medication.

Seizures usually last a short time. The brain works normally between seizures. Billions of brain cells pass messages to each other and these affect what we say and do. When there is too much electrical activity, messages can get mixed up and cause seizures.

People can have different types of seizures depending on the area of the brain involved.

The most well-known seizures are tonic-clonic seizures where you lose consciousness and fall over. You stiffen and then jerk. These seizures affect the whole brain.

Absence seizures are less obvious. They are brief and sometimes others will not notice them. You may not realise you have had an absence seizure.

### Here are six facts about epilepsy you should know:

- It's a physical condition
- It's the most common neurological condition
- It's the tendency to have repeated seizures
- It's often misdiagnosed
- It's different for everyone
- Only seizures are called "epileptic", not people. A better choice of words is "person with epilepsy".

## What causes epilepsy?

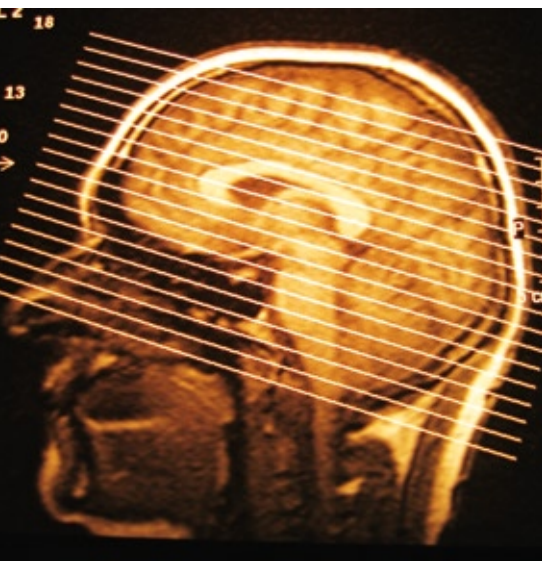
You will want to know why you are having seizures. Sometimes epilepsy can be caused by different things like scarring on the brain from a head injury or infection. When the reason for your epilepsy is found it is called **symptomatic epilepsy**.

Most of the time the cause of epilepsy is not known. This is called **idiopathic epilepsy**. It is thought there may be a family link for this kind of epilepsy. Research is finding that some types of epilepsy can run in families. Sometimes a vulnerability to seizures can be passed on.



There are over 40 types of seizures. This means people with epilepsy have different experiences.

Our brain controls all our speech, movement, emotions, memory, vision, hearing and much more. Different parts of the brain control different things. What happens during a seizure depends on which area of the brain is involved and what it controls.



Seizures can be generalised or partial. Generalised seizures involve the whole brain. Partial seizures affect only part of the brain.

**Partial seizures** are either simple or complex.

A **simple partial seizure** affects one area of the brain:

- You may experience an unusual taste or smell or twitching
- You know the seizure is happening but cannot stop it
- You will not have any loss of awareness.

A **complex partial seizure** affects a larger area of the brain:

- You may experience strange or unusual feelings
- You may lose your sense of time and appear distant from what is happening and who is around
- You may behave in an unusual way. This could be smacking your lips, plucking at your clothes, or moving aimlessly around a room
- Unlike simple partial seizures you will have a loss of awareness
- This could put you in danger if, for example, you walk onto a busy road during this type of seizure.

**Generalised seizures** affect the whole brain. You will lose awareness during these. There are different types of generalised seizures. These include tonic-clonic, absence, tonic, myoclonic and atonic seizures. See our Seizures factsheet for more information.

Some things can make you more likely to have a seizure. These are called seizure triggers. They can be (in no particular order):

- missing medication
- feeling ill or hot
- stress or boredom
- lack of sleep
- missing meals
- dehydration
- too much alcohol
- menstruation (monthly period)
- recreational drugs
- flickering and flashing lights (less than five per cent of people with epilepsy are affected by this).

Keep a diary of your seizures. This helps you find any triggers. Call our Helpline for a free seizure diary.

