SUDEP Action

Making every epilepsy death count

Live well with epilepsy

A guide for parents and carers

What is epilepsy?

Epilepsy is a neurological condition that affects the brain and nervous system, causing seizures. Seizures are a burst of electrical activity in the brain that temporarily affect how it works. They can cause a wide range of symptoms.

Epilepsy is a complex condition which can be difficult to understand. Staying safe means having key up-to-date information to make the best decisions possible.

Your child can lead a great life with epilepsy and knowing the risks associated with the condition can help them to do that.

What matters most is understanding their epilepsy and the seizures they have – their type, timing and severity, how well controlled they are, and how they are impacted by lifestyle choices.

All people with epilepsy have the right to information about risks to help them live as safely as possible. Young people are no exception.

Being a parent or carer is never easy. Looking after a child with epilepsy is harder still because there is so much to think and worry about. Having to confront difficult issues and face tough but important conversations is something no one would choose to do.

However, please don't feel you are alone, because there are people ready and willing to help. By arming yourself with information and understanding epilepsy risks, you will be taking huge positive steps to help your child live safer.

Did you know?

- There are over 20 different types of seizure
- One in 20 people will experience a seizure in their lifetime
- At least 21 people die because of epilepsy each week with most deaths happening at home

What is SUDEP?

SUDEP stands for Sudden Unexpected Death in Epilepsy. It’s when someone with epilepsy dies and no other cause of death can be found. Many of those who die are often young and otherwise healthy. It’s not known what causes SUDEP, but research has shown that actions can be taken to reduce risks for many people with epilepsy. Taking positive steps to reduce seizures as much as possible is the best defence against SUDEP.

Previously, it was thought that SUDEP in children was less common than in adults, but current research now suggests previous numbers were underestimated and that the risk of SUDEP in children with epilepsy is broadly similar to that in adults. Risk increases if a child has a more complex form of epilepsy, for example, Dravet Syndrome.

It’s vital you talk directly with your child’s clinician about SUDEP and THEIR SUDEP risks.

Understanding seizures

It’s important to understand and recognise your child’s type and pattern of seizures. You should discuss this with your child’s clinician – because there are different risks, according to the type and pattern of the seizures.

For example:

Generalised Tonic-Clonic Seizures (GTCS)

These seizures are what most people picture when they think of a seizure and can be the most severe. They are when a person loses consciousness, becomes stiff (often falling to the ground) and shakes or convulses.

Sleep-related (nocturnal) Seizures

These happen when a person is asleep, or shortly after waking. This type of seizure puts people at a higher risk of death compared to other seizure types.

Status Epilepticus

Status epilepticus is when a seizure lasts a long time or when you have one seizure after another without recovering in between. Rescue medications are used to stop the seizures.

Cluster Seizures

There is no single definiton for cluster seizures but it’s generally when a group of seizures happen more often than you’re used to within a certain span of time.

Be seizure aware

For many, managing epilepsy is possible by medication. Understanding seizure triggers helps with the management of risk.

Although seizures are spontaneous and unpredictable, there are often personal triggers that you will come to recognise, for example, ill health, stress, changes in routines or sleep patterns, flashing lights or forgetting to take epilepsy medication, also known as anti-seizure medication (ASM) or anti-epileptic medication (AED).

Managing seizures

It's important your child has regular clinical reviews, **at least yearly,** to check:

- **There are no changes to their epilepsy, health or wellbeing**
- **They are still on the right medication for them**

If your child is seizure free but you notice changes to their health, speak with their clinician in case it is related to their epilepsy or medication.

Anyone having seizures, whether one a year or many a day, is considered to have active epilepsy.

It's important to have regular reviews with a clinician. This may be a GP, neurologist, epilepsy specialist nurse or learning disability nurse.

When your child has a general convulsive seizure

What to do...

- ✓ Stay calm and talk reassuringly to them.
- ✓ Turn them on their side to prevent choking and into the recovery position after the seizure.
- ✓ Loosen tight clothing and place something soft under their head if you can.
- ✓ Avoid putting anything in their mouth.
- ✓ Time how long the seizure lasts.
- ✓ Stay with them until they are awake and alert, or help arrives. Do not give them anything to eat or drink until they are fully alert.

There are more than 50,000 children with epilepsy in the UK. Lots of help is available so do not feel you are alone.

Remember...

