



What Your Doctor Won't Tell You About Epilepsy: It Can Kill You

Doctors know about SUDEP, or sudden unexpected death in epilepsy. Why don't they tell their patients about it?



By [Kurt Eichenwald](#)

I don't remember where it was. I don't remember the woman who told me. It was just another horror story, one of the seemingly endless tales shared with me in recent months by family members of people with [epilepsy](#). But this was the one that tore at me the most.

Her son had epilepsy. She heard him in his room, where he had been asleep, having a convulsion. She rushed to be with her child, and when the [seizure](#) stopped, she climbed into bed with him and wrapped her arms around him. She wanted to comfort him, as any mother would, to be there when he regained consciousness, to assuage his fears. She awoke the next morning with her son still in her arms, seemingly asleep.

The boy was dead. He had passed in the night without a sound or a movement. One second he was sleeping, and the next, without warning, he was gone.

A Son Dies; His Parents Had No Idea He Was at Risk

His parents had had no idea that his epilepsy could be fatal. Their doctor had never mentioned it.

The same was true of the family I met in Colorado, whose son died in college and was not discovered for two days. It was the same with a young man I mentored, convincing him that even with epilepsy, he could pursue his goal of a career as a television sportscaster. Not long after achieving his dream, epilepsy killed him in his sleep. His doctor had not told him this could happen, and neither had I.

At least I had an excuse. Even though I have a type of epilepsy that puts me at a higher risk of death, no one told me either. I couldn't share information with the kid whom I mentored when I didn't know it myself. In that, I was just like untold numbers of other people with epilepsy and their families who have been kept in the dark by their neurologists.

SUDEP, the Most Frequent Epilepsy Killer

All of these people died from SUDEP — sudden unexpected death in epilepsy — one of several ways that epilepsy kills. Another is [status epilepticus](#), a single seizure or multiple seizures that last more than five minutes; between 10 and 30 percent of the people who experience status epilepticus die within 30 days.

Then there is [suicide](#); people with epilepsy are 5 times more likely to take their own lives than the general population. The list goes on of causes of death directly related epilepsy: [aspiration pneumonia](#), drowning during a seizure, car accidents, falls, burns, and cardiovascular problems exacerbated by [anticonvulsants](#).

But SUDEP is believed to be the most frequent epilepsy-related killer. It is at least the sixth leading neurologic cause of death but the second largest in lost years of potential life, following only strokes. Taken together, that data shows that people are killed by SUDEP at a far younger age than most other neurologic causes of death.

Lack of Resources, Lack of Research, Lack of Knowledge on Epilepsy Deaths

Notice how the previous paragraph used the phrases “believed to be” and “at least.” I hate those phrases because they reflect not only an infuriating aspect of epilepsy but also the impotence of the community that suffers with the disease.

Even though epilepsy causes significant loss of life, even though more people have the disease than have Alzheimer's, autism, and multiple sclerosis combined, the money raised for research and advocacy is comparatively trifling. The numbers are “believed to be” because the scarce resources available for epilepsy make it challenging to fund comprehensive studies on mortality. And the consequences are that no one knows the actual death rate for sure.

“The inability to accurately quantify epilepsy-related deaths is a major obstacle to progress, as are our difficulties comparing results of studies with different methods,” writes [Orrin Devinsky, MD](#), one of the most prominent epilepsy researchers, in [February 2016 in the journal *Neurology*](#). In his article, Dr. Devinsky describes how two small research projects on SUDEP mortality presented results with a 250-fold difference in findings. The reason? One study, from Finland, relied on clinical records and detailed investigations of the cases; the other, from Ohio, used findings in death certificates.

Death Certificates Often Fail to List Epilepsy as a Cause of Death

Medical examiners, unfamiliar with the sudden stoppage of life that can happen with epilepsy, rarely use SUDEP as a cause of death. For example, a 37-year-old man with generalized seizures since age 12 died in his sleep, which is common with SUDEP. The medical examiner found mild coronary artery thickening and used coronary disease as the cause of death. Epilepsy was not even mentioned on the death certificate.

The same thing often happens when people develop pneumonia after involuntarily inhaling material in their mouths during a seizure and subsequently die. The epilepsy is rarely cited as even a contributing factor in death; pneumonia is cited instead.

If You Don't Ask About SUDEP, They Won't Tell You

Making all of this dramatically worse is the neurologists and epileptologists who — out of arrogance, ignorance, or fear — refuse to tell all of their patients about the risks of death in epilepsy. For some reason, pediatric oncologists are able to talk about mortality even with little children, but epilepsy specialists do not even uniformly tell adults of the risk.