## First aid for a tonic-clonic seizure

### What to do

- **Keep calm.** Once a seizure starts it will generally stop on its own

- Check the time to see how long the seizure lasts

- Move any objects that could cause injury

- Put something soft like a rolled up jacket or cushion under the person's head to stop injury

- Loosen tight clothing around the neck

- Remove any glasses

- Stop other people crowding around

- Check for medical identification like a bracelet or necklace as this may have more information on the person's epilepsy

- Check the person's **care plan** if they have one

- Turn the person onto their side into the recovery position as soon as the jerking stops

- Protect the person's privacy, particularly if they have emptied their bladder or bowels

- Speak softly and gently when you tell the person what has happened

- Remember they may be confused for a while after a seizure.

### What is a care plan?

Some people with epilepsy have care plans which contain information about their seizures. If they need emergency medication the care plan will have details of this. Emergency medication can only be given by people named in the care plan and who are trained in the procedure.

### What NOT to do

- **Do not** move the person unless they are in danger eg on a busy road or at the top of stairs

- **Do not** try to stop the jerking or restrain the person

- **Do not** put anything in the person's mouth or between their teeth

- **Do not** offer the person anything to eat or drink until they are fully conscious.

### Call an ambulance if

- it is the person's first seizure

- the person is badly injured

- the jerking lasts for five minutes or a longer time than is usual for that person (if the person has a care plan this will have information on their usual length of seizure)

- one seizure follows another with no recovery time in between

- the person is having problems breathing after the seizure has stopped.

### More information

Our First aid for seizures factsheet also has information on how to help someone with other types of seizures.

## Diagnosis and tests

It can be difficult to diagnose epilepsy as there is no single test. If you have a seizure go and see your doctor straightaway. You will usually be referred to a specialist. They are skilled in knowing what causes seizures.

Adults usually see a consultant neurologist or a consultant physician with a special interest in epilepsy. Children usually see a paediatric neurologist or a paediatrician.

The specialist will want to know what happened and what the seizure looked like. If someone saw you have the seizure bring them to your appointment. The specialist will ask you about your medical history.

Remember, many people have seizures but this does not mean they have epilepsy.

You may also have tests done. These can sometimes give information on the cause or type of epilepsy.

An EEG (electroencephalogram) records the brain's electrical activity. During a seizure this activity is disrupted. It helps to do an EEG at a time when you are most likely to have a seizure. However, unusual brain activity can also sometimes be seen between seizures. Your specialist will use your EEG recording as only one part of the investigation to see if you have epilepsy. See our Diagnosis factsheet for more information.

Brain scans like CT (Computerised Tomography) or MRI (Magnetic Resonance Imaging) show a picture of the brain. The doctor can look to see if there is anything which may be causing seizures.

## Treating epilepsy

### Medication

If the specialist diagnoses epilepsy, you are usually prescribed epilepsy medication. This controls seizures for many people.

You may worry about side effects. In many cases, these side effects are mild.

### **Tell your doctor straight away if you develop a skin rash.**

Side effects often stop once your body gets used to the medication. Talk to your doctor or epilepsy specialist nurse if you are worried about this.

You may decide not to take epilepsy medication because of side effects. Without medication, you could have more seizures and risk injury. Before you make this decision it is important you speak to your doctor or epilepsy specialist nurse.



Some epilepsy drugs can interact with other tablets like the contraceptive pill. See our Treatment factsheet for more information.

If you have not had any seizures for a number of years you may want to speak to your doctor to see if you can slowly come off your medication. This will depend on the type of epilepsy you have. Some people decide to keep taking their medication in case they have a seizure. They may be worried, for example, that they will lose their driving licence if they have a seizure while coming off epilepsy medication.

**Do not stop taking your medication without medical advice.**

## Surgery

A small number of people with epilepsy can have surgery. If a person's epilepsy is caused by scarring in one area of the brain it may be possible to remove the damaged part. This can successfully stop the seizures for many people. Lots of tests need to be done before surgery. This is to be sure that the part of the brain being removed is not needed for an important function like memory or speech.

