

# Information for carers of people with epilepsy and a learning disability



# Epilepsy Action – together we can change lives

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

Together we can:

- Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
- Run local events and support groups, so that fewer people have to face epilepsy alone
- Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

**It's only your support that can make this life-changing work possible.**

**Please donate today.**

You can call the Epilepsy Action fundraising team on 0113 210 8851 or donate online at **[epilepsy.org.uk/donate](https://epilepsy.org.uk/donate)**  
You can also stay up-to-date with all the latest epilepsy news and information by joining Epilepsy Action. Membership starts from just £1 a month - join today by calling 0113 210 8800 or sign up online at **[epilepsy.org.uk/join](https://epilepsy.org.uk/join)**

Thank you.



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For the most up to date version of this content, please scan this code and visit our webpage:

[Carers of people with epilepsy and a learning disability. www.epilepsy.org.uk/living/for-carers](http://www.epilepsy.org.uk/living/for-carers)



## Being a carer

This information is for carers of someone with epilepsy and a learning disability. By carer we mean anyone who is caring for someone as a family member, friend or support worker.

Caring for someone can be a real joy. And it can be really demanding. It can be hard to find your way around all of the different services on offer, and to look after your own wellbeing at the same time.

As a carer you should be listened to and involved in making decisions alongside the person you are caring for. You should also be offered a carer's assessment.



## Having a learning disability

People with a learning disability are all different. There will be differences between the experiences of people with mild, moderate, severe and profound learning disabilities, as well as many other differences that will be unique to each person.

People with a learning disability often have worse health than people without a learning disability. A number of barriers can stop people with a learning disability from getting good quality healthcare, such as:

- Not having the correct diagnosis, or not getting it soon enough
- Carers not feeling listened to
- Not adjusting treatment in response to the person's needs, or changes in their health
- Different care providers not working together in a joined up way

The National Institute for Health and Care Excellence (NICE) say that people with learning disabilities should be on a learning disabilities register with their doctor. This helps doctors and healthcare staff to offer extra support.

As well as an annual review with their doctor to look at general health issues, they should also have an annual review of their epilepsy with an epilepsy specialist.

# The link between epilepsy and learning disabilities

Out of every 100 people with a learning disability, around 22 also have epilepsy. This means epilepsy affects about one in five people with a learning disability.

The more severe the learning disability the higher the possibility that the person will also have epilepsy.

A smaller number of people with Down's syndrome have epilepsy (two out of every 100). But if someone with Down's syndrome also has dementia, they are then much more likely to develop epilepsy.

It is often harder to support someone when they have two or more health conditions.



# A quick guide to epilepsy

## What is epilepsy

Epilepsy is a condition that affects the brain, causing repeated seizures. In the UK, there are around 630,000 people living with epilepsy.

Electrical activity is happening in our brain all the time. An epileptic seizure happens when there is a sudden burst of intense electrical activity in the brain.

The epileptic activity causes a temporary disruption to the way the brain normally works, so the brain's messages become mixed up. The brain is responsible for all the functions of the body. What happens during a seizure will depend on where in the brain the epileptic activity begins, and how widely and quickly it spreads.

Epilepsy can start at any age and there are many different types. Some types of epilepsy last for a limited time and the person eventually stops having seizures. But for many people epilepsy is a life-long condition.

## Different seizure types

There are a lot of different seizure types. How a seizure affects someone with epilepsy depends on what area of the brain is involved. Some people only have one type of seizure, whilst others have more than one type.

During a seizure, the person might lose consciousness or may stay aware of what's happening around them. They might have strange sensations, or movements they can't control. Or they might go stiff, fall to the floor and shake.

Epilepsy Action has more information about seizure types on our website: [epilepsy.org.uk/info/seizures](https://www.epilepsy.org.uk/info/seizures)

## Causes of epilepsy

Possible causes of epilepsy include:

- Brain damage, for example damage caused by a stroke, head injury or infection
- Brain tumours
- The way the brain developed in the womb
- Changes in a person's genes

But in over one third of all people with epilepsy, doctors don't know the cause.

For people with a learning disability, the cause of their learning disability can also be the cause of their epilepsy.

As doctors understand the causes of learning disability better, it is becoming clear that certain genetic causes, such as in Rett syndrome or Angelman syndrome, are linked with particular patterns of epilepsy. A syndrome is a group of signs and symptoms that, added together, suggest a particular medical condition.



