Learning Disabilities & Autism
SUDEP & Seizure Safety Resources

SUDEP Action

Making every epilepsy death count

NHS
South Yorkshire
Integrated Care Board

About SUDEP

SUDEP usually happens when a person with epilepsy dies suddenly, often during or following sleep.
It can happen with or without evidence of seizure.
SUDEP stands for Sudden Unexpected Death in Epilepsy.

The biggest risk factor is not being seizure free, especially if someone has had **generalised tonic clonic seizures or nighttime seizures** in the past year. These are also the seizure types most linked to injuries, emergencies and early death. There are other risks associated, including worsening mental health. Other non-SUDEP sudden deaths in people with epilepsy include accidents, drownings, suicide and **Status Epilepticus,** where convulsive or non-convulsive seizures last more than five minutes or involve repeating seizures without recovery in-between.

When a person with epilepsy dies suddenly, the case should be independently reviewed so that care can be improved.

NHS RightCare good practice – SUDEP & seizure safety

Because people with epilepsy face much higher risks of premature death, regular monitoring and coordinated care is vital. Research in Cornwall since 2010 shows that using the SUDEP and Seizure Safety Checklist in GP and hospital settings helped reduce risk and improve communication with patients and families from 10% to 80%.

The best way to lower the risk of SUDEP is to reduce seizures as much as possible. Regular epilepsy risk reviews are important, so people understand their risks, treatment options, and safety choices. However, many prevention of death reports – and other independent reports into epilepsy related deaths over two decades – show that important parts of good practice are missing.

“Good care should always include regular reviews with clear information about epilepsy and SUDEP risk, treatment options and choice.”

Helping people live long and well

Information is vital for people with epilepsy and their families so they can make the best decisions to manage their condition well. Without this knowledge, they cannot make informed choices. Easy access resources are made available by SUDEP Action to support people with epilepsy and a learning disability or autism, their families, professional carers and clinicians. These resources support and facilitate important conversations before decisions are made.

Mind the gap: problems found in care

1 **Epilepsy and seizure risks are not clearly recorded.**

2 **Medicines and treatment options are not reviewed or optimised.**

3 **Awareness of SUDEP risk is missing or is not understood for the individual.**

4 **Structured epilepsy risk tools, designed to support people, are not used.**

5 **People with a learning disability with capacity, families and carers – and appropriate health professionals – are not involved in safety discussions, including conversations about the use of helpful devices.**

Clive's way

Clive was a gentle, caring man who loved painting, gardening and music. He was optimistic, kind and deeply devoted to his family, never forgetting a birthday or special occasion. Clive also had a learning disability and epilepsy.

At 47, he died suddenly following a seizure and cardiac arrest. Clive was at high risk of Sudden Unexpected Death in Epilepsy (SUDEP).

His family fought for answers. An independent review later found 'multiple, systemwide failures' in the care he received, including poor decision making around moving him between settings and a lack of appropriate epilepsy safe environments. These failings placed him at higher risk of SUDEP. After his death, investigations should have, but did not, follow national epilepsy guidance. Clive's independent review was clear; these failings to support him with his epilepsy were contributory to him living for ten years in an inappropriate psychiatric hospital, far from his family.

Clive should not have died.

Listen to Clive's sister Elaine talk about his legacy to prevent future deaths

One in five people with a learning disability have epilepsy. Epilepsy is treatable but awareness of risk is poor.

*In the UK, people with learning disabilities and epilepsy die on average **six years earlier** than those with learning disabilities alone (there are further inequalities for people from African and Asian ethnicities). Epilepsy is also a leading cause of death in people with autism.*

The Clive Treacey Checklist

The Clive Treacey Checklist is for commissioners and health providers. It was developed with providers and families as part of a NHS Midlands action plan with system partners.

Checklist **Guidance doc** **Report**



SUDEP awareness training

Oliver McGowan training is important and required, but it does not cover the SUDEP and epilepsy risk communication gap. If you want to learn more, SUDEP Action offers a paid-for service, including a 90 minute online SUDEP awareness course for carers and clinical teams. This covers the latest information on risk prevention, good practice and how to support carers when asking for reasonable adjustments and SUDEP checks during annual reviews.

SUDEP Action can also provide training on using the SUDEP and Seizure Safety Checklist. Contact info@sudep.org

Night monitors

Many epilepsy related deaths happen at night, and research shows that monitoring during sleep can help keep people safer. There are different devices that can detect seizure movements and alert family members, carers, or support centres. These include mattress sensors, watches, phones, listening devices, and video monitoring. The best approach is for health professionals, the person with epilepsy and their family and / or their carer to decide together what device is most suitable.

Some people use anti-suffocation pillows, which are designed to improve airflow around the face. However, they have not been proven to prevent suffocation or SUDEP, and they cannot guarantee safety during nighttime seizures. Using one is a personal choice, not a proven protection.