## Vagal Nerve Stimulator

Some people have a Vagal Nerve Stimulator (VNS) fitted under their collar bone to treat their epilepsy. The vagus nerve runs from the neck to the brain stem. The Vagal Nerve Stimulator sends electrical impulses along this nerve. It has reduced seizures for some people. It can also make seizures less severe.

## Complementary therapies

You may find these helpful, especially if stress is a trigger for your seizures. There are currently few scientific studies to show how complementary therapies could help people with epilepsy.

If you want to use a complementary therapy speak to your doctor or epilepsy specialist nurse first. With any complementary therapy, it is important to find a qualified therapist who is a member of a professional body. Make sure that you tell the therapist that you have epilepsy before the treatment begins.

There are some herbal medicines you should avoid. These include St Johns Wort and evening primrose oil. Also avoid certain essential oils such as hyssop, rosemary, sage, sweet fennel and wormwood. These can trigger seizures in some people.

Do not replace your epilepsy medication with complementary therapies. If you stop your epilepsy medication suddenly, you are more likely to have a seizure. See our Treatment factsheet for more information on complementary therapies.



# Living with epilepsy

Helen Butler is only 27 but has already achieved a lot in life. She is married to Craig and runs her own business designing websites. Helen was nine when her first seizure started. Her epilepsy appears to be drug resistant, and she is now being assessed for brain surgery to help control her seizures.

When you see Helen you also get to meet Shadow. He attracts attention not just because he is a gorgeous Siberian Husky but because he wears a “Service Dog” jacket.

Wearing his blue jacket puts Shadow into “work mode”. Helen explains why this dog boosts her confidence and makes her a bit more independent especially when Craig works away from home.

“My mother-in-law works in a doctor’s surgery and she heard about seizure dogs.

“I knew there was a charity in Sheffield, called Support Dogs. I also did a lot of internet research on training seizure dogs. We wanted to get a pet anyway so I thought ‘why not combine the two?’ In the end, I decided to do the training myself.

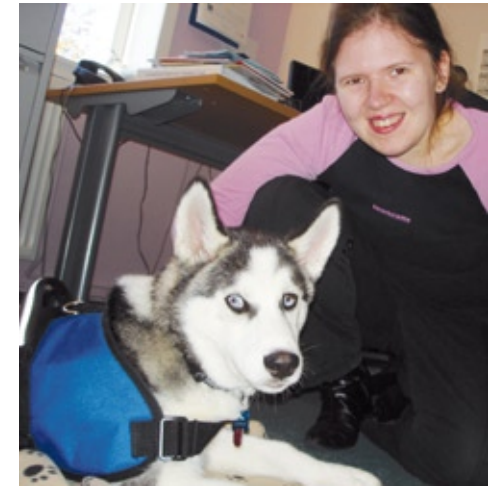
**“We chose his name after ‘me and my shadow’, he follows me everywhere...”**

Shadow has developed an instinct for knowing when Helen is about to have a seizure. She takes a warning aura first and her dog stays with her during and after a seizure.

“One time I took him for a walk. I had a seizure, fell over and was totally out of it. I had no idea where I was. My nose was all bruised and there were cuts all over my face. Shadow took me all the way home, leading me to the back door of the house.

“He can also sense my auras. When he does, he stops playing and immediately comes and sits with me. When I fall over, he licks my face and hands and sits with me until I come around. I wouldn’t say it has made a difference to the number of seizures I’ve had. But I definitely come round more quickly afterwards because I am more relaxed with Shadow there to look after me.”

Helen has always been open about her epilepsy and is keen to raise awareness wherever she goes. She has encountered her fair share of prejudice and negative reactions but tries not to let this get the better of her. She points out that looking for work can be a problem. “When agencies or employers hear about my epilepsy and that I have a service dog, they say they need to check but often don’t phone back.” This is one of the reasons why Helen has decided to set up her own business.



What’s next for Helen? “I would like to do a bit more awareness raising to change people’s attitudes and bring epilepsy out of the shadows. I am thinking of writing a regular column for a newspaper.”

