Health information

- The link between epilepsy and learning disabilities
- Definition of epilepsy
- Causes of epilepsy
- Different seizure types
- Diagnosing epilepsy
- Epilepsy medicines
- Other conditions
- Other ways of treating epilepsy
- Seizure diaries
- First aid
- Care plans
- Emergency treatment for seizures that last a long time
- Safety
- SUDEP
- NICE guidelines and treatment
- In hospital

Living with epilepsy and a learning disability

- Education
- The equality laws
- Social care
- Financial support
- Epilepsy Action resources
- Useful organisations
Information for carers of people with epilepsy and a learning disability

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.

Amongst 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 hundred people with a learning disability, twenty two 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 (2 out of every hundred). 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.\(^4\)

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.\(^5\) The brain is responsible for all the functions of your body. What happens to you during a seizure will depend on where in your 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 when you’re very young, and some start later in life. Some types last for a short time and other types can last for the whole of your life.

Epilepsy Action has an introduction to [living with epilepsy](#).

**Causes of epilepsy**

Some people develop epilepsy because of brain damage caused by a difficult birth, a severe blow to the head,\(^6\) a stroke,\(^7\) or an infection of the brain such as meningitis.\(^8\) Very occasionally the cause is a brain tumour.\(^9\)

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.

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

---

\(^4\) Epilepsy prevalence, incidence and other statistics, Joint Epilepsy Council, September 2011
\(^6\) NHS choices 2012 Epilepsy – Causes [online] Available at: [http://www.nhs.uk/Conditions/Epilepsy/Pages/Causes.aspx](http://www.nhs.uk/Conditions/Epilepsy/Pages/Causes.aspx) [accessed 20 November 2012]
\(^7\) NHS choices 2012 Epilepsy – Causes [online] Available at: [http://www.nhs.uk/Conditions/Epilepsy/Pages/Causes.aspx](http://www.nhs.uk/Conditions/Epilepsy/Pages/Causes.aspx) [accessed 20 November 2012]
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.

Epilepsy Action has more information about seizure types

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 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 and non-convulsive status can be underdiagnosed
- A number of people with learning disabilities and epilepsy also have non-epileptic seizures.

An electroencephalogram (EEG) is one of the more common tests for epilepsy. It will show what is happening to your 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 guidelines and diagnostic tests

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.\(^5\)

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 Action has more information about diagnosing epilepsy and about the NICE guidelines

**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\(^6\)

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 pill reminders see the Disabled Living Foundation website

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 most common triggers for seizures:

- Not taking epilepsy medicine as prescribed
- Feeling tired


\(^6\) E. Brodtkorb, 2004, Management of Epilepsy in people with Learning Disability, In: Shorvon, Perucca, Fish and Dodson (Eds.) The Treatment of Epilepsy, second edition, Massachusetts, Blackwell, p 216
- Not getting enough sleep
- Stress
- Alcohol
- Flashing or flickering lights
- Menstruation (periods)

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

**Sleep disorders and metabolic conditions**

Between three and six out of every ten 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 your 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 it may be useful to share with the 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.

---

22 Delivery of epilepsy care to adults with intellectual and developmental disabilities. - PubMed - NCBI. Available at:
• People with epilepsy and a learning disability may well have side-effects which are different from the general population. 
• Small side-effects could explain someone’s reluctance to take epilepsy medicine
• Small side-effects could result in behaviour problems
• Having too much of an epilepsy medicine in your system 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 many of the older epilepsy medicines can cause osteoporosis.

Always check with your doctor or pharmacist before giving someone over-the-counter medicines. Some of the older 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. Here are some of the conditions:

• Psychiatric disorder
• Depression
• Anxiety
• Behavioural problems
• Autism
• 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.

**Behaviour disorders**

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-oesophageal 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 intervals.

---


31 Consensus guidelines into the management of epilepsy in adults with an intellectual disability. - PubMed - NCBI. Available at: [Accessed October 27, 2015].p693

32 Consensus guidelines into the management of epilepsy in adults with an intellectual disability. - PubMed - NCBI. Available at: [Accessed October 27, 2015].p692
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.

