

Safety and lifestyle advice for children with epilepsy

Families often have concerns about safety and lifestyle when their child has a diagnosis of epilepsy. This leaflet is designed to highlight the main issues and give tips on how to minimise those risks and lead as normal a life as possible.

Not everything in this leaflet will apply to your child as it depends on their age, seizure frequency and type.

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Safety in the home

In the bathroom

All children with epilepsy need to take extra care when bathing due to the risk of drowning during a seizure.

- If younger children have a bath an adult **MUST** stay with them at all times.
- For older children a shower is safer than a bath as the water runs away.
- If a bath is the only option, keep the bath water very shallow.
- Having an adult in the bathroom is the safest option. As children get older having someone just outside or using a portable baby monitor would allow for privacy and would mean that someone could hear if a seizure happened and act quickly.
- Bathroom doors should not be locked. Have a sign that can be hung on the door to let other people know that the bathroom is in use.
- A bathroom door that opens outwards is safer in case the child has a seizure by the door.

Bedroom and living areas

If possible avoid very hard flooring. More cushioned flooring such as carpets or lino will provide a softer landing if a child falls during a seizure. A soft rug or carpet at the bottom of the stairs may be useful to cushion any fall. Edge and corner guards are widely available to cover any sharp corners on furniture that may be a risk.

If your child has seizures at night consider using bed guards or make sure the area around the child's bed is safe from hazards if they fall out. A bed lower to the floor may also reduce the risk of injury. Having a baby monitor will also allow you to hear the child.

Swimming, sports and other activities

Swimming

Swimming in a pool with a lifeguard is safe for children with epilepsy but the lifeguard should always be informed. Ideally, everyone with epilepsy should always swim with a family member/ friend who would know what to do if they had a seizure.

Seizures are more likely to happen when the child is unwell; so avoid swimming at these times.

Also avoid swimming at very busy times as it may be more difficult for the lifeguard to observe if the child has a seizure.

How to deal with a seizure in the water:

Tonic clonic seizure: (unconscious, stiffening and jerking of limbs)

- From behind, tilt the child's head so it is out of the water.
- If possible, move the child to shallow water, while holding their head above water.
- Don't restrain their movements.
- Once jerking movements have stopped move them onto dry land.
- Place in recovery position and stay with them until recovered.
- Call an ambulance if you think the child may have swallowed or breathed in water, even if they now appear fine.
 - Or if the seizure lasts longer than is usual for the child or longer than 5 minutes.
 - Or if an injury has occurred.

Absence/focal seizure: (vacant episode, mild seizure)

- Protect the child from danger by guiding them away from deep water or holding their head above water.
- When they recover check if they need to get out of the water as they may be drowsy or confused.

Water sports

Life jackets should always be worn when taking part in water sports. Swimming in water such as the sea, lakes or rivers which do not have a lifeguard is not advisable, especially if swimming alone.

Scuba Diving is not recommended at all for people with epilepsy due to the life threatening risk if a seizure happens whilst underwater. The British Sub-Aqua Club currently states that divers must be off anticonvulsants and seizure free for at least 5 years to consider taking part in scuba diving.

Sports

Having the opportunity to take part in sport and leisure activities is important for everyone, including children with epilepsy. With the right support and the relevant safety precautions, there is little that someone with epilepsy would need to avoid. However, it is always a good idea to follow the rules and recommendations in terms of safety equipment.

To take part in some sports or activities, a medical form may need to be completed. This information should only be used to help the organiser complete a risk assessment and make reasonable adjustments if necessary.

Epilepsy Action has a good webpage on many different sports and what precautions should be taken: www.epilepsy.org.uk/info/sports-leisure

For younger children play parks and soft plays are safe as there is cushioned flooring. Climbing trees or climbing ladders or other heights which do not have a safe surface is not advisable.

Cycling

- Normal safety precautions include wearing high-visibility clothing and protective head gear is particularly important if your child wants to cycle.
- If seizures are not fully controlled, avoid cycling on busy roads and by rivers or canals.
- If seizures are frequent, it is advisable not to cycle on public roads altogether, until seizures are under better control.

Medicines and lifestyle

Many health conditions are improved when people lead a healthy lifestyle. For children with epilepsy having good sleep routine and regular meals can improve seizure control.

- It is important to take medication at regular times and not miss any doses.
- Incorporate taking their medicines into a daily routine.
- It may be useful to have the tablets in a pillbox which is labelled with days of the week.
- Some people find setting an alarm on their phone to remind them twice a day is useful.
- If your child vomits within 30 minutes of taking the medication then the full dose can be repeated.
- If your child forgets their medication:

Twice a day regime:

- Less than 4 hours late: take the dose and continue the following doses as usual.
- More than 4 hours late: miss that dose and take the following doses as usual.

Once a day regime:

- Take the medication for that day if they are less than 12 hours late.



Side effects of medication

Unfortunately, medication to control seizures often has side effects, these are usually worse when commencing on a new medication and then usually settle down to a tolerable level. The most commonly reported side effects are:

- Drowsiness
- Lack of energy
- Behaviour change
- Disturbance in sleep pattern
- Slowing down of processing speed effecting concentration and memory

It is common practice that young people who take medication to control their epilepsy are given up to 25% extra time for their exams. The school will need to apply to the exam board.

