HAVE THE DISCUSSION

Knowing about and discussing SUDEP with your health care team is important. Ask your medical professional about your risk:

- 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?

BE AN AMBASSADOR FOR THE SUDEP INSTITUTE

Have you been affected by SUDEP or are you living with epilepsy and want to make a difference by raising awareness about death in epilepsy? Do you want to share your journey? If so, join us as an Ambassador for the SUDEP Institute. Contact us at SUDEP@efa.org.

KNOW THE SUDEP FACTS

More than **1 out of 1,000** with epilepsy die from SUDEP each year.

= 100

SUDEP is the leading cause of death among young adults with poorly controlled seizures

For people with poorly controlled seizures, the risk of SUDEP is much higher:

1 out of 150 each year

The best way to prevent SUDEP is to work with your health care team to have as few seizures as possible.

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.

ABOUT THE EPILEPSY FOUNDATION

The Epilepsy Foundation, a national nonprofit with more than 45 network partners throughout the U.S., has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures.

The mission of the Epilepsy Foundation is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. For additional information, please visit **epilepsy.com/sudep**.

EPILEPSY® FOUNDATION

CONTACT US

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WHAT IS 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 Sudden Unexpected Death in Epilepsy (SUDEP) is difficult to talk about.

EACH YEAR ABOUT 1 OUT OF 1,000 ADULTS AND CHILDREN WITH EPILEPSY DIE FROM SUDEP.

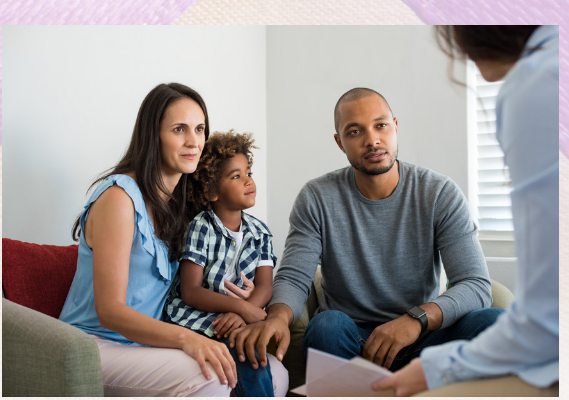
SUDEP is said to occur when a person with epilepsy dies unexpectedly and was otherwise healthy. The death is not known to be related to an accident or seizure emergency such as status epilepticus. However, it occurs more frequently in people with epilepsy whose seizures are poorly controlled. When an autopsy is done, no other cause of death can be found.

SUDEP and mortality in epilepsy can be an uncomfortable topic. With education and awareness, people living with epilepsy can feel empowered to understand their risks and work with their health care team to understand seizure management and a lifestyle plan to live each day to the fullest.

WHAT IS THE SUDEP INSTITUTE?

The Epilepsy Foundation is dedicated to helping people living with epilepsy. The SUDEP Institute empowers people living with epilepsy with information and education about SUDEP. We also urge medical professionals to openly discuss reducing risk with their patients. We accomplish this by:

- Conducting SUDEP education and awareness for people living with epilepsy, their families, and medical professionals
- Driving and supporting research into the causes of and ways to prevent SUDEP
- Offering bereavement support services via phone, email, text or an online community for those affected by loss from epilepsy
- Working collaboratively with other organizations involved with epilepsy to support and find the answers to SUDEP



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 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.

> **“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.”**
>
> – Orrin Devinsky, MD, director of the New York University Langone Comprehensive Epilepsy Center and SUDEP Advisory Board member

STRIVE FOR SEIZURE CONTROL

Each person with epilepsy is different. While many people with epilepsy can achieve seizure control with available treatments, some cannot. However, with information, people living with epilepsy can feel empowered to have the information they need to minimize their risk for SUDEP.

☐ 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.

☐ 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 Response Plan.