



# Knowing the risk of SUDEP: Two family’s perspectives and The Danny Did Foundation

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**Mark Stevenson** lost his 20-year-old son Tyler to SUDEP in 2011. Since then, he has been a strong advocate in increasing awareness and understanding among the medical community and families whose lives’ have been impacted by SUDEP.



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## SUMMARY

There is much debate in the epilepsy community about whether neurologists should discuss the risk of sudden unexpected death in epilepsy (SUDEP) with their patients and family members. Those in favor purport that patients have a right to know about SUDEP. Opponents say the risk is so low that discussions only worry patients and families, especially if there is nothing that can be done to prevent SUDEP. North American surveys show that the epilepsy community knows little about SUDEP and neurologists are unlikely to talk about it. However, surveys of those bereaved by SUDEP show that an overwhelming majority of the parents, spouses, and family members want to be told about SUDEP immediately after the diagnosis of epilepsy. This article is written by two families bereaved by SUDEP and their strong belief that neurologists should have the discussion about the risk of SUDEP soon after the diagnosis of epilepsy.

**KEY WORDS:** Sudden unexpected death in epilepsy, Sudden unexpected death, Family, Epilepsy, Risks.

## THE STEVENSONS

It is every parent’s worst nightmare—a late-night knock at the door by police officers who ask to speak to the parents. This is how we learned about Tyler’s death due to sudden unexpected death in epilepsy (SUDEP). Tyler was a sophomore at the University of Colorado Boulder. We learned that he most likely passed away in his sleep on Friday night/Saturday morning and that he lay in his bed face down for almost 48 h in his college dorm room, alone. The stench of Tyler’s decomposing body alerted residents that something was wrong, and they called Campus police. We buried him in January 2011. We watched his casket get lowered to the ground. We will never see him again.

SUDEP is a term my wife and I have come to know all too well following Tyler’s death. Our research and interactions with other families who have lost loved ones to SUDEP join us in a shared sorrow that we were never advised that their loved one could die from epilepsy. As I look back, Tyler was seen by neurologists at six medical centers around the United States, and none of them ever told us that he could die from a seizure. There appears to be much debate among professionals as to whether providers should bring up the risk of SUDEP with patients and families. Supporters say

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“yes” and compare it to sudden infant death syndrome (SIDS). Supporters also say that SUDEP should be presented in a nonalarming manner, and that the risk is low.

In 2013, my wife and I participated in an updated North American study led by Dr. Nair in Toronto. Parents who lost loved ones to SUDEP and parents whose living children had epilepsy were interviewed. The structured interviews included questions about if, when, how, and by whom would you want to be told about SUDEP. My wife and I responded similarly, and we both wished that we would have been told by Tyler’s first child neurologist in the first one to two visits. In retrospect, it is perplexing that during Tyler’s first appointment, the child neurologist talked about brain surgery. Brain surgery is not alarming to a parent? We wish that we would have been told about the incidence of SUDEP and the risk factors involved. Would this have made a difference? I believe, yes! In between Tyler’s freshman and sophomore years at college, he asked to have a dorm room by himself. We reluctantly agreed, but if we would have known about SUDEP beforehand, we would have never let him room alone. We also lost the opportunity to provide Tyler with seizure-monitoring devices. Instead, we learned about SUDEP after Tyler died, as have many other parents of sons and daughters with epilepsy. This is a *horrible* way for a parent to learn about SUDEP.

There is little evidence on the advisability of discussing the risk of SUDEP with patients and their families. Those against this position argue that harm, or at the very least, distress, might ensue, with no subsequent effect on risk reduction. Their position is that SUDEP is ill understood and cannot be prevented. Some are concerned that the physician might be legally liable in the event of death for not having discussed this issue with the patient or parents.<sup>1</sup> They also argue for the right to not know. Some hold the view that patients with mild epilepsy are at very low risk, and that discussions should be reserved for those with severe epilepsy.<sup>1</sup> In reviewing the literature, we see now that Tyler was in the high risk category for SUDEP: seizures at night in his sleep; tonic-clonic seizures; lack of seizure control with his current antiepileptic drugs (AEDs); young, male with epilepsy diagnosis at a young age; failed surgery; and multiple medication changes.

