

Specialist Nurse will arrange to meet up with you and your child to run through more detail about epilepsy.

The nurses can arrange to see you at home or in the hospital. The nurses can give you useful advice on the following topics:

- drug treatments
- employment
- driving
- alcohol
- social and leisure activities
- safety
- first aid
- women's issues (preconception, pregnancy etc.)
- travel or holidays
- finance (benefits and insurance)

Working together for you

The Epilepsy Specialist Nurses can also visit your child's school to provide training sessions and first aid advice.

The aim of the team is to help people understand epilepsy through education and training. We are able to work with professionals and non-professionals involved in your care.

Further information

- **Epilepsy Action**
Website: www.epilepsyaction.org.uk
Telephone: 0808 800 5050
- **Epilepsy Society**
Website: www.epilepsysociety.org.uk
Telephone: 01494 601400

Contact details

If you have any other questions please call the Epilepsy Specialist Nurses on

Telephone: 01483 571122 **ext** 4207

Reference sources

NICE (2012) 'The Epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care' NICE clinical guideline 137. www.nice.org.uk/guidance/cg137

ILAE (2014) 'Definition of Epilepsy' www.ilae.org/Visitors/Centre/Definition-2014.cfm

PALS and Advocacy contact details

Contact details of independent advocacy services can be provided by our Patient Advice and Liaison Service (PALS) who are located on the right hand side as you enter the main reception area. PALS are also your first point of contact for health related issues, questions or concerns surrounding RSCH patient services.

Telephone: 01483 402757

Email: rsc-tr.pals@nhs.net

Opening hours: 9.00am–3.00pm
Monday to Friday

If you would like information documents in large print, on tape or in another language or form please contact PALS.

Past review date: N/A
Future review date: May 2020
Author: Natalie Baines
PIN170525–1270



Newly diagnosed epilepsy

Children's Outpatients Department



Patient information leaflet

What is epilepsy?

Epilepsy is a condition that starts in the brain. The brain controls everything we do in our body by sending out electrical messages. These messages make actions or feelings occur. Seizures happen when these messages get mixed up and they can affect people differently. They may make someone stop and stare, limbs may move suddenly, they may fall to the ground, act or walk around confused or fall to the ground and all limbs shake.

How is epilepsy diagnosed?

Epilepsy is diagnosed when someone has at least two seizures in more than a 24 hour period which are not related to anything else such as an illness. There are many different types of epileptic seizures.

Focal seizures affect a part of the brain and the person can be conscious throughout their seizure. They may act confused, pull at their clothes, chew their lips.

Generalised seizures mean that the sudden extra electrical messages cover the whole brain and the person is unconscious. They may stop and stare for a few seconds known as absences. They may have sudden fast movements of their arms, fall to the ground and all their limbs shake.

Which tests may be done?

- **EEG (Electroencephalogram)**
This is a test to record the electrical pattern of the brain. Sticky pads are put onto different parts of the head. It does not hurt and you do not have to do

anything to your hair beforehand. It is a routine test that people have done when epilepsy is suspected. It can sometimes help to diagnose a particular type of epilepsy to help when deciding the correct treatment choice. A lot of the time it does not show any epileptic brain activity.

- **MRI (magnetic resonance imagery)**
This test is used for some people if the EEG shows an area of the brain where there is epileptic brain activity. This test will help see if there is an area in the brain that may possibly be shaped differently or might be scarred.

How do I look after my child during a seizure?

Most seizures do not last that long and will stop by themselves.

Focal seizures

- Stay with your child, reassure them and make sure they are safe.
- Never restrain them.
- Some children may miss or forget information when the seizure is happening. Ensure the child has the opportunity to catch up with what has been missed.

Generalised seizures (tonic/clonic seizures)

- The 'tonic' part of the seizure is when the body becomes stiff and the 'clonic' part refers to when the limbs are shaking or jerking. This type of seizure usually lasts no longer than a couple of minutes.

What to do:

- Assess the area to make it safe. If necessary move furniture, never move your child unless they are in danger.
- Cushion the head from head injury.
- Time the seizure from the beginning.
- Reassure your child as hearing can be the last and first sense to finish and start when having a seizure.
- Roll your child into the recovery position when the seizure has finished.
- Never put anything into your child's mouth during a seizure.
- Do not attempt to give any food or drink until they are fully recovered.

Call an ambulance if:

- You know it is someone's first seizure.
- The seizure lasts for 5 minutes or more (generalised seizure).
- One seizure continues one after the other without any recovery between.
- Your child is injured.
- Your child's breathing is compromised.
- You believe they need medical assistance.

What services do the epilepsy team offer?

Once your child has been diagnosed with epilepsy, one of our Epilepsy Specialist nurses will get in contact. The Epilepsy