

# SUDEP

(Sudden Unexpected Death in Epilepsy)



**Many people with epilepsy, and their families, are very concerned about the potential complications of seizures. While the following information can be frightening to think about, it is important that parents and patients are provided with honest information regarding the risks associated with epilepsy.**

**Most people with epilepsy live a full and healthy life. However, there are real risks associated with epilepsy. The most serious complications of epilepsy include physical injury and death. While death from seizures is rare, especially in children, death is a real risk in individuals with uncontrolled seizures.**

**This handout contains very frank information regarding the possibility of death in persons with epilepsy. Please discuss further questions or concerns regarding SUDEP and other epilepsy-related risks with your neurology provider.**

## What is SUDEP?

SUDEP is the sudden, unexpected death of an otherwise healthy person with epilepsy. The individual's death is not caused by a seizure emergency (such as status epilepticus) or a seizure-related accident. A distinct cause of death is not identified on autopsy.

## What causes SUDEP?

Researchers are not certain what causes SUDEP. In some situations, there is evidence of seizure at the time of death, but often this is not the case. Currently, a great deal of research is focused on possible causes of SUDEP. Possible causes of death include difficulties with breathing, heart rhythm, or brain function in individuals with seizure. Death may be caused by a combination of these factors, or some other cause that has not been discovered yet.

SUDEP occurs most often at night, or when the individual is sleeping. Because death is often not witnessed, there are often unanswered questions regarding the cause or circumstances of death.

## How common is SUDEP?

SUDEP affects 1 in 1000 people with epilepsy every year. However, it is more frequent in people with severe or uncontrolled epilepsy.

## Who is at risk for SUDEP?

The greatest risk factor for SUDEP is uncontrolled, or frequent, seizures. It seems that individuals with generalized tonic-clonic seizures ("grand mal" seizures) are at the greatest risk. Individuals with only absence or myoclonic seizures are not known to be at risk for SUDEP. The risk of SUDEP is much lower in children than in adults. While all the factors that contribute to SUDEP are unknown, the severity of your (or your child's) epilepsy is a contributing factor.

Other possible risk factors include the following:

- Young adult age (20–40 years old)
- Not taking medications regularly or as prescribed
- Suddenly stopping or switching medicines
- Having epilepsy for a long time
- Having epilepsy since a young age
- Intellectual disability (IQ<70)



# SUDEP

(Sudden Unexpected Death in Epilepsy)



## How can I reduce the risk of SUDEP or other epilepsy-related death or injury in myself or my child?

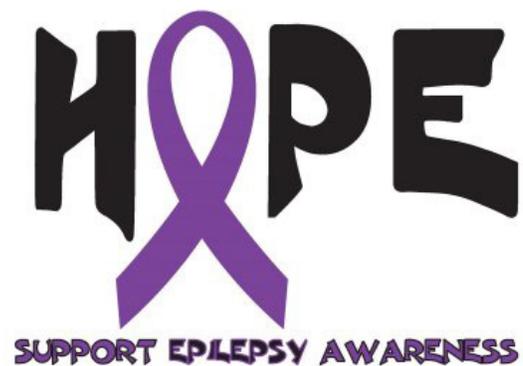
- Control and prevent seizures as much as possible by working closely with your neurology provider.
- Take medications regularly and as prescribed.
- Discuss other non-medication treatment options with your epilepsy specialist if medicines aren't keeping seizures under control.
- Talk to your neurology provider about having your heart checked by a cardiologist. This is important in people who do not have a clear cause for epilepsy on MRI or imaging studies.
- Identify and avoid seizure triggers (missed medications, sleep deprivation, illness and fever, stress and fatigue, etc.).
- Ensure that family, educators, childcare workers, co-workers, and friends are aware of seizure first aid and CPR techniques.
- Practice proper seizure precautions, particularly with activities such as bathing, swimming, and climbing.
- Take good care of yourself or your child. Get proper sleep, practice good nutrition and hydration, and get regular exercise. Minimize alcohol use and avoid recreational drug use. Minimize stress and fatigue, whenever possible.

## I am worried about the risk of SUDEP. Who should I talk with?

Discuss your questions and concerns directly with your neurology provider. While SUDEP is rare, it is common to be scared about the risk of injury or death from seizures. There are many resources for individuals and families coping with epilepsy, including epilepsy organizations and support groups.

### Resources and References:

<http://www.cdc.gov/epilepsy/sudep/>  
<http://www.epilepsy.com/learn/impact/mortality>  
<http://www.epilepsy.com/get-help/about-sudep-institute>  
<http://www.sudepaware.org/>  
<http://pame.aesnet.org/>



### Child Neurology Consultants of Austin

6811 Austin Center Blvd. Suite 400, Austin, TX 78731

(512)494-4000

[www.childneurotx.com](http://www.childneurotx.com)



Child Neurology  
Consultants of Austin