Please contact us for further information:

Head Office:
01235 772850
info@sudep.org

SUDEP Action Scotland:
0131 516 7987
www.sudep.org

Support (direct line):
01235 772852
support@sudep.org

SUDEP.ORG

SUDEP Action

Making every epilepsy death count

SUDEP - explained

A short guide for the health professional

Sudden Unexpected Death In Epilepsy (SUDEP) is the term used when a person with epilepsy dies without warning and where the post-mortem fails to establish any other cause of death.

What are the criteria for categorising a death as SUDEP?

According to Nashef et al (2012)[1], 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
- Post-mortem examination does not reveal a cause of death

Such 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.

In the absence of a post-mortem, deaths may only be classified as 'probable' SUDEP. Where a competing cause of death is present, the death can be classified as `possible' SUDEP.

[1] L.Nashef, E.So, P. Ryvlin, T.Tomson. 2012. Unifying the definitions of sudden unexpected death in epilepsy Epilepsia, 53(2):227–233

How common is SUDEP?

Sudden death is estimated to be nearly 24 times more likely in people with epilepsy than in the general population. It also disproportionately affects young adults, which may explain why epilepsy deaths are in the top 10 of all causes of premature mortality in the UK and represent a significant public health burden. The data suggests that SUDEP deserves the same attention as other life-threatening events, such as SIDS (Sudden Infant Death Syndrome) or sudden death associated with heart disease.

Recent studies estimate the incidence of SUDEP at about one death per 1,000 people with epilepsy per year. Reported rates may be an underestimate because of poor case identification due to lack of awareness and inconsistencies in the investigation and recording of the deaths. In adults and children with medically intractable epilepsy, rates may approach 1 in 100 people per year.

It appears that children have lower rates of SUDEP, at 0.2 to 0.4 deaths per 1,000 among the population affected by epilepsy per year. However, rates of sudden death in children with epilepsy may still be more than 10 times that of children in the general population.

What causes SUDEP?

It is unlikely that a single cause will explain all SUDEP deaths.

Cardiac arrhythmias may occur in the context of seizures, and seizure-induced physiological changes may promote arrhythmias in susceptible individuals. Respiratory mechanisms of death are supported by animal models and there is clinical evidence of oxygen desaturation in both convulsive and non-convulsive seizures. Some individuals may experience prolonged cerebral suppression following a seizure, which may be associated with central apnea leading to cardiac arrest. It is possible that an individual may carry several physiologic risk factors that together result in death.

What are the risk factors?

The severity of someone's epilepsy is the most reliable risk factor. Generalised tonic-clonic seizures make a person more likely to experience SUDEP and the risk increases with the number of convulsive seizures per year. It should be noted, however, that there are deaths every year in people who suffer infrequent seizures too.

Other factors that have been identified include:

- Nocturnal seizures
- Young adult age
- Poor adherence to epilepsy treatment
- Earlier age of epilepsy onset (before 16 years of age)
- Longer duration of epilepsy
- Symptomatic epilepsy
- Male gender

Can SUDEP be prevented?

National clinical guidelines recommend that the risk of SUDEP can be minimised by optimising seizure control and being aware of the potential consequences of nocturnal seizures.

- Aim for prompt referral of people with uncontrolled seizures to a specialist epilepsy team
- Ensure that patients are taking their seizure medication correctly
- Talk to patients and their family members about SUDEP and ways of reducing risk. Consider discussing EpSMon, a smartphone app – to help them regularly assess and monitor their risks. More information is available at www.epsmon.com
- Use the SUDEP and Seizure Safety Checklist, an evidence-based clinical tool to monitor your patients' risks at each review. Find out more at https://www.sudep.org/checklist

There is some evidence that nocturnal supervision in the form of room sharing or monitoring devices may reduce the risk of SUDEP, although this requires further study.

After a death

Please register any epilepsy-related death with the Epilepsy Deaths Register, as anonymised information can be very useful to our ongoing research. It's also important to remember that SUDEP can be devastating for family members and distressing for professionals. Our support team of qualified counsellors have expertise in this area and are advised by experts in epilepsy and pathology. Find out more at https://epilepsydeathsregister.org/

SUDEP.ORG