

For more information visit:

- <https://www.epilepsy.org.uk/info/education/learning-and-behaviour>

Or look at this report by Young Epilepsy about children with epilepsy in school:

- <http://bit.ly/Chessreport2014>

What about medicines?

The doctor may have started an epilepsy medication. This will depend on the type and frequency of seizures, and the expected path the epilepsy may follow. You can get more information about medicines here:

- www.medicinesforchildren.org.uk

We have a 'Top Tips for Taking Medicines' leaflet. It is best to start as you mean to go on; allowing older children to take some control (with supervision) usually helps. Most children should be helped to learn what their medicine is called and how much they take every day-and where it comes from! We find the more you involve your child the more likely they will remain compliant and continue to take their medicine.



Please bring your medicines to ALL your appointments. Your epilepsy team can check the brands, strengths and doses with you.

What about monitoring equipment?

The monitoring you do as a parent cannot be replicated by machine, although we know some families may need some additional help. There are different types available, from a simple baby monitor to sophisticated pieces of kit. You can get more information here:

- <http://bit.ly/EpilepsyActionAlarmsandmonitors>

There may be help available to fund these pieces of equipment. Try www.turn2us.org.uk and search under 'grants'.

Email joanne.whittick@bsuh.nhs.uk for an electronic version of this leaflet.

Other useful numbers and contacts

**For Non-Urgent Advice
or Out of Hours GP Service
ring NHS 111 by dialing 111**

**Paediatric Epilepsy Nurse Specialist
01273 696955 Ext. 62545
or epilepsy secretary Ext. 2318
or joanne.whittick@bsuh.nhs.uk**

**Children's Emergency Department
01273 696955 Ext. 2593
BSUH patient advice & liaison service
(PALS)
01273 696955 Ext. 4029 or 4588**

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Newly diagnosed with epilepsy?



Information for relatives and carers

This leaflet is to help you access more detailed information when your child has been diagnosed with epilepsy. Most organisations mentioned have helplines and we can help you contact them if needed.

Where can I find information about epilepsy?

There is a lot of information about epilepsy available on the internet. It's important to use good quality websites.

Epilepsy Action is a good organisation and you can get a lot of information from their website. It also has an area for children and young people as well as schools:

- www.epilepsy.org.uk

We can recommend a few organisations who have useful and relevant information.

Other good sites include:

- www.epilepsyresearch.org.uk
- www.epilepsydiagnosis.org
- www.epilepsysociety.org.uk
- www.youngepilepsy.org.uk

An excellent site to learn about how the brain works is [Neuroscience for Kids](http://neurok.html):

- <http://faculty.washington.edu/chudler/neurok.html>

A number of epilepsy-specific groups have also been set up by interested professionals and/or families on websites and social media - check with the team.

What is epilepsy?

According to Epilepsy Action:

"Epilepsy is a condition that affects the brain. When you have epilepsy, it means you have a tendency to have epileptic seizures."

Electrical activity is happening in our brain all the time, as the cells in the brain send messages to each other. A seizure happens when there is a sudden burst of intense electrical activity in the brain. This causes a temporary disruption to the way the brain normally works, so the brain's messages become mixed up. The result is an epileptic seizure.

What happens to you during a seizure depends on what part of your brain is affected".

(Epilepsy.org.uk, <https://www.epilepsy.org.uk/info/what-is-epilepsy>, September 2018)

How can I keep my child safe?

Part of our job is to help you manage your child's epilepsy and to make sure your child can do everything they want to. Here are a few tips to keep your child as safe as possible. This is by no means an exhaustive list. If your child wants to do new activities do a little risk assessment first! Think about what might happen if your child had a seizure during the activity.

- **Riding a bicycle or scooter in traffic:** parks and footpaths are safer and make sure a helmet is worn
- **Climbing above head height**
- **Being by an unguarded open fire/flame**

- **Swimming:** inform the pool attendant and have a friend with you who knows what to do
- **Taking a bath:** a shower is preferable or bath in shallow water, with someone else in the room
- **Road and public transport safety:** use a zebra or pelican crossing and stand well back from the road and platform edge in train stations.

What should I tell nursery or school?

They need to know your child has been diagnosed with epilepsy. It is important that you clearly explain what this means. Lots of people do not realise there are different types of epilepsy and seizures. Educational settings are obliged to create an individual care plan. Your clinic letter can help them write this. Ask your epilepsy nurse to help as well. Schools are welcome to get in touch.

What about learning and behaviour?

Most children who have epilepsy will not have any difficulties whatsoever with learning or behaviour. However, epilepsy is a brain condition and we don't always know why someone has developed it (sometimes we do). The underlying reason that a person has epilepsy may also cause other difficulties. This is usually evident long before a diagnosis of epilepsy is made. Epilepsy is a varied condition and children will have very different experiences of how their epilepsy affects them and the impact it has. It is important to get the help they need in place as soon as possible.