

# What You Need to Know About **SUDDEN UNEXPECTED DEATH IN EPILEPSY - (SUDEP)**



## What is SUDEP?

SUDEP stands for Sudden Unexpected Death in Epilepsy.

It's the term used when a person with epilepsy dies without warning signs and no cause of death can be found. People with epilepsy and their families should know what SUDEP is and ways to reduce the risk of SUDEP.

## How common is SUDEP?

On average, SUDEP affects about 1 out of every 1,000 people with epilepsy. Some patients have greater or lesser risk. This fact sheet will help everyone learn ways to reduce their risk.

Learning more about SUDEP is an important first step to help prevent it.



## What causes SUDEP?

SUDEP usually happens at night or during sleep. SUDEP may occur after having a seizure, but not always.

Although exact causes of SUDEP are not known, research is being done to learn more. Possible causes of SUDEP include:

- Heart rhythm problems during a seizure.
- Breathing interruptions during a seizure that last a long time.
- Changes to brain function during a seizure that affect heart rate and breathing.

Your health care provider and the organizations listed at the end of this fact sheet can help you stay informed about new research.

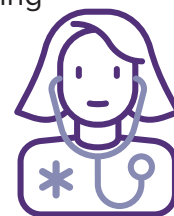
## Who is at greatest risk of SUDEP?

- People who have frequent or uncontrolled seizures.
- People who regularly miss seizure medications or those who do not take their medicines as prescribed.
- People who have grand mal seizures (tonic-clonic seizures).
- People with nighttime seizures.



## How can I reduce my risk?

The best way to reduce SUDEP risk is to have as few seizures as possible. If your seizures remain uncontrolled after initial treatment, speak to your health care provider about seeing an epilepsy specialist or getting evaluated at a specialized epilepsy center. See contact information at the end of this fact sheet.



Here are some specific things you can do to reduce your seizure risk:

- Keep regular appointments with your health care provider. Build a relationship with them.
- Take seizure medications as prescribed and talk to your provider about any concerns.
- Take good care of yourself. Get enough rest, exercise, eat healthy, and avoid stress.
- Talk to your health care provider about behaviors that can cause seizures, like excessive alcohol use, substance use, or not getting enough sleep.
- Keep a journal of things that happened before a seizure, so you know your triggers, including where and when the seizure occurred.
- Avoid sleeping in a prone (face-down) position.

## How to Be Safe During a Seizure

People with epilepsy can take actions to make sure they are safe when a seizure happens, such as:

- Avoid swimming in deep water (deeper than waist level). Swim with a partner who could carry you if needed and wear a floatation device when around water.
- Use a shower instead of taking a bath. If you must take a bath, let someone know.
- At home, pad sharp furniture corners and avoid area rugs that can cause tripping.

- Position yourself far enough away from an open flame (e.g., campfire, backyard fire pit, or fireplace).
- Avoid ladders and open heights (e.g., roofs).
- Try not to use power tools where there is risk of serious injury. If using power tools, use protective gear and safety guards.
- Don't smoke.

More information about safety during a seizure, including guidance for others on how to safely interact with you, is available at:

<https://www.epilepsy.com/preparedness-safety/staying-safe>.

## Help is Easy to Find

You don't have to figure out epilepsy or SUDEP on your own. There are many epilepsy organizations that provide support and resources for individuals and families trying to learn more about SUDEP.

### Get Connected with an Epilepsy Specialty Center Near You

The National Association of Epilepsy Centers (NAEC) can help you find an epilepsy specialty center near you. Search by state or zip code at:

<https://www.naec-epilepsy.org/about-epilepsy-centers/find-an-epilepsy-center/>



### Regional Epilepsy Organizations in NYS

- **Epilepsy Foundation of Northeastern New York, Inc.**  
Albany, NY 12205 | (518) 456-7501  
<https://www.efneny.org>
- **Epilepsy Foundation of Long Island**  
East Meadow, NY 1155 | (516) 739-7733  
<https://www.epicli.org/>
- **Epilepsy Alliance of West Central NY, a part of EPI (Empowering People's Independence)**  
Rochester, NY 14620 | (585) 442-4430 ext. 2741  
<https://www.epiny.org/>  
<https://epiny.org/epilepsy/sudep/>
- **Epilepsy Society of Southern NY/Capabilities Partnership, Inc.**  
West Nyack, NY 10994 | (845) 627-0627 ext. 112  
<https://cpiny.org/>
- **Epilepsy Foundation of Metropolitan New York**  
New York, NY 10006 | (212) 677-8550  
<https://www.efmny.org/>
- **Epilepsy Association of Western New York**  
Buffalo, NY 14222 | (716) 883-5396 ext. 407  
<https://epilepsywny.org/>

### National Epilepsy Organizations and Resources

- **American Epilepsy Society (AES)**  
<https://www.aesnet.org/>
- **Partners Against Mortality in Epilepsy (PAME)**  
<https://pameonline.org/>
- **SUDEP Action Day**  
<https://sudepactionday.org/>
- **U.S. Centers for Disease Control and Prevention**  
<https://www.cdc.gov/epilepsy/about/sudep/index.htm>
- **Epilepsy Foundation of America**  
<https://www.epilepsy.com/programs/sudep-program>
- **Epilepsy Alliance America**  
<https://www.epilepsyallianceamerica.org/>
- **Danny Did Foundation**  
<https://www.dannydid.org/epilepsy-sudep/about-sudep/>
- **CURE Epilepsy**  
[https://www.cureepilepsy.org/signature\\_programs-sudep-sudden-unexpected-death-in-epilepsy-overview/](https://www.cureepilepsy.org/signature_programs-sudep-sudden-unexpected-death-in-epilepsy-overview/)
- **SUDEP Action "SUDEP and Seizure Safety Checklist"**  
<https://www.sudep.org/checklist>
- **Preventing Epilepsy Deaths Toolkit, from the Child Neurology Foundation**  
<https://preventingepilepsydeaths.org/>