## **Diagnosing epilepsy**

A doctor can sometimes find it difficult to recognise when someone with a learning disability is having seizures. This is where your knowledge as a carer of the person will be valuable. Here are some things to bear in mind:

- It is not always easy for doctors to find the right diagnosis, as there are a number of conditions that can cause symptoms similar to epilepsy
- Some behaviours that are related to a learning disability can look similar to seizures, for example absence seizures
- People with a learning disability might find it difficult to describe their symptoms
- A video recording of the person having a seizure can really help with accurate diagnosis
- A number of people with learning disabilities and epilepsy also have dissociative (non-epileptic) seizures

## **Tests used in diagnosing epilepsy**

The epilepsy specialist might arrange for genetic testing to be carried out if it isn't clear what is causing the person's epilepsy. A genetic test is usually done using a sample of blood or saliva. The sample is sent to a laboratory to be analysed. The test looks at the person's genes to see if there are changes that might cause epilepsy.

An EEG (electroencephalogram) is one of the more common tests for epilepsy. It will show what is happening to a person's brainwaves using sensors placed on the person's scalp. If there is

something unusual about the brainwave pattern, this could be because of epileptic activity.

Sometimes a doctor will also want to use an MRI (magnetic resonance imaging) scan to try to find out the cause of the epilepsy or the learning disability.

For some people with a learning disability, having an EEG or MRI may feel really difficult. You may want to discuss with the doctor or epilepsy nurse any ways they can suggest to help with this.

You can ask for information to be adapted so that the person you are caring for can understand and prepare for the tests. One example of this is Easy Read information.

## Epilepsy treatment and care

People with epilepsy and a learning disability should be offered the same treatments for their epilepsy as everyone else. They should also:

- Have a review of their epilepsy treatment at least once a year
- Be offered a general health check every year (for adults and children 14 years old and over)
- Be given clear information about their epilepsy in a way they can understand, such as Easy Read (taking time to explain it to them as well)
- Have 'reasonable adjustments' so that they can use health services the same as everyone else, such as more time for appointments
- Be given support to make their own decisions where possible

All of the different professionals involved in the person's care should try to work in a joined-up way. If the person you care for has more than one health condition, this can be hard to manage.

NICE has published a document summarising these recommendations. [Website: epilepsy.org.uk/nice](http://epilepsy.org.uk/nice)

## **Care plans**

Everyone with epilepsy should have a care plan. This is especially important if the person may need emergency treatment for their seizures. The plan should be drawn up by a medical professional, the person the care plan is about and their carers.

It can be helpful to take this care plan to doctors and hospital appointments, even if the appointment is not related to epilepsy. This is because the doctors may have a question about the epilepsy treatment or seizures. It is a good idea to keep the care plan somewhere you can quickly find it, so that you can take it with you in an emergency.

Epilepsy Action has care plans. If you would like a simpler version you could also have an Easy Read healthcare passport. [Website: ekhft.nhs.uk/my-healthcare-passport](http://ekhft.nhs.uk/my-healthcare-passport)

## **Consent to treatment**

Consent to treatment means a person must give permission before they receive any type of medical treatment, test or examination. Before someone can give their consent to treatment, they must be given all of the information about

what the treatment involves, and have the capacity to understand the information given to them. They should also be able to use the information to make an informed decision, without being influenced by other people such as doctors, friends or family.

The NHS website has some helpful information on consent to treatment and how capacity is assessed: [nhs.uk/conditions/consent-to-treatment/](https://www.nhs.uk/conditions/consent-to-treatment/)

## Possible seizure triggers

Knowing the possible seizure triggers for the person you look after can help to limit the number of seizures they have. It can also help with getting the dose of their epilepsy medicine right. These are the things people say sometimes trigger seizures:

- Not taking epilepsy medicine as prescribed
- Feeling tired and not sleeping well
- Stress
- Alcohol
- Flashing or flickering lights
- Monthly periods (menstruation)
- Missing meals
- Having an illness that causes a high temperature

Keeping a seizure diary is a good way to try and find out what might trigger seizures.

## Epilepsy medicines

The main treatment for epilepsy is with epilepsy medicines. For many people, being on the right dose of the right epilepsy medicine or medicines can mean their seizures stop completely.

It can be difficult for some people with a learning disability to swallow tablets. You can usually ask to have the medicine in a more manageable form, such as liquid or powder, to help the person take their medicine exactly as prescribed.

