

# Sudden Unexplained Death in Epilepsy (SUDEP)

## Frequently Asked Questions

### What is SUDEP?

A death is referred to as a "SUDEP" when a seemingly healthy person with epilepsy dies unexpectedly and no reason for the death can be found.

### What causes SUDEP?

Irregularities in heart rhythm, breathing dysfunction, disturbance in brain circulation, and seizure-induced hormone and metabolic changes have all been suggested as potential causes of SUDEP. Recently, the first potential gene for SUDEP has been identified that controls the normal rhythm of the heart.

### How is SUDEP determined

In most cases, an autopsy is required to rule out other causes of death. Other factors are also considered, like: the person had epilepsy; was in reasonably good health; and the death was not the direct result of a seizure.

### How often does SUDEP occur?

The incidence of SUDEP differs greatly depending upon the population studied. In general, the risk is small for a person with epilepsy. In any given year, about one out of every 3,000 people with epilepsy will succumb to SUDEP. On the other hand, people with uncontrolled seizures (especially generalized convulsions), the risk of SUDEP is one in 100. People with absence or myoclonic seizures are not known to have increased risk for SUDEP.

### Is it SUDEP if there was no evidence of a seizure?

The patient has to have a diagnosis of epilepsy for SUDEP to be considered. However, in SUDEP, the death may not be the direct result of a seizure. It is not certain what role seizures play in the death process. The absence of a seizure prior to death does not preclude it from being deemed SUDEP.

### Is SUDEP genetic?

There are some studies that suggest genetic factors may play a role, but no definite information is available at this time.

### Should I talk to my doctor about SUDEP?

If your doctor has not spoken to you about the health risks associated with epilepsy including SUDEP, schedule an appointment to meet with him or her.

### Who is at risk for SUDEP?

Some risk factors associated with SUDEP are:

- Seizures that can't be controlled
- Treatment with multiple anticonvulsant drugs
- Long-standing chronic epilepsy
- Generalized tonic-clonic seizures
- Seizures that happen at night (nocturnal seizures)
- Failure to take antiepileptic medication as prescribed
- Stopping the use of antiepileptic medicine abruptly
- Developmental delays
- Onset of epilepsy at a young age

### Can one reduce the risk of SUDEP?

Maximize seizure control by taking antiepileptic medications as prescribed. If medicines do not work, then consider other therapies such as epilepsy surgery, the vagus nerve stimulator, or a ketogenic diet. Avoid any potential seizure triggers and maintain a seizure diary to keep record of things that occurred before a seizure (such as, were you ill, tired, stressed, hungry? Where did the seizure occur and what time of day was it?).

Eat well, get enough rest and, exercise regularly and keep stress to a minimum. Consider nighttime supervision.

Heart rate monitors, breathing alarms and knowledge of emergency resuscitation measures including CPR and use of a defibrillator may also be helpful.

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## Frequently Asked Questions (continued)

### Can an anti-suffocation pillow prevent SUDEP?

There is no data to support the use of these pillows. However, you may wish to discuss any possible benefits with your doctor.

### Do audio monitoring devices help?

This type of device could alert you to a seizure that is accompanied by audible sounds but may not alert you that your loved one has stopped breathing.

### Can I donate my loved one's tissues to research?

At this time, there is no national repository that collects tissue and other samples to be used in research on SUDEP. However, Dr. Alica Goldman is a neurologist specializing in the field of epilepsy. She and her colleagues at The Department of Neurology at Baylor College of Medicine are conducting a research study called *Ion Channels in Epilepsy*.<sup>\*</sup> The aim of the research is the identification of the genetic risk factors that predispose an individual to epilepsy and to sudden death. This study is funded by The National Institutes of Health (NIH)/The National Institute for Neurological Disorders and Stroke (NINDS). In order to perform this research, the investigators need a blood sample or a small piece of fresh tissue from the person who died as a result of the seizure disorder.

If you would like to learn more about this study or for participation, please contact Dr. Alica Goldman (goldman@bcm.edu) or the study coordinator, Ms. Melissa Lambeth (lambeth@bcm.tmc.edu).

*\* This epilepsy study listing is for information purposes only; and the reader assumes full responsibility and risk for the appropriate use of the information provided. The information concerning the study was sent to the Epilepsy Foundation by the investigator or staff conducting the research. The Epilepsy Foundation, its affiliates, officers, directors, employees and agents do not warrant or guarantee the accuracy or completeness of this information and specifically disclaims any liability therefore.*

### Is there support for families of SUDEP victims?

Contact any of the organizations with websites listed below or contact your local Epilepsy Foundation affiliate.

#### Epilepsy Foundation

[www.epilepsyfoundation.org/about/SUDEP](http://www.epilepsyfoundation.org/about/SUDEP)

#### SUDEP Aware

[www.sudepaware.org](http://www.sudepaware.org)

#### Epilepsy Bereaved

[www.sudep.org](http://www.sudep.org)

#### Epilepsy.com

[www.epilepsy.com/epilepsy/SUDEP](http://www.epilepsy.com/epilepsy/SUDEP)



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