



SIGN

Scottish Intercollegiate Guidelines Network

Part of NHS Quality Improvement Scotland



Epilepsy in children and young people

Booklet for patients and carers



Corporate member of
Plain English Campaign
Committed to clearer communication.

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What is this booklet about?

We have written this booklet for parents and carers of children and young people who have epilepsy. It is based on the recommendations from a national clinical guideline on how to look after children and young people with epilepsy.

The booklet will help to make you aware of tests and treatments that your child should expect to receive from the NHS. To make it easier to read, we talk about 'children' throughout this booklet but the advice applies to children and young people aged from one month to 19 years.

This booklet gives information about:

- ⦿ diagnosis and tests;
- ⦿ information, care and treatment;
- ⦿ epilepsy at school;
- ⦿ teenagers with epilepsy; and
- ⦿ where to get more information.

We have listed a number of support organisations at the end of the booklet where you can get more information.

On page 15 there is an explanation of all the medical terms we have used.

What is epilepsy?

Epilepsy is the tendency to have seizures caused by a temporary disturbance in brain activity. It affects around 7000 children and young people in Scotland. Most schools have at least one child with epilepsy.

There are many different types of epilepsy that need different treatments. Most children who have epilepsy will respond well to treatment and their seizures will stop. Many will grow out of their epilepsy and will no longer need treatment.

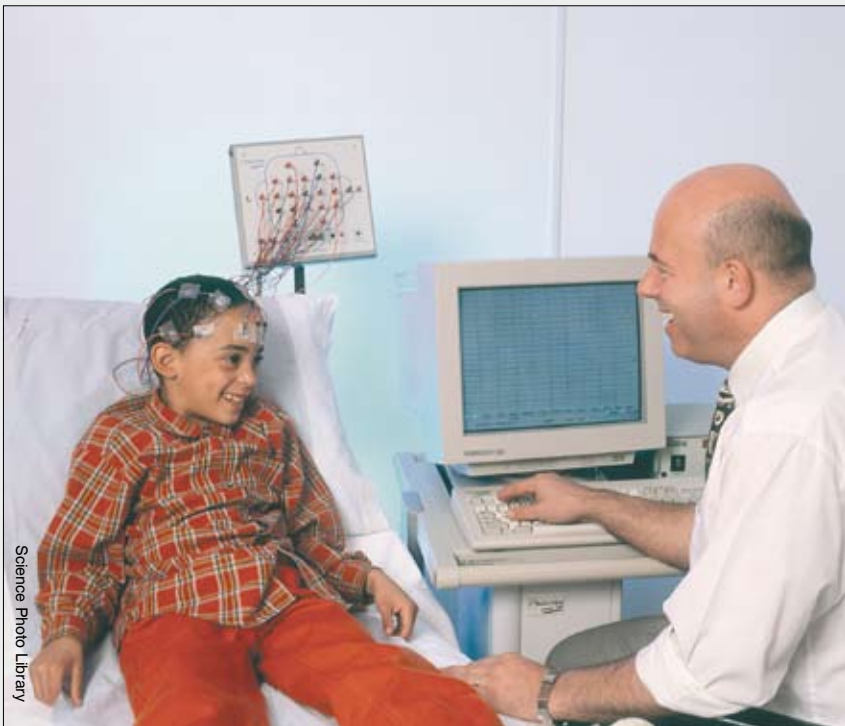


Diagnosis and tests

How will I find out if my child has epilepsy?

Fits, faints, jerks and blackouts are common in children. Less than half of these will be epileptic seizures. It can be very difficult to diagnose epilepsy in children and it may take some time before doctors can be sure that your child has epilepsy.

Epilepsy in children should be diagnosed by a paediatric neurologist or paediatrician with expertise in childhood epilepsy. A doctor will not usually diagnose epilepsy if your child has only had one seizure.



The doctor will talk to your child about the seizure. The doctor may also want to talk to anyone who saw your child having a seizure. This is so they can find out as much as possible about what happened before, during and after the seizure.

