

# SUDEP: What You Need to Know

Kelly Cervantes:	00:00	I'm Kelly Cervantes, and this is <i>Seizing Life</i> , a weekly podcast produced by Citizens United for Research in Epilepsy, CURE.
Kelly Cervantes:	00:18	SUDEP, or <a href="#">Sudden Unexpected Death in Epilepsy</a> , is finally receiving the attention it deserves. This is an issue that is near and dear to CURE. We were one of the early advocates for SUDEP research, thanks to the efforts of board members Jeanne Donalty and Gardiner Lapham. Our guest today, Tom Stanton, continues the fight as the Executive Director of the Danny Did Foundation. He is all too familiar with SUDEP after it took the life of his four-year-old nephew Danny, for whom the organization is named.
Kelly Cervantes:	00:47	Thank you, Tom, so much for joining us today to talk about this