## THE STANTONS

On Saturday morning December 12, 2009, I was on a gym floor, at a common early morning practice in my role as an assistant basketball coach at a local high school. I’d received several phone calls from my older brother Mike, which was unusual for the time of day. When I called him back, he could barely speak. All he could muster was, “Danny is dead.” His son, my nephew, had been found lifeless in his bottom bunk bed by his older brother John. It was just a few months before Danny’s 5th birthday.

A parent’s most critical role is to ensure the safety of their children. Because they did not know the full spectrum of

risks that his epilepsy presented, including SUDEP, Danny’s parents were not sufficiently informed to be able to make the best possible decisions for his health and safety. Doctors talk about the various risks that accompany seizures on a regular basis—relative to swimming, bathing, driving, and the possibility of head trauma. To omit the single most significant risk a person can face, death, is unconscionable, particularly when SUDEP is described by the National Institutes of Health (NIH) as the most common form of epilepsy-related death.<sup>2</sup> It is impossible to know if being informed about SUDEP would have prevented Danny’s death. Danny’s parents felt a great sense of betrayal and anger at not being told. That is the aftermath when you feel you have been robbed of an entire lifetime of opportunities with your son.



Danny with his uncle Tom.

While it is a mantra, information is power. During the first or second visit with their neurologist, Danny’s parents wish that their doctor had said to them, “We know your son is only experiencing his seizures during sleep. Nocturnal seizures are one of the factors that increase his risk for something called sudden unexpected death in epilepsy death, or SUDEP. There is no known 100% prevention for SUDEP, but watchfulness and early intervention—being present during or just after his seizure—will be a big advantage for Danny and could reduce the risk. Here is some more information on SUDEP that you can read about.”

Most parents are not seeking a drawn out conversation about SUDEP. They simply do not want SUDEP to be left entirely out of the conversation. Acting as though parents are incapable of digesting “scary” information is an inappropriate and minimizing tact. But when a parent is flying blind, they are powerless to protect their child. When a doctor provides that information in an open and honest way, it builds trust and respect, and offers parents the opportunity to make informed decisions.

In 2010, Danny’s parents founded the Danny Did Foundation. The name comes from the last sentence of Danny’s obituary, written by his dad: “Please go and enjoy your life. Danny did.” The mission of the foundation is to prevent deaths caused by seizures, and to enhance communication between doctors and families regarding the risk of SUDEP. The aim is not to cause fear or stress, but to empower parents and adults with epilepsy with the knowledge to make informed decisions. Danny Did believes that information

Table 1. Other family's perspectives on not being given counseling on SUDEP<sup>5,6</sup>

<p>People do not die from epilepsy. That is what we were told when William died as a result of a seizure in 1988. So now we know that people can die as result of a seizure. I wish I had known that when William died. . . .</p> <p>Jennifer Preston</p>	<p>The cause of death was SUDEP; something I had never heard of. Like most parents in my position, I wondered if I had done enough.</p> <p>What could I have done differently?</p> <p>Ross Sheridan</p>	<p>We thought she had her whole life ahead of her. She had been diagnosed (epilepsy) when she was 13 years old; we knew nothing of SUDEP.</p> <p>Denise Brown</p>
<p>SUDEP was never raised. While reading an article about epilepsy it hit me: Eric had died from SUDEP. As a father I had to tell the coroner my son's cause of death. When I explained SUDEP to him he said 'oh, we've had 3 or 4 similar cases in the past year'. Clearly, SUDEP is underreported. 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 a chance.</p> <p>Steve Wulchin</p>	<p>A few months after his fourth birthday, he had a seizure that was not associated with a fever. Before his epilepsy workup was even complete and before he had a chance to become therapeutic on his medication, Henry died in his sleep from SUDEP. I have shared our story publicly to raise awareness of the need for research as well as the need for providers to discuss SUDEP with their patients.</p> <p>Gardiner Lapham</p>	<p>At first, we thought she may have died from an aneurysm, heart attack, or maybe sleep apnea. The initial autopsy was inconclusive. We requested further testing. Her autopsy report indicated the likely cause was SUDEP. What in the heaven's name was SUDEP? We continue to mourn our loss. Kristy's twin is still angry that we weren't told about SUDEP.</p> <p>Janine Mifsud</p>
<p>No one ever told us she could die from this, nor have we even heard of SUDEP till after her death. I often ponder, should we have known this, would we have allowed her to experience all those childhood joys of sleepovers and school camps? Would we tell another family with a child who had epilepsy? Of course we would.</p> <p>Geoff and Wendy Leigh</p>	<p>I first heard of SUDEP when it appeared on Erin's death certificate. The hospital had not contacted us, and we had to search the Internet for death in epilepsy and discover what SUDEP was. When asked (neurologist), he explained that his practice was not to routinely inform about SUDEP because he didn't want to cause distress and there was nothing Erin could have done.</p> <p>Janet Casey</p>	<p>Six weeks later we learned that Kristen had died from epilepsy. How could she possibly just die? I did not know that having epilepsy could be fatal. Nobody warned me of the risk of SUDEP and now my daughter and grandson are lost forever.</p> <p>Father of Kristen</p>

