Epilepsy and learning disabilities

Epilepsy Action and NHS Tayside – working together to support people with epilepsy.
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.

Join us...

You can help us in our vital work by becoming a member. All members receive our magazine *Epilepsy Today*, free cover under our unique personal accident insurance scheme and access to our services and conferences.

“Our vision is to live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction”

*Epilepsy Action, vision statement*
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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.

Acknowledgements

Our thanks to Prof M Kerr, Welsh Centre for Learning Disabilities, Centre for Health Sciences Research, Cardiff University, who reviewed and contributed to this booklet. Also to Mencap, who provided information about the causes of learning disabilities.
The meaning of learning disabilities

People with learning disabilities find it a lot more difficult to learn and understand than people without learning disabilities. They may find it hard to use what they have learned in practical ways. Because of this, they are likely to 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.

The causes of learning disabilities

A learning disability is caused by something that affects the way the brain develops, usually before, during or soon after birth. These are some examples.

- **Before birth**, damage to the central nervous system (the brain and the spinal cord) can cause a learning disability. Rarely, a child can be born with a learning disability if their mother has an accident or illness while she is pregnant. Some babies are born with learning disabilities if they have a genetic problem, such as Down’s syndrome.

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

- **After birth**, a learning disability can be caused by early childhood illnesses, such as meningitis, or accidents, which cause problems with the child’s development.

In about five out of every 10 people with a learning disability, the cause is never found. As the knowledge of genetics increases, more causes are being identified.
About epilepsy

If someone is diagnosed with epilepsy, it means they have a tendency to have seizures (sometimes called fits). Seizures can happen in any part of the brain. The brain is responsible for all the functions of our mind and body. So, what someone experiences during a seizure will depend on which part of the brain is affected by the seizure.

The link between learning disabilities and epilepsy

Learning disabilities can be caused by damage to the brain. This damaged part of the brain can then become irritable and cause epileptic seizures. These seizures might not appear until many years after the damage 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.) Examples of syndromes where someone might have epilepsy and learning disabilities are Down’s, Rett’s, Sturge-Weber, Lennox-Gastaut, and Landau-Kleffner syndromes.

Diagnosis and treatment

NICE and SIGN Guidelines
The National Institute for Health and Clinical Excellence (NICE) is an organisation that provides guidance on treatments and care for people using the NHS in England, Wales and Northern Ireland. In Scotland the Scottish Intercollegiate Guidelines Network (SIGN) performs a similar role. The NICE Guidelines (2004) and SIGN Guidelines (2003) on the treatment of epilepsy, state that people with learning disabilities should have the same access to treatment for their epilepsy as anybody else. They may also have additional treatment needs, which should be met by appropriate health professionals.
The difficulties of diagnosing epilepsy

Epilepsy can be difficult to diagnose. This is because there is no one test that will say for certain that someone has epilepsy. Diagnosing epilepsy in a person with learning disabilities can be even more difficult. This is for several reasons. Some people with learning disabilities have repetitive behaviours, or movement disorders that can be mistaken for partial seizures. In addition, they might find it hard to communicate what has happened to them, or how they feel. Also, people may feel that certain behaviours are caused by seizures. An epilepsy specialist is the best person to decide which symptoms are related to epilepsy, and which are not. This is important to make sure the person gets the best treatment for their condition.

Information on how epilepsy is diagnosed is available from Epilepsy Action.
Referral to a specialist

A person with a learning disability, who may also have epilepsy, should be referred by their GP to an epilepsy specialist for an assessment. This may be at a general epilepsy clinic or at a specialist epilepsy clinic for people with learning disabilities. These are some of the questions that might come up.

- 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, behavioural or medical problems?
- What kind of anti-epileptic drugs (AEDs) have been prescribed? Do you know the dosage? Do these cause any problems?
- Have any different AEDs been prescribed in the past? If so, why were they changed?
- Have any drugs been prescribed for any other condition?
- Have any tests, such as EEG, CT or MRI scans been done?

This information will be used in an individual treatment plan. It will help a carer to give the help or care that is needed.

The NICE and SIGN Guidelines (see page 6) recommend that people with epilepsy should have their epilepsy and treatment reviewed every year.

Emergency care

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 30 minutes or longer, or a series of seizures without becoming conscious in between. This is called status epilepticus.
Research shows that using rescue medicine can stop the seizures at home or in the community. Diazepam is given rectally (in the back passage). Midazolam is given buccally (inside the cheek or nose.)

