



## SUDEP (Sudden Unexpected Death in Epilepsy) Backgrounder

### What is SUDEP?

Most people with epilepsy, or seizure disorders, live a full and healthy life. Some people with epilepsy may lose their lives from accidents or the underlying cause of their seizure condition, such as tumors or genetic syndromes. However, the leading cause of epilepsy-related death is believed to be SUDEP, or Sudden Unexpected Death in Epilepsy. SUDEP is a relatively uncommon condition in which people with epilepsy in their usual state of health die unexpectedly without a clear cause. Seizures are suspected to have occurred prior to death, but when an autopsy is done, no other cause of death can be found.

### How common is SUDEP?

SUDEP occurs in approximately one out of every 1,000 persons with epilepsy each year. Further, it occurs more frequently in people with epilepsy whose seizures are poorly controlled with medications. As many as one out of every 150 people with poorly controlled epilepsy die from SUDEP annually. SUDEP is the leading cause of death in young people with certain types of uncontrolled epilepsy and is associated with having frequent generalized tonic-clonic seizures, also known as grand mal seizures. People experiencing only absence seizures (brief staring episodes) or myoclonic seizures (seizures that cause brief jerking movements) are not known to have increased risk for sudden death.

### What causes SUDEP?

No one knows what causes SUDEP. Most often, it occurs at night or during sleep when the death is not witnessed, leaving many questions unanswered.

Current research into the possible causes of SUDEP is focusing on problems with breathing, heart rhythm and brain function that occur with a seizure.

- **Breathing:** A seizure typically may cause a person to briefly stop breathing (apnea). If these pauses last too long, they can reduce the oxygen delivery to the heart and the brain, which can be life threatening if not treated immediately. In addition, a person's airway may sometimes become obstructed or blocked during a convulsive seizure, leading to suffocation (inability to breathe).
- **Heart Rhythm:** Rarely, a seizure may cause a dangerous heart rhythm or cardiac arrest.
- **Brain Function:** Seizures may suppress or interfere with the function of vital areas in the brainstem, so that breathing and heart rate may temporarily not work properly.
- **Other:** SUDEP may result from more than one cause, or from a combination of breathing difficulty, abnormal heart rhythm and changes in brain function. Or, it may result from factors researchers have yet to discover.

*"Research and educational activities in SUDEP have exploded in the last few years. Recent research studies have given us an increasing understanding of how seizures could adversely affect the brain, the heart and the lungs, and how these effects could potentially lead to SUDEP," said Elson So, MD, Mayo Clinic, College of Medicine and President of the American Epilepsy Society.*

### Who is at risk for SUDEP?

The greatest risk factor for SUDEP is frequent seizures, especially generalized tonic-clonic (grand mal) seizures.

Other risk factors being evaluated include:

- Epilepsy beginning at an early age

- Having epilepsy for a long time
- Not taking medications as prescribed
- Stopping or changing medications suddenly
- Young adult age (20-40 years old)
- Intellectual disability (IQ<70)

Studies have shown a correlation between the number of seizure medications taken by a person with epilepsy and risk for SUDEP. However, taking multiple medications often indicates severe epilepsy requiring more aggressive treatment. Studies that have taken seizure frequency into account have not found an increased risk of SUDEP due only to taking multiple seizure medications.

### **How can someone reduce the risk of SUDEP?**

The best way to prevent SUDEP is to have as few seizures as possible.

- Get the best seizure control possible. This may involve actions such as:
  - Taking medication as prescribed.
  - Visiting a doctor regularly, especially if seizures are not controlled.
  - If medicines do not work, other therapies should be considered such as epilepsy surgery, vagus nerve stimulation, or dietary therapy.
- Maintain good physical care of yourself. Eat well, get enough rest and regular exercise, avoid drinking too much alcohol or using recreational drugs, and minimize stress when possible.
- Be aware of any potential seizure triggers and take steps to avoid them whenever possible. For example, keep a record of what may have occurred prior to a seizure (such as illness, tiredness, stress, missing medications, and where and when the seizure occurred).
- Talk to your doctor about having a complete cardio evaluation. This is particularly important for people with uncontrolled epilepsy who don't have any evidence on MRI of a structural cause for their epilepsy.
- Make sure family and co-workers know what to do for seizure first-aid. Take extra precautions around water, including swimming and bathing.

*"People facing epilepsy should know the full range of possible outcomes that stem from their seizures. Having knowledge about SUDEP will empower people with epilepsy to form the best possible treatment plan and help to minimize their risk," said Tom Stanton, Executive Director of the Danny Did Foundation.*

### **Does SUDEP have an underlying genetic component?**

There are some studies that suggest genetic factors may play a role, but no definitive information is available at this time. Several research efforts are looking into genetics and SUDEP.

### **Why aren't doctors talking about SUDEP?**

*"Doctors may not talk about SUDEP because they are concerned about upsetting patients and families, especially if the risk is low," said Jeff Buchhalter, MD, PhD, FAAN, Director, Comprehensive Children's Epilepsy Program, Alberta Health Services. "People with epilepsy should know about the risk of death with epilepsy so as to be reassured if their risk is low or pursue more vigorous therapy if their risk is high."*

Talking about SUDEP may be hard for doctors, nurses and other health care providers to do because there is still a lot we don't know about SUDEP. A discussion about the possibility of death may be difficult. Healthcare professionals may want to wait until they know a person better or when they have determined that there may be an elevated SUDEP risk.