Find out more

EpSMon: Epilepsy self-monitoring

EpSMon is free to download and use in the UK. It's designed to help people with epilepsy, and /or their carers, record and review details about seizures and other epilepsy-related information. It shares useful general educational content about epilepsy and the risks linked to the condition.

It is suitable for those aged 18+, or from 16 if the user is transitioning to adult epilepsy services. EpSMon helps with:

- Tracking seizures
- Logging medication info
- Setting reminders
- Viewing recorded data
- Tracking patterns
- Learning about epilepsy

Available on the App Store

GET IT ON Google Play

EpSMon is 100% free in the UK and available on IOS and Android

See what risks have gone up, what risks have gone down or what risks have stayed the same.

Medication

Effective medication is the first line of defence against SUDEP, yet poor medication management is a common issue. It is especially important during medication reviews that the most effective medication(s) are offered in a timely way – and to ask for a SUDEP and Seizure Safety Check. Sodium valproate, for example, is an effective medication for generalised seizures with easy read resources and video support available.

Prescribing and reviewing valproate

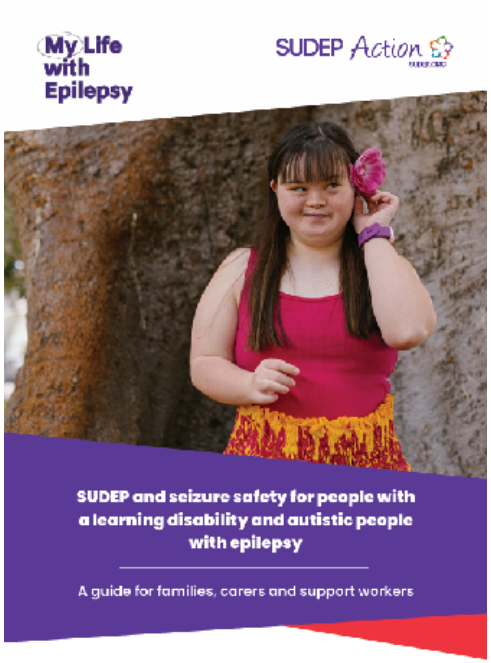
Medicine shortages

Someone with epilepsy or an individual carer can sign up for a Charlie Card – this can help with awareness of SUDEP and seizure safety when dealing with pharmacies. Please contact **info@sudep.org** for organisation requests.

Resources

My Life With Epilepsy

A downloadable easy-read leaflet and video made by, and for, people with epilepsy and learning disabilities.



Download here

FOR CARERS

A downloadable easy-read leaflet, 'Reducing Epilepsy Risks' is also available.

Download here

Advocacy for the SUDEP & Seizure Safety Checklist

There are two versions of the SUDEP and Seizure Safety Checklist – one for adults (over 18) and one for children. Carers can ask health professionals to use the SUDEP and Seizure Safety Checklist in clinic with patients, especially at annual reviews or medication reviews. You can ask for these as a reasonable adjustment.

This video shows the importance of checks in primary care and hospital services

The adult version of the SUDEP & Seizure Safety Checklist is available on most GP systems. Both the adult and the paediatric versions can be registered for by clinicians.

Register for the Checklist

> *Many wrongly assume that SUDEP is less common in children than adults.*

“The Epilepsy Deaths Register is more than a keeper of stories, it's a catalyst for change.”

The Epilepsy Deaths Register (EDR) is a safe and secure platform for those bereaved by epilepsy and for professionals to provide information about the deaths of people with, or suspected to have had, epilepsy.

Research teams are finding out more about epilepsy-related deaths, including SUDEP. However, there is still much more work to be done to prevent future deaths.

Knowing why people with epilepsy have died, allows researchers to build a better picture of the condition and helps keep people safer in the future.

Sharing information by reporting to the EDR helps research teams carry out new research, which could help learn lessons from those who have died, in the hope of also saving future lives.

Check out the EDR website

After a death

There is no right or wrong way to grieve, and no time limit either. Grief changes over time, and support may be needed months or even years after a death. SUDEP Action still supports people who first contacted them decades ago.

Clive Treacey’s tragic death was initially recorded as ‘heart related’, even though he had several clear SUDEP risk factors. The Royal College of Pathologists' guidance was not followed.

It is important to signpost families to SUDEP Action.

The charity has vast experience in supporting those who are bereaved, as well as aiding coroners in understanding true causes of death.

Bereaved families and health professionals can also share information after a death on SUDEP Action’s confidential research platform, the Epilepsy Deaths Register (EDR) epilepsydeathsregister.org.

Information provided to the EDR is used in worldwide research projects, to improve services for people living with epilepsy and prevent future deaths.

You can reach the SUDEP Action support team by calling 01235 772852 or emailing info@support.org

This digital booklet was created by South Yorkshire ICB with SUDEP Action after reviewing deaths of people with epilepsy who also had a learning disability or autism. Their findings showed significant differences across services.

SUDEP Action

Making every epilepsy death count

01235 772850 · www.sudep.org · info@sudep.org

18 Newbury Street, Wantage, Oxon OX12 8DA