

**AIM FOR
ZERO**

#AIMFORZERO

**STRIVING
TOWARD A
FUTURE FREE
FROM SUDEP
(SUDDEN
UNEXPECTED
DEATH IN
EPILEPSY)**

An Epilepsy.com Special Report



**EPILEPSY
FOUNDATION**
SUDEP INSTITUTE

Introduction

The 3 million people in the United States living with epilepsy need to know about the potentially deadly impact of a single seizure and how they can strive to #AimForZero seizures to reduce their risk of Sudden Unexpected Death in Epilepsy (SUDEP).

Families Speak Out: John Popovich lost his 19-year-old son John Paul to SUDEP

John Paul had his whole life ahead of him, full of promise, to explore and learn about the world around him and make a positive difference in the lives of others.

For those reading this, if your child, loved one, or someone you know has had seizures, I urge you to be proactive and learn what you can about SUDEP. Make the inquiry with your doctor; take the time to learn about this silent killer that so few doctors will initiate discussion about. In doing so, you may save a life. Our son would have wanted that.⁴

Every year, 1 in 150 people who have uncontrolled seizures dies from SUDEP.¹ Accordingly, experts regard SUDEP as the leading epilepsy-related cause of death²; however, in a recent survey of more than 1,000 people with epilepsy and caregivers of people with epilepsy, only 18% of respondents reported having discussed the risk of SUDEP with their doctor.³

When people with epilepsy and their caregivers are empowered with information to understand SUDEP, they can take action to reduce risk of harm. To respond to this urgency, raise awareness, and promote steps that can help prevent SUDEP, the Epilepsy Foundation's SUDEP Institute is issuing this Epilepsy.com Special Report and launching a dedicated #AimForZero hashtag to facilitate greater discussion of SUDEP.

Four Behaviors to Fight Seizures and SUDEP

#AimForZero encourages people with epilepsy to adopt four critical actions to reduce their risk of SUDEP: take medication as prescribed; get enough sleep; limit alcohol; and strive to stop seizures. Putting these behaviors into action can be challenging for people with epilepsy — and their efforts must be supported by caregivers and healthcare team members.

Take medication
as prescribed



Get enough
sleep



Limit
alcohol



Strive to stop
seizures



EXPERT INSIGHT:

Why is communicating about SUDEP critically important?

“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.”⁵

- Orrin Devinsky, MD,

Director of the New York University Langone Comprehensive Epilepsy Center.

What is Epilepsy?

Epilepsy is a medical condition that affects a person's brain and nervous system. When a person has two unprovoked seizures or one unprovoked seizure with the likelihood of more, they are considered to have epilepsy. Epilepsy has been shown to have a significant impact on health-related quality of life, and this impact is directly related to the frequency of seizures.⁶

The severity of epilepsy varies a great deal between individuals; some have infrequent seizures that can be controlled with medication, dietary therapies, surgery, or neurostimulation devices. Others with epilepsy suffer many seizures a day that are not responsive to any current therapy, despite the best available care.

Epilepsy also has a very large economic cost. A study conducted in 1995 of the indirect and direct costs of epilepsy found that treatment costs for the then estimated 2.3 million people with epilepsy exceeded 12.5 billion dollars. According to researchers, “Epilepsy is unique in the large proportion of costs that are productivity-related, justifying further investment in the development of effective interventions.”⁷

What is a Seizure?

A seizure happens when a person's brain cells misfire, sending too many electrical signals at once. These uncontrolled signals can cause changes in a person's awareness, movement, or sensation. Seizures are generally described in two major groups: primary generalized seizures and focal (also known as partial) seizures. The difference between these types is in how and where they begin.

- + Primary generalized seizures begin with a widespread electrical discharge that involves both sides of the brain at once. One type of generalized seizure is the tonic-clonic seizure. It is what most people think of when they think of a convulsive seizure and was known in the past as a grand mal seizure. During this type of seizure, a person loses consciousness, muscles stiffen, and jerking movements are seen. It usually lasts from 1 to 3 minutes and can take much longer for a person to recover.
- + A focal seizure occurs when an electrical disturbance takes place in a limited area of the brain.⁸ If the seizure stays small, a person may have a funny feeling for a few seconds, like a brief intense emotion or a strange sensation in the stomach. If the seizure spreads, a person may have small spells of confusion or abnormal behavior. Sometimes small movements, like lip-smacking or hand motions, may be seen by others, or there may be larger seizures with vocalizations or larger movements, or even falls. If the seizure spreads to the entire brain, a generalized or convulsive seizure may occur, as described above.