The Epilepsy Foundation's SUDEP Institute encourages people with epilepsy to ask their healthcare team about their risk of SUDEP and the steps they can take to reduce that risk. To aid in the discussion, they have developed an educational infographic titled "Managing Epilepsy & Seizures: Facts to Help Keep You Safe."

*"We hope this infographic will empower people with epilepsy to take steps to lower their risk and build awareness so we can work together to prevent SUDEP," said Cyndi Wright, Director of the SUDEP Institute.*

The infographic and other brochures can be accessed at <http://www.epilepsy.com/sudep/brochures>.

## What is the Epilepsy Foundation doing to prevent SUDEP?

To ensure SUDEP gets the public awareness and research attention it deserves, the Epilepsy Foundation launched the SUDEP Institute in 2013. The SUDEP Institute is an initiative led by the Epilepsy Foundation in collaboration with American Epilepsy Society, Citizens United for Research in Epilepsy, Danny Did Foundation, SUDEP Aware, and other leading epilepsy organizations and experts to help prevent Sudden Unexpected Death in Epilepsy.

*“For people living with epilepsy, SUDEP has been and is still a relatively hidden risk,” said Phil Gattone, President and CEO of the Epilepsy Foundation.*

Through awareness, education, research and supportive care programs, the SUDEP Institute supports individuals and families living with epilepsy or having lost someone from epilepsy; neurologists; epilepsy specialists; primary care physicians; nurses; coroners; medical examiners; first responders; researchers; pharmaceutical and device companies and Epilepsy Foundation affiliates.

The SUDEP Institute’s strategic objectives are to:

- Develop initiatives to support SUDEP education, awareness and prevention methods targeting epilepsy communities, including medical examiners and coroners.
- Research the causes and methods of prevention of SUDEP and epilepsy mortality, including support of a comprehensive national SUDEP registry.
- Introduce SUDEP support network counseling and resources for individuals and families living with epilepsy or having lost someone from epilepsy.

## What SUDEP research is happening today?

The Epilepsy Foundation strongly supports SUDEP research. In addition to researching the causes and prevention of SUDEP, another area of critical focus is on collecting SUDEP case information and data. This requires developing an accurate diagnosis of SUDEP at autopsy and tissue donation for SUDEP and epilepsy mortality research. The Epilepsy Foundation is actively supporting SUDEP legislation and policy changes. Recently, Illinois and New Jersey passed SUDEP legislation and the Epilepsy Foundation affiliate network is working regionally to increase awareness and set epilepsy mortality policies nationwide. In order for these efforts to be effective, the SUDEP Institute is spearheading collaboration with coroners, medical examiners, epileptologists and epidemiologists to develop new autopsy protocols for collecting valuable information for scientific research. Partners in this effort include the National Association of Medical Examiners (NAME), the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

The North American SUDEP Registry (NASR) is a study to help discover the causes of SUDEP. The multicenter NASR provides clinical data, DNA and brain tissue for the scientific community to study.

For more information visit <http://sudep-registry.org/>.



### Meet Eric

Eric Wulchin’s family first became aware of his seizures on March 28, 2006, when they woke up to a loud crash – the result of his first seizure. Other seizures followed. His family knew that something was wrong.

They took Eric to the Mayo Clinic, where the 16-year-old was diagnosed with epilepsy.

Most people with epilepsy live a long and fulfilling life, and that seemed to be the silver lining for Eric. Doctors explained that some people living with epilepsy may

lose their lives from accidents such as drowning or “status epilepticus,” where seizures last more than five minutes, but it wasn’t likely.

It appeared that doctors were able to get Eric’s seizures under control. But on July 9, 2009, tragedy hit. Steve Wulchin found his son lying lifeless, half on his bed, half on the floor. Eric had died from Sudden Unexpected Death in Epilepsy, also known as SUDEP, in the middle of the night.

After his son's death, Steve looked for answers. He shared with Eric's doctor and coroner what he learned from an article on epilepsy and SUDEP. Both admitted they had never heard of SUDEP.

*"If I had been made aware of SUDEP, could I have saved Eric's life? Possibly yes, possibly no. But without being told, I wasn't given the chance," said Steve Wulchin. "It all starts with awareness."*

Steve helped drive the creation of the Epilepsy Foundation SUDEP Institute and today serves on the Executive Team working to get SUDEP the awareness and research it deserves.

### **For more information and resources on SUDEP:**

Please visit: <http://www.epilepsy.com/sudep> for more information.

### **About the Epilepsy Foundation**

The Epilepsy Foundation, a national nonprofit with affiliated organizations throughout the United States, has led the fight against epilepsy since 1968. The Foundation's mission is to stop seizures, find cures and overcome the challenges created by epilepsy. For additional information, please visit <http://www.epilepsy.com>.

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