Table 1. Continued.

<p>We, and Jordan, spent a lot of time researching epilepsy on the internet and eventually learned of SUDEP from two lines of text in some hospital literature. It was classified as 'rare' and didn't seem to apply to Jordan. Then the horrific day of November 2, 2010, only 12 months after her first seizure, we found Jordan face down in her bed, victim to SUDEP! We are left with the 'whys and hows' and many unanswered questions. Deb and Dave Fawcett</p>	<p>We pushed for a referral to a pediatrician who thought that Becky might be having epileptic seizures in addition to migraine and arranged for her to undergo EEG and MRI scans. There was no mention of SUDEP. Three days after her death we heard about sudden unexpected death in epilepsy for the first time in the form of passing reference from the coroner's office. Some Web searching uncovered the Epilepsy Bereaved website and our first viewing of the acronym SUDEP... and the horror associated with it. Parents of Becky</p>	<p>Autopsy results were consistent with SUDEP. We were stunned and confused. What was SUDEP? How could this have happened? Would it have made a difference if Christopher knew about SUDEP? There is nothing worse than losing a child but to feel Christopher did not have all the information he needed to make informed decisions makes it especially cruel. He didn't have a level playing field. Knowing this information may have saved his life... what do you do with that? Jeanne Donaty</p>
<p>The exact cause of death is unknown as of yet; however the signs point to SUDEP. The family has been supported by Epilepsy Bereaved, and we believe the work they do in raising awareness about SUDEP and in providing support to families, is invaluable. The Dattani Family</p>	<p>I asked the coroner to consider SUDEP as a possible cause of death having learnt, through my own research on the Internet, of its under reporting on death certificates. No doctor had mentioned SUDEP to me. Alaine Morrison</p>	<p>Generally Jane's doctors were fantastic and I believe the six or seven she saw over the years never considered SUDEP as a risk. Jane last saw a doctor about six weeks before her death. Her doctors were as shocked by her death as we were. David McLachlan</p>

about SUDEP should optimally come from a doctor, but until that is common practice, the foundation works to fill the communication gap by raising awareness about SUDEP, in both the epilepsy community and mainstream society. The foundation also shares information about monitoring devices and technologies that can help to enable early intervention when seizure activity occurs. To date, Danny Did has helped families spanning 47 states and 6 countries gain access to these resources. The foundation is a continuation of Danny's place in the world, and through it, he continues to help others and spread happiness as he would if he were alive today.

## THE LITERATURE

The incidence of SUDEP ranges from 0.09 to 0.35 per 1,000 person years, and in epilepsy surgery candidates or patients who continue to have seizures after surgery, the incidence ranges from 6.3 to 9.3 per 1,000 person years.<sup>1</sup> It is widely known that SUDEP is underreported in this country due to the lack of awareness, lack of mention of epilepsy on death certificates, and the different coroner/medical examiner systems in each state. We believe that the discussion about SUDEP should follow how parents learn about SIDS. Before the Back-to-Sleep public health campaign in the 1980s, the SIDS rate was 3 in 2,000 live births. After the campaign, the SIDS rate is now 1 in 2,000 live births.<sup>3</sup> The most dramatic decline in SIDS occurred in the years immediately following the first nonprone sleep recommendation, which is directly attributed to population-based interventions.<sup>4</sup> Once the pediatricians got onboard the Back-to-Sleep campaign, the number of deaths decreased dramatically.