While at least 3 out of 10 people have seizures that currently can't be controlled, many more are living with seizures that can be controlled better.

About Seizure Control

The majority of people with epilepsy have seizures that can be controlled with drug therapy. However, at least 3 out of 10 people with epilepsy continue to have seizures because available treatments do not completely control their seizures.⁹ The Epilepsy Foundation is committed to accelerating ideas into therapies to stop seizures for the one third of people living with epilepsy who have persistent seizures despite all existing therapies and who are already following the behaviors outlined in this report.

Among the 70% who could respond to medications, many are not seizure free, settling for “good enough” or living with bothersome side effects.

For example, studies show that among adults with active epilepsy (more than one seizure in the last year), a large number do not take medications to stop their seizures nor do they see an epilepsy specialist (also known as an epileptologist).

In recent years, the epilepsy community has recognized that living with the best seizure control possible and aiming for “zero seizures” should be a goal all people with epilepsy and their health care providers strive to reach.¹⁰

Despite this consensus among experts in the epilepsy community, survey results showed only half of respondents with epilepsy considered “no seizures of any type” as the primary definition of good seizure control. Other commonly reported definitions of seizure control include “having seizures that don't impact day-to-day life,” “significant reduction in seizures,” “only having auras,” or “only having seizures in bed, at night.”¹¹

Caregivers of people with epilepsy rated “no seizures” as critically important. However, the majority did not feel that the people (in their care) had good seizure control. Another alarming survey finding is that 1 in 3 people who said they had achieved seizure control reported having seizures monthly or, in many cases, more frequently.

It is crucial to understand, however, that complete seizure control — meaning zero seizures ever — can reduce the risk of SUDEP or accidents from seizures.

Having a
generalized
tonic-clonic
seizure
increases the
risk of SUDEP
for a person
with epilepsy.

EXPERT INSIGHT:

What actions could reduce seizure risk?

“Ensuring receipt of effective treatment through physician engagement, compliance, monitoring (e.g., anti-epileptic drug [AED] levels), and regular follow-up and communication of their seizure status. Seeking professional reassurance that everything appropriate has been done to lower seizure burden, whether medically with new AED options or with epilepsy surgery and the newer surgical options.”¹³

- Samden Lhatoo, MD,

Professor of Neurology at Case Western Reserve University School of Medicine.

Survey results showed that “seeing an epileptologist (epilepsy specialist)” and “visiting your doctor regularly” were considered steps to reduce the risk of having a seizure and improve epilepsy management (35% and 22%, respectively). Respondents ranked these behaviors far below “taking medications” (90%) and “getting enough sleep” (72%).¹⁴ This may indicate that people with epilepsy recognize proper medication and sleep management are important for epilepsy management. People with epilepsy underestimate the importance of their physician and the key role of a specialist in helping explore all treatment options for complete seizure freedom.

SUDEP: A Deadly Result of Uncontrolled Seizures

People with epilepsy die prematurely at a higher rate compared to the general population.¹⁵ The most common cause of death from epilepsy is SUDEP. There are at least 2,750 cases of SUDEP each year — meaning that almost 1 in 1,000 adults with epilepsy will die as a result of SUDEP every year.¹⁶ For adults with uncontrolled seizures, the risk increases to 1 in 150.¹⁷

SUDEP is almost always associated with generalized tonic-clonic seizures and is less likely after focal seizures. Experts agree it is imperative to reduce the number of generalized tonic-clonic seizures experienced by people with epilepsy.

Uncontrolled seizures can pose a deadly threat for people with epilepsy.

Having a generalized tonic-clonic seizure increases the risk of SUDEP for a person with epilepsy. This singular fact makes an indisputable case for urgently addressing seizure control. Uncontrolled seizures can pose a deadly threat for people with epilepsy.

EXPERT INSIGHT:

Why is the goal of zero seizures so important?

