

SUDEP

INFORMATION FOR Healthcare Providers



Criteria for SUDEP (Nashef et al, 2011):

- sudden and unexpected death in an individual with epilepsy
- death may be witnessed or unwitnessed
- excluding deaths due to trauma, drowning and/or status epilepticus
- autopsy examination does not reveal a cause of death

In the absence of an autopsy, deaths may be classified as 'probable' or 'possible' SUDEP. SUDEP deaths most often occur at night or during sleep. There is often, but not always, evidence of a seizure before death. A seizure at the time of death is not needed for diagnosis of SUDEP.

WHAT IS SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) refers to the death of a person with epilepsy, without warning and where no cause of death could be found.



HOW COMMON IS SUDEP?

Sudden death is estimated at nearly 24 times more likely in people with epilepsy than in the general population.

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 per 100 people per year.

It appears that children have lower rates at 0.2 to 0.4 deaths per 1,000 children with epilepsy per year. However, rates of sudden death in children with epilepsy may 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. Advances in research are identifying critical risk factors and a number of possible mechanisms for SUDEP.

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 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 a cardiac arrest. It is possible that an individual may carry several physiologic risk factors that together result in death.

RISK FACTORS FOR SUDEP

The most reliable risk factors for SUDEP are related to epilepsy severity. **The best established factor is frequent generalized tonic-clonic seizures. The risk of SUDEP goes up with the number of convulsive seizures per year.** Other factors that have been identified include:

- earlier age of epilepsy onset (before 16 years of age)
- longer duration of epilepsy
- symptomatic epilepsy
- male gender

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

Continued on next page

SUDEP



INFORMATION FOR Healthcare Providers (continued)

SUDEP PREVENTION

There is no proven prevention strategy for SUDEP. However, the risk of SUDEP can be reduced. The strongest risk factor is frequent generalized tonic-clonic (grand mal) seizures; therefore, seizure reduction is the primary goal.

- Counsel people with epilepsy, their families and caregivers about the risk of SUDEP and ways to reduce seizures.
- Encourage adherence with seizure medications.
- Promptly refer people with uncontrolled seizures to specialized epilepsy centers for evaluation and treatment, including epilepsy surgery.

ADVANCING KNOWLEDGE IN SUDEP – WHAT YOU CAN DO

Awareness and research efforts to find the cause and prevention of SUDEP are intensifying. Healthcare providers play a vital role.

- Include SUDEP in discussions about the risks associated with epilepsy.
- Encourage research participation, particularly immediately after a SUDEP event, when the tissue donation process is time critical.
- Talk to your colleagues about SUDEP – become a local expert! Give rounds on the topic or make SUDEP brochures available in communal areas (downloadable from the Making Sense of SUDEP website).

For the most current information about SUDEP, how to discuss it, research opportunities and to sign up to the campaign eNewsletter visit the campaign website.

AWARENESS IS THE FIRST STEP TOWARDS DETERMINING THE CAUSE AND PREVENTION OF SUDEP

- People with epilepsy should be informed about the risk of SUDEP so they can make decisions to lower their risk.
- Raising awareness among healthcare providers and death investigators will improve identification of SUDEP cases and aid research into causes, risk factors and possible preventive solutions.
- SUDEP deserves the same attention as other life-threatening events, such as SIDS (Sudden Infant Death Syndrome) and sudden death associated with heart disease.

© SUDEP Aware 2012
Photos of models used as illustrative content.

HCP/APR 12