

What is SUDEP?

The facts

SUDEP Action 
Making every epilepsy death count



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

Can SUDEP be prevented?

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.

Having regular epilepsy risk reviews is therefore essential for understanding risks.

Assessing your personal risk is not something you do as a one-off. It needs to be done regularly so it becomes part of your ongoing care plan.

It's therefore important to have open and ongoing discussions with your doctor / support team to maintain or improve safety.

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 are the risk factors?

Anyone having seizures could be at risk of dying prematurely because of them. The frequency and severity of someone's seizures is a key sign that they are at more risk. However, SUDEP also occurs in people who have infrequent seizures too. Research has identified many risk factors, including:

- **Generalised tonic-clonic seizures**

Risk increases with the number of convulsive seizures experienced.

- **Seizures when sleeping or shortly after waking**

Sometimes known as nocturnal seizures.

- **Not taking anti-seizure medication as prescribed**

- **Seizures not controlled by medication**

Also known as drug-resistant or treatment-resistant epilepsy.

- **Changing lifestyle factors**

These can increase risk and impact on routines and / or stress, for example, moving house, going to university for the first time or pregnancy.

- **Gender**

SUDEP is more common in men, but women can still be at risk.

- **How long you've had epilepsy**

Another risk factor is how long someone has lived with epilepsy, and if it started at a young age. Risk is higher in young adults.

- **Other health conditions**

How common is SUDEP?



Recent studies estimate the incidence of SUDEP at about one death per 1,000 people with epilepsy, per year. Reported rates may be underestimated.



This equates to at least 600 deaths from SUDEP in the UK every year.



SUDEP disproportionately affects young adults, which may explain why epilepsy deaths are in the top ten of all causes of premature mortality in the UK.

Being seizure free is life-changing

For someone with epilepsy the difference between being seizure free and having seizures can be life transforming. The best way to prevent SUDEP is to have as few seizures as possible.

SUDEP accounts for about 50% of epilepsy deaths. There needs to be a shift in thinking so communicating information about SUDEP risks becomes a mainstream, normal feature of epilepsy care.

What's the criteria for categorising a death as SUDEP?

SUDEP is an appropriate description in the following circumstances:

- A person with epilepsy dies suddenly or unexpectedly.
- Death may be witnessed or unwitnessed.
- Death due to trauma, drowning and/or status epilepticus has been excluded.
- The post-mortem examination does not reveal a cause of death.

These deaths most often occur at night or during sleep. Although there is often some evidence of a seizure before death, this is not always the case.

When there isn't a post-mortem, death may only be classified as 'probable SUDEP'. Where a competing cause of death is present, death can also be classified as 'possible SUDEP'.

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