More information about emergency medicines is available from Epilepsy Action.
Individual treatment plans

People with learning disabilities are often cared for by a wide range of service providers. It’s important that they all know what to do in case of an emergency. If a person is likely to need emergency medicine, they should have an individual treatment plan. This should give essential information about when, and how, emergency medicine should be given. If the person doesn’t have a treatment plan, an epilepsy or learning disability nurse should be able to arrange one. The person with epilepsy should be involved in the writing of the treatment plan, if they are able.

Consent

It’s important that the person who has a history of status epilepticus is involved as much as possible when a treatment plan is being written. This will give them the chance to give their informed consent. Some people with epilepsy and learning disabilities are not able to make decisions about how they are treated. This means they can’t give informed consent.
Each country in the UK has rules that say who should make important treatment and care decisions on behalf of people who can’t give consent.

**Mental Capacity Act 2005**

The Mental Capacity Act 2005 is a law which covers people in England and Wales. It provides clear legal guidelines for making decisions for people over the age of 16 who can’t make decisions for themselves. The Act says that people should be able to understand what the medical treatment is, what it will do, and why it is being proposed for them. They also need to be able to understand the benefits and risks of the treatment, and whether other treatments could be used instead. The Act says that the person should understand what will happen to them if they don’t have the treatment. They should also be able to remember information long enough to make a decision. And, most importantly, they should have a choice of what happens to them, without being put under any pressure.
Adults with Incapacity (Scotland) Act 2000
In Scotland, the Adults with Incapacity (Scotland) Act 2000 allows doctors to authorise medical treatment, if the person doesn’t have the capacity to consent themselves. People with learning disabilities who can’t consent to treatment may also have a Welfare Guardian appointed under this Act. This guardian is able to consent to medical treatment on behalf of the person with a learning disability.

Consent in Northern Ireland
In Northern Ireland, there is no specific law to protect people who can’t give consent to their treatment. Therefore, the Mental Capacity Act, which covers England and Wales, is used as guidance.

Meeting people’s health needs
In England a strategy has been produced to shape the future of learning disability services. It’s called Valuing People Now (2009). In Scotland there’s a similar strategy called The same as you? (2000). These strategies stress the importance of people with learning disabilities having the same access to services as everyone else. For this to happen, everyone with learning disabilities should have a health action plan. A GP, nurse or other health professional should be able to arrange for a health action plan to be drawn up. However, when the epilepsy is more complex, it’s likely that a specialist service will help draw up this plan.

Treatment of seizures
Why we treat seizures
Anti-epileptic drugs (AEDs) are given to reduce or stop seizures. This is because a person who has uncontrolled seizures may be injured and need hospital treatment or even die early. They may not be able to drive or work in certain jobs. All decisions on treatment are designed to improve the person’s quality of life.
Anti-epileptic drugs (AEDs)
The main way of treating epilepsy is with anti-epileptic drugs (AEDs). It’s important that these are taken every day, as prescribed by the doctor. Doctors generally prefer monotherapy (using one AED at a time). When one AED doesn’t work, polytherapy (more than one drug) is usually the next step. Because AEDs don’t all work in the same way, it may be that two different AEDs together could improve seizure control. Many doctors would rather not give more than two drugs at a time.

Drug level monitoring
It can be useful in some circumstance, such as when people are having seizures or side-effects from their anti-epileptic drugs (AEDs), to measure blood levels. This is done by taking a blood sample. Blood levels show the amount of a drug in the body. If blood levels of AEDs are too high, they can cause unpleasant side-effects. If the blood levels are too low, the drug might not control seizures. Drugs can produce very different blood level readings in different people, even if they take exactly the same amount of drugs. This is because it takes some people longer than others to break down the AEDs in their bodies and get rid of each dose.
Drug levels can only be used as a general guide. And some AEDs are not suitable for measuring in this way. So, a doctor or nurse shouldn’t usually change the dosage of AEDs on the basis of drug levels alone. The AED phenytoin is an exception to this. The doctor or nurse should also take into account how the person feels, and any problems they are having. It’s also important they look out for symptoms such as drowsiness or unsteadiness, which could be a sign the person is taking too many AEDs. If you are caring for someone, you could keep a record of any of these signs or symptoms, to show the doctor or nurse. You might want to keep a special seizure/side-effect diary for this purpose.

