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

Your support

We hope you find this booklet helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action.

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.
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Introduction

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.

In the first section you’ll find health information. This covers the link between epilepsy and learning disabilities and facts about epilepsy and epilepsy medicines. We also look at how to get the best care and treatment for the person you look after.

The second section covers information on living with epilepsy. This includes education and the equality laws. And we signpost you to information on social care and financial support. Finally there’s a list of useful organisations.
Being a carer

Caring for someone can be a real joy. And it can be really demanding.

Among other things it can be hard to:
• Get the information you need about the person you’re looking after
• Get service providers to take your role seriously and involve you in information and decisions
• Have enough time and energy to find places of possible support for you both
• Stay healthy enough in mind and body to continue being the best carer you can be

We hope these pages will help you with some of those things.

Health information

The link between epilepsy and learning disabilities

People with a learning disability are not one group. There will be major differences between the experiences of people with mild, moderate and severe learning disabilities.

Out of every 100 people with a learning disability, around 22 of them 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.

As a carer you will know it’s harder to support someone and to access care for them when they have two or more health conditions.

**Definition of epilepsy**

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

Having epilepsy always means that you have a tendency to have 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. This is often referred to as epileptic activity. 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.

For this reason, there are many different types of seizure, and each person will experience epilepsy in a way that is unique to them.
There are many types of epilepsy. Some types start at a very young age, and some start later in life. Some types last for a short time and other types can last for the whole of life.

**Causes of epilepsy**

Some people develop epilepsy because of brain damage caused by a difficult birth, a severe blow to the head, a stroke, or an infection of the brain such as meningitis. Very occasionally the cause is a brain tumour.

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. In around six out of 10 people, doctors don’t know the cause of their epilepsy.

**Different seizure types**

There are a lot of different seizure types. They can happen in any part of the brain. Some seizures are generalised, meaning they affect both halves of the brain. Others are focal, meaning they affect a small part of the brain. The brain is responsible for all the functions of our mind and body. What happens to someone during a seizure will depend on where in their brain the seizure is happening.
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 really valuable. Here are some things to bear in mind:

- Accurate diagnosis is not always easy
- Epilepsy can be over-diagnosed in people with challenging behaviour, especially if one of the things they do is stare
- Focal seizures can be under-diagnosed
- Non-convulsive status can be under-diagnosed (see p17)
- A number of people with learning disabilities and epilepsy also have dissociative (non-epileptic) seizures

An electroencephalogram (EEG) is one of the more common tests for epilepsy. It will show what is happening to a person’s brainwaves during the EEG. If there is something unusual about the pattern, this could be because of epileptic activity.

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

NICE (National Institute for Health and Care Excellence) guidelines and diagnostic tests

NICE is an independent organisation that provides guidelines for treatment and care for people using the NHS in England, Northern Ireland and Wales. The guidelines are for healthcare professionals, local authorities, charities, and patients and their carers. They are to help them make decisions about healthcare,
public health or social care services. They are also to make you aware of the services available, and to have the confidence to ask for the treatment, care, and information you need.

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

The NICE guidelines reflect this possible difficulty and will hopefully give you some back-up in getting the tests to happen in the most manageable way for the person you look after. You can find the particular guidelines at 1.16:

1.16.2.1 Those with learning disabilities may require particular care and attention to tolerate investigations
1.16.2.2 Facilities should be available for imaging under anaesthesia, if necessary

Website: nice.org.uk/guidance/CG137
**Epilepsy medicines**

For most people epilepsy medicine is the best and often only option for controlling seizures. For many people being on the right dose of the right epilepsy medicine or medicines can mean their seizures stop completely.

It can be really difficult or upsetting for some people with a learning disability to swallow tablets. There are usually a variety of forms of the medicines, such as liquids and granules, available. So it’s worth getting the one that is most manageable in order to make sure the person takes 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

For everyone with epilepsy the aim is to get the best possible seizure control. 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. The aim of any treatment should be to help the person reach the best quality of life possible for them.

