Introduction

This information is for anyone who cares for someone with epilepsy and learning disabilities. It looks briefly at what it means to have a learning disability and how learning disabilities and epilepsy might be linked. It also looks at diagnosing and treating epilepsy and how someone who has epilepsy and learning disabilities can get the best care.

About learning disabilities and epilepsy

The meaning of learning disabilities
People who have learning disabilities find it a lot more difficult to learn and understand than other people. They may find it hard to use what they have learned in practical ways. This means they will need help and support with everyday living skills. Some people need high levels of help and support. Other people, with some help, are able to live quite independently.

Some people with learning disabilities prefer the term 'learning difficulties'. In the UK, 'learning difficulties' tends to be used to describe specific learning problems.

More information about learning disabilities in the UK is available from Mencap: Freephone: 0808 808 1111 (UK only). Website: www.mencap.org.uk

The causes of learning disabilities
Around one in every four people with epilepsy has learning disabilities. Around half of all people with learning disabilities has epilepsy. A learning disability is caused by something that affects the way the brain develops. This can happen before, during or soon after birth. These are some examples.

---

Before birth - damage to the baby’s brain and the spinal cord can cause a learning disability. If a pregnant woman is ill or has an accident, particularly a road traffic accident, her baby may be born with learning disabilities. Some babies are born with learning disabilities if they have a genetic problem, such as Down’s syndrome.

During birth - a child can be born with a learning disability if they don’t get enough oxygen during birth.

Soon after birth - a child can develop a learning disability if they have had a serious illness, such as meningitis, or brain injuries. These cause problems with the way the brain develops.

Some children who are born too early will have learning disabilities.

Sometimes, the cause of learning disabilities can’t be found.

About epilepsy

If you have epilepsy, it means that you sometimes have seizures. Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity. This intense electrical activity causes a temporary disruption to the way the brain normally works, meaning that the brain’s messages become mixed up. The result is an epileptic seizure.

Your brain is responsible for everything your body does. What happens to you during a seizure will depend on which part of your brain the epileptic activity begins, and how widely and quickly it spreads. There are many different types of seizure and each person will have epilepsy in a way that is unique to them.

Epilepsy Action has more information about seizures.

The link between learning disabilities and epilepsy

Damage to the brain can cause learning disabilities. The damaged part of the brain can then become irritable and cause epileptic seizures. Some people might not start having seizures until many years after the damage has happened.

In some people, epilepsy and learning disabilities can both be part of a syndrome. A syndrome is a group of signs and symptoms that, added together, point to a particular medical condition. These are some examples of syndromes where a person might have epilepsy and learning disabilities.

- Down’s syndrome
- Rett’s syndrome
- Sturge-Weber syndrome
- Lennox-Gastaut syndrome
- Landau-Kleffner syndrome

Epilepsy Action has more information about syndromes.

---


Diagnosing epilepsy in people with learning disabilities

Epilepsy is difficult to diagnose. This is because there is no one test that can say that someone has epilepsy. Diagnosing epilepsy in a person with learning disabilities can be even more difficult. This is for several reasons. For example, some people with learning disabilities have repeated behaviours, or movement disorders, which can be mistaken for seizures.

They might find it hard to let others know what has happened to them, or how they feel. An epilepsy specialist is the best person to decide which symptoms are epilepsy, and which are not. This is important to make sure the person gets the best treatment for their condition.

Epilepsy Action has more information about diagnosing epilepsy.

Visiting the doctor

This information is a guide to questions that may come up at an appointment with the epilepsy specialist. Sometimes, your family doctor or an epilepsy nurse will go through these, or similar questions, with you

- When did the seizures start?
- When do the seizures happen?
- How often do they happen?
- Are there any possible cause(s)?
- What do the seizures look like?
- Are there any particular seizure triggers?
- Is there a known cause for the person’s learning disabilities?
- Does the person have any physical, behavioral or medical problems?
- What kind of epilepsy medicine have they been prescribed?
- Do you know the dose? Does the epilepsy medicine cause any problems?
- Have they had any different epilepsy medicines prescribed in the past? If they have, why were they changed?
- Have they had any medicine prescribed for any other condition?
- Have they had any tests, such as EEG, CT or MRI scans?

The answers to these questions can be used to make a diagnosis and write an individual care plan. This is sometimes known as a patient care plan. Lancashire Teaching Hospitals NHS Trust has kindly agreed to let Epilepsy Action use their patient care plan. Copies of this are available from Epilepsy Action.

