

## Reducing Your Child's Risk

It is important to talk with your child's doctor about their risk of SUDEP.

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

If their seizures continue, talk with their 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 Parent or Caregiver of  
a Child with Epilepsy



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

# What SUDEP Means to a Parent or Caregiver of a Child 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.<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 My Child's Doctor

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



**Questions to consider—**

- What can I do to reduce my child's risk of SUDEP?
- What should I do if they forget to take their seizure medication?
- What steps should I take if it is decided to change their seizure medication?
- What medications provide the best seizure control for my child?
- Is there any equipment I need at home to help reduce their risk for SUDEP?
- Are there any specific activities they should avoid?
- What instructions should I give family, friends, and teachers if they have a seizure?
- How should I supervise them 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).