- ✓ Do not restrain or try to move your child whilst they are having a seizure (unless they are in danger).
- ✓ Call an ambulance if you are concerned. Call 999 and ask for an ambulance if it's the first time your child has had a seizure, the seizure lasts longer than is usual for them or if the seizure lasts more than five minutes. Also ask your doctor / nurse for a plan, when to seek emergency help.

Stress / mental wellbeing

It is thought that one in four people will have a mental health condition at some point in their lives. This includes anxiety and feeling depressed. For people living with long-term conditions such as epilepsy, this risk is higher. Whatever your child is experiencing, help is available so please be reassured that things can be done to improve how they are feeling.

Please speak to your child's clinician / clinical team if you have any concerns or questions.

Live safely with epilepsy

Medication & seizure control

- ✓ Ensure medications are taken as prescribed and you get prescriptions on time.
- ✓ If you feel your child’s medication isn’t right for them, speak to a clinician immediately. Ask questions. And be prepared to ask them again if you aren’t satisfied with the response.
- ✓ Getting the best seizure control possible for your child should be your priority.
- ✓ Understand your child’s personal seizure triggers. Know what they need to do to stay safe and what to avoid.
- ✓ Prioritise their personal wellbeing and try to reduce stress.
- ✓ Speak to a clinician if you notice any changes in your child’s seizures, medication side effects or mood.

Plan ahead

When seizures occur:

- Keep a seizure record to help spot patterns or changes.
- Put emergency contacts into your phone’s directory.
- Modify or arrange your home to make it as safe as possible should your child have a seizure.
- Ensure your child carries key information with them about their epilepsy (wear a medical ID bracelet or carry an information card).
- Use your support network, involving family, friends, carers, health professionals and people at work.
- Take extra medication with you, if possible, when you travel or go away. If you are holidaying abroad, get proper advice before you go away, such as when to take medication in different time zones.
- Avoid unsupervised baths. Showers are a safer alternative. Consider life jackets & lifeguard supervision for activities.

Moving from paediatric to adult services

Typically, a child will transition to adult services between the ages of 16 and 18 but planning for this should begin much earlier. The better the planning, the better the transition will be. Moving from paediatric (children's) to adult epilepsy services is an important transition that needs careful management as it coincides with so many other changes that may be happening in your child's life.

Around the time of transition, there should be a complete review of your child's epilepsy diagnosis and treatment. Healthcare professionals should make sure the transition is tailored to suit your child's specific needs.

You and your child need to understand their care plan, the support they will be getting and how this will be delivered. Children's health services often deal with a number of issues your child has, not just their epilepsy. However, in adult services, the epilepsy clinic will deal only with your child's epilepsy.

Young people develop at different rates, and this means different individuals do not handle responsibility identically. It's important to get a feeling for when someone is ready to receive information and to tailor the support you give accordingly. This should be something you discuss with your health professionals – so plans can be put in place to give your child the right amount of independence at the right time.

What matters most is that your child feels they can play an active part in their own care plans and be well trained to identify risks and act on them.

It's all about preparing them over time so they can take on information and gradually gain the skills to keep themselves safe.

The Children's SUDEP and Seizure Safety Checklist

Working with Cornwall Partnership NHS Foundation Trust and Young Epilepsy, SUDEP Action created a paediatric version of its SUDEP and Seizure Safety Checklist.

This project grew from an appreciation that clinicians needed a tool to help them tailor their conversations with children, young people and their parents, to provide the necessary care, support and assessment of risk.

We believe this Checklist will lead to better two-way discussions between clinicians and patients / families.

Ask your clinician about it – and find out more at www.sudep.org

The EpSMon app

Our EpSMon app (for over-16s) is designed to help you understand your own personal epilepsy risks so you can make informed decisions about when to book GP appointments and review your care plan.

EpSMon provides key information for you and your clinician – helping you better understand your condition and when you need to take positive action to live more safely.

Download from the App Store or get it at Google Play. More at www.sudep.org

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SUDEP Action's website has more information and resources about living well with epilepsy, reducing risks, and providing support to anyone bereaved by epilepsy:

www.sudep.org

SUDEP Action provides all resources, tools and information, including our EpSMon app, to people for free. However, if you would like to support our work we would welcome any donation, large or small.

Go to sudep.org and click on the 'donate' link, or scan the QR code

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