A guide for

Health Professionals

SUDEP Action

Making every epilepsy death count

At least 21 people with epilepsy die each week. Most are young and, apart from having epilepsy, in otherwise good health.

80% of these deaths are avoidable with optimal care. Many of these deaths are due to SUDEP.

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 during the post-mortem. Many of those who die are often young and otherwise healthy.

What causes SUDEP?

It is not known for sure, but it's unlikely that there's a single cause to explain all SUDEP deaths. Possible reasons it happens include:

- Brain function – seizures may suppress or interfere with the function of vital parts of the brain
- Breathing changes – a seizure may cause someone to have pauses in breathing. If these last too long, oxygen in the blood may reduce to dangerous levels
- Heart rhythm changes
- Other causes – either from a combination of the above or because of factors not yet known

The first line of defence: The right medications for each individual

Medications that control seizures are the first line of defence against sudden fatality. Seven in 10 people with epilepsy could be seizure free by getting access to the right medicines for them at the right time.

Because epilepsy is different from person to person, medications need to be tailored to suit. Sometimes, this will bring challenges for health professionals. For example, MHRA regulations restrict the prescribing of sodium valproate due to the increased risk of causing problems in children born to women taking it in pregnancy. However, for many people, sodium valproate remains the most effective medication for controlling their seizures.

Health professionals need to support patients as individuals, to balance decision-making and help them live as safely as possible.

Seizure control is key to reducing risk

Every health professional supporting a person with epilepsy has a responsibility to identify patient risks and work to reduce them. Without adequate seizure control, people cannot lead their best lives. Many people living with uncontrolled seizures suffer serious injury or job losses or cannot drive or attend schools and colleges.

Seizure control is crucial to reducing risk. And seizures can be life threatening.

1

Have difficult but vital conversations with patients about the risks that come with epilepsy.

2

Too many grieving families still tell us no one ever warned them that epilepsy could be fatal, or are angry that risks were downplayed.

3

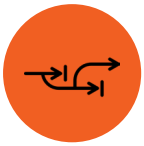
Don't leave families with the pain of that nagging question that probably won't ever leave them. 'What if?'

Remember...

Patients need to be armed with the facts so that – with your help – they can make the best decisions for their personal situation.

Epilepsy care is personal

Patients have a right to be heard and they also have the right to choice and a say in their own care plans.



Risk isn't linear, it fluctuates

Because risk can change from one review to another, avoid classing people as 'high or low risk'.

People have a right to info

People with epilepsy have a right to know about the risks that come with their condition.

What you say really matters

Learnings from the National Institute for Healthcare and Research (NIHR) show the importance of avoiding exam-style questions when talking to patients. Therefore, avoid phrases such as 'what do you know about risk?' and be specific in your language.
It's not about what you say – it's about what is heard. Repeat key information, check understanding and consider providing written information too, so that patients have something to refer back to.

A parent's viewpoint

"Our gorgeous girl suffered her first epileptic seizure when she was nine and lived bravely with epilepsy through her teenage and early adult years. And throughout that whole period, not one consultant, doctor, GP or specialist nurse told us of the phenomenon that ultimately took her life, SUDEP – sudden unexpected death in epilepsy. One consultant told us he generally didn't raise SUDEP as it made for a difficult conversation. Not as difficult as the conversation we were having with him after her death."

Use our safety checklist tools

Potentially fatal risks can be reduced if our SUDEP and Seizure Safety Checklist is used in clinical settings. This is our free evidence-based tool helping UK clinicians in their discussions with people about epilepsy risks. Our Checklist is designed to be completed in the clinic to promote meaningful conversations about risk with epilepsy patients. It provides a baseline for comparing changing risk factors over time. Find out more at sudep.org
We also have a Paediatric SUDEP & Seizure Safety Checklist available at sudep.org

Our website: for more safety guidance and risk information

Our EpSMon app: Check. Track. Live.

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