The doctor may also want your child to have some other tests to help with the diagnosis. They will discuss with you any tests that are needed. These may include an electrocardiogram (ECG), electroencephalogram (EEG) or brain scans such as magnetic resonance imaging (MRI) or computed tomography (CT).

We describe these tests in the glossary on page 15.

It is important to remember that not all children will need all tests and your doctor will be able to discuss this with you and your child.

Information, care and treatment

What information should I have?

You and your child have a right to clear, accurate and suitable information on your child's condition. You should be told about:

- ⦿ your child's type of epilepsy;
- ⦿ possible treatments; and
- ⦿ if and how your child's day-to-day life might be affected.

This information should be provided in a way that you find easy to understand. You and your child should have the chance to discuss any relevant issues. You may also like to talk to an epilepsy nurse specialist or someone from a voluntary-sector organisation.

You should be given information to take home, such as leaflets, fact sheets and videos. These should be in a format that you, your child, your family or carers find helpful.

You should be told who to contact for help or advice. Voluntary-sector organisations provide a wide range of services including information, advice, support and training. Many have helplines and websites. (See the contact details on page 13.)

Who will be involved in my child's care?

Your child should have their own management plan that describes how their epilepsy will be managed. This plan should be agreed with you and your child. You should be given copies of letters from the specialist clinic to your GP or your child's paediatrician.

Your child's specialist should see your child at least once a year. This gives you and your child the opportunity to discuss any relevant issues and to make sure you are up to date with any new developments in caring for people with epilepsy.

You and your child should be able to see an epilepsy nurse specialist.

The nurse can give you up-to-date information and advice. They can also be a link between your family, the school and other professionals involved in your child's care.

What treatment choices are there?

Your child should start taking antiepileptic medication under the guidance of a specialist (a paediatric neurologist or paediatrician with experience in epilepsy).

Your child, your family (if appropriate) and the specialist should decide together whether or not to start treatment after a full discussion about:

- ⦿ the type of seizures and whether or not they are likely to continue;
- ⦿ the risk of having seizures in various situations;
- ⦿ the possible side effects and benefits of different treatments; and
- ⦿ how long the treatment should continue.

If your child's epilepsy medicine is causing side effects or if your child is still having seizures, you should contact someone in the epilepsy team.

Up to 70% of children who have epilepsy grow out of their seizures. If your child has not had a seizure for two years, your doctor should discuss with you the possibility of reducing and stopping their medication.

How long does a seizure last?

Most seizures in children are short and last for less than five minutes. If a seizure lasts for longer than five minutes, it is called a 'prolonged seizure'. If a prolonged seizure is not controlled, it can lead to status epilepticus which is a seizure lasting for 30 minutes or longer.

Status epilepticus can be life-threatening and needs to be treated quickly in hospital.

What happens if my child has had a prolonged seizure?

If your child has had a prolonged seizure, you may be prescribed an emergency treatment. There is a choice of two emergency treatments that you can use. These are:

- ⦿ midazolam; or
- ⦿ diazepam.

Midazolam is a liquid that you drip into your child's cheek or nose. Diazepam also comes as a liquid that is given into the child's bottom (rectum). The doctor or epilepsy nurse specialist will discuss the treatment with you and help you to decide which is the best treatment for your child.

What is 'sudden unexpected death in epilepsy' (SUDEP)?

A very small number of children with epilepsy can die from their epilepsy. This can be because of seizure-related accidents or the condition (if that is known) that is causing the epilepsy.

Sometimes the death cannot be explained and this is known as SUDEP.

SUDEP is very rare in childhood but the risk does increase in the late teenage years and early adulthood. The risk relates to a number of factors, including the type of epilepsy. You can discuss the risk to your child with your doctor or epilepsy nurse specialist.

Epilepsy in school

Does the school need to know about my child's epilepsy?

You may be concerned about your child having a seizure at school and what this might mean for them. Your child should be allowed to take part in the full range of school activities.

You should be given information about epilepsy for the school. You can discuss with the epilepsy team the most appropriate way to do this.

