

(1) Parents: Epilepsy basics

Facing a diagnosis of epilepsy as a family can be challenging. We have written this series of information factsheets specifically for parents covering many aspects of living with epilepsy. If you have any questions or simply want to talk to someone, contact us on our confidential freephone helpline 0808 800 2200.

We have more specific and detailed information on many of the subjects covered in this information series, which you can download from our website www.epilepsyscotland.org.uk or request from our helpline.

If you do not know where to start, make us your first point of contact. We are here to help.

Introduction

The word 'epilepsy' refers to many different types of epilepsy which will affect people in different ways. If your child has just been diagnosed, you may find it reassuring to know that the majority of children respond well to anti-epileptic drugs and become seizure free. This means that for those children, their lives will usually not be affected by their epilepsy.

Much of the information contained in this series of factsheets for parents will focus mainly on those children (and their families) who continue to have seizures and those who may need additional support and help.

How common is epilepsy?

Around 55,000 people in Scotland have epilepsy, an estimated 5,000 to 7,000 of which are children and young people¹.

¹ SIGN, No 81 Diagnosis and management of epilepsies in children and young people, March 2005

What is epilepsy?

Epilepsy is a neurological condition which affects the brain. It is very common and can affect anyone at any age but children and young people are more likely to develop epilepsy.

Epilepsy is 'the tendency to have more than one seizure which starts in the brain'. Approximately 1 in 20 children (and adults) will have a seizure during their lifetime. This does not necessarily mean they have epilepsy. There could be a number of reasons why someone has a one-off seizure, such as having a high temperature.

What causes epilepsy?

In most cases there is no identifiable cause. More research is being done in this area, and it is now increasingly thought that there could be an underlying genetic cause. Genetic does not necessarily mean inherited. Genetic epilepsy can also be caused by a new genetic change. It is rare for genetic epilepsies to be caused by one gene alone. There are usually other genetic and environmental causes as well.

Your doctor will usually ask you if someone else in your family has epilepsy. If you have other children and are concerned about them also developing epilepsy, talk to your doctor or epilepsy specialist nurse. You may also be offered genetic counselling.

An identifiable cause for epilepsy could be a severe head injury or an infection of the brain (encephalitis) or meningitis.

Is epilepsy for life?

Many children will grow out of their epilepsy by the time they become adults. It will depend on which type of seizure or epilepsy syndrome a child has.

There are children who will continue to have seizures. Some will also have other physical or learning disabilities. If your child has difficulty to control seizures as well as other physical or learning disabilities, this series of factsheets for parents may address some of the issues you and your family may be facing.

Epilepsy syndrome

You may be told that your child has an 'epilepsy syndrome'. This term refers to a group of symptoms which occur together. There are many different syndromes such as Dravet Syndrome or Lennox-Gastaut Syndrome. The factors which help determine which epilepsy syndrome a child may have include:

- ✧ the age of a child when the seizures started
- ✧ the type of seizures, for example, where in the brain the seizures start
- ✧ a family history of epilepsy
- ✧ any other problems, for example, a learning disability
- ✧ the EEG recording (more on this in our Parent's factsheet 'No. 5 Diagnosing epilepsy')
- ✧ whether or not the seizures are likely to stop

A clear diagnosis can help a specialist choose the most appropriate treatment. It may also help give a better picture of what you can expect in the future.

Epilepsy often develops over time and sometimes a child's symptoms, seizure frequency and seizure pattern do not always fit into a specific syndrome. It is, therefore, not always possible to diagnose an exact syndrome.

If your child has been diagnosed with a specific syndrome, and you want to know more about it, speak to your child's epilepsy specialist nurse or doctor. Charities such as **Contact** www.contact.org.uk, 0808 808 3555, or **Young Epilepsy** www.youngepilepsy.org.uk, 01342 831342 may also be able to provide further support and information.

The charity Contact may also be able to put you in touch with other families whose children have the same syndrome. Talking to other parents can often be a source of information and support. Bear in mind though that another family's experience is not likely to be exactly like your own, even if your children share the same syndrome. You can also make contact with other parents via social media. There are many condition specific Facebook pages often set up by parents, allowing parents to connect from all over the world and exchange experiences.

Help from Epilepsy Scotland

If you do not know where to start or want to talk about anything mentioned in these factsheets, please telephone our helpline on 0808 800 2200.

Whatever your question or concern, we are happy to talk to you. We can act as a first point of contact taking the time to listen. We will attempt to answer any additional questions not covered by our factsheets or give you details of someone who can.

We will keep any personal details you disclose to us strictly confidential and will never pass these on unless you give us your specific permission. We will always respect your anonymity if you prefer not to give your name.