Epilepsy Action has more information about seizures, triggers for seizures, epilepsy medicines and tests for epilepsy.

Keeping a record of seizures

It can be useful to keep a written record of when seizures happen. A record should include the dates and type of seizures. It might also record any other details, such as late nights, periods, or illness. All of these can be triggers of epileptic seizures for some people.
Seizure diaries are available from Epilepsy Action.

**Treatment of epilepsy in people with learning disabilities**

**NICE and SIGN Guidelines**

NICE is the National Institute for Health and Clinical Excellence (NICE). It provides guidelines on treatments and care for people using healthcare, public health, or social care services in England, Wales and Northern Ireland.

The Scottish Intercollegiate Guidelines Network (SIGN) provides guidelines for the National Health Service in Scotland.

The NICE Guidelines (2012) and SIGN Guidelines (2005 and 2010) on the treatment of epilepsy, say that people with learning disabilities should have the same access to treatment for their epilepsy as anybody else. If they have additional treatment needs, the most appropriate health professionals should meet those needs.

Epilepsy Action has more information about the NICE and SIGN guidelines.

**Why seizures are treated**

The most common way seizures are treated is with epilepsy medicines. If someone is still having seizures, they might be injured or even die early. Epilepsy medicines help to stop seizures happening, but they don’t cure epilepsy.

Epilepsy Action has more information about the treatment of epilepsy.

**Treating people with epilepsy and other conditions**

People with learning disabilities may have other conditions. For example, they may have a number of health problems and possibly some physical disabilities. The following are some of the more common conditions.

- Feeding or swallowing problems. These make it difficult to eat a good diet or take epilepsy medicines and other medicines.
- Constipation and urine infections. These can cause more seizures.
- Communications difficulties. These can make it difficult to talk about problems, or make needs known.

**Emergency treatment for seizures that last a long time**

Most people have seizures that only last for a short time. These seizures usually stop by themselves, and don’t need emergency treatment.

Some people have seizures that last for longer than 30 minutes, or have one seizure that follows another without becoming conscious in between, for 30 minutes or more. This is called status epilepticus and it is a medical emergency.

---

If you think somebody is having an episode of status epilepticus, you should call for an ambulance.

Epilepsy Action has more information about status epilepticus

**Help and support in the community**

**Community teams for people with learning disabilities**
Community teams for people with learning disabilities (CTLDs) include different professionals, such as nurses, social workers, physiotherapists, occupational therapists, speech and language therapists, psychologists and psychiatrists. CTLDs help and support people with learning disabilities. They are also able to refer to other professionals, if needed. A family doctor, specialist or social worker can refer people to local CTLDs. The person you care for, or you as a carer, can also contact your CTLD direct.

The following organisations can tell you more about services in your area.

- **England and Wales** – your local Social Services office
- **Northern Ireland** – Department of Health, Social Services and Public Safety
- **Scotland** – your local Social Work Department
- **All of UK** - Your local Citizens Advice Service, tel: 0207 833 2181 (for details of your local branch), website: www.adviceguide.org.uk
- Your local library.

**Further sources of information**

**British Institute of Learning Disabilities**
Telephone: 01562 723 010 (from the UK)
Website: www.bild.org.uk

**Carers UK**
Carers Line: 0808 808 7777 (from the UK)
Website: www.carersuk.org.uk

**Mencap**
Learning disability helpline: 0808 808 1111 (from the UK)
Website: www.mencap.org.uk

**Scope**
Scope response helpline: 0808 800 3333 (from the UK)
Website: www.scope.org.uk

---

Publications and DVDs for people with learning disabilities available from Epilepsy Action

**Finding out about epilepsy** (spiral-bound wipe clean book)
An excellent learning tool. It was written by specialists experienced in working with people with epilepsy and learning disabilities.
Published by Epilepsy Action.

**Managing your epilepsy** (DVD and video)
This features a cast of young people with learning disabilities. It looks at living with epilepsy and how best to manage it.
Produced by Epilepsy Action

Please contact Epilepsy Action to order these publications.
The Epilepsy Helpline, freephone: 0808 800 550
Epilepsy Action’s online shop: [shop.epilepsy.org.uk](http://shop.epilepsy.org.uk)

**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](http://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 Prof. M. Kerr, Welsh Centre for Learning Disabilities, who reviewed and contributed to this information. We would also like to thank Mencap, who provided information about the causes of learning disabilities.

**Date:** September 2012  
**Due for review:** September 2015  
**Code:** B010.02

**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 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