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This information is not intended as medical advice.

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This leaflet has been created by SUDEP Action, a charity dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths. It is the only UK charity specialized in supporting and involving people bereaved by epilepsy.

SUDEP Action 
Making every epilepsy death count

SUDEP Action is delighted to work in collaboration with Epilepsy Action Australia to distribute this leaflet.



**Epilepsy
Action
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life changing impact

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.¹



What are the criteria for categorising a death as SUDEP?

According to Nashef et al, SUDEP is an appropriate description in the following circumstances:¹

- 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.¹

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

How common is SUDEP?

Sudden death is estimated to be nearly 24 times more likely in people with epilepsy

than in the general population.² SUDEP disproportionately affects young adults and when comparing years of potential life lost from neurological disease, SUDEP is second only to stroke.³

Studies estimate the incidence of SUDEP at about one death per 1,000 people with epilepsy per year.⁴ 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 with medically intractable epilepsy the rate may approach 1 in 100 people with epilepsy per year.⁵

The risk of SUDEP for children is lower than adults; approximately 1 in every 4,500 children with epilepsy, although most of the risk occurs in association with complicated epilepsy.⁶

What causes SUDEP?

The cause of SUDEP is not yet known. It is unlikely that a single cause will explain all SUDEP deaths. Researchers are investigating a range of possibilities such as the effect of seizures on breathing and the heart. It is possible that an individual may carry several physiological risk factors that together result in death.⁷

See the international resource the SUDEP Global Conversation
www.sudepglobalconversation.com

What are the risk factors?

Generalised tonic-clonic seizures (GTCS) increase the likelihood of SUDEP; this risk increases with the number of convulsive seizures per year. Having 1-2 GTCS a year can increase the risk of SUDEP 5 times. Three or more GTCS a year can increase risk up to 15 times. Nevertheless, it should be noted that deaths do also occur in people with less frequent seizures.⁷

Other factors include:⁷

- Nocturnal seizures and lack of night-time surveillance
- Poor medicines adherence
- Earlier age of epilepsy onset (before 16 years of age)
- Longer duration of epilepsy
- Young adult age
- Male gender

There are also known risk factors associated with epilepsy mortality in general. For further information visit <https://www.epilepsy.org.au/about-epilepsy/epilepsy-and-risk>

Can SUDEP be prevented?

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. Discussing risks for SUDEP and epilepsy mortality with your patients is important to help them make informed decisions to reduce risks where possible.

- 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 about SUDEP and risk reduction. Patient information is available from www.epilepsy.org.au
- Use the SUDEP and Seizure Safety Checklist, an evidence-based clinical tool to monitor your patients' risks. Register interest in the tool at <https://www.sudep.org/checklist>

There is some evidence that nocturnal supervision such as room sharing or monitoring devices may reduce the risk of SUDEP, however, there is currently no intervention that can be recommended to prevent SUDEP. Nevertheless, some patients or carers will choose to trial a seizure monitoring device.

After a death

SUDEP can be devastating for family members and distressing for professionals. Guidelines recommend professionals offer condolences to families following a death, referring them to relevant bereavement organisations.⁸

Any epilepsy-related deaths can be registered with the Epilepsy Deaths Register. Anonymised information supports ongoing research. Families can register information at <https://epilepsydeathsregister.org/>

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