

SUDEP Action



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EPILEPSY: REDUCING RISK AND BUILDING HEALTHIER LIFESTYLES

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Parent's & Carer's Guide

LIVING WITH EPILEPSY AND BALANCING RISK



1 in every 200 children live with epilepsy

That's around 60,000 children with epilepsy in the UK.

Most people with epilepsy can live normal lives with careful management of their condition and by understanding the risks that are raised by having epilepsy.

When your child is diagnosed your child's **Epilepsy Specialist Nurse (ESN)** or **Paediatrician** should discuss the different risks associated with epilepsy and how you can make informed choices to reduce them where possible.

Share as much as you can about your child's epilepsy, with them and others in their life (e.g. their doctors, nurses, teachers, family members and friends) to help reduce their risks

You may be anxious and worried about this, but learning and talking openly about their epilepsy and how to manage it is an important way to help reduce their risk

This will give them confidence about their epilepsy, helping them develop epilepsy / risks self-management skills, as they gain more independence

Different children will require different precautions at different times. Not all of the following will apply to all children – but it is important you know about all epilepsy risks so you can take positive action.



SEIZURES

Seizures affect people differently, and each come with different risks, which can vary for each person over time. Seizures can cause a problem because they affect your child's awareness or can lead to a fall. Seizures themselves also come with risks, particularly if they last for a long time, occur in a cluster or affect their breathing or heart rhythm.

Be aware if your child has:



Generalised tonic-clonic seizures (sometimes called 'grand mal' or convulsive seizures)



Seizures that take place during sleep



Convulsive seizures that last 30 minutes or more (called status epilepticus or 'status')



Seizures that occur in a cluster (one after another)



Seizures that are difficult to control with treatment



Your child has other neurological problems

WHEN YOUR CHILD HAS A SEIZURE

Your doctor, nurse or clinician will have given you advice of what to do during a seizure.

This may include:

Stay calm and talk reassuringly to them

Turn them on their side to prevent choking and into the recovery position after their seizure

Loosen tight clothing and place something soft under their head if you can

Time how long the seizure is lasting

Never put anything in their mouth

Stay with them until they are awake and alert, or help arrives. Don't give them anything to eat or drink until fully alert

Never restrain or try to move your child while they are still seizing (unless in danger)

- Call an ambulance if:
- the seizure lasts longer than five minutes
 - they begin having cluster seizures (one seizure straight after another)
 - they injure themselves badly during their seizure

PROLONGED CONVULSIVE SEIZURES

If your child is thought to be at risk of prolonged convulsive seizures, their Clinician may give you an emergency care plan including key information and emergency medication. **Inform those who also take care of your child (e.g. other family members and close friends, their school, club leaders etc.) about what to do.**

SEIZURES WHEN ASLEEP



If your child has seizures at night or during sleep, consider using a monitor to alert you (e.g. an alarm device or audio monitor such as a baby monitor). Your child's Clinician can discuss this and advise on available options. **More information and questions to ask about devices Clinician are available at www.sudep.org**

Learn how to turn your child into the recovery position after a seizure and, if possible, encourage a sleeping habit which avoids sleeping on their front. If your child is sleeping away from home, check that the adults in charge also know what to do should they have a seizure when asleep.



PREVENTING INJURIES

It's important to know of potential dangers so you and your child can discuss them with their Clinician and take action to reduce them:



FALLS



- Avoid having hard flooring to prevent injury if your child falls during a seizure
- Keep stairs and walkways clear from obstructions
- Consider covering sharp edges on furniture with edge/corner guards
- Consider using toughened safety glass or double glazing for doors and windows, or safety film to go over existing glass
- Ensure wide opening windows or balconies have suitable locks to prevent falls during a seizure



In the bedroom:

Place your child's bed away from radiators, sharp edged furniture & not against the wall in case they have a seizure when asleep

Consider a low bed and placing pillows or a mattress on the floor next to the bed in case they fall out during a seizure



BURNS AND SCALDS



- Consider using cable ties to avoid trailing appliance wires which could cause burns or scalds if pulled during a seizure
- Use a guard for open fires and radiators
- Carefully monitor the water temperature when your child is bathing
- Place saucepan handles away from the cooker edge when cooking in case they are knocked during a seizure
- Supervise your child during barbeques and bonfires, especially if they wander or fall during seizures

If you find yourself worrying about how best to balance the need to keep your child safe, with the need to encourage your child's growth and independence, while also managing their epilepsy please do speak to your child's Clinician for support. Further information about SUDEP can also be found at www.sudep.org and www.sudepglobalconversation.com

WATER SAFETY

If your child has seizures, it is important to take care around water to avoid the risk of drowning or injury:

- Swimming should be discretely supervised by an adult aware of your child's epilepsy (who could come to their aid if needed)
- Make sure your child is supervised around ponds or pools. If possible secure the area with fencing



BATHING



- Encourage your child to have a shower instead of a bath
 - Having a shower cubicle instead of a shower over the bath is safer
 - Wrap a towel around the taps if the shower is over the bath to help avoid injury if your child falls
 - Use either a plastic or safety glass shower screen/cubicle, or a shower curtain to reduce chance of injury should they have a seizure
 - Encouraging your child to sit while in the shower may reduce the risk of injury
 - If possible, have a shower with a flat floor (instead of a shower tray) so water doesn't collect
- Supervise your child when bathing in case they have a seizure
- As they get older, encourage them to leave the door unlocked when in the bathroom in case they have a seizure. Consider using a 'vacant/engaged' sign instead
- Consider fitting an outward opening bathroom door in case they have a seizure behind the door



SPORT AND OTHER ACTIVITIES



Your child can take part in many sports or leisure activities if they have support and the right safety precautions in place.

