Epilepsy

Information for parents and guardians

We have given you this factsheet because your child has been diagnosed with epilepsy. We hope it will help to answer some of the questions you may have and give you some practical safety information for the care of your child. Please ask any of our staff if you have further queries or need help while you are with us.

What is epilepsy?

Epilepsy is one of the most common medical conditions affecting the brain and it can affect people of all ages. People with epilepsy have recurrent seizures, so having one seizure doesn't necessarily mean a child has epilepsy. For more advice and information on epilepsy, please visit **www.epilepsy.org.uk**.

What is a seizure?

A seizure is a brief disruption of the brain's normal electrical activity, which leads to a variety of symptoms. The symptoms experienced by the person with epilepsy during a seizure depend on where in the brain the abnormal electrical activity occurs.

Most children with epilepsy can lead full and active lives. It is estimated that around three quarters of children with epilepsy will either be able to control their condition with medication or grow out of it. The chances of this happening will depend on the type of epilepsy a child has.

Most children, including those who never outgrow epilepsy, don't have any other medical problems. They can go to mainstream schools and participate in most sports.

What can trigger a seizure?

For many people with epilepsy, seizures seem to happen randomly. However, some people find that particular things make it more likely that they'll have a seizure. These things are known as triggers. Triggers aren't the actual cause of the epilepsy. Even if a person only ever has a seizure in response to a particular trigger, it is the disruption in the brain that makes it send off the clusters of messages that result in a seizure.

Triggers can include:

- not taking, stopping or regularly missing doses of medication that would otherwise control seizures
- lack of sleep
- high temperature, illness or vomiting (medicine may not be taken as well, if at all)
- stress or excitement (good or bad), such as school, exams, recent arguments, birthdays, holidays or big events
- missing meals and/or being hungry
- alcohol and recreational drugs

During a seizure

We have created a personalised emergency care plan for your child. This will be outlined at the top of their clinic letter. If your child has a seizure, it is important to:

- ensure your child is safe by cushioning their head and removing any dangerous objects, such as headphones, glasses and heat sources
- (if possible) gently turn your child on their side, but do not hold them down or put anything in their mouth
- time the seizure (if it lasts more than five minutes or you're particularly worried about your child, call 999)
- stay with your child and talk calmly to them while they recover, as they may be confused or tired

General safety advice

You will need to assess the risks and benefits of your child's daily activities in order to decide what your child may and may not do. Whenever possible, your child should be involved in these decisions. Every situation is different. When you assess the risks you should consider the answers to the following questions:

- How old is your child?
- How capable is your child?
- How often does your child have seizures?
- Do they get a reliable warning before seizures occur?
- What kind of seizures do they have?
- If they had a seizure during the activity, what consequences would there be?

Although it is important to assess the risks for children with epilepsy, they should also be encouraged to live life as other children of their age and ability.

Water safety

Children must be supervised in the bath at all times to reduce the risk of drowning. Older children should be encouraged to use a shower (preferably one that has a seat).

Bathroom doors should remain unlocked and your child should tell a family member when they are having a shower.

When your child is swimming, tell the lifeguard that your child has epilepsy. If they are in open water, make sure your child is always within arm's length of an adult and stays within a suitable depth of water.

Road safety

If your child is walking alone, they should try to stay on well-lit roads and cross at designated crossing points.

When they are on a bike or scooter, your child should wear a well-fitting cycle helmet.

If epilepsy prevents your child from driving, they may be eligible for an off-peak travel concessionary bus pass. For more information visit **www.southampton.gov.uk** and select 'SmartCities card/bus pass' under 'Roads and Parking'.

Night-time safety

Seizures that happen at night can be worrying, as they are often not seen. We recommend that your child does not sleep in the top of a bunk bed or on a high sleeper. This is to make sure that they are easily accessible if a seizure occurs and also to prevent falls from a height during a seizure. Ideally your child will sleep with their door open as it will be easier to hear if they have a seizure, but remember to respect their privacy as much as possible.

Make sure the bed area is clear of clutter or anything your child could become tangled in or injure themselves on during a seizure. For example, move away any:

- phone chargers or other wires
- headphones
- fairy lights
- blind cords

Although we are not able to recommend or endorse any external products, many people use night-time safety devices, such as video monitors and anti-suffocation pillows. More information on night-time safety equipment can be found online at **www.youngepilepsy.org.uk** and **www.esuk.uk.com**.

Epilepsy identification

Your child may choose to carry or wear some form of epilepsy identification, especially if they're out on their own regularly. This could be an ID card or medical identity jewellery. These can be purchased from **www.medicalert.org.uk/products**.

Emergency contact and medical details should be entered into the mobile phone of any young person with epilepsy who has their own phone. Medical ID apps are also available for smartphones.

What is sudden unexpected death in epilepsy (SUDEP)?

The risk of SUDEP is generally low. SUDEP can be a difficult subject to talk and think about. However, knowing a little about SUDEP and the risks around having seizures might help you to work out what risks apply to your child and how to reduce them, so you can feel more confident and reassured.

Factors that are thought to increase a person's risk of SUDEP include:

- early age of epilepsy onset (before 16 years of age)
- having uncontrolled seizures (particularly generalised tonic-clonic seizures
- missing doses of epilepsy medication
- being a young adult (particularly males)
- having seizures at night or when alone

We will give you a separate information leaflet about SUDEP. Please do ask us if you have any questions or concerns. We will be happy to discuss this, or anything else relating to epilepsy, at any time.

Medication

You can find the details of your child's current medication at the top of their most recent clinic letter. You should know the main side effects of your child's seizure medicines. Information on epilepsy medication can be found online at **www.medicinesforchildren.org.uk**.

Be aware that some side effects occur from interactions between seizure medicines and other medicines your child takes (even over-the-counter and herbal supplements). Some foods, such as grapefruit juice, can affect medicine intake and lead to higher levels of the medicine in the blood.

Contact us

If you have any questions or concerns, you can contact us using the details below.

Your child's consultant is: ___________________________________

Your child's consultant	Secretary's telephone number
Dr Pryde	023 8120 4315
Dr Tisovszky	023 8120 4310
Dr Gillespie	023 8120 4337
Dr Williams	023 8120 3528

Paediatric epilepsy nurses

Telephone: **023 8120 2551** (Monday to Friday, 7am to 5pm)
Email: **uhs.schpens@nhs.net**

Non-emergency telephone: **023 8120 2551** (Monday to Friday, 7am to 5pm)

When leaving a message, please leave **your child's name, date of birth, hospital number** and a **contact number to call back**. We will try to respond to you within two to three days.

Emergency telephone: **999**

Donations

With the help of generous donations from previous patients and their families, we have been able to enhance the services we provide for children with epilepsy.

If you would like to make a donation to the children's epilepsy fund, please visit **www.southamptonhospitalscharity.org/southampton-childrens-hospital/donate-to-the-childrens-hospital/** and select 'Children's epilepsy' from the drop-down menu.

For a translation of this document, or a version in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital please visit **www.uhs.nhs.uk/additionalsupport**

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