"Prevention of SUDEP must involve realistic efforts to reduce generalized tonic-clonic seizure frequency in order to avert the occurrence of this devastating epilepsy outcome."¹⁸

- Dale C. Hesdorffer, PhD,
Professor of Epidemiology at Columbia University.

One in 3

survey respondents reported experiencing **one seizure every month in the past year.**



Only 1 in 4

individuals reported having **no seizures in the past year.**¹⁹

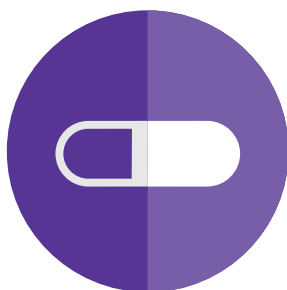


Understanding and Preventing Risk Behaviors

There are a number of situations or behaviors that can increase the risk or likelihood of seizures. To help people with epilepsy reduce risk of seizures and SUDEP, experts have identified four actionable behaviors. This essential “to-do list” includes:

- 1. Take medication as prescribed**
- 2. Get enough sleep**
- 3. Limit alcohol**
- 4. Strive to stop seizures**

Take Medication as Prescribed



There are many different medicines that can help prevent or stop seizures. These are sometimes called anti-epileptic drugs (AEDs) or anti-seizure drugs. Medicine is the most common way of treating epilepsy and is almost always the first treatment tried.

Anti-epileptic drugs will successfully control seizures for nearly 7 out of 10 people with epilepsy. Some medicines tend to work better for certain kinds of seizures than for others. If one medicine fails, another or a combination of medicines may work better. The medications do not fix the problem that causes seizures; rather, they help stop seizures from occurring.²⁰

However, these medicines to control seizures only work if they are taken consistently as prescribed. The brain needs a constant supply of seizure medicine to continue to stop and prevent seizures. When doses are missed or the medicine is taken irregularly, the level of medicine in the body decreases. Changing levels increases the risk of more seizures.

In a self-reported survey, more than 9 out of 10 people with epilepsy said they take medications as prescribed by their healthcare providers. However, large-scale analyses suggest rates of adherence are much lower; in fact, published studies demonstrate more than 70% of people with epilepsy do not adhere to their medication regimens.²¹

When doses are missed or the medicine is taken irregularly, people are at greater risk of having seizures.

There are many reasons why people do not take medicines as prescribed, including memory problems, side effects, or instructions that are too complicated. Taking medications as the doctor instructs is not easy and may require special effort and training.

People with epilepsy should not be embarrassed about discussing any difficulty they may be having. It is critical to work with their health care providers, talk about side effects and how to manage them, and find easier ways of taking medicine consistently, such as setting a daily alarm or using a text or diary reminder system. Taking these steps and acting on them is the only way for the medicine(s) to work effectively to prevent seizures.²²

The Epilepsy Foundation's website epilepsy.com provides additional information about [the risks of missing doses of seizure medicines](#).

Other therapies, such as dietary changes or complementary or alternative therapies, may be added to medicine as part of a complete treatment plan for a person with epilepsy. These additional therapies also require following doctor's instructions to provide the greatest benefits.

#AimForZero Missed Medications

EXPERT INSIGHT:

How important is taking medicines as prescribed for preventing seizures?

"A single missed dose of medication can cause a seizure, even if a dose has been missed many times before without a seizure. Taking medications is a must — aim for no missed doses."²³

- Orrin Devinsky, MD

Get Enough Sleep



Research shows that there is a significant relationship between sleep deprivation and seizures in people with epilepsy.

Research shows that there is a significant relationship between sleep deprivation and seizures in people with epilepsy.²⁴

Supported by this research, epilepsy specialists and advocates consistently discuss the importance of getting enough sleep with people living with seizures. Survey results show that 3 out of 5 people with epilepsy report they get adequate sleep.²⁵

According to the Centers for Disease Control and Prevention (CDC), sleep requirements change with age, and there is no “magic number” because individual sleep needs vary. The recommended amount of sleep for children is 10 to 12 hours per day, for teenagers 9 to 10 hours, and for adults 7 to 8 hours. If people with epilepsy are not getting the recommended amount of sleep, do not wake up feeling rested, or do not have energy for their daily activities, they should work with their healthcare provider to find ways to ensure they are getting enough sleep. People who also have a sleep disorder or seizures at night can be sleep deprived too. People with interrupted or poor quality of sleep should talk with their healthcare provider.