Epilepsy Action has more information about epilepsy medicines, surgery, VNS and the ketogenic diet.

**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

**First aid**
Epilepsy Action has more information on first aid, including what to do if someone is in a wheelchair.

**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.33

Epilepsy Action has care plans. These are not in Easy Read but you could use one alongside an Easy Read healthcare passport

Website: ekhuft.nhs.uk/my-healthcare-passport

**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.

**What type of seizures 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](https://nhs.uk/Conditions/Consent-to-treatment/Pages/Introduction.aspx)

Epilepsy Action has more information on emergency treatment for seizures that last a long time.

**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.

Epilepsy Action has information about safety and about daily living aids

**SUDEP**

Sudden unexpected death in epilepsy is a difficult topic, but something it’s really important for you to know about as a carer. Epilepsy is the second highest cause of death for people with learning disabilities.

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.\textsuperscript{35}

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.

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

NICE guidelines and treatment

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.

In order to get the best healthcare for the person you are looking after, you need to know about the NICE guidelines.\textsuperscript{36} 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.\textsuperscript{37}

\textsuperscript{35} The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care | 1-Guidance | Guidance and guidelines | NICE. Available at: https://www.nice.org.uk/guidance/cg137/chapter/1-Guidance [Accessed September 30, 2015].

\textsuperscript{36} The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care | 1-Guidance | Guidance and guidelines | NICE. Available at: https://www.nice.org.uk/guidance/cg137/chapter/1-Guidance [Accessed September 30, 2015].

The Challenging Behaviour Foundation provides information and support.
Helpline: 0300 666 0126
Website: challengingbehaviour.org.uk/contact

In hospital
NHS Choices is a government health website. It has a range of useful guidance about getting
the person you look after the best care and treatment while in hospital.
Website: nhs/Livewell

In particular you may find it useful to download an Easy Read hospital passport. Here are
two options:
• Easy Health hospital passport template
  Website: ekhuft.nhs.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)
Epilepsy Action has information on the responsibilities of schools, an IHP template and
information on support for children with special needs
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.

Epilepsy Action has more information on the equality laws

**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. Also NHS Choices is a good source of a range of information on social care. This includes:

- Getting the right social care for adults
- Getting the right social care for children
- How to get adaptations and daily living aids in your home
- Finding respite care
- Finding the right accommodation
- Finding residential care
- Tackling the question What will happen after I die?

**Financial support**

NHS Choices is a very good source of information on financial support for a carer of a person with a learning disability.

- Carers allowance
- PIP
- Direct payments
- Personal health budgets
- Continuing care

**Useful organisations**

**Carers Trust**
Website: [carers.org](http://carers.org)

**Carers Direct**
Telephone: 01436 671389
Website: [carersdirect.com](http://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
Telephone: 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
Telephone: 020 7803 1100
Website: learningdisabilities.org.uk/

**NHS Choices**
nhs.uk

**Epilepsy Action resources**

**Managing your epilepsy**
A DVD for people with learning disabilities, their families, carers or professionals working with them.

**Easy read information**

- Information about epilepsy
- Epilepsy medicines
- Different epileptic fits
- First aid

**About this information**

This information 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 information, please contact us at epilepsy.org.uk/feedback

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

**Our thanks**
Epilepsy Action would like to thank Professor M. Kerr, Welsh Centre for Learning Disabilities for his contribution to this information. Professor Kerr has no conflict of interest.

**Date:** November 2015  
**Due for review:** November 2018  
**Code:** B010.03

**Your support**
We hope you have found this information 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 [www.epilepsy.org.uk/donate](http://www.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 to the address below.

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.

**Epilepsy Action Helpline**
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

**Contact details**
Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800. A registered charity (No. 234343) and company limited by guarantee (No. 797997) in England.

© Copyright Epilepsy Action 2016