



## What is SUDEP?

SUDEP is an abbreviation that stands for Sudden Unexpected (or Unexplained) Death in Epilepsy. SUDEP is defined as a sudden death in a person with epilepsy, who was otherwise healthy, that cannot be explained by an accident, injury or status epilepticus (continuous seizures for longer than 30 minutes). Many physicians and nurses who don't specialize in epilepsy treatment are not familiar with this condition.

SUDEP is more common in people with severe epilepsy and those who have developmental delay. It is uncommon in children and most often occurs between the ages 18 and 50 years. It accounts for 8-17% of deaths in people with epilepsy. It has been hard to get accurate numbers for the risk of this condition as studies of large numbers of cases have not been done and there can be inconsistencies in the identification, investigation, and recording of the deaths. A recent study from Finland was one of the first to look at this prospectively. These researchers were able to follow 245 children diagnosed with epilepsy for 40 years (children with febrile seizures and a single seizure were not included). They found that no child under 14 years old suffered SUDEP and that a five-year period of no seizures (on or off medication) markedly reduced the risk of SUDEP.

Other researchers have estimated the risk of SUDEP at 1:500 to 1:1000 for people with epilepsy living in the community. This is as much as 24 times higher for sudden death than the general population in comparable age groups.

We do know that often the victims of SUDEP are found in bed and there is evidence of a recent generalized convulsive seizure. Some of the cases are found to have sub-therapeutic blood levels of their anti-epileptic drugs (AEDs).

The risk of SUDEP is highest in adults with uncontrolled nocturnal tonic-clonic seizures. Risk factors that could also make a person more susceptible to SUDEP are: longer duration of epilepsy, male gender, learning disability, young adult age, and possibly those taking more than one AED. The research is not in agreement yet about whether more AEDs simply means that the seizures are harder to control, or that any of the specific AEDs can be identified as leading to higher risk.

Researchers are currently investigating potential factors that could cause SUDEP. Hypothetical causes include genetic, cardiorespiratory, or neurophysiologic problems.

What can people do to prevent SUDEP? These are much the same things that they do to look after themselves and keep their seizures under the best control possible. These include taking AEDs as prescribed and not missing any doses, following up with their doctor and specialist if the medications are not working and they are still having seizures. Bringing a good seizure diary of when the seizures happen and what they are like to the doctor's office will help the doctor to make the best adjustments to the AED doses. It is also important to avoid things that might trigger more seizures such as alcohol, sleep deprivation, street drugs, or mixing in other medications.



In care facilities or group homes where adult patients are known to have frequent nocturnal seizures, the staff need to be aware of this danger and monitor these individuals for some hours after major motor seizures. Some type of alarm system for heart rate may be useful. However, as we try to promote independence for anyone capable of living on their own, knowledge of SUDEP may cause undue anxiety, and will require considerable time and tact to be discussed appropriately. If you want to talk about SUDEP with your physician it will be important to do it when there is time, and you might have to make this request for a future appointment.

How and when to discuss SUDEP with patients and their families and caregivers is another subject of some debate. It is hard to talk about a condition that is still unexplained by definition. How much information is warranted or appropriate to pass on varies from one situation to another.

A 2006 article in the British literature reported on a survey of specialists who treat patients with epilepsy. It indicated that only 4.7% said that they discuss SUDEP with their patients with epilepsy and it's believed that the percentage is similar in North America. In discussions amongst professionals, there is concern about causing unnecessary anxiety in patients and families who already have significant problems. In this paper most clinicians said that they usually only speak about SUDEP with their patients if they're asked about it.

More information about SUDEP is available from these websites:

[www.epilepsy.com/sudep](http://www.epilepsy.com/sudep) is a section of the epilepsy.com website that offers detailed information about SUDEP along with information about new developments and research into it

[www.sudepaware.org](http://www.sudepaware.org) is an organization dedicated to raising awareness and understanding of Sudden Unexpected Death in Epilepsy (SUDEP), with the ultimate goal of finding its cause(s) and prevention.

Approved for circulation in 2013 (sp/eb)

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