## Free prescriptions

People with epilepsy get free prescriptions. Your epilepsy drugs and any other medicines you are prescribed will be free.

To get your free prescriptions you need a medical exemption certificate to show the pharmacist. Pick up an EC92A form from your GP surgery. Fill out parts one and two and then take it to your GP. They will fill out the rest and send it off. You will then be sent the exemption card.

## Free bus pass

If you have had a seizure in the last year you are entitled to a free bus pass. This lets you travel across Scotland on the bus free. It will also give you reduced fares on local trains.

Children between five and 17 who have had a seizure in the last year can have a free bus pass. Adults who are on Disability Living Allowance (high mobility and/or high or middle rate care) or Attendance Allowance can also have a free bus pass. Call our Helpline and we will send you a form.



## Disabled Person's Railcard

People with epilepsy who take medication but still have regular seizures can buy a Disabled Person's Railcard. This then gives one third off train fares in the UK. Call **0845 605 0525** or check the website **[www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk)**

## Benefits

Some people with epilepsy get benefits. It depends how they are affected by their epilepsy. If a person cannot work they may get Incapacity Benefit. Those who need extra care or help in getting around may get Disability Living Allowance.

If you care for someone with epilepsy you may be able to get carer's benefit. Your local benefits agency or Citizens Advice Bureau can tell you more.

If you have had a seizure you need to stop driving and tell DVLA (Driving Vehicle Licensing Authority). After twelve months with no seizures (with or without medication) you can get your driving licence back. This is as long as the doctor thinks you are safe to drive. If three years have passed and you still have seizures in your sleep, but none when awake, you will be able to hold a driving licence. See our Driving factsheet for more information.

You may get a warning before a seizure. Not everyone has this though. It can be difficult when you do not know when you will have a seizure

In an emergency it helps if people know about your epilepsy and what is usual for you. Think about carrying an 'I have epilepsy' card. Epilepsy Scotland can send you this card free. You can also get medical identification jewellery such as wristbands, pendants or watches. We can tell you where to buy these.

If you have unpredictable seizures there are things you can do to keep yourself safer. Having a shower is safer than taking a bath. There are still some risks with showering. Try these to cut risks:

- Make sure the temperature control works
- Don't use very hot water
- Use a shower chair
- Use a shower with a flat floor
- Do not use a shower with a high lip as water can become trapped if you fall
- Use an 'Occupied' sign on the door so you can leave the door unlocked.

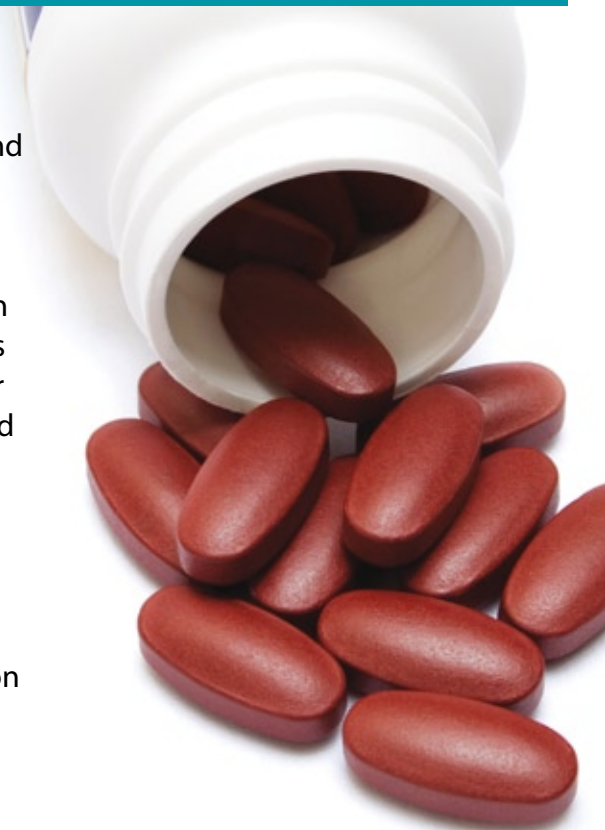
You can ask your local social work department to arrange for an occupational therapist to visit. They can look at ways to keep you as safe as possible in your home.