Each medication will come with a long list of possible side effects. Most of these are very rare but if you are concerned about any side effects speak to your GP or epilepsy nurse for advice.

Bone Health

Studies have shown that long term use of anticonvulsants can affect bone health, so taking a vitamin supplement that has calcium and vitamin D may be helpful. Taking regular exercise and having safe exposure to sunlight is also recommended.

Photosensitivity

Photosensitive epilepsy is when seizures are triggered by flashing lights or contrasting light and dark patterns. Photosensitive epilepsy is not common, approximately only 5% of people with epilepsy are photosensitive. An EEG test can diagnose photosensitivity. This type of epilepsy usually responds well to treatment. Flashing or patterned effects can make people with or without epilepsy feel disorientated, uncomfortable or unwell. This does not necessarily mean they have photosensitive epilepsy.

Between 3-30 hertz (flashes per second) are the common rates to trigger seizures but this varies from person to person. While some people are sensitive at frequencies up to 60 hertz, sensitivity under 3 hertz is not common.

Ofcom regulates material shown on TV in the UK. The regulations restrict the flash rate to 3 hertz or less, a warning will be issued if there is going to be a high level of flashes on a programme. In cinemas due to the size of the screen and the low intensity, it is rare for seizures to be triggered this way. Computer games also have regulations on the flash rate allowed so are unlikely to cause a seizure.

Tips on how to minimise the risk of a seizure:

- Take regular breaks from the screen.
- Sit well back from the screen.
- Watch TV, or play computer games in a well-lit room.

For some, sunlight coming through the trees, blinds or reflecting on water can cause a seizure.

If your child is suddenly exposed to a potential risk, then covering 1 eye completely while moving away from the risk can greatly reduce the chance of a seizure.

Having a diagnosis of photosensitive epilepsy means that the child is less likely to outgrow their epilepsy so the doctor will recommend medication is taken long term.

Holidays and travel insurance

When booking travel insurance it is important to let the insurance company know that your child has epilepsy. If a hospital admission is required due to the epilepsy whilst on holiday and the insurance company was not aware it could cost you a lot of money that you won't be able to claim back.

Always pack any medication in your hand luggage. Suitcases can get lost. Pack extra medication in case there are any delays. Try to take medication at usual UK time if possible.

Disability living allowance (DLA)

DLA is a benefit to help with the extra costs of looking after a child who has a disability or health condition. If your child's epilepsy is well controlled and it doesn't affect their day to day life then you are unlikely to be able to claim. But if you think you may be entitled to claim DLA have a look on the Cerebra website. Cerebra is a charity for children with any neurological condition including epilepsy. They have a free step-by-step guide to filling in the DLA claim form. You can also request a copy of this guide by calling 0800 328 1159.



Sudden Unexpected Death in Epilepsy (SUDEP)

In rare instances, a person with epilepsy dies during the night for no obvious reason. This is called Sudden Unexpected Death in Epilepsy (SUDEP). No one knows what causes SUDEP, there may be evidence that a person had a seizure but this is not always the case.

Recent studies estimate the incidence of SUDEP as 1 death in every 1000 epilepsy patients per year. It appears that children have a lower rate of SUDEP in the range of 1 in 3000 (0.003%).

Although we don't know for certain why it happens, there are some situations that are thought to make SUDEP more likely in certain people:

- SUDEP is thought to happen during or following a seizure, so uncontrolled or poorly controlled seizures are a risk.
- SUDEP is thought to be more likely in people with frequent seizures, particularly generalised tonic clonic seizures, than in people with infrequent seizures.

How to minimise the risk of SUDEP

- Maximising seizure control is vital. Make sure anti-epileptic medications are taken as prescribed on a daily basis and around the same time each day.
- Have a healthy lifestyle, sleep well.
- Anti-suffocation pillows which have holes in to aid breathing are available but there is no evidence to prove that they prevent SUDEP.
- Bed alarms which can alert parents/carer to a seizure are also available but again there is no evidence to support their use in preventing SUDEP. They may not alarm to every seizure and also may produce false alarms when there is no seizure activity.



Additional Information

We have a paediatric webpage which can be accessed from the Royal United Hospital website by entering 'paediatric epilepsy' into the search box. Or you can scan the following QR code. The website has useful information on mental health, challenging behaviour, sleep and many other topics



SCAN ME

I hope the information in this leaflet is useful. Please contact me if you have any questions or would like more information.

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The majority of this information was taken from the following 3 websites and was correct at the time of publication. (Jan 2022)

Epilepsy Society: www.epilepsysociety.org.uk

Epilepsy Action: www.epilepsy.org.uk

Young Epilepsy: www.youngepilepsy.org.uk

Royal United Hospitals Bath NHS Foundation Trust
Combe Park, Bath BA1 3NG
01225 428331 www.ruh.nhs.uk

Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital. Email ruh-tr.pals@nhs.net or telephone 01225 825656/ 826319