Vagus nerve stimulation (VNS)
Vagus nerve stimulation (VNS) is a treatment for epilepsy where a small device (similar to a heart pacemaker) is put under the skin in the chest. This is attached to a lead which is connected to the vagus nerve in the side of the neck. Stimulating the vagus nerve can mean someone could have fewer, less severe seizures. The VNS seems to work well for some people, but not for others.

Ketogenic diet
The ketogenic diet is a diet that is high in fats and low in carbohydrates. It’s sometimes used to treat children with difficult to control epilepsy. Although some children find the diet unpleasant and difficult to follow, other children manage it very well. The ketogenic diet should only be used under the supervision of a doctor and a dietician specialising in the ketogenic diet.

Currently, there are no centres offering the ketogenic diet for adults in the UK. This might change in the future, when more research has been done.

Further information on the treatment of epilepsy is available from Epilepsy Action.
Other healthcare needs

People with learning disabilities tend to have more healthcare needs than many other people. They can have a number of health problems and often also have physical disabilities. The following are some of the more common healthcare needs.

• Feeding or swallowing difficulties. These will make it difficult to eat a good diet or take anti-epileptic drugs and other medicines.
• Constipation and urine infections. Urine infections and constipation can cause more seizures.
Keeping a record

It can be helpful to keep a written record of when a person’s seizures happen. This should include the dates and what kind of seizures they were. It may be useful to record any other details, such as having a late night, a period, or being unwell. All of these are known triggers of epileptic seizures for some people.

*Seizure diaries and more information about triggers are available from Epilepsy Action.*
Other information/resources – help and support

Community teams for people with learning disabilities (CTLDs)
CTLDs are made up of 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 and are also able to refer people to other professionals, if needed. A GP, specialist or social worker can also refer people to local CTLDs. As a carer, you or the person you care for, can also contact CTLDs 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
• Your local Citizen’s Advice Bureau (CAB)
• Your local library

Epilepsy Action
Epilepsy Helpline: freephone 0808 800 5050; helpline@epilepsy.org.uk; text 07797 805 390; www.epilepsy.org.uk

British Institute of Learning Disabilities
General enquiries: 01562 723 010; www.bild.org.uk

Carers UK
Carers line: 0808 808 7777; www.carersonline.org.uk

Mencap
Learning disability helpline: 0808 808 1111; www.mencap.org.uk

Scope
Scope response helpline: 0808 800 3333; www.scope.org.uk
Publications and DVDs for people with learning disabilities

Finding out about epilepsy (spiral-bound wipe clean book)
An excellent learning tool, written by specialists with many years’ experience in epilepsy and learning disabilities.
Published by Epilepsy Action.

Managing your epilepsy (DVD and video)
Featuring a cast of young people with learning disabilities, it explains different aspects of epilepsy and how to manage it.
Produced by Epilepsy Action

Getting on with Epilepsy
Spiral-bound book for people with learning disabilities and epilepsy and their carers.
Gaskell Publications. Available through Royal College of Psychiatrists: 020 7235 2351; www.rcpsych.ac.uk

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If you would like to know where we’ve got our information from, please contact us. Please quote B010.01

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.
Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline, freephone 0808 800 5050, email helpline@epilepsy.org.uk, text 07797 805 390 or visit our website www.epilepsy.org.uk

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Please contact the Epilepsy Helpline to request your free information catalogue.

Information is available in the following formats: booklets, fact sheets, posters, books, videos, DVDs and CDs.

Information is also available in Braille and large text.

Epilepsy Action’s support services

Local meetings: around 100 local branches offer support across England, Northern Ireland and Wales.

Volunteers: these are local people (usually with epilepsy or with a family member who has epilepsy) who have been specially trained by Epilepsy Action to give advice on a one-to-one basis. They can also give presentations about epilepsy to groups of people.

forum4e: our online community provides an opportunity to contact other people with epilepsy from all over the world, in a safe and secure website: www.forum4e.com (For ages 16 years and over.)

Live online advice: from time to time we run regular advice forums, where trained advisers answer your epilepsy questions live on our website. For more details, visit www.epilepsy.org.uk/liveadvice

If you would like more information about any of these services, please contact the Epilepsy Helpline or visit our website.
Epilepsy and learning disabilities

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Please return the completed form to:
Epilepsy Services, Epilepsy Action, FREEPOST LS0995, Leeds LS19 7YY
How to contact us

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 Typetalk 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 07797 805 390

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.
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freephone 0808 800 5050  text 07797 805 390
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All paper used to make this booklet is from sustainable forests.