A small number of people with epilepsy die each year. In Scotland around 100 epilepsy related deaths happen. Half of these are sudden and unexpected. This is called Sudden Unexpected Death in Epilepsy. SUDEP mostly affects younger adults. The risk is higher for people who have uncontrolled seizures. The risk is low for most people with epilepsy.

You can lower the risk by:

- taking your epilepsy medication as prescribed
- keeping a seizure diary to help you identify and avoid your seizure triggers
- going to all your medical appointments and talking with your doctor or nurse
- being safe - our Safety factsheet has more information.

We have written a leaflet on SUDEP with Epilepsy Bereaved ([www.sudep.org](http://www.sudep.org)). Phone our Helpline if you want a copy of this leaflet. You can also talk to our Helpline staff if you are worried about SUDEP.



## Education

Schools have a duty to support children with epilepsy. If your child needs extra support with their school work speak to your child's teacher. Children may miss information if they have absence seizures or if they are off school because of their epilepsy. You can call **Enquire** on **0845 123 2303** for more information. They will advise you on how your school can provide additional support to your child.



## Employment

You may be worried about your job if you have epilepsy. People with epilepsy have legal rights to be treated fairly when in a job or looking for work. These rights are part of the Disability Discrimination Act (DDA) 1995. Jobs in the armed forces are the only exception. They do not have to follow DDA rules.

If your seizures are well controlled, there is no reason why you can't do most jobs. If your seizures are unpredictable you may need to think about the type of work you do. This is for health and safety reasons. If you are worried about your work situation please call our Helpline. You can find out about your rights in our free Employment factsheet. We can also send you 'An employer's guide to epilepsy'.

## Social life

Alcohol can trigger seizures in some people with epilepsy. Usually, drinking in moderation is fine. However, it's best to speak about this to your doctor or epilepsy specialist nurse first.

Alcohol affects how well your body absorbs epilepsy medication. Don't stop taking your epilepsy medication even if you are drinking.

Less than five per cent of people with epilepsy have seizures triggered by flickering or flashing lights. This is called photosensitive epilepsy. The TV can be a seizure trigger for someone who has photosensitive epilepsy. LCD screens are safe as they stop any flicker. We can give you more information on photosensitive epilepsy.



Epilepsy can affect you differently, depending on whether you are a man or a woman.

To help you answer those questions that are important to you, we have written a separate guide for women and one for men. Call our Helpline if you want a copy.

We hope this guide has given you some useful information. At times it can be difficult living with epilepsy. It may help you to talk to someone in confidence. When you feel like this, call our Helpline.

We also have a lot of information on our website at [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk). Our Helpline staff can also tell you about local epilepsy support groups, and any other support that is available.



Epilepsy Scotland can give you further information on:

Factsheets:	Guides:
<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Driving</li> <li>• Employment</li> <li>• First aid for seizures</li> <li>• Leisure</li> <li>• Memory</li> <li>• Safety</li> <li>• Seizures</li> <li>• SUDEP (Sudden Unexpected Death in Epilepsy)</li> <li>• Treatment</li> <li>• Triggers (includes information on alcohol and photosensitive epilepsy)</li> </ul>	<ul style="list-style-type: none"> <li>• A parent's guide to epilepsy</li> <li>• A woman's guide to epilepsy</li> <li>• An employer's guide to epilepsy</li> <li>• Epilepsy and later life</li> <li>• Guidelines for teachers</li> <li>• Looking after someone with epilepsy and learning difficulties</li> <li>• Men and epilepsy</li> </ul>

We also have information leaflets designed for people with learning difficulties. These include:

- All about epilepsy
- Safety and epilepsy
- Living with epilepsy

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 or language, please call **0808 800 2200**.

# epilepsy scotland

Scotland's voice for epilepsy

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