

Why is it important to discuss mortality in epilepsy?

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 Sudden Unexpected Death in Epilepsy (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.

Unfortunately, SUDEP kills more Americans than either of these.

People with epilepsy may have a higher mortality risk if they have one or more of these risk factors:

- Ongoing bilateral tonic-clonic seizures
- Nocturnal seizures
- Lack of anti-seizure treatment
- Living alone
- Adults, 85 and older
- Male gender
- Black, non-Hispanic
- Genetic conditions
- Drug-resistant epilepsy
- Sleep deprivation

KNOW THE SUDEP FACTS

For people with uncontrollable epilepsy, the risk of SUDEP is much higher - about **1 out of 150 people each year**

SUDEP is the leading cause of death among **young adults** with uncontrolled epilepsy

Have A Discussion

Knowing about epilepsy related deaths and SUDEP is a tough topic. Having a discussion with your health care team can be uncomfortable, yet it is needed. It is important to talk to your medical professional about your risk and how to best manage your seizures:

- ✓ How can you lower your risk?
- ✓ What should you do if you have another seizure?
- ✓ How can you prevent future seizures?
- ✓ Are there other treatment options like surgery, neurostimulation devices, or a dietary therapy that can reduce your seizures and lower your risk for SUDEP?
- ✓ What should you do to reduce your risk of SUDEP if you have seizures at night?
- ✓ Should you consider a device to warn someone that you are having a seizure?
- ✓ Should you consider sharing a bedroom?

Mortality and SUDEP

When a person is diagnosed with epilepsy it can be overwhelming and they often have questions about their life and future. Getting reliable information and working closely with your health care team is key to dealing with the challenges of a life with seizures. Often, mortality in epilepsy such as SUDEP can be difficult to talk about.

SUDEP is said to occur when a person with epilepsy dies unexpectedly and was otherwise healthy. The death is not known to be related to an accident or seizure emergency such as status epilepticus. When an autopsy is done, no other cause of death can be found.

The exact causes of SUDEP are not well understood but it is likely due to problems with consciousness, breathing and heart function following a seizure. Many but not all instances of SUDEP occur at night, when seizures are not witnessed.



A Life Remembered: Melissa's Story

Melissa Schlobohm-Clover died unexpectedly of SUDEP on March 13th, 2022 at the age of 37. She had epilepsy since she was 18. Her family didn't know about SUDEP and are heart broken. She didn't let Epilepsy get in the way of enjoying life and having a successful career.

She left us way too soon, her spirit was infectious and her laugh lit up a room. We miss her every day but the one that loves her most called you home. This is not good-bye but see her later someday. -- Shaun Clover, Melissa's husband

Each year about **1 out of 1,000** adults and children with epilepsy die from SUDEP.

Aim for Seizure Control

Each person with epilepsy is different.

Many people with epilepsy can stop their seizures with treatment. But for some, seizures continue even with medication. These are called uncontrolled seizures.

If you still have seizures that happen without a clear reason —like a fever, illness, or missed medication—your seizures may be uncontrolled. Another name for this is drug-resistant or medically refractory epilepsy.

People who have seizures that involve shaking or losing consciousness (called convulsive seizures) have a higher risk for SUDEP.

Knowing more can help you feel more in control and take steps to lower your risk.



Take your medicine on time, every day – exactly as prescribed.



Get enough sleep. There is a significant relationship between sleep deprivation and seizures in people with epilepsy.



Avoid or limit alcohol and illicit substances.



Know your seizure triggers and develop plans to minimize them.



Keep a diary of seizures, test results, and questions for your doctor.



Create and share your own Seizure Action Plan.



Epilepsy-related mortality should be a public health priority.

There are at least 2,750 U.S. cases of SUDEP every year. In comparison, in 2013, sudden infant death syndrome (SIDS) caused 1,575 deaths, and accidental exposure to smoke, fire, and flames caused 2,760 deaths.

Learn more with us

We are dedicated to helping people living with epilepsy. With other partner organizations, we are empowering people living with epilepsy with information, awareness, and education about epilepsy related mortality and SUDEP. We also urge medical professionals to openly discuss reducing SUDEP risk with their patients and caregivers.



If you would like more information about SUDEP, visit epilepsy.com/SUDEP or email sudep@efa.org.

If you have lost a loved one to SUDEP, please contact the Epilepsy & Seizures Helpline for information and support.

Epilepsy & Seizures Helpline
1-800-332-1000
epilepsy.com/helpline

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ISBN: 979-8-89883-000-7

Ask Questions about Mortality and Epilepsy



Melissa's story is one of love, laughter, and light - a life cut short by SUDEP. Her memory reminds us why it's vital to talk about the risks of living with epilepsy. Speak with your health care team.

Awareness, education, & action can save lives.