

## Contact details

The Children and Young Person's Epilepsy Team, Lister Hospital

Telephone: **01438 285319**

Email: [paediatricpilepsyservice.enh-tr@nhs.net](mailto:paediatricpilepsyservice.enh-tr@nhs.net)

## Support organisations

Printed here are a number of national organisations that can provide help, information and advice to parents:

- **Epilepsy Action** is the leading organisation working with people affected by epilepsy. They have an excellent website which provides information for children in a child friendly form.  
For more information telephone **0808 800 5050**  
[www.epilepsy.org.uk](http://www.epilepsy.org.uk)
- **Young Epilepsy** is a national charity that provides medical assessment, rehabilitation, care and education for children and young people whose lives have been adversely affected by epilepsy and other neurological conditions.  
[www.youngpilepsy.org.uk](http://www.youngpilepsy.org.uk)
- **Epilepsy Society** is the UK's largest medical charity in the field. They provide a confidential helpline for everyone affected by epilepsy.  
**Helpline: 01494 601 400**  
**Enquiries: 01494 601 300**  
[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

## Other support networks

There are local parent groups that can offer advice and support for carers of children with epilepsy. Please ask for further information at your child's clinic appointment.

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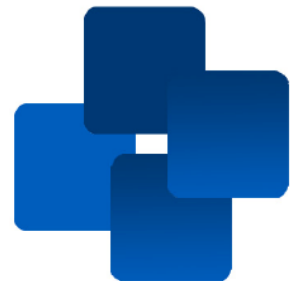
[www.enherts-tr.nhs.uk](http://www.enherts-tr.nhs.uk)

You can request this information in a different format or another language.

# Patient Information

## Welcome

### Epilepsy Service for Children and Young People



## Introduction

This leaflet is designed for parents/carers of children who have a diagnosis of epilepsy. We hope you find it useful.

## My Team

Throughout your child's journey with us, they will be seen by a named consultant with a specialist interest in epilepsy, and a clinical nurse specialist (CNS).

**My consultant is** \_\_\_\_\_

**My nurse is** \_\_\_\_\_

As a team we can help by providing information to you and your family on all aspects of epilepsy including prognosis, medication, safety, lifestyle, education, triggers and other factors. This is to empower and encourage you and your family to continue to lead as full a life as possible.

## Contact details

You may need to contact the following people at some point during your child's journey with us:

- ◆ For queries about your child's clinic letter or clinic appointment details, please telephone the **Contact Centre** on **01438 284444**
- ◆ For queries about your child's medication or for additional advice, please contact the **Children and Young Person's Epilepsy Team** on **01438 285319** or by email on [paediatricpilepsyservice.enh-tr@nhs.net](mailto:paediatricpilepsyservice.enh-tr@nhs.net)

## What is epilepsy?

Epilepsy is the tendency to have repeated seizures (sometimes known as fits) which start in the brain. The brain is responsible for many different functions and therefore seizures can feel and look very different in each child. For example, staring or jerking of limbs or shaking all over the body.

There are some tests which can be done to find out the cause of epilepsy but sometimes no cause can be found. The type of epilepsy, and cause if known, will be discussed with you.

Epilepsy can affect anyone and can begin at any age. However, with a few sensible precautions, most will be able to do the things other children can do.

## What test may I need?

You may need an **Electroencephalogram (EEG)**. This is a brain wave test. It usually takes half an hour to an hour. This test shows whether there is abnormal seizure activity in certain areas of the brain between seizures.

## Medicine

Most children with epilepsy are prescribed epilepsy medicine. The aim of treating seizures with epilepsy medicines is to control the seizures so that the child can get on with their life. There are many different epilepsy medicines available and your child's epilepsy specialist will recommend the best one for your child.

It may take a while to find the right dose of the right medicine for your child. Once their seizures are controlled, they will still usually need to take epilepsy medicine for a while. At their regular appointments with their specialist, their medication will be reviewed and if they have remained seizure free for a while they may be able to be weaned off it.