

Safety advice for parents / carers / children and young people with a diagnosis of epilepsy

Being aware of risks and keeping children with epilepsy safe is extremely important. The following will not apply to everyone, for example you or your child may be seizure free, or may have prior warning to a seizure and are able to move out of dangerous situations. The following are suggestions – more information on safety can be found on the websites listed at the end of this leaflet.

For advice call:

Paediatric Epilepsy Nurse Specialists

Cath, Tel: 07385 384089 / Abi, Tel: 07876 740219
Roald Dahl Epilepsy Transition Nurse Specialist

Hannah, Tel: 07721 599778

Safety around the house

- Keep stairs free from obstruction; a stair-gate is useful if there are concerns about falling down the stairs during a seizure. Put a soft rug or carpet at the bottom of the stairs to cushion any falls.
- Remove or cover sharp edges, use radiator guards and cooker guards. Only use electrical
 equipment such as hairdryers, hair straighteners when somebody is at home and, where
 possible, use electrical equipment that will turn itself off after a period of time.
- Cordless kettles, irons, hair straighteners that switch off automatically are a safer option. Having a lid on a kettle that locks shut prevents scalds and burns.
- Make sure there are no trailing wires attached to appliances that could cause a fire or burns if pulled over. Cable tidies (available from DIY hardware stores) can keep wires out of the way.

In the bathroom

Where possible, baths should be avoided, as the risks of drowning are increased. However, we recognise that this is not always possible, particularly for smaller children.

• **Bathing:** Younger children should be supervised at all times. When showering sit down where possible. Running a shallow bath and putting cold water in first could help prevent scalds if you or your child had a seizure and fell into the water. Always turn off the taps before getting into the bath. Consider the following tips for safe bath temperature for preventing scalds in the bath:

- Ensure that the water coming out of the taps is a maximum of 44°C. This is a low-risk temperature for hot water burns. A valve or thermostatic mixing valve at the water heater or on the hot water supply piping to the bathroom can be fitted to ensure this.
- Install anti-scald devices on taps and shower outlets. These are available from hardware and safety product stores.
- o Parents/carers should consider child-resistant taps or tap guards in the bath.
- Turn on the cold water first, then the hot. When turning the water off, turn the hot water off first to stop the tap from heating up.
- Bathe in shallow water. Always ensure a responsible adult is at home and they know that you are having a bath or shower.
- Having a non-slip mat in the bath can help to avoid a person slipping down into the bath in the event of a seizure.
- The bathroom door should be left unlocked and preferably ajar, so if a seizure occurs it can
 be heard. Leaving a towel in the door can enable entry if you or your child has a seizure and
 has become trapped behind the door. Do not leave clothes/or anything behind the door which
 may prevent entry.
- Locks that can be opened from the outside or having an 'Engaged' sign on the door enables privacy, but means that someone else can open the door if help is needed.
- If a seizure occurs while in the bath, the plug should be pulled out immediately and the child/young person's head should be supported. Avoid trying to get them out of the bath when they are having a seizure, unless they are in danger, as this may cause injury to them and yourself.

Sleeping:

Parents are often worried about what will happen if their child has a seizure at night and they don't hear it.

- Alarms/monitors can be useful; however, we do not routinely recommend these to parents/carers. However, information can be found regarding alarms on the recommended websites at the end of this leaflet.
- It is also important to move the bed away from radiators and walls to prevent burns or limb injuries.
- Lowering the bed and using bed guards will lessen injuries. However, a bed guard should not allow limbs/head to become caught/or restricted during a seizure as this can cause an injury.
- Placing cushions/mattress on the floor beside the bed will help cushion a fall.
- Have a pull cord above the bed for your main light, or wall lights behind the bed instead of a bedside table with a lamp

In the garden:

- Avoid getting close to bonfires or barbecues that you could fall on during a seizure
- If you wander during a seizure ask someone to stay with you when near bonfires and barbeques

- Avoid having ponds/pools
- If you do have ponds/pools in the garden make sure they are securely fenced off when you are alone in the garden.

Activities:

Computer/electronic equipment:

- Avoid using for long periods of time without a break.
- It is also important that the room is well lit and avoid sitting too close to the screen.

Swimming:

- Always inform the pool attendant/lifeguard so they are aware. You or your child should not swim unaccompanied. Somebody who knows how to help if a seizure occurs should be either on the side of the pool or in the pool, but is specifically watching you or your child at all times.
 It is important to recognise that the lifeguard is watching everyone so may not be the first person to notice if you or your child are having a seizure.
- Swimming alone is not advised.
- Avoid going down flumes/slides, or to areas where you or your child are not visible to the person watching you, or the lifeguard.
- · Avoid swimming in open waters.

Cycling:

- Make sure you or your child always wears a helmet!
- Always try to cycle with a friend and avoid busy roads.
- Cycle on the cycle path as this is safer if a seizure occurs.

Climbing:

 You or your child should avoid climbing anything taller than your/their own height, unless safety equipment or harness is used.

Seizures first aid for parents and carers:

See below first aid support when someone has a seizure:

- Try to stay calm.
- Look around is your child in a dangerous place? If not, don't move them. Move objects such as furniture away from them, to avoid them hurting themselves.
- Note the time the seizure starts.
- Stay with them. If they don't collapse but seem blank or confused, gently guide them away from any danger. Speak quietly and calmly.
- If they have collapsed to the ground, cushion their head with something soft. Loosen any tight clothing around their neck.
- Do not hold them down.
- Do not put anything in their mouth.

- Check the time again. If a convulsive (shaking) seizure doesn't stop after 5 minutes, call for an ambulance (dial 999).
- After the seizure has stopped, put them into the recovery position and check that their breathing is returning to normal. If their breathing sounds difficult after the seizure has stopped, call for an ambulance (dial 999).
- Stay with them until they are fully recovered.
- Do not give them anything to eat or drink until they are fully recovered.

After a seizure your child may feel tired, disorientated and anxious. They may also have a headache and their muscles may ache. It is important to let your child rest/sleep.

Dial 999 if:

- One seizure follows another without any recovery in between.
- The seizure lasts longer than 5 minutes.
- If your child is badly injured during the seizure.
- They have inhaled vomit or water
- You are concerned about your child during or after the seizure has finished.

Useful websites for information on seizures and epilepsy:

Epilepsy Action - www.epilepsy.org.uk

Epilepsy Society – <u>www.epilepsysociety.org.uk</u>

Young Epilepsy - www.youngepilepsy.org.uk

Epilepsy Space (16 years +) - Home - The Epilepsy Space

RBH Paediatric Epilepsy Service:

Consultant Paediatricians

Dr Sarah Hughes

Dr Ahmed Aldouri

Helpful contacts and telephone numbers:

NHS 111

RBH Children's Accident & Emergency 0118 322 6876

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

Written by Victoria Urban. July 2017

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