



SUDEP FACTS

WHAT IS SUDEP?

SUDEP is Sudden Unexpected Death in Epilepsy. SUDEP refers to the death of a person is when a person with epilepsy who was in their usual state of health dies suddenly and unexpectedly. The death is not known to be related to an illness, accident or seizure emergency such as status epilepticus. When an autopsy is done, no other of cause of death can be found.



WHAT IS THE CAUSE OF SUDEP?

Most often SUDEP occurs during or right after a seizure. SUDEP may have more than one cause or result from a combination of problems. Difficulty with breathing, heart rhythmns or brain function may contribute to SUDEP. Research is being done to look at all possible causes and potential genetic links.



WHO IS AT RISK FOR SUDEP?

Approximately 1 in 1000 people with epilepsy die from SUDEP each year. The greatest risk factors for SUDEP are uncontrolled generalized tonic clonic seizures (also called convulsions) and seizures that happen at night. Missing doses of seizure medicine and drinking alcohol may lead to poor seizure control and affect a person's risk for SUDEP too. While SUDEP can occur at any time, it happens more often in people who have had seizures for many years.



HOW CAN I LOWER MY RISK OF SUDEP?

The first step to lowering your risk for SUDEP is to take your seizure medication regularly and at the right dose. If seizure medicine along doesn't control seizures, talk to your doctor about other ways to possibly control your seizures. Ask for a referral to an epilepsy specialist at an accredited epilepsy center. Learn how to avoid seizure triggers, get enough sleep and don't use alcohol or drugs. It's important to make sure other people in the home know seizure first aid too.

WHAT SHOULD I BE ASKING MY DOCTOR?

- What is my risk for SUDEP?
- What can I do to reduce my risk?
- What should I do if I miss a dose of my medication?
- What should I do if I have a seizure?
- Can I be referred to an epilepsy specialist?
- Where can my family obtain training in seizure first aid?
- What activities or behaviors increase my risk?
- What should I tell my family about my epilepsy and SUDEP?
- I'm having seizures, should we consider a change in my treatment?
- Should I consider using a device to warn someone that I'm having a seizure?
- I have seizures in my sleep, should I consider sharing a bedroom?



HOW CAN THE SUDEP INSTITUTE HELP?

The SUDEP Institute (SI) works to raise awareness to prevent SUDEP and support people bereaved by SUDEP and other epilepsy-related deaths. The SI can will help you learn about participating in SUDEP-related research. We can also help advocate for or coordinate the death investigation process.

If you are bereaved by SUDEP, please call 1-800-332-1000 or email SUDEP@efa.org to speak with our caring information specialists who can assist you with bereavement support services.

Visit epilepsy.com/SUDEP for more information, tools and SUDEP resources.