



Sudden Unexpected Death in Epilepsy Incidence Rates and Risk Factors

This information sheet is provided to help you understand the evidence regarding the number of occurrences and risk factors for sudden unexpected death in epilepsy (SUDEP). This document is a service of the American Academy of Neurology (AAN).

The AAN is the world's largest association of neurologists and neuroscience professionals. Neurologists are doctors who identify and treat diseases of the brain and nervous system. The AAN is dedicated to promoting the highest quality patient-centered neurologic care.

Experts from the AAN and the American Epilepsy Society (AES) carefully reviewed the available scientific studies on SUDEP. The following information is based on evidence from those studies and other key information. The information summarizes the main findings of the 2017 AAN and AES guideline on SUDEP.

To read the full guideline, visit AAN.com/guidelines.

Overview

Sudden unexpected death in epilepsy (SUDEP) is a poorly understood and catastrophic risk of epilepsy. The sensitive nature of this infrequent but important risk with patients and families prompted the need for evidence-based information about SUDEP. The goal of this practice guideline is to examine how often SUDEP occurs and what factors increase the risk of SUDEP.

What is SUDEP?

SUDEP is an uncommon but known complication of epilepsy. SUDEP is the sudden, unexpected death of a person with epilepsy who is otherwise healthy. The cause of death in SUDEP is unknown, but evidence discussed below does indicate certain risk factors.

How often does SUDEP happen each year?

Occurrence rate in children

SUDEP is **rare in children**. Each year, **1 in 4,500** children with epilepsy will die of SUDEP.

Occurrence rate in adults

SUDEP is **uncommon in adults**. Each year, **1 in 1,000** adults with epilepsy will die of SUDEP.

What are the risk factors for SUDEP?

Generalized tonic-clonic seizures (GTCS)

The occurrence of generalized tonic-clonic seizures (GTCS), is a risk factor for SUDEP. GTCS is a type of seizure that involves the entire body with convulsions and loss of consciousness. The greater the frequency of GTCS, the greater the risk of SUDEP. Reducing the number of GTCSs (e.g., with effective treatment), may reduce the risk of SUDEP. **Seizure freedom from GTCS is strongly associated with a decreased SUDEP risk.**

Other risks

Other risks with low evidence exist and should be discussed in more detail with your treating clinician.

This guideline was co-developed with the American Epilepsy Society and endorsed by the International Child Neurology Association.

This statement is provided as an educational service of the American Academy of Neurology. It is based on an assessment of current scientific and clinical information. It is not intended to include all possible proper methods of care for a particular neurologic problem or all legitimate criteria for choosing to use a specific procedure. Neither is it intended to exclude any reasonable alternative methodologies. The AAN recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on all of the circumstances involved.

The AAN develops these summaries as educational tools for neurologists, patients, family members, caregivers, and the public. You may download and retain a single copy for your personal use. Please contact guidelines@aan.com to learn about options for sharing this content beyond your personal use.

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