

SUDEP (Sudden Unexpected Death in Epilepsy)

This handout contains frank information regarding SUDEP and the risk of death in persons with epilepsy. Please discuss any questions or concerns regarding SUDEP or other epilepsy-related risks with your child's neurology provider.

Most people with epilepsy live full and healthy lives. However, epilepsy is associated with increased risks of physical injury and death. Some more common risks (e.g., drowning and car accidents) are frequently addressed in outpatient visits. SUDEP (sudden unexplained death in epilepsy) isn't always discussed because providers may not want to frighten or overwhelm patients and their caregivers. However, it is a risk that patients with epilepsy and their caregivers should be aware of. According to a brochure on SUDEP from epilepsy.com:

In a 2016 survey, almost all caregivers and nearly 2 in 3 people with epilepsy said they worry about death from epilepsy or seizures. Almost half of respondents said learning more about SUDEP could make a difference in how they approach seizure control. People know about the dangers of fire and Sudden Infant Death Syndrome (SIDS), but there is very little awareness about the risk of death from epilepsy. And unfortunately, SUDEP kills more Americans than either of these.

What is SUDEP?

SUDEP refers to deaths in people with epilepsy that are not caused by injury, drowning, or other known causes. Most, but not all, cases of SUDEP occur during or immediately after a seizure, but no immediate cause of death is identified.

What causes SUDEP?

Scientists and researchers are still learning about SUDEP and its causes. Possible contributing factors may include difficulties with breathing, heart rhythm, or brain function in individuals with seizure.

How common is SUDEP?

- More than 1 out of 1,000 people with epilepsy die from SUDEP each year.
- SUDEP is the leading cause of death among young adults with poorly controlled seizures.
- SUDEP is rare in children, with reported rates ranging from 0.2 to 0.4 per 1,000 people.
- People with only absence or focal aware ("simple partial") seizures are not known to have increased risk for SUDEP.

Who is at risk for SUDEP?

The greatest risk factor for SUDEP is uncontrolled seizures. People who have 3 or more generalized tonic-clonic seizures a year have a 15-fold increased risk of SUDEP. Seizure freedom, particularly freedom from generalized tonic-clonic seizures, is strongly associated with decreased SUDEP risk.

Other risk factors include the following:

- Young adult age (20-40 years old)
- Missing medication doses, or suddenly stopping or switching medicines
- Having epilepsy for a long time
- Having epilepsy from a young age

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- Intellectual disability (IQ < 70)
- Sleeping prone (on your stomach) may be a risk factor

How can I reduce the risk of SUDEP or other epilepsy-related death or injury in myself or my child?

- Work closely with your neurology provider to control or minimize seizures.
- Take medications regularly and as prescribed.
- Identify and avoid seizure triggers (missed medications, sleep deprivation, illness and fever, stress and fatigue, etc.).
- If seizures are uncontrolled on medication, talk to your neurologist about other treatment options like surgery, neurostimulation devices, or a dietary therapy that can reduce your seizures and lower your risk for SUDEP.
- Talk to your neurology provider about having your heart checked by a cardiologist. This is important in people who do not have a clear cause for epilepsy on MRI or imaging studies.
- Ensure that family, educators, childcare workers, co-workers, and friends are aware of seizure first aid and CPR techniques.
- Practice seizure precautions, particularly with activities such as bathing, swimming, and climbing.
- Take good care of yourself or your child. Get proper sleep, practice good nutrition and hydration, and get regular exercise.

Do seizure monitoring devices or sleeping with someone else in the room decrease risk of SUDEP?

Most cases of SUDEP are unwitnessed. Having someone available at night to help during and after a seizure may be one way to minimize risk of SUDEP. For example, someone could help provide first aid and reposition the person after their seizure so their breathing isn't blocked. However, having another person in the room or wearing a monitoring device is often not practical or desired, and more scientific evidence is needed to prove that these factors are effective in preventing SUDEP.

I am worried about the risk of SUDEP. Who should I talk with?

Discuss your questions and concerns directly with your neurology provider. While SUDEP is rare, it is common to be scared about the risk of injury or death from seizures. There are many resources for individuals and families coping with epilepsy, including epilepsy organizations and support groups.

Resources and References:

<https://www.cdc.gov/epilepsy/about/sudep/index.htm>

<https://www.epilepsy.com/learn/impact/mortality>

<https://www.epilepsy.com/programs/sudep-institute>

<https://www.sudep.news/>

<https://www.epilepsy.com/volunteer/spreading-awareness/aimforzero>

<https://www.epilepsy.com/sites/default/files/atoms/files/SUDEP%20Institute%20Brochure%20Rev%202011-2018.pdf>