Epilepsy and learning disabilities

www.epilepsy.org.uk
Epilepsy Helpline: 0808 800 5050
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 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.

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

This booklet 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

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 they 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)
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: www.epilepsy.org.uk/shop
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 learning disability experts. If you would like to know where our information is from, or there is anything you would like to say about the booklet, please contact us.

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.

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Code: B010.02

Acknowledgements

Epilepsy Action would like to thank Professor Mike Kerr for his contribution. Professor Kerr has declared no conflict of interest.
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 in the recovery position when the seizure has finished (see the pictures)
- Stay with them until recovery is complete
- Be calmly reassuring

![Diagram of first aid steps](image)

**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
- The seizure continues for more than five minutes
- One seizure follows another without the person regaining consciousness between seizures
- The person is injured
- 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
- The seizure continues for more than five minutes
- The person is injured
- You believe the person needs urgent medical attention
Further information

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

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

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue.

Epilepsy Action’s support services

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

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at www.forum4e.com

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.
Epilepsy and learning disabilities

Please complete this form to tell us what you think of this publication.

How useful have you found this publication?

☐ Very useful  ☐ Useful
☐ Quite useful  ☐ Not at all useful

Is the language clear and easy to understand?

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☐ Clear and easy to understand
☐ Quite clear and easy to understand
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Does this publication cover all you want to know about the topic?

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Epilepsy Action
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LEEDS
LS19 7YY

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

Telephone the Epilepsy Helpline freephone 0808 800 5050
Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm
Our helpline staff are Text Relay trained

Write to us free of charge at
FREEPOST LS0995, Leeds LS19 7YY
Email us at helpline@epilepsy.org.uk or visit our website:
www.epilepsy.org.uk Text your enquiry to 0753 741 0044
Send a Tweet to @epilepsyadvice

About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people’s cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative, about our services.

To ensure the quality of our services we may monitor calls to the helpline.
Epilepsy Helpline:
freephone 0808 800 5050
www.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.