There are additional considerations about sleep that are important for people with epilepsy. The majority of SUDEP cases occur during the night and often times the person is found face down in bed. For these reasons, people with epilepsy are encouraged to use a seizure alert device or share a bedroom with someone who can provide seizure first aid.

For more information and tips on improving sleep, visit the [Epilepsy Foundation website](#).

#AimForZero Lost Hours of Sleep

Limit Alcohol



Seizure medicines can lower a person's tolerance for alcohol.

For most people with epilepsy, small amounts of alcohol do not cause seizures.²⁶ However, exceptions can include people with a history of alcohol or substance abuse, or those with a history of alcohol-related seizures.²⁷

Seizure medicines can lower a person's tolerance for alcohol, increasing the immediate effects of the alcohol. In other words, people get drunk faster. For people with epilepsy who drink alcohol, driving can be especially dangerous because both alcohol and seizure medicines can affect a person's awareness, reflexes, coordination, and ability to drive safely.

All people with epilepsy are at a high risk of seizures after drinking three or more alcoholic beverages. Survey results show that only 2 out of 5 people with epilepsy avoid alcohol.²⁸

The Epilepsy Foundation provides information on its [website](#) about the risks of alcohol for triggering seizures and offers tips for people with epilepsy and their caregivers, such as avoiding binge drinking, i.e., drinking too much at once or over long periods of time.²⁹ Alcohol-related seizures do not usually occur when a person is intoxicated. Usually they occur afterwards, when the alcohol is leaving the body, or the following morning.

Limit Alcohol. #AimForZero Seizures

Strive to Stop Seizures



There are many proactive steps people with epilepsy can take once they have committed to exploring all options.

The Epilepsy Foundation wants people with epilepsy to know that “No seizures, no side effects” should be the ultimate goal of epilepsy treatment.³⁰ Unfortunately, too many people with epilepsy whose seizures can be controlled accept continued seizures in their life — and may be unaware of potential strategies to prevent them. The Epilepsy Foundation believes that even one seizure is not acceptable and is taking steps through research and the development of new therapies to work toward no seizures for all people living with epilepsy.

For many people living with epilepsy today, the disease can be controlled with available therapies and good seizure-management practices including the support of an epilepsy specialist. And for people with the most severe types of difficult to control epilepsy, there are steps an individual can take to lower one’s risk, including participating in research to find new, more effective therapies.

Regardless of one’s current level of seizure control, there are many proactive steps people with epilepsy can take once they have committed to exploring all options to stop seizures. These range from identifying and tracking seizure triggers to exploring epilepsy surgery or devices with an epilepsy specialist, to participating in clinical studies to accelerate new therapy development. For more information and tips, visit the [Epilepsy Foundation website](#).

These steps will help most people living with seizures improve seizure control and quality of life. The one third of people living with persistent seizures even with existing therapies and already following these seizure management practices may want to consider participating in medical research that can lead to effective treatments. For more information on epilepsy clinical trials and research, visit the [Epilepsy Foundation website](#).

Strive to #AimForZero Seizures

EXPERT INSIGHT:

What are the keys to reducing SUDEP risk?

“The best way to reduce the risk of SUDEP is to get seizures under control, particularly the seizures that are most likely to be associated with SUDEP, namely generalized tonic-clonic seizures. If seizures are not controlled, it is important to seek specialized care. Epilepsy specialists often can increase the likelihood of seizure freedom using medication, surgery, or devices. People can also decrease their personal risk of SUDEP by taking their medications and not missing doses, since missed doses can lead to breakthrough seizures, which can be very dangerous.”³¹

- Jacqueline French, MD,
Chief Scientific Officer for the Epilepsy Foundation
and Professor of Neurology at New York University.

Learning more about SUDEP could make a difference in how people with epilepsy approach seizure control.