For someone who is likely to have trouble remembering to take their epilepsy medicine, there are a variety of reminder devices available. For more information on medicine reminders, see the Disabled Living Foundation website: [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk)

There are small differences between versions, or brands, of epilepsy medicine which can affect the way the medicine works. If you notice a change in seizures following a version change it is important to tell your doctor or pharmacist. Some people may need to stay on the same version of their epilepsy medicine.

[For more information on switching epilepsy medicines, visit epilepsy.org.uk/switch](http://epilepsy.org.uk/switch)

For everyone with epilepsy, the aim is to get the best possible seizure control with as few side effects as possible. For a person with a learning disability it's especially important that seizure control isn't the only thing the doctor considers when prescribing epilepsy medicine. They should be helping the person reach the best quality of life possible for them.

## Side effects of epilepsy medicine

As a carer you are likely to notice changes in emotional and physical health and behaviour of the person you are looking after. This information may help with what to look out for. And what you notice will be important to share with the doctor.

- Some side effects may be missed by a doctor who doesn't know the person you look after very well. They may think that a problem the person has with understanding, co-ordination or behaviour may be because of the learning disability, when it could be a side effect of an epilepsy medicine
- People with epilepsy and a learning disability may well have side effects that are different from other people
- Side effects could cause someone to be reluctant to take epilepsy medicine
- Side effects could result in behaviour problems
- Having too much of an epilepsy medicine could result in behaviour problems
- Taking more than one epilepsy medicine lead to more side effects
- Side effects could reduce the person's ability to understand things

## Epilepsy medicines and problems with bone health

People taking epilepsy medicines for a long time have an increased risk of osteoporosis. This is a condition that weakens bones, making them more likely to break. Your doctor may give the person you look after medication and vitamins to maintain the health of their bones. You can ask their epilepsy specialist to

review their level of risk and discuss tests that are available. Epilepsy Action has more information about epilepsy medicines and problems with bone health.

### **Taking other medicines**

Always check with the doctor or pharmacist before giving someone over-the-counter medicines. Some epilepsy medicines will interact with these as well as prescribed medicines. This can make them less effective or causing unwanted side effects.

## **Other treatment options**

### **Epilepsy surgery**

Epilepsy surgery is a treatment option for some people with seizures that can't be controlled by taking epilepsy medicines. The assessment for surgery is complex but it should be offered where it is believed that the person is suitable, and the benefits of surgery outweigh the risks. The aim of brain surgery is to try to stop or reduce the number of seizures, and improve the person's quality of life.



## Vagus Nerve Stimulation

If surgery isn't a treatment option, the doctor may discuss the possibility of vagus nerve stimulation (VNS). This involves a small electrical device, like a pacemaker, which is implanted under the skin of the person's chest. The device sends electrical impulses to your brain through a nerve in your neck called the vagus nerve. The aim is to reduce the number of seizures you have and make them less severe.

## The ketogenic diet

The ketogenic diet is a specialist medical diet which is much higher in fats and lower in carbohydrates than a typical diet. The diet is a treatment option for some people whose seizures are difficult to control. This includes people with certain epilepsy syndromes, such as Lennox-Gastaut and Dravet syndrome. Epilepsy Action has more information about epilepsy medicines, surgery, VNS and the ketogenic diet.





## **Other health conditions**

There are a number of other conditions that can go with having a learning disability and epilepsy. It is just as important that these get diagnosed and treated as well as the learning disability and the epilepsy. Here are some of the conditions:

### **Sleep disorders**

Many people with a learning disability will also have a sleep disorder. This is often undiagnosed. It's important to get this treated as it may well be making the person have more seizures.

### **Metabolic conditions**

It is also important that the person you look after is screened for metabolic disorders. These happen because of abnormal chemical reactions in the body. They are responsible for a range of different health conditions. Having one of these conditions untreated could make it more difficult for a doctor to understand why someone's seizures are happening. It could also make it difficult to know what side effects of epilepsy medicines someone might be experiencing. The best thing to do is to ask the epilepsy doctor or GP if they think screening for metabolic disorders is needed. Many people will have been tested in childhood or have causes that make it clear there is no metabolic disorder.

### **Mental health issues**

People with epilepsy are more likely to develop mental health problems like depression or anxiety. Medicines for epilepsy can

have an effect on a person's mood so it is a good idea to talk this through with a specialist.