Below is some information which will help you to help the doctor choose the best 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 mean that the dose of their epilepsy medicine isn’t increased unnecessarily. These are the things people say trigger seizures:
• Not taking epilepsy medicine as prescribed
• Feeling tired
• Not getting enough sleep
• Stress
• Alcohol
• Flashing or flickering lights
• Menstruation (periods)
• Missing meals

Fever and infection can also make it more likely that someone will have a seizure. Changes in other medicines, especially stopping sedating medicines, can also trigger seizures.

Sleep disorders and metabolic conditions
Between three and six out of every 10 people with a learning disability (30% to 60%) will 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.

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 and 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.

**Side-effects of epilepsy medicine**

As the carer you are likely to notice changes in emotional and physical health and behaviour of the person you are looking after. Here is some information which may help you decide what may be useful to share with a doctor:

- A person with a severe learning disability is more likely to have side-effects than someone with a milder learning disability
- Small 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 the general population
- Side-effects could explain someone’s reluctance to take epilepsy medicine
- Side-effects could result in behaviour problems
- Having too much of an epilepsy medicine could result in behaviour problems
- Taking a number of epilepsy medicines can often result in significant side-effects
- Side-effects could reduce the person’s ability to understand things
It is also worth knowing that a number of the older epilepsy medicines can cause osteoporosis. Always check with the doctor or pharmacist before giving someone over-the-counter medicines. Some epilepsy medicines have long lists of medicines that interact with them.

**Other 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. There are a number of conditions, such as: psychiatric disorders, anxiety, behavioural problems, autism and attention deficit/hyperactivity disorder.
Psychiatric disorders
People with learning disabilities and epilepsy are more likely to develop psychiatric disorders than people with learning disabilities alone. Some doctors avoid treating psychiatric disorders, such as depression, with medicine because they think that they will provoke seizures. Evidence shows they can be safe and effective. It is important to bear in mind that epilepsy medicines can be a cause of psychiatric disturbances. It could be possible to change them so that the disturbances no longer happen. It is a good idea to talk this through with the doctor.

Some doctors have seen that barbiturates, benzodiazepines, vigabatrin, tiagabine and levetiracetam can cause psychiatric disturbance, especially in someone with a family history of psychiatric disorder. But it is important never to stop taking prescribed medicines without medical guidance.

Behavioural problems
As well as the side-effects of epilepsy medicines already listed, there are many other possible reasons for behavioural disturbance in a person with a learning disability and epilepsy. Here are some possible causes:
• Gastro-oesophagal reflux
• Sleep disturbance
• Appetite change
• Ability
• Communication
• Environmental issues
• Autistic traits
Autism
Diagnosing seizures in someone who already has a learning disability and autism can be complex. A video of the person’s seizures can be particularly helpful in this situation.

If the person you look after has all three conditions it is vital for the various professionals involved to communicate with each other.

Other ways of treating epilepsy
For some people who are still having seizures despite trying a number of epilepsy medicines, epilepsy surgery may be an option. The assessment for surgery is complex but it should be offered to patients where it is believed epilepsy is coming from one part of the brain. When a person with a learning disability is suitable for surgery the results can be very good.

If surgery isn’t a treatment option, the doctor may discuss the possibility of vagus nerve stimulation (VNS) or the ketogenic diet.

VNS is a treatment for epilepsy where a small device is implanted under the skin below the left collar bone. This device, similar to a pace-maker, is called a generator. The generator is connected to a thin wire, which stimulates the vagus nerve in the person’s neck at regular times throughout the day. This sends impulses to the brain, which helps to prevent electrical activity that causes seizures.
The ketogenic or modified Atkins diet is sometimes used to try and help children whose seizures cannot be reduced or stopped with epilepsy medicine. The diet is higher in fats and lower in carbohydrates than a typical diet. Just occasionally this may be suggested for an adult.

**Seizure diaries**

Keeping a seizure diary is a good way of having a record of someone’s health day by day. It’s also a really efficient way of showing a neurologist possible connections between changes in someone’s seizure control, general health, dose changes and side-effects. Epilepsy Action has seizure diaries.