When we started researching SUDEP, we were very disheartened about the lack of education, awareness, and support for those bereaved by SUDEP. The coroner and the death investigator did not know about SUDEP. More people are diagnosed in this country each year with epilepsy than with multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's combined—yet epilepsy receives fewer federal dollars per patient than each of these neurologic conditions.<sup>2</sup> People are dying from seizures due to accidents, status epilepticus, suicide, and most commonly, SUDEP, but the medical community is only just starting to warn patients and families of this potential risk of SUDEP. In 2005, Canada, the United Kingdom, Australia, and other European countries were far ahead of the United States in SUDEP research and awareness.<sup>5</sup>

People should be aware of the publications "Sudden Unexpected Death in Epilepsy: The Global Conversation"<sup>5</sup> and "Sudden Unexpected Death in Epilepsy: Continuing the Global Conversation."<sup>6</sup> They are a compilation of international articles on SUDEP research interwoven with 25 personal stories of sons and daughters, ages infant to middle age, lost to SUDEP. In 23 of the 25 family stories shared,

the parent stated that no one ever told them about SUDEP prior to the death of their son or daughter (Table 1). The American Epilepsy Society (AES) and Epilepsy Foundation joint task force on SUDEP recommended educating all people with epilepsy about SUDEP as part of their overall education about the harm of seizures, except in rare extenuating circumstances.<sup>7</sup> They also suggested investigating methods to determine when and how to best inform patients about SUDEP and creating standardized and widely available education material.<sup>7</sup>

In a Canadian survey, 56% of Canadian pediatricians were aware that children with epilepsy were at increased risk of SUDEP.<sup>8</sup> In discussions about doctors talking to their patients about SUDEP, the range of barriers were discussed, including perceived lack of significant risk, belief that the risk could not be influenced, not yet having established a doctor-patient relationship, risk-benefit ratio against disclosure, lack of time, insufficient information/knowledge of SUDEP, lack of support network for the patient, and SUDEP information being available from other sources.<sup>8</sup>

In a study of 36 parents of 21 children with epilepsy, and one-to-one interviews with six parents of four children who had died suddenly, there was unanimity among parents in favor of disclosure, generally at the time of diagnosis. This could be through face-to-face discussion with the pediatric neurologist, with support from other health care professionals, and backed up by pamphlets and reliable Internet resources.<sup>9</sup>

Another study revealed that a physician's duty includes education and counseling of patients regarding their condition and prognosis, and this includes truth-telling.<sup>10</sup> It concluded that worries about catastrophic psychological harm from SUDEP disclosure were unfounded in the literature. There was evidence for benefit of disclosing "bad news" or uncertainty that allows for adjustment and adaptation. Highlighted in the study was the importance of a caring, emotionally supportive physician. The conclusions were that it was not a question of "if" but "how" SUDEP is discussed, and stressed the need to tailor information to the individual patient or family. Exceptions to disclosure where the disclosure would be harmful for the rare patient with unique, cultural, physiologic, or social contexts.<sup>10</sup>



The Stevensons; Tyler is on the far right.

## CONCLUSION

We have a dichotomy in the epilepsy community—doctors do not want to talk about SUDEP with their patients because they do not want to “worry” them, and the families wish that they were told about SUDEP before their loved one died. Physicians are taught to cure, make people well, and control epilepsy. Patients with the most severe forms of epilepsy have a greater risk of death than those without, but physicians will talk to those families about all of the risks including death. Surgeons also discuss the possibility of death before procedures now seen as routine including arthroscopies, cholecystectomies, and appendectomies. Do people worry when they are going to have surgery? Perhaps, but at least they are told about *all* the risks so that they and their family, can be informed. If the neurologists, or others caring for those living with epilepsy, does not want to inform their patients or parents about the risk of SUDEP, then who will? Will the bereaved families have to find out on their own? In the United States and Canada the police, paramedics, EMTs, coroners, and medical examiners tell the family. The Internet has sites on SUDEP, but patients and families need to know where to look. This way of learning about SUDEP isn't right! At the very minimum neurologists and others caring for patients with epilepsy should talk to those at high



risk. It will take a grassroots effort to get neurologists and others working directly with epilepsy patients and their families to engage in the discussion of the risk of SUDEP.

## DISCLOSURE OR CONFLICT OF INTEREST

Mark J. Stevenson has no conflicts of interest to disclose. Thomas F. Stanton is an employee of the Danny Did Foundation. We confirm that we

have read *Epilepsia's* position on the issues involved in ethical publication and affirm that this report is consistent with these guidelines.

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