We have more information about health and wellbeing on our website: [epilepsy.org.uk/living/health](http://epilepsy.org.uk/living/health)

## Other things to consider

There are many other possible things that might cause a problem for someone with a learning disability and epilepsy.

Here are some possible causes:

- Heartburn or acid reflux. This is a burning feeling in the chest caused by stomach acid travelling up towards the throat. If it keeps happening, it's called gastro-oesophageal reflux disease (GORD)
- Constipation
- Another condition, such as autism or attention deficit hyperactivity disorder (ADHD)



# Safety

There are many different things to help a person with epilepsy and a learning disability stay safe. These include ways to avoid injury inside and outside the home, seizure alarms and helmets.

## Doing a safety check

A safety check helps you decide whether something is safe for the person you care for. If there are risks, it helps you work out what could be done to make that activity safe enough for them to do.

There's more information on our website but the main steps are:

- 1. Think about their seizures** – what happens, how often they happen, specific triggers. Keep a seizure diary or download an app to help get any information about patterns or triggers. Knowing about triggers and patterns can offer some useful information about how to make an activity safe
- 2. Think about what the risks would be if they had a seizure**
- 3. Make a plan to do things that reduce those risks**

## Seizure alarms and monitors

Epilepsy Action can't give advice on what sort of device would best meet your needs or recommend a particular product. This is because there is a lack of good quality research into how reliable and useful they are for people with epilepsy.

There isn't enough evidence to show that using a seizure alarm or monitor can guarantee someone's safety during a seizure. But some people with epilepsy have found using alarms and monitors helpful as part of a risk reduction plan.

We do have information and cost estimates on our website for a range of alarms and devices, bed monitors, video tools and apps. There is also some information about applying for funding for these. Epilepsy Action has information about safety, safety aids, and first aid, including what to do if someone is in a wheelchair.



## Epilepsy related risks

Every year in the UK, around 1,000 people die from causes related to epilepsy. Knowing about these is important as it can help you to identify and reduce the risks.

Some people die during seizures because of a condition called status epilepticus, or as a result of an accident or drowning. In other cases there's no clear reason why a person with epilepsy has died. When this happens, it's called sudden unexpected death in epilepsy (SUDEP).

### SUDEP

Sadly, people that have epilepsy and a learning disability face some bigger risks than other people. For example, they are more likely to die earlier than other people. So it's especially important, for you as a carer, to know about sudden unexpected death in epilepsy (SUDEP).

No one can say exactly who will be affected by SUDEP, but research has shown there are some things that can put someone at increased risk:

- Having tonic-clonic seizures
- Having sleep seizures
- Not taking epilepsy medicine regularly

## Reducing the risk of SUDEP

The most effective way to reduce the risk of SUDEP is to have as few seizures as possible, especially tonic-clonic seizures. Here are some suggestions to help:

- Taking epilepsy medicines every day, exactly as they've been prescribed. If the person you care for doesn't like their medicine or the side effects, talk to their epilepsy specialist so they can make changes
- Find out in advance what to do if the person you care for misses a dose of medicine, or they have vomiting or diarrhoea after taking it
- Try to avoid situations which may trigger seizures. Common triggers include missing a dose of epilepsy medicines, lack of sleep, stress and drinking too much alcohol
- If seizures are not fully controlled, ask to be referred to an epilepsy specialist for a review. The specialist may be able to suggest changes to their epilepsy medicines, or other treatment options

Epilepsy Action has information on bed alarms and SUDEP and how to reduce the risks.

SUDEP Action has SUDEP information in Easy Read.

Website: [sudep.org](http://sudep.org)

## Status epilepticus and emergency treatment

Most people with epilepsy have seizures that last a short time and stop by themselves. But sometimes, a seizure can last too long and become status epilepticus (you may hear it shortened

to just 'status'). It happens when a seizure doesn't stop in the usual time, or when someone has seizures one after another without recovering in between. Status epilepticus can happen with any type of seizure but there are 2 main types:

### **Convulsive (tonic-clonic) status epilepticus**

Convulsive status epilepticus is when:

- A tonic-clonic seizure lasts for 5 minutes or more, or
- One tonic-clonic seizure follows another without the person regaining consciousness in between

If either of these things happen, the person needs urgent treatment to stop the status before it causes long-term damage. If convulsive status epilepticus lasts for 30 minutes or longer it can cause permanent brain damage or even death.