According to a [report from the *Journal of Neurology, Neurosurgery, and Psychiatry*](#), only 5 percent of neurologists in the United Kingdom tell all of their epilepsy patients about SUDEP. Just 26 percent tell the majority of their patients, 61 percent inform a few, and 7.5 percent stay completely silent with all patients. And even with those pathetic results, the doctors who told their patients said that most of the time, it was only because the patients had asked about SUDEP.

While no studies have been conducted to determine how many neurologists tell those with epilepsy about all of the risks of death associated with the disease, the numbers are certainly smaller.

Neurologists Say They Don't Want to Scare Patients ...

Why don't they tell? I have spoken to a number of neurologists at galas for epilepsy charities and at the annual conference for epilepsy doctors, and the answers are often the same: They don't want to scare patients and only want to tell those they assess as being at the highest risk of death.

But a person with epilepsy can die from SUDEP even after experiencing one or two convulsions. And given that I have never met someone whose family member died of SUDEP who was told of that possibility by a doctor, obviously neurologists' ability to identify those most at risk is poor.

Who's a good example of someone at risk for SUDEP who didn't know about it? Me. Not only did I have no idea SUDEP existed until recently but doctors and officials at the Epilepsy Foundation have told me in recent weeks that I likely survived this potential killer. After experiencing a convulsion many years ago, I stopped breathing while still unconscious. I made no sounds to suggest there was a problem, but someone noticed I was turning blue. After being alerted, another person shook me aggressively and then slapped me hard a couple of times. I resumed breathing.

But They're Depriving Us of the Option to Take Precautions

Whether to tell a patient of this risk is literally a life-and-death choice made by the doctor, often with no input from the patient. If those of us with epilepsy know the risks, we can take precautions that we otherwise might not.

"Most SUDEP occurs in sleep when someone is alone and unmonitored," Devinsky writes. "Sharing a room or a bed or using nocturnal audiovisual monitoring may reduce risk, suggesting that someone nearby to provide basic aid during or following a seizure may be lifesaving. Devices can alert family members and caregivers that a seizure is occurring so they may administer rescue medication, roll the person on his or her side, or stimulate the person to improve respiration and arousal after a seizure. We must inform patients and families about the risk of death."

The family members I have met whose loved one died of epilepsy universally agree.

Family Members Want to Know Their Loved Ones Could Die

The Noweteski family, who lost their 24-year-old son Russell to SUDEP, wrote an open letter to health professionals that the Epilepsy Foundation posted on its website, effectively begging doctors to stop keeping secrets about SUDEP. Russell experienced eight seizures in seven years. Doctors considered him controlled. Then, as he was nearing graduation from college, he was found dead on his bedroom floor.

"Why weren't we told this could happen?" says the open letter, which was signed by the whole family. "Can you imagine the heart-wrenching feeling of wondering if there was something more we could have done to prevent this? How are we to be okay with the idea that we may have failed to protect our son by every means possible? Had Russell understood what he was really up against, would he have been more diligent with his meals, medication, and sleep? Would it have made a difference?"

"Had even one of the doctors who managed his care told us about SUDEP would we have celebrated his 25th birthday this week rather than grieved the 6-month anniversary of his Sudden and Unexpected Death?" the letter says. "Who knows? But it hurts so very much to have to wonder."

The story is the same in other letters posted at the Epilepsy Foundation site.

These Parents First Heard of SUDEP at Their Children's Funerals

Kristan Bagley Jones said she first learned about SUDEP at the funeral of her son Evan, who died from epilepsy at 19. "I do not know why I did not learn about SUDEP from his doctors," she writes. "Perhaps they thought Evan or I could not handle this information? I do not know the answer to that question, but I know without a doubt in my heart, Evan would have wanted to

know about his risks.”

Another young man, John Paul Popovich, also died at 19, when he was home on a visit from college. His parents, John and Karen Popovich, also learned of SUDEP for the first time at their son's funeral.

“I learned about the many other SUDEP tragedies that have struck innocent families and changed their lives forever, just as it has changed our lives,” the Popoviches write in a letter posted on the site. “It seems one common denominator in each of these stories is that the family had never heard of SUDEP and/or their doctor had never mentioned it.”

Bereaved Families Are Demanding Change

A story I have heard frequently is about people who went off of their anticonvulsants at the suggestion of a neurologist without being told of the risk of SUDEP, and then died soon after.