Communication May Save Lives: Taking the Critical First Step

Despite how often SUDEP occurs, healthcare providers are hesitant to discuss SUDEP with people with epilepsy. According to Wendy Miller, PhD, RN, CCRN, assistant professor, Department of Science of Nursing Care at Indiana University School of Nursing, “The consequence of providers’ hesitance to discuss SUDEP is that patients and their family members are uninformed about the possibility of sudden death due to epilepsy, whether from SUDEP or other causes of epilepsy-related mortality (e.g., status epilepticus, accidental drowning, suicide). For example, several medical examiners told us that they avoid SUDEP on death certificates since they have occasionally had families who are adamant that their neurologists told them that seizures are never fatal.”³²

Survey results showed that 95% of caregivers of people with epilepsy worry about the person in their care dying from epilepsy or seizures.³³ When asked about SUDEP awareness, however, the majority of both people with epilepsy and caregivers reported that they had not had a discussion about SUDEP with a healthcare provider.³⁴

Importantly, 40% of respondents with epilepsy stated that learning more about SUDEP could make a difference in how they approach seizure control. And, nearly half of the respondents who were caregivers stated that learning more about SUDEP could make a difference. These respondents stated that the knowledge could positively impact seizure management in caring for people with epilepsy.

EXPERT INSIGHT:

How can talking to your doctor help reduce SUDEP risk?

“Over time doctors, and particularly epilepsy specialists, have come to realize that it is important to discuss SUDEP and other seizure risks with people with epilepsy, even though the conversation can be difficult. The discussion about SUDEP needs to be done at a time when people are ready to absorb this information. It is important to emphasize that the risk is low, but is not zero, and that people can reduce their own personal risk by taking their medication and aiming for seizure freedom.”³⁵

- Jacqueline French, MD

“People with epilepsy can enhance the level of communication with their physician by being proactive in addressing these issues during outpatient visits.”³⁶

- Philippe Ryvlin, MD, PhD,
Professor of Neurology, Lyon University, France

“The best action is to keep yourself informed about everything there is to know about your epilepsy. Work with your doctor to develop a treatment plan and stick to it.”³⁷

- Joseph Sirven, MD,
epilepsy.com Editor-in-chief and Professor of Neurology and
Chairman of the Department of Neurology, Mayo Clinic, Arizona.

Take medication
as prescribed



Get enough sleep



Limit alcohol



Strive to stop
seizures



#AimForZero

The Epilepsy Foundation SUDEP Institute, comprised of leading epileptologists and epilepsy organizations, is urging people living with epilepsy and their caregivers to aim for zero sudden deaths from epilepsy and seizures by adopting and practicing four key actions: take medication as prescribed, get enough sleep, limit alcohol, and strive to stop seizures.

Healthcare providers must also be part of the effort to raise awareness about the risks of having seizures and help people living with epilepsy take action to reduce these risks.

Social media platforms offer people living with epilepsy and the people caring for them opportunities and forums to discuss important issues about how to aim for a life without seizures and reduce their risks for SUDEP. For these reasons, the SUDEP Institute has launched the hashtag **#AimForZero** — encouraging those active on social media to use the hashtag while discussing SUDEP, the importance of seizure control, and the four key behaviors to reduce risk.

The Epilepsy Foundation recognizes that for 3 out of 10 people living with epilepsy, a life without seizures is not within reach right now. However, adopting the four actionable behaviors recommended here, and working towards the best seizure control possible, may help reduce the risk of SUDEP in people living with epilepsy.

EXPERT INSIGHT:

What is the devastating impact of SUDEP?

“Every death from SUDEP is a tragedy that resonates through the epilepsy community and creates a sense of fear about the future. Over time we have come to understand that for many people this fear may be among the most difficult aspect of having epilepsy. The best way to reduce and ultimately eliminate SUDEP is for people to be as honest as possible, so that their physician can create the best possible plan for each individual person that increases their likelihood of 100 percent compliance with medication. Every person with epilepsy should continue to seek the best care and continually take a journey toward the best seizure control that they can achieve.”³⁸

- Jacqueline French, MD

To learn more about SUDEP and spread the word about SUDEP prevention, visit epilepsy.com/AimForZero

Background/Note to Readers

Three initiatives were conducted to provide critical information to inform this report, referred to as:

- + “Survey results,” which includes information obtained from a survey of more than 1,000 people with epilepsy and people who are caregivers for people with epilepsy
- + “Expert opinion,” which includes the responses to questions fielded among key opinion leaders in epilepsy research and treatment
- + “Research studies,” which includes an extensive medical literature review of salient topics

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