If someone with epilepsy is at known increased risk of a dangerous type of status epilepticus, their doctor may prescribe them emergency medicine (sometimes called rescue medicine). It's usually only prescribed for convulsive status epilepticus.

### **Types of emergency medicine**

There are two main types of emergency medicine licensed for use in the UK

- **Buccal midazolam:** this is given by plastic syringe, between the person's gums and cheek. Brand names include Buccolam and Epistatus
- **Rectal diazepam:** this is inserted into the person's bottom (given rectally). Brand names include Diazepam RecTube and Stesolid

## Non-convulsive status epilepticus

Some people with epilepsy, particularly people with learning disabilities or an epilepsy syndrome, can have **non-convulsive** status epilepticus. They happen when a non-convulsive seizure, such as an absence or focal impaired awareness seizure, lasts too long.

These can be harder to spot because the signs and symptoms can be less obvious. For example, someone who is in absence status or focal impaired awareness status may appear confused and less responsive than usual, or have changes to their speech or behaviour for no clear reason.

Non-convulsive status epilepticus can also be very serious for some people, depending on the cause of the seizure. If someone you care for is at risk of any type of status epilepticus, their specialist should tell you the signs to look out for, and when to get help.

Non-convulsive status epilepticus usually needs specialist assessment and an EEG test to diagnose it and check for other possible causes that might have similar symptoms.

[Epilepsy Action has more information on status epilepticus and seizures that last a long time.](#)



# Support for carers

## Education

Schools now have a legal responsibility to support children with medical conditions. This includes making sure that:

- Everyone is able to participate fully in the life of the school
- The staff understand epilepsy and are able to support students with the condition
- All students who need one, have an individual healthcare plan (IHP)

Epilepsy Action has information on the responsibilities of schools, an IHP template and information on support for children with special needs.

Mencap, an organisation that supports people with learning disabilities, has a range of information on education.

Website: [mencap.org.uk](http://mencap.org.uk)



## Moving from children's to adult services

Until the age of 18, services for young people with long-term health conditions are provided by child health and social care services. Between the ages of 16 and 18, children will start to gradually move to adult services. This is sometimes called 'transitioning'.

The NHS stress that this should be an ongoing process that is tailored to the child's needs. They recommend that planning for this transition should begin when the young person is 13 or 14 at the latest. You might want to start talking to your healthcare professionals about transitioning to adult services when your child reaches this age. Having a long transition period can be helpful as adult services tend to be quite different to children's services. Adult services can feel less 'joined-up' and often rely on you to take a more active role in managing your healthcare.

**The Epilepsy Space** is a website created by Epilepsy Action specifically for people aged 16-25, and was created with young people. While not designed for people with learning disabilities, there are sections on safety and gaining independence that might be useful: [epilepsyspace.org.uk](http://epilepsyspace.org.uk)

## Social care

Your Community Learning Disability Team could be a good source of support for you and the person you care for. The services they offer might vary depending on where you live, but they can often provide group or individual sessions for people with learning disabilities, help create care plans, or provide

training for carers. Your local council should be able to tell you how to get in touch with them.

The NHS website is also a good source of information on social care. [Website: nhs.uk/conditions/social-care-and-support-guide](https://www.nhs.uk/conditions/social-care-and-support-guide)

This information includes:

- Introduction to care and support
- Help from social services and charities
- Care services, equipment and care homes
- Money, work and benefits
- Care after a hospital stay
- Support and benefits for carers
- Practical tips if you care for someone
- Caring for children and young people
- Making decisions for someone else

## **Financial support**

If you care for someone with epilepsy, you may be able to claim government benefits or get help through financial support schemes. Epilepsy Action has information about benefits on the website, including the different schemes that are available depending on whether you live in England, Scotland, Wales or Northern Ireland: [epilepsy.org.uk/living/benefits](https://www.epilepsy.org.uk/living/benefits)

The NHS website is a good source of information on financial support for a carer of a person with a learning disability: [nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/](https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/) Citizen's advice also have information about applying for carer's allowance and other benefits.

## The equality laws

The person you are caring for is protected under the equality laws if they have a disability. Organisations need to complete an individual risk assessment in order to refuse access to a building or service. If they identify any risks, they will need to consider what reasonable adjustments they may be able to put in place to make it possible for the person to access the service. They can only refuse access if they can't identify and make any reasonable adjustments.

You are also protected because you're caring for someone covered by the equality laws. This means you can take action if you think you've been treated unfairly because you're a carer. For example, you can't be refused a promotion at work because of your caring responsibilities.