**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. Epilepsy Action has care plans. These are not in Easy Read but you could use one alongside an Easy Read healthcare passport. Website: ekhufnhs.uk/my-healthcare-passport

**Guidelines and treatment**

In order to get the best healthcare for the person you are looking after, you need to know about the National Institute for Health and Care Excellence (NICE) guidelines.
There are NICE guidelines about treatment and care for someone with epilepsy. And there are some specific guidelines for people with epilepsy and a learning disability. These can be found at 1:16.

In particular, it is worth knowing about this one:

1.16.3.1 Enable children, young people and adults who have learning disabilities, and their family and/or carers where appropriate, to take an active part in developing a personalised care plan for treating their epilepsy while taking into account any comorbidities. (These are other conditions which can happen at the same time as learning disabilities.)

Website: nice.org.uk/guidance/cg137/chapter/1-Guidance

There are specific NICE Guidelines for someone with challenging behaviour and a learning disability.

Website: nice.org.uk/guidance/ng11

The Challenging Behaviour Foundation provides information and support.

Helpline: 0300 666 0126
Website: challengingbehaviour.org.uk/contact
Emergency treatment for seizures that last a long time

Many people have seizures that last for less than 5 minutes and stop without any treatment. However, some people have seizures that last longer than 5 minutes. Seizures that last longer than 30 minutes can cause damage to the brain, or even death. This is also the case for a cluster of shorter seizures that last for 30 minutes or more. In both cases, this is known as status epilepticus. Seizures lasting for more than 5 minutes need treating before they turn into status epilepticus. Any type of seizure can become status epilepticus.

Tonic-clonic (convulsive) status epilepticus
During a long convulsive tonic-clonic seizure, the body struggles to circulate oxygen. When this happens, the brain doesn’t get enough oxygen. Over a long period, this can lead to brain damage and death.

Other types of status epilepticus
Other types of seizures can also turn into status epilepticus, so also need treating if they last more than 5 minutes.

Non-convulsive status epilepticus
Some people with epilepsy, particularly people with learning disabilities or an epilepsy syndrome, have a different type of status epilepticus. They may just appear to be vacant. Or they might have some minor twitches in their face or rolling of their eyes. These can be symptoms of non-convulsive status epilepticus. The only clues to this will be changes in their brainwave patterns that can be seen on an
electroencephalogram (EEG). It’s important that you are aware of this, as it can last for weeks, if not treated.

Rectal diazepam and buccal midazolam are both used as an emergency treatment. Buccal midazolam has the advantage of not compromising a person’s dignity when it’s used. The issue of consent to emergency treatment can be a challenging one for the person involved and the carer. The NHS Choices website has some helpful information on definitions of consent and what to do if that is difficult to get.
Website: nhs.uk/Conditions/Consent-to-treatment/Pages/Introduction.aspx
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.

SUDEP

People with epilepsy and a learning disability are more likely to die early than other people. So it’s especially important to know about sudden unexpected death in epilepsy (SUDEP). This is a difficult topic, but something it’s really important for you to know about as a carer.

Here is the NICE guideline that underlines that:

1.16.3.7 Healthcare professionals should be aware of the higher risks of mortality for children, young people and adults with learning disabilities and epilepsy and discuss these with them, their families and/or carers.

The most important thing about SUDEP is knowing the way to reduce risks. The biggest cause of SUDEP is night time convulsive seizures. Make sure the doctor knows about these because reducing the number of night time seizures is the best way to reduce the risk of SUDEP. If the person you look after is still having night time seizures it is a really good idea to get some sort of bed alarm or listening device so you know when they are happening. Doctors also recommend you sit with the person for up to an hour after the seizure has finished.
**In hospital**

NHS Choices has a range of useful guidance about getting the person you look after the best care and treatment while in hospital.

