Sudden Unexpected Death in Epilepsy (SUDEP)

**DEFINITION** [1]

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
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<td>Sudden unexpected witnessed or unwitnessed, non-traumatic and non-drowning death occurring in benign circumstances, in an individual with epilepsy, with or without evidence of a seizure and excluding documented status, in which post-mortem exam does not reveal cause of death.</td>
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<td><strong>Probable</strong>:</td>
<td>same definition as above, but without post-mortem.</td>
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<td><strong>Possible</strong>:</td>
<td>competing cause of death present.</td>
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**INCIDENCE:**

- 0.09-2.3 / 1000 patient years: Across all ages in community based studies.
- 9.3 / 1000 patient years: In epilepsy surgical referrals.

Camfield [2] offered a paediatric perspective of epilepsy. In a study of children with epilepsy where a cohort were followed for twenty years, he concluded:

- Neurologically normal children with newly diagnosed epilepsy do not face an increased risk of death over the next 20 years.
- For those with severe neurological handicap, death rate may approach 25% over next 20 years, but death is related to deficits, not seizures.
- **Overall incidence of SUDEP in children of 0.1/1000 patient years.**

**RISK FACTORS:**

- Onset of epilepsy <16 years
- Epilepsy > 15 years
- Frequency of generalised tonic-clonic seizures
- Nocturnal seizures
- Symptomatic aetiology

**LONG-TERM MORTALITY IN CHILDHOOD-ONSET EPILEPSY:** [3]

- Cumulative risk of unexplained death in childhood onset epilepsy was 7% at 40 years.
- Among subjects with idiopathic or cryptogenic epilepsy, there were no unexplained deaths < 14 years.
- Median age of SUDEP: 25 years (4-49).

In a study [4] of SUDEP recorded in monitoring units, all deaths were nocturnal and had a lack of supervision. The majority
were in the prone position; medication had been decreased or ceased. The mechanism of death was cardiorespiratory with terminal apnoea followed by cardiac arrest.

**CAN WE PREVENT SUDEP?**

- Preventing seizures is the most effective way to prevent epilepsy-related deaths, in particular SUDEP.
- Nocturnal Supervision (e.g. sharing bedroom, listening device, frequent checks) [5]
- One possible intervention may include seizure alerting devices but data is lacking.

**RECOMMENDATIONS:**

The NICE Guidelines advise that information on SUDEP should be included in the education given to patients and carers to show why preventing seizures is important. Tailored information on the patient’s relative risk of SUDEP should be part of the counselling checklist for children, young people and adults with epilepsy and their families and/or carers.

There is literature to support that parents/families/carers want information and that doctors frequently do not provide it. [6]

If the risk is low, the conversation is often reassuring. If the risk is high, the specific intent is to encourage compliance and to achieve better seizure control.

**WHEN TO DISCUSS SUDEP?**

It is important to recognise barriers to disclosure: comfort, knowledge, opportunity.

There are opportunities:

- At diagnosis
- Following questions by family
- Intractable epilepsy
- Poor compliance
- Surgical referral
- Drug discontinuation or lifestyle change
- When patient has unaddressed fear regarding risk

**RESOURCES:**


[www.sudepaware.org](http://www.sudepaware.org)
[www.epilepsy.com/sudep](http://www.epilepsy.com/sudep)
[www.epilepsyaustralia.net](http://www.epilepsyaustralia.net)
[www.sudep.org](http://www.sudep.org)

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Langan et al. (2005). Case-control study of SUDEP. Neurology, 64:1131-33
Gayatri et al. (2010). Parental and physician beliefs regarding the provision and content of written sudden unexpected death in epilepsy (SUDEP) information. Epilepsia; 51: 777-782.