- Some people find they have fewer seizures when active, but for others, strenuous exercise/activity can increase the chances of a seizure. Seek advice from your child's Clinician for advice
- Be careful around heights. For example, avoid climbing above 6 foot unless using proper climbing safety equipment
- Check that your child is supervised during activities by an adult who knows about their epilepsy and what to do if your child has a seizure

TRAVEL

Children and young people with epilepsy can travel and go on holiday like any others, with the right support and precautions to minimise risks.



Take extra medication in case your travel is unexpectedly delayed



Give them their medication at regular intervals, making gradual adjustments to timings if there is a time difference



Check the expiry date of any emergency medication for prolonged seizures if needed and always have it with you



If you are not traveling with your child make sure an accompanying adult knows about their epilepsy and what to do during a seizure (including emergency medication if required)

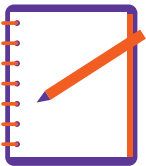


Take their medication in the original packaging; know the 'brand' and scientific names as these can vary



If travelling by plane, put your child's medication in your hand luggage in case your luggage is lost or delayed

- Inform the airline beforehand of your child's epilepsy
- Check what you can do if their medication is in liquid form (due to flight safety restrictions)



Ask your child's Clinician to write a letter with details of your child's condition and the medication (Consider translating this if required)

Check your holiday insurance covers emergency medical treatment for your child's epilepsy



Avoid letting your child become overtired or dehydrated from the travelling



Consider encouraging them to have a sleep during the day if planning to stay up later at night

MENTAL HEALTH AND EMOTIONAL WELLBEING

Being diagnosed with and living with epilepsy can be difficult for some children and young people. Common issues include anxiety, depression, low self-esteem or a lack of confidence.

 **Contact clinician:**

If the changes are sudden, increasing, extreme, or continue for more than 2-3 weeks

Children and young people show emotional distress in different ways from adults, so it is important to be aware of changes in your child's mental health and emotions. Speak to their Clinician if you notice any changes or have concerns.

SUDEP – THINGS TO CONSIDER OR DISCUSS



Each year roughly 600 people with epilepsy will die suddenly with no obvious cause. This is called **Sudden Unexpected Death in Epilepsy, (SUDEP)**.

Knowing about the risks and your child can seem worrying, but it is a positive first step to help you take action to reduce them

The risk of this for children with epilepsy is lower than adults, but it is something you should be aware of and should speak to your child's Clinician about. They should provide further information about your child's individual level of risk (this varies between people with epilepsy).

See SUDEP **Action's** leaflet, **SUDEP – WHAT YOU NEED TO KNOW**
A guide for parents
or visit www.sudep.org
for more information.

GAINING INDEPENDENCE AND TRANSITION

Independence is important as children become young adults, and living with epilepsy can make it seem harder to feel like others in a peer group. **It is important your child knows the best ways to both gain independence but also stay safe:**

Medication side effects:

encourage them to be honest with their Clinician to help them find a balance between seizure control and minimising any side effects

Medication adherence:

taking them regularly as prescribed can help seizure control and help reduce risk of injury or worse

Driving a vehicle:

to do this, seizure control will be vital.
Help them to take positive steps to self-manage their epilepsy

Alcohol and substance use:

can affect their epilepsy and medication, and could have serious consequences

Sex and contraception: can be discussed with their Clinician. It's important they feel able to be honest and ask questions, so they can make informed choices

Special thanks to Dr Colin Dunkley and the Children's Epilepsy Workstream in Trent (CEWT) network for their support and help with this leaflet

WORKING WITH YOUR CHILD'S HEALTHCARE TEAM

The best way to reduce epilepsy risks is to help your child to have as few seizures as possible, and encourage them to build healthy habits in managing their condition. Help them with this by:



Keeping regular appointments with their Clinician



Helping them to take their medication as prescribed



Keeping a seizure record to help spot patterns and changes

Speaking to their Clinician if you notice any changes with your child's seizures, moods or medication side effects



Identifying and avoiding their seizure triggers



Asking their Clinician about other epilepsy treatments, alternative to medicine



Always carrying key information about their epilepsy with you/them



MOVING FORWARD

Make sure those around your child know they have epilepsy and what they can do to help them during and after a seizure. Completing a care plan can help with this

Talk to your child's Clinician about how to minimise their risks and about SUDEP – share this information with your child, family and child's carers so informed choices can be made

Work with your child's Clinician to find the best way to treat their seizures, identify triggers and lower their risks. Keep a seizure diary to help with this

Visit our website to get the latest news and research on epilepsy risks and freely available resources to help you manage your child's risks

SUDEP Action are the only UK charity solely dedicated to **reducing epilepsy deaths**, **raising awareness of epilepsy risks** and **supporting those bereaved** by epilepsy. Constantly working with leading clinicians, epilepsy specialists and researchers to help raise awareness of these risks and how to reduce them. Also, providing free, award-winning tools and resources to support people with epilepsy and their families/carers.

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Epilepsy Bereaved (founded 1995) is part of SUDEP Action.