

Information for parents / carers of children and young people following a first fit or seizure (without a temperature)

Following admission to the Emergency Department (A&E) or paediatric wards after a first seizure, this leaflet aims to provide children, young people and their parents and carers with some basic general information on seizures and safety.

What is a seizure?

Watching your child have a seizure can be very frightening experience, but children rarely suffer long-term harm. The words seizure, convulsion and fit all mean the same thing. The brain has millions of nerve cells (or neurons) which control the way we think, move and feel. The nerve cells do this by passing electrical signals to each other. If these signals are disrupted, or too many signals are sent at once, this causes a seizure. This then results in an alteration of sensation, behaviour, such as staring blankly or unusual movements. Or consciousness may be affected whereby your child may become stiff or floppy, their breathing or colour may change, they may fall to the floor and have some jerking of their limbs; this may also involve them biting their tongue. They may also be incontinent.

What causes a seizure?

It may not always be clear as to what has caused a seizure. Seizures can occur in as many as 1 out of 200 children and many will not experience a further seizure. Even if your child is diagnosed with epilepsy and continues to experience seizures, it is not always a lifelong condition. 75% of children either grow out of their epilepsy or are well-controlled by medication.

Are there different types of seizure?

Yes, there are many different seizures and not all are due to epilepsy. Epileptic seizures all start in the brain. However, there are other types of seizures which may look like epileptic seizures but they do not start in the brain. For example, some seizures are caused by conditions such as low blood sugar (hypoglycaemia) or a change to the way the heart is working. Some very young children have 'febrile convulsions' (jerking movements) when they have a high temperature. These are not the same as epileptic seizures.

Does this mean my child has epilepsy?

No, as mentioned above, if your child has had more than one unprovoked seizure they will then be investigated further by consultant paediatricians (doctors specialising in the care of children) with a specialist interest in epilepsy. However, this does not always mean your child will be diagnosed as having epilepsy.

Safety and first aid

Following a first seizure, whether this is epileptic or not, it remains important to let your child take part in normal activities. However, extra supervision may be required in certain situations and environments.

The following are some areas where some safety precautions should be taken however, this list is only general. There is extensive information regarding safety and taking part in activities that can be found on the Epilepsy Action and Epilepsy Society websites.

- **Bathing** – children should be supervised at all times. Older children should be encouraged to shower and where possible to sit down. If a shower is not possible, bathe in shallow water. Always ensure a responsible adult is at home and make sure they know when the child is having a bath or shower. The 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 the young person has a seizure and become trapped behind the door.
- **Make the home environment safe** – remove sharp edges, apply radiator guards and cooker guards.
- **Swimming** – always inform the pool attendant/lifeguard and children should not swim unaccompanied.
- **Cycling** – make sure the child always wears a helmet! Children should try to always cycle with a friend and avoid busy roads.
- **Climbing** – children should avoid climbing anything taller than their own height.
- **Sleeping** – often parents are worried about what will happen if their child has a seizure at night and they don't hear it. Sometimes, baby alarms/monitors can be useful if your child makes noises. Bed alarms can also pick up movement.
It is also important to consider moving the bed away from radiators and walls to prevent burns or limb injuries. Lowering the bed and using bed guards will lessen injuries. Placing cushions/mattress on the floor beside the bed will help cushion a fall.
- **Driving** – if your teenager has had a seizure, whether it is epileptic in nature or not, they have to stop driving and inform the DVLA (information is available from Epilepsy Action and Epilepsy Society regarding driving standards).

Is it safe for my child to use the computer/electronic equipment?

The answer to this is yes. However, avoid using for long periods of time without a break. It is also important that the room is well lit and sitting too close to the screen is avoided.

What can I do if it happens again?

Watching your child have a seizure can be a very frightening experience and perhaps the most difficult thing for parents/carers is the fact that there is very little they can or should do:

- 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.
- If in public, maintain their dignity and privacy as much as possible.
- 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.
- You are concerned about your child during or after the seizure has finished.

What happens next?

First Fit Clinic: You will be contacted by the Dingley Child Development Centre admin team to organise a telephone appointment with the epilepsy nurse. This does not mean your child has epilepsy; we offer the follow-up telephone call to make sure you have all the relevant safety information and discuss any queries you may have. If you have not received an appointment within two weeks of being discharged, please contact the team on 0118 322 7531 Option 1, and ask for an appointment for the First Fit Clinic. Alternatively, email rbb-tr.cat7@nhs.net

It is important that you tell your child's school and anybody that may take responsibility for them at times, when your child has experienced a seizure, so that they can be aware of safety aspects and first aid procedures if needed.

Following admission to A&E or the paediatric ward, if your child has further seizures they will then be followed up as soon as possible by the paediatric consultant, who will take a thorough history and may decide on further investigations. If your child does experience further seizures it is very important to have a description from a witness as this can be extremely helpful in diagnosis, for example, capturing seizures using a mobile phone camera as a video/or alternative, can be particularly helpful for diagnosis and treatment.

We understand that witnessing a seizure can be a very frightening experience for you. If your child does have further seizures or you feel you would like further advice or support leave a message for the paediatric epilepsy nurses on either of the mobile numbers below. If you need urgent medical attention, seek advice from your nearest Children's Emergency Department (A&E).

RBFT Paediatric Epilepsy Service

Consultant Paediatricians: Dr Sarah Hughes and Dr Ahmed Aldouri

Paediatric Epilepsy Nurses: 07876 740 219 or 07385 384 089

Useful websites (epilepsy and seizures)

Epilepsy Action – www.epilepsy.org.uk

Epilepsy Society – www.epilepsysociety.org.uk

Young Epilepsy – www.youngpilepsy.org.uk

Further advice

NHS 111

RBH Children's Emergency Department (A&E) 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.

Paediatric Epilepsy Nurses, July 2023

Next review due: July 2025