

SUDEP – Sudden Unexplained Death in Epilepsy Frequently Asked Questions & Answers

Q: Can someone die from epilepsy?

A: Most people with epilepsy live a full life span. However, there are serious health risks associated with epilepsy including the risk of premature death:

- Accidents such as drowning, burning, choking, or falling can occur during a seizure, and may result in injuries that are serious or potentially life-threatening.
- Sometimes, epilepsy is a symptom of a more serious underlying condition such as a stroke or a tumor that carries an increased risk of death.
- Persons with epilepsy have an increased risk for depression and suicide.
- Very prolonged seizures or seizures in rapid succession, a condition called *status epilepticus*, can also be life threatening. Status epilepticus can sometimes occur when seizure medication use is stopped.
- People with epilepsy have a risk of dying suddenly and unexpectedly from Sudden Unexplained Death in Epilepsy (referred to as SUDEP). SUDEP is defined as sudden unexpected death in persons with epilepsy that occurs during normal activity (often during sleep), with or without evidence of a seizure, in which post mortem examination (i.e. an autopsy) does not reveal any other cause of death.

Q: What causes SUDEP?

A: The possibility of sudden death in people with epilepsy has been documented as far back as the 1800's. There has been increased awareness of SUDEP over the past 2-3 decades and it is presently acknowledged as a serious risk factor in epilepsy. While a clear understanding of SUDEP and how to prevent it are still lacking, growing interest on the part of medical professionals and researchers has resulted in identifying risk profiles and important clues to the underlying causes of SUDEP. Irregularities in heart rate and rhythm, breathing dysfunction, disturbance in brain circulation, and seizure-induced hormone and metabolic changes have all been suggested as potential causes of SUDEP. It is not yet known what role seizures play in SUDEP.

Q: How is SUDEP diagnosed?

A: SUDEP can only be confirmed by an autopsy. The most common criteria used for the diagnosis of SUDEP are (Leestma, et al 1997):

- The person has epilepsy, which is defined as recurrent unprovoked seizures.
- The person died unexpectedly while in a reasonable state of health.
- The death occurred suddenly.
- The death occurred during normal activity.
- An obvious medical cause of death could not be determined at autopsy.
- The death was not the direct result of status epilepticus.

Q: Who is at risk for SUDEP?

A: While SUDEP can happen to anyone with epilepsy, ~~it appears that~~ some people are at higher risk than others.

The risk factors most consistently associated with SUDEP are:

- Poor seizure control
- Use of 3 or more antiepileptic drugs
- A long duration of epilepsy

Other risk factors include:

- Generalized tonic-clonic seizures
- Seizures that happen at night (called nocturnal seizures)
- Not taking antiepileptic drugs as prescribed
- Stopping the use of antiepileptic drugs abruptly
- Developmental delays
- Onset of epilepsy at a young age

Q: How often does SUDEP occur?

A: At present, there is no place in the United States that is tracking and collecting data on the incidence of SUDEP. While some studies have been done in other countries including a large-scale investigation that was conducted in Great Britain in (? 2002), understanding of incidence remains limited. Of the studies that have been done, the following has been observed:

- SUDEP appears to be a rare occurrence among people who have been newly diagnosed with epilepsy, and among people who have been seizure free for two or more years.
- The incidence of SUDEP among people with high risk factors is higher than previously thought.

- There is a significantly increased rate of occurrence among people with chronic uncontrolled epilepsy.

Q: How often does SUDEP occur in children with epilepsy?

A: While it has long been believed that SUDEP happens more often to adults than to children, and to males more often than females, the data regarding incidence by age and gender is conflicting.

Q: What can be done to prevent SUDEP?

A: While our understanding of SUDEP and how to prevent it is still unfolding, there are measures that people with epilepsy and their families can take to try and reduce their risk:

- Seizure control is the most important. Thus taking medication as prescribed is essential. If medications do not work, then other therapies such as epilepsy surgery, the vagus nerve stimulator, and the ketogenic diet may be considered.
- Eat properly, get enough rest and regular exercise and keep stress to a minimum whenever possible.
- Be aware of and avoid any potential seizure triggers by keeping a record of things that occurred before a seizure (i.e., were you ill, tired, stressed, hungry? Where did the seizure occur and what time of day was it? Etc.)
- Night time supervision
- Heart rate monitor
- Breathing alarm
- Knowledge of emergency resuscitation measures including CPR and use of a defibrillator

Q: Can using an anti-suffocation pillow prevent SUDEP?

