

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

Q: Can people die from epilepsy?

A: Most people with epilepsy live a full life span. However, there are potential factors associated with living with epilepsy and seizures that may increase the risk of early death:

Sometimes epilepsy is a symptom of a more serious condition, such as a stroke or a tumor that carries an increased risk of 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.

Persons with epilepsy have an increased risk for depression and suicide.

Very long seizures or seizures that happen quickly, one after another (called status epilepticus), can also be life-threatening. Status epilepticus can sometimes occur when seizure medicine is stopped suddenly.

Some people with epilepsy may die suddenly, without explanation. This is called SUDEP which stands for Sudden Unexpected Death in Epilepsy. SUDEP is not well understood, although it is suspected, sometimes, to be related to heart rhythm problems during a seizure. SUDEP occurs more often among people with convulsive seizures, especially generalized tonic-clonic seizures.

Optimizing seizure control and use of safety measures can reduce the risk of epilepsy-related death.

Q: How is SUDEP determined?

A: A death is referred to as a 'SUDEP' when a seemingly healthy person with epilepsy dies unexpectedly and no reason for the death can be found. In most cases, an autopsy is required to rule out other causes of death. The most common criteria used to determine whether a death is due to 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 (often during sleep and found in or near the bed).

An obvious medical cause of death could not be determined at autopsy.

The death was not the direct result of status epilepticus.

Q: How often does SUDEP occur?

A: Although there have been no large scale studies of SUDEP in the U.S., data are available from a variety of sources. The most important thing to remember is that the incidence of SUDEP differs greatly depending upon the population studied.

Elson So, M.D., Professor of Neurology and Chair of Electroencephalography at Mayo Clinic College of Medicine in Rochester, Minnesota and past chair of the Joint SUDEP Task Force of the American Epilepsy Society and the Epilepsy Foundation states "for a person with epilepsy, in general, the risk is small, at one in 3,000 persons over a one-year period. For a person with poorly controlled seizures, especially generalized convulsions, the risk is one in 100 persons over one year. Persons with absence or myoclonic seizures are not known to have increased risk for SUDEP."

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

A: As with adults, the answer depends on how severe the epilepsy is. In general, however, risks are lower in children than in adults (Leestma, et al 1997).

Q: What causes SUDEP?

A: Irregularities in heart rhythm, breathing dysfunction, disturbance in brain circulation, and seizure-induced hormone and metabolic changes have all been suggested as potential causes of SUDEP (Surges, et al 2009). Recently, the first potential gene for SUDEP has been identified that controls the normal rhythm of the heart (Goldman et al, 2009).

Q: Who is at risk for SUDEP?

A: While SUDEP can happen to anyone with epilepsy, some people are at higher risk than others (Torbjörn, et al 2008).

Risk factors most consistently associated with SUDEP are:

Poorly controlled seizures

Treatment with multiple anticonvulsant drugs

Having long standing chronic epilepsy

Other risk factors include:

Generalized tonic-clonic seizures

Seizures that happen during sleep

Not taking anticonvulsant medicine as prescribed

Stopping the use of anticonvulsant medicine abruptly

Developmental delays

Onset of epilepsy at a young age

Q: What can be done to reduce the risk of 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 to reduce their risk:

Maximize seizure control. Take medication as prescribed. If medicines do not work, then consider other therapies such as epilepsy surgery, the vagus nerve stimulator, and the ketogenic diet.

Eat well, get enough rest and regular exercise and keep stress to a minimum whenever possible.

Be aware of and avoid any potential seizure triggers. Keep a record of things that occurred before a seizure (such as, were you ill, tired, stressed, hungry? Where did the seizure occur and what time of day was it?).

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 are no data to support the use of these pillows. However, you may wish to discuss any possible 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 or her. Questions to ask include: What risks do I/my family member have for SUDEP? What can we do to reduce 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?

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).

In order to perform this research, the investigators need a blood sample or a small piece of fresh tissue from the person who died as a result of the seizure disorder.

If you would like to learn more about this study or for participation, please contact Dr. Alica Goldman at (email: agoldman@bcm.edu) or the study coordinator, Ms. Melissa Lambeth at (email: lambeth@bcm.tmc.edu; or phone: 713-798-2227).

*This epilepsy study listing is for information purposes only; and the reader assumes full responsibility and risk for the appropriate use of the information provided. The information concerning the study was sent to the Epilepsy Foundation by the investigator or staff conducting the research. The Epilepsy Foundation, its affiliates, officers, directors, employees and agents do not warrant or guarantee the accuracy or completeness of this information and specifically disclaims any liability therefore.

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

A: Contact any of the organizations with websites listed below or contact your local Epilepsy Foundation affiliate <http://www.epilepsyfoundation.org/aboutus/AffiliateLookup.cfm>

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

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