One person who experienced this was Dakota Jankowski, who died at 16 from epilepsy. Her mother, Kellie Jankowski, also posted an open letter to doctors on the Epilepsy Foundation website. “Not once, when she met the criteria for coming off the meds, was SUDEP ever mentioned to us,” she writes. “If it had, would we have changed our minds about her coming off the meds? I am not sure, but that right was taken away from us.

“My understanding is that many healthcare professionals do not discuss SUDEP with parents or patients. Some are afraid that it will scare the parents. How can a parent make the right decisions if they are not given the proper facts? Would you want that right taken away from you and in turn you lose a child?”

Jankowski then adds a demand. “Please provide all facts to those with epilepsy. Allow them to make the choices they want based on ALL information given. This is your responsibility as a caregiver.”

A Ray of Hope in an Automated SUDEP Risk Assessment Tool

It is amazing that many doctors either don't hear these pleas or ignore them. The resistance by many doctors to talking about the risk of death, or even to assess how high that risk might be for a particular patient, has pushed a research group that includes Greenwich Biosciences to start developing a computer program for pediatric neurologists called [CHICA \(Child Health Improvement Through Computer Automation\)](#).

The system provides a questionnaire for parents, which is delivered on a computer tablet. If the answers they fill out suggest a heightened possibility of SUDEP, the computer tells the doctor to talk about it.

My Message to Neurologists: How Dare You?

I have struggled mightily with this column. I have cried, and raged, and swallowed my fury. So many children, adults, and friends — all full of promise, all fighting for a full life — did not have a chance to take precautions, to potentially save themselves or be saved, because neurologists chose to say nothing. While CHICA is an advancement, the idea that doctors have to be *prompted by a computer* to mention the risks of death is horrifying.

To neurologists, when I say this, I am echoing the words I have heard throughout the country from people who have lost loved ones:

How dare you? How dare you decide *for us* whether we should know about the risks of death? How dare you mask your own discomfort about discussing SUDEP and other potential killers from epilepsy by pretending you are keeping silent for our benefit? *How dare you?*

These are our lives, not yours. Tomorrow, someone will die of SUDEP. And when their loved ones discover you never told them

the risk, they will condemn you with every fiber of their soul, like so many families before them.

Tell, for God's sake.

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Important: The views and opinions expressed in this article are those of the author and not Everyday Health.

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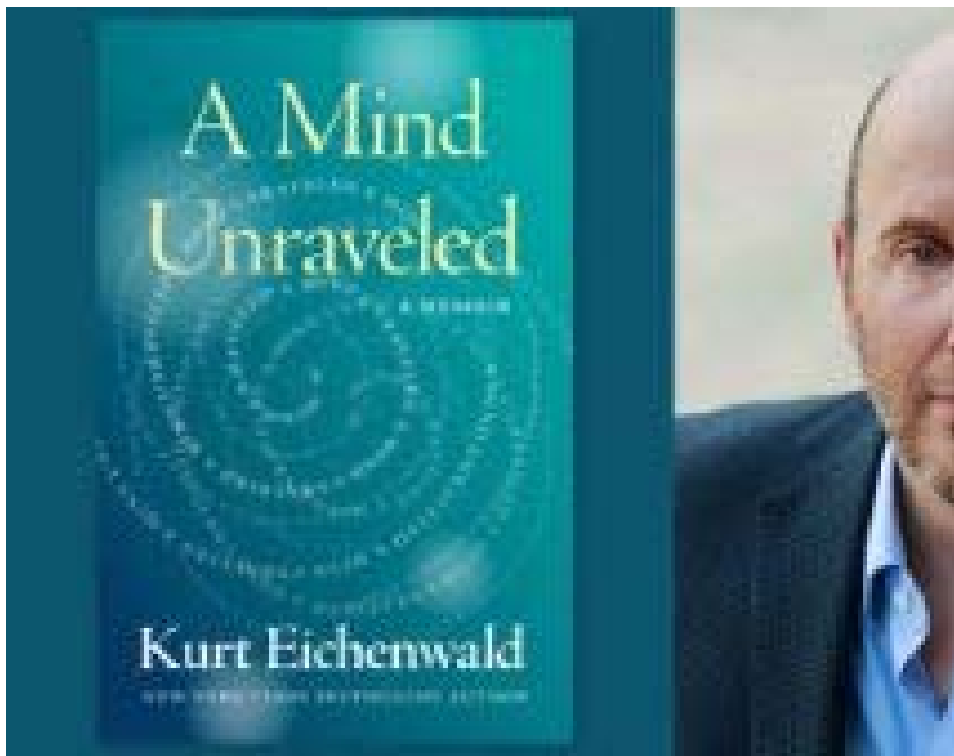
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