

WHAT IS SUDEP?

Each year roughly 600 people with epilepsy will die suddenly with no obvious cause. This is called **SUDDEN UNEXPECTED DEATH IN EPILEPSY**, or **SUDEP**.

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. It is a difficult issue to discuss, but they should provide further information about your child's individual level of risk (this varies between people with epilepsy), and importantly what positive steps you can take to keep your child as safe as possible.

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.

HOW COMMON IS IT?

In the UK approx 40-80 children with epilepsy die unexpectedly each year. The rates of SUDEP in children (Under 18s) appear to be much lower than in adults, about 1 child dying out of 4,500 each year. This risk rises with more complex types of epilepsy, e.g. Dravet Syndrome. While this is a low number, it is not something that should be ignored. There are things you can do that might reduce your child's risk, and knowing about risk means you can make informed choices about their care.

WHAT CAUSES IT?

Although SUDEP may be described as 'rare' or 'uncommon', this does not mean it should not be discussed with you and your child by your Paediatrician or Epilepsy Specialist Nurse. It is really important you are aware of all potential risks so you can discuss the best ways to manage and reduce them with your child. The cause of SUDEP is unknown. Similarly, to the condition **SUDDEN INFANT DEATH SYNDROME (SIDS)**, SUDEP occurs more often (but not always) at night. In SUDEP, there is often evidence of a seizure before death, though this is not always the case.

It is unlikely that a single cause will explain all SUDEP. It is currently thought that the deaths are most likely to be related to a heart or breathing problem. Research has identified important risk factors and various possible causes of SUDEP, but further research is still needed.

WHAT ARE THE RISK FACTORS?

The strongest risk factor for SUDEP is having frequent generalised tonic-clonic seizures (sometimes called convulsive seizures). The more frequent these seizures are, the higher the risk of SUDEP.

OTHER RISK FACTORS INCLUDE



Night time seizures and seizures which occur during sleep



Prolonged convulsive seizures that last more than five minutes (called status epilepticus or 'status')



Seizures that occur in a cluster (one after another)



Seizures that are difficult to control with treatment



Not taking Anti-Epileptic medication (AEDs) regularly as prescribed, or stopping AEDs completely

OTHER SIGNIFICANT LONG-TERM HEALTH CONDITIONS

HELP REDUCE THEIR RISK AND BUILD HEALTHY HABITS

The best way to reduce the risks associated with epilepsy and SUDEP is to help your child to have as few seizures as possible and encourage them to build healthy habits in managing their condition.

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.

SUDEP Action works with leading clinicians, epilepsy specialists and researchers to help raise awareness of these risks and how to reduce them. They are the only UK charity solely dedicated to reducing epilepsy deaths, raising awareness of epilepsy risks and supporting those bereaved by epilepsy. We provide free, award-winning tools and resources to support people with epilepsy, their families/carers and clinicians in understanding, managing and reducing risks.

SUDEP Action



SUDEP.ORG



SUDEP: WHAT YOU NEED TO KNOW

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Parent's & Carer's Guide

CARE

- Keep regular appointments with your child's Clinician – they should have a regular epilepsy review (even when transitioning from paediatric to adult care)



- Help them to take their medication regularly and reliably



- Try to modify your home or other daily environments to avoid seizure-related injuries



- Take extra precautions around water; including swimming or bathing:



- Choose showers rather than baths, unless bathing is supervised at all times

- Swimming should be discretely supervised by an adult aware of your child's epilepsy (who could come to their aid if needed)

SEIZURES

- Identify and try to avoid their seizure triggers (e.g. stress, reduced sleep, flashing lights, certain foods)



- Keep a seizure record to help spot patterns and changes (take along to discuss with their Clinician)



- Learn how to turn your child into the recovery position after a seizure and, if possible, encourage a sleeping habit which avoids them sleeping on their stomach (prone position)

- Ask their Clinician about other epilepsy treatments (e.g. surgery or the ketogenic diet) if medications are not enough to control seizures

- If your child is at risk of prolonged convulsive seizures, their Clinician should give you an emergency care plan including training and medication

- Make sure other caregivers (e.g. family members, friends, their school, club leaders etc.) also know what to do

- 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). Their Clinician can discuss this and advise on available options



LIFESTYLE

- Carry key information about their epilepsy with you/them always (e.g. a summary, care plan or copy of clinic letters)



- A medical ID bracelet or card could be helpful in case they have a seizure when you are not with them
- Put emergency contact details into their mobile phone (if they have one)

- Talk to their Clinician about concerns about:



- Changes to your child's epilepsy eg: seizure frequency, severity, triggers, recovery
- Medication side affects (but don't make any changes to your child's medication before doing so)
- Changes to your child's moods
- Sex and contraception (when appropriate)

For further information on epilepsy risks and how you can reduce them see our 'Epilepsy – Reducing risk and building health habits' leaflet and visit www.sudep.org

Further information about SUDEP can also be found at www.sudep.org and www.sudepglobalconversation.com