

## Reducing Your Risk

It is important to talk with your doctor about your risk of SUDEP.

Taking medication as prescribed by a doctor is a top priority for reducing risk.

If your seizures continue, talk with your doctor about other options related to medication and treatment or consult with an epilepsy specialist.

Learn More About SUDEP  
At The Following Web sites:

[www.cdc.gov/epilepsy](http://www.cdc.gov/epilepsy)

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

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

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

### Sources

1. Devinsky O. Sudden unexpected death in epilepsy. *New Engl J Med.* 2011;365:1801-11.
2. Tomson T, Nashef L, Ryvlin P. Sudden unexpected death in epilepsy: current knowledge and future directions. *Lancet Neurol.* 2008; 7(11):1021-31.
3. Epilepsy Foundation. First Aid for Generalized Tonic-Clonic Seizures Web site. Available at <http://www.epilepsyfoundation.org/aboutepilepsy/firstaid/generalized-tonic-clonic-seizures.cfm>.

## Sudden Unexpected Death in Epilepsy (SUDEP)



What SUDEP Means  
to a Person Living  
with Epilepsy



**Centers for Disease  
Control and Prevention**  
National Center for Chronic  
Disease Prevention and  
Health Promotion

# What SUDEP Means to a Person Living with Epilepsy

## What is SUDEP?

For people with epilepsy, the risk of Sudden Unexpected Death in Epilepsy (SUDEP) is an important concern. SUDEP refers to deaths in people with epilepsy that are not caused by injury, drowning, or other known causes. Often SUDEP occurs with evidence of an associated seizure.<sup>1</sup>

### The risk of SUDEP appears increased in people who—

- Have frequent or uncontrolled seizures.
- Have generalized tonic-clonic (grand mal) seizures.
- Do not take seizure medication regularly as prescribed.
- Use excessive alcohol.<sup>1</sup>

Estimates of SUDEP risk vary, but the average from general population studies suggests that each year there is approximately 1 case of SUDEP for every 1,000 people with epilepsy.<sup>2</sup>



## Talking with Your Doctor

Getting the facts about SUDEP is important. As a person living with epilepsy, one of the best places to start is your doctor's office. Ask your doctor about SUDEP and how it can affect your life.



### Questions to consider—

- What can I do to reduce my risk of SUDEP?
- What should I do if I forget to take my seizure medication?
- What steps should I take if it is decided to change my seizure medication?
- What medications provide the best seizure control for me?
- Is there any equipment I need at home to help reduce my risk for SUDEP?
- Are there any specific activities I should avoid?
- What instructions should I give family, friends, and teachers if I have a seizure?
- How should I be supervised at night?

## First Aid for a Convulsive (Grand Mal) Seizure

- Clear the area around the person to remove hard or sharp objects.
- Loosen any ties or clothing around the person's neck that might make it hard to breathe.
- Turn the person gently onto their side to help keep their breathing passages clear.
- Put something flat and soft, like a folded jacket, under the head.
- Stay with the person until the seizure ends naturally and they regain awareness.

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Do *not* try to force the person's mouth open or place anything in the mouth or between the teeth.

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Most seizures stop by themselves within 5 minutes, followed by a gradual return of consciousness. If a person is known to have epilepsy, it is usually not necessary to call for emergency medical help. However, help should be sought if—

- The seizure has not stopped after 5 minutes, or one seizure quickly follows another.
- Breathing does not resume normally when the seizure movements stop.
- The person suffers an injury.<sup>3</sup>

More information is available at [www.epilepsyfoundation.org/resources/medical/firstaid.cfm](http://www.epilepsyfoundation.org/resources/medical/firstaid.cfm)