Epilepsy Action has more information on this: [epilepsy.org.uk/living/your-rights](http://epilepsy.org.uk/living/your-rights)

## Epilepsy Action resources

Epilepsy Action has resources available to download and print on our website: [epilepsy.org.uk/living/for-carers](http://epilepsy.org.uk/living/for-carers) This includes Easy Read information for people with epilepsy and learning disabilities.

## Useful organisations

### **Citizens Advice**

Website: [citizensadvice.org.uk](http://citizensadvice.org.uk)

### **Carers Trust**

Website: [carers.org](http://carers.org)

### **Carers Direct**

Telephone: 0300 123 1053

Website: [carersdirect.com](http://carersdirect.com)

## **Carers UK**

Helpline: 0808 808 7777

Website: [carersuk.org.uk](http://carersuk.org.uk)

## **Mencap**

Supporting people with  
a learning disability

Helpline: 0808 808 1111

Website: [mencap.org.uk](http://mencap.org.uk)

## **Scope**

Making the country a better  
place for disabled people

Helpline: 0808 800 3333

Website: [scope.org.uk](http://scope.org.uk)

## **Foundation for people with learning disabilities**

Influencing policies and services

Tel: 020 7803 1100 Website:

[learningdisabilities.org.uk](http://learningdisabilities.org.uk)

## **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 else you would like to say about this booklet, please contact us.

To find out why you can trust Epilepsy Action's information, please contact us or visit [epilepsy.org.uk/trust](http://epilepsy.org.uk/trust)

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## **Disclaimer**

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.

## 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 on their side (in the recovery position) when the seizure has finished (see picture)
- 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 **or**
- The seizure continues for more than five minutes **or**
- One seizure follows another without the person regaining consciousness between seizures **or**
- The person is injured **or**
- 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 **or**
- The seizure continues for more than five minutes **or**
- The person is injured **or**
- You believe the person needs urgent medical attention

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair.

## Epilepsy Action's support services



helpline

Our friendly helpline team offer confidential advice and information to anyone affected by epilepsy:

### **Freephone 0808 800 5050**

Staff are text relay trained and able to offer advice and information in 150 languages, via an interpreting service.

### **Live chat**

Visit [epilepsy.org.uk](http://epilepsy.org.uk) to chat with a member of the helpline team. We usually reply to chat requests within 5 minutes.

### **Email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)**

Send us your question about epilepsy. We aim to reply within 48 hours (on workdays).

To see our opening hours and find out more about the support we offer visit: [epilepsy.org.uk/helpline](http://epilepsy.org.uk/helpline)



talk and support

Our Talk and Support groups offer an opportunity to connect with others affected by epilepsy. You can join a group which meets face-to-face or online.



befriending

Our befriending service links people who are affected by epilepsy to a volunteer befriender. Your befriender can listen if you are going through a difficult time and could also help you take steps towards positive change.

**Continued on page 35**



## Information for carers of people with epilepsy and a learning disability

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

Yes	No	
		I feel more informed about issues to do with epilepsy
		I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse/other (cross out those that don't apply)
		I have talked to my employer/colleague/teacher/family/ other (cross out those that don't apply) and they have improved how well they support me
		I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline, support groups or forum4e

**Please tell us how you think we can improve this information**

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Please return the completed form to:

**FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action,  
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY**

You can also give us feedback online. Visit [epilepsy.org.uk/feedback](http://epilepsy.org.uk/feedback)

Thank you.

**epilepsy** *action*

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**counselling**

Our counselling service is available to adults living in Northern Ireland and Wales who are affected by epilepsy, caring for someone affected by epilepsy, or the parent of someone affected by epilepsy.



**family support  
Northern Ireland**

Our family support services offer support to families and carers of people affected by epilepsy in Northern Ireland and Wales.

**To find out more about the services we offer, including ways to get in touch and how to apply, visit:  
[epilepsy.org.uk/support-for-you](http://epilepsy.org.uk/support-for-you).**

## **Information about epilepsy**

Epilepsy Action has a wide range of information on our website about many different aspects of epilepsy. You can also download our information as a factsheet.

**If you would like our information printed in large text, you can order this by contacting the Epilepsy Action Helpline.**

## Epilepsy Action Helpline:

freephone 0808 800 5050  
[epilepsy.org.uk](http://epilepsy.org.uk)



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### Environmental statement

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