A: There is no data to support the use of these pillows. However, you may wish to discuss any potential benefits with your doctor.

Q: Would using an audio monitoring device alert us to the possibility of SUDEP?

A: This type of device could alert you to a seizure that is accompanied by audible sounds but may not alert you that your loved one has stopped breathing.

Q: How do I talk with my doctor about SUDEP?

A: If your doctor has not spoken to you about the health risks associated with epilepsy including SUDEP, schedule an appointment to meet with him/her.

Questions to ask include: What risks do I/my family member have for SUDEP? What measures are available to me/my family member for reducing the risk of SUDEP?

Q: Is SUDEP genetic?

A: There are some studies that suggest genetic factors may play a role, but no definite information is available at this time.

Q: Is it SUDEP if there was no evidence of a seizure?

A: The patient has to have a diagnosis of epilepsy for SUDEP to be considered. However, in SUDEP, the death may not be the direct result of a seizure. It is not certain what role seizures play in the death process. The absence of evidence of a seizure prior to death does not preclude it from being deemed SUDEP.

Q: Can I donate my loved one's tissues to research and if so whom do I contact?

A: At this time, there is no national repository that collects tissue and other samples to be used in research on SUDEP.

However, Dr. Alica Goldman is a neurologist specializing in the field of epilepsy; she and her colleagues at The Department of Neurology at Baylor College of Medicine are conducting a research study called "Ion Channels in Epilepsy*". The aim of the research is the identification of the genetic risk factors that predispose an individual to epilepsy and to sudden death. This study is funded by The National Institutes of Health (NIH)/The National Institute for Neurological Disorders and Stroke (NINDS).

Dr. Goldman has published results of her research to date: 'Molecular Trigger' For Sudden Death In Epilepsy Found. *ScienceDaily*. Retrieved February 19, 2010, <http://www.sciencedaily.com/releases/2009/10/091014144720.htm>

"Second gene associated with SUDEP found in brain, not heart "
<http://www.bcm.edu/news/item.cfm?newsID=2057>

Q: What can I do for support after the death of a loved one?

A: Information on grief support services in your area may be obtained by contacting any of the following resources:

- The Epilepsy Foundation Western/Central Pennsylvania (EFWCP). Contact information for the office closest to you may be found on the EFWCP website:
- Your health insurance provider
- Your county mental health office. Contact information may be obtained via the internet by searching under the name of your county for "mental health services" .

- Any of the organizations with websites listed in the question & answer section below.

Q: Where else can I get more information about SUDEP?

A: www.sudep.org – Epilepsy Bereaved
www.epilepsy.com – Epilepsy.com
www.sudepaware.com – SUDEP Aware

References

LeestmaJE, AnnegersJF, BrodieMJ, etal. Sudden unexplained death in epilepsy: observations from a large clinical development program. *Epilepsia* 1997; 38: 47-55.
Torbjörn T, Nashef L, Ryvlin P. Sudden unexpected death in epilepsy: current knowledge and future directions. *The Lancet*, 2008, Volume 7: 1021-1031.

Surges R, Thijs R, Tan H, Sander J. Sudden unexpected death in epilepsy: risk factors and potential pathomechanisms. www.nature.com/neurology September 2009, Volume 5: 492-504

For further reading:

Case-control study of SUDEP. Langan, Y., Nashef, L., & Sander, J.W.; *Neurology* **64**, 1131-1133 (2005)

'Molecular Trigger' For Sudden Death In Epilepsy Found. *ScienceDaily*. Baylor College of Medicine (2009, October 15).

Mortality Risk in an Adult Cohort with Newly Diagnosed Unprovoked Epileptic Seizure: A Population-Based Study, Hans Lindsten, LENNART Nystrom and Lars Forsgren, *Epilepsia*, 41(11): 1469-1473, 2000

Studies are still being conducted and much more research is needed to answer the many questions which remain about SUDEP. The questions and answers listed above address some of the more basic and frequently asked questions related to SUDEP. For answers specific to your experience with epilepsy, please refer to your physician.

For more information about SUDEP, seizures, epilepsy or the programs available through the Epilepsy Foundation Western/Central Pennsylvania, please call 800-361-5885, visit www.efwp.org or contact one of the EFWCP regional offices.

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