Website: nhs.uk/Livewell

In particular you may find it useful to download a hospital passport. Here are two options:

- East Kent healthcare hospital passport template, extensive but not Easy Read
  Website: ekhufnhs.uk/my-healthcare-passport

- Easy Read Healthcare passport. This one is suitable for hospital but can also be used more generally
  Website: easyhealth.org.uk/hospital-passports-(leaflets)
Living with epilepsy and a learning disability

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)

Mencap, an organisation which supports people with learning disabilities, has a range of information on education. Website: mencap.org.uk

The equality laws

The person you are caring for is protected under the equality laws. You are also protected as someone who may face discrimination because you’re caring for someone also covered by the equality laws.

If the person you are looking after is being refused access to a place or a service, you will need to check if the organisation has done an individual risk assessment. If they haven’t, they need to do one. And then if they do identify any actual risks, they will need to consider what reasonable adjustment 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 cannot identify any possible reasonable adjustments.
Social care

As a full time carer it’s not always easy to find the time or the energy to look for the information and resources you may need. Your Community Learning Disability Team could be a good first local point of support for you. Your local social services or council should be able to tell you how to get in touch with them.

There is also a great deal of information about social care and financial support for carers on the NHS Choices website.

Our thanks

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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 professionals.

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Useful organisations

**Carers Trust**
Website: carers.org

**Carers Direct**
Telephone: 01436 671389
Website: carersdirect.com

**Carers UK**
Helpline: 0808 808 7777
Website: carersuk.org.uk

**British Institute of Learning Disabilities**
Supporting organisations which provide services for people with learning disabilities
Tel: 01562 723 010
Website: bild.org.uk

**Mencap**
Supporting people with a learning disability
Helpline: 0808 808 1111
Website: mencap.org.uk

**Scope**
Making the country a better place for disabled people
Helpline: 0808 800 3333
Website: scope.org.uk

**Change**
Easy Read publications
Website: changepeople.org/easy-read-services

**Foundation for people with learning disabilities**
Influencing policies and services
Tel: 020 7803 1100
Website: learningdisabilities.org.uk

**NHS Choices**
Website: nhs.uk

**Epilepsy Action resources**

**Managing your epilepsy**
A DVD for people with learning disabilities, their families, carers or professionals working with them.
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 is in a wheelchair.
Further information

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

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

Epilepsy Action has a range of online courses and learning resources about epilepsy.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue. Or download a copy at epilepsy.org.uk/catalogue

Epilepsy Action’s support services

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

Coffee and chat groups: these give people living with epilepsy the chance to meet new people, share experiences and learn more about life with epilepsy.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy aged 16 years or over. Join at forum.epilepsy.org.uk

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.
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.

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<td>I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline, support groups or forum4e</td>
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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

Thank you.
Epilepsy Action
FREEPOST RTGS-LEYK-XGCK,
New Anstey House,
Gate Way Drive,
Yeadon,
Leeds LS19 7XY

Registered charity in England (No. 234343)
Ways to contact the Epilepsy Action Helpline

**Telephone: freephone 0808 800 5050**
We are usually open 8.30am to 5.30pm, Monday to Friday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.

**Email: helpline@epilepsy.org.uk**
Email us your question about epilepsy. We aim to reply within 48 hours (on work days)

**Text: 0753 741 0044**
Text us and we aim to send a text reply back to your phone within 24 hours (on work days)

**Twitter: @epilepsyadvice**
Tweet us with your question and we will tweet back (on work days)

**Post: New Anstey House, Gateway Drive, Leeds, LS19 7XY**
Write to us and we aim to reply within seven working days

About the Epilepsy Action Helpline

We do:
• Provide confidential advice and information about epilepsy to anyone
• Give general medical information
• Give general information on legal and welfare benefit issues related to epilepsy

We do not:
• Tell people what to do
• Offer a medical diagnosis or suggest treatment
• Take up people’s legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

We welcome feedback, both positive and negative, about our services.
Epilepsy Action Helpline:
freephone 0808 800 5050
epilepsy.org.uk

Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
tel 0113 210 8800  email epilepsy@epilepsy.org.uk

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low-chlorine bleached paper. All paper used to make this booklet is
from well-managed forests.