



## SUDEP Resources

### More information:

- [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) –  
Epilepsy Foundation of America
- [www.epilepsy.com](http://www.epilepsy.com) – Epilepsy.com
- [www.sudepaware.org](http://www.sudepaware.org) – SUDEP Aware

### Bereavement/grief organizations:

- [www.compassionatefriends.org](http://www.compassionatefriends.org) –  
The Compassionate Friends
- [www.sudep.org](http://www.sudep.org) – Epilepsy Bereaved

## Our Mission

The Epilepsy Foundation of Minnesota leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy.



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# Understanding Sudden Unexplained Death in Epilepsy (SUDEP)

## 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.

### Common criteria:

- The person had epilepsy, defined as recurrent unprovoked seizures.
- The person died unexpectedly while in a reasonable state of health.
- The death occurred suddenly.
- The death occurred during normal activity, often during sleep and found in or near the bed.
- An obvious medical cause of death could not be determined at autopsy.
- The death was not the direct result of status epilepticus.

Most people with epilepsy live a full life span. However, there are potential factors associated with living with epilepsy and seizures that may increase the risk of early death.



## What causes SUDEP?

**More research is needed to fully understand what causes SUDEP. Potential causes may include, but are not limited to:**

- Irregularities in heart rhythm
- Breathing dysfunction
- Disturbance in brain circulation
- Seizure-induced hormone and metabolic changes

### Risk factors most consistently associated with SUDEP:

- Poorly controlled seizures
- Treatment with multiple anticonvulsant drugs
- Having long standing chronic epilepsy

### Other risk factors include:

- Generalized tonic-clonic seizures
- Seizures that happen during sleep
- Not taking anticonvulsant medicines as prescribed
- Stopping the use of anticonvulsant medicine abruptly
- Developmental delays
- Onset of epilepsy at a young age

## What can be done to try to reduce the risk of SUDEP?

- Maximize seizure control. Take medication as prescribed. If medicines do not work, then consider other therapies such as epilepsy surgery, the vagus nerve stimulator and the ketogenic diet.
- Eat well, get enough rest/regular exercise and keep stress to a minimum whenever possible.
- Be aware of and avoid any potential seizure triggers. Keep a record of things that occurred before a seizure.
- Night time supervision and devices for monitoring heart and breathing activities have not yet been proven to reduce SUDEP risk.
- Knowledge of emergency resuscitation measures, including CPR and use of a defibrillator.

## How do I talk with 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. Questions to ask include: What risks do I/my family member have for SUDEP? What can we do to reduce the risk of SUDEP?