Your child's school should also be offered the opportunity to discuss what should happen if your child has a seizure at school. This should include managing your child's safety (ideally with your involvement). Schools should also be made aware of how to get suitable training for their staff on epilepsy.

Will epilepsy affect my child's behaviour and learning?

Some children with epilepsy may have difficulties with learning or their behaviour. The epilepsy team will regularly review your child's progress in school. Your child may need further assessment and help.

Educational and clinical psychologists can be helpful in supporting both your child and school staff.

Epilepsy and teenagers

What if my teenager has epilepsy?

You should encourage your teenager to be as independent as possible and make their own decisions about their epilepsy and lifestyle.

The epilepsy nurse specialist should give them information about driving, employment, relationships, alcohol, recreational drugs, contraception, pregnancy, and free prescriptions.

Any information should come in the format that is best for them, for example leaflets, videos or CD-ROMs. They should know about risks that might come with epilepsy and its treatment. If there is anything they don't understand, they should ask the epilepsy team.

They can find more useful information from the organisations listed in this booklet.

Sources of further information

Epilepsy Action

New Anstey House, Yeadon

Leeds LS19 7XY

Epilepsy Helpline: 0808 800 5050

Phone: 0113 210 8800

Fax: 0113 391 0300

E-mail: helpline@epilepsy.org.uk

Website: www.epilepsy.org.uk

Epilepsy Connections

100 Wellington Street

Glasgow G2 6DH

Phone: 0141 248 4125

Fax: 0141 248 5887

Website: www.epilepsyconnections.org.uk

Epilepsy Managed Clinical Network

Website: www.epilepsymcn.scot.nhs.uk

Epilepsy Scotland

48 Govan Road

Glasgow G51 1JL

Helpline: 0808 800 2200

Phone: 0141 427 4911

E-mail: enquiries@epilepsyscotland.org.uk

Website: www.epilepsyscotland.org.uk

National Society for Epilepsy

Chesham Lane

Chalfont St Peter

Bucks SL9 ORJ

Helpline: 01494 601 400

Phone: 01494 601 300

Fax: 01494 871 1927

Website: www.epilepsynse.org.uk

Quarriers

Quarriers Village

Bridge of Weir

Renfrewshire PA11 3SX

Phone: 01505 616000

Fax: 01505 613906

E-mail: enquiries@quarriers.org.uk

Website: www.quarriers.org.uk

Glossary

Clinical psychologist - Clinical psychologists work with people with psychological or mental-health problems. They can work in hospitals, health centres, and child and adolescent mental-health services. Clinical psychologists are not medical doctors.

ECG (Electrocardiogram) - An electrical recording of your heart rhythm.

Educational psychologist - Educational psychologists work in the education system to help children who are experiencing problems at school. They must have a professional qualification in educational psychology and teaching experience, but are not medically trained.

EEG (Electroencephalogram) - An electrical recording of your brain activity.

CT scan (Computed tomography) - A type of scan using X-rays that give a picture of your brain.

MRI scan (Magnetic resonance imaging) - A type of scan using magnets that gives a more detailed picture of the brain than CT.

Paediatrician - A doctor who specialises in treating children.

Paediatric neurologist - A doctor who specialises in diseases involving the nervous system and brains of children.

Status epilepticus - A kind of prolonged epileptic seizure that lasts 30 minutes or more.

Space for your notes

What is SIGN?

SIGN write guidelines which give advice to doctors, nurses, therapists, other healthcare staff and patients about the best treatments that are available. We write them by working with doctors, nurses and other NHS staff and with patients, carers and members of the public. The guidelines are based on the most up-to-date medical evidence.

Other formats

If you would like a copy of this booklet in another language or format such as large print, please contact:

Karen Graham
Patient Involvement Officer
Phone: 0131 623 4740
E-mail: Karen.graham2@nhs.net



This booklet is based on a clinical guideline issued to all NHS staff.

The 2005 guideline was developed by SIGN, the Scottish Intercollegiate Guidelines Network. It is based on published evidence.

You can download the full clinical guideline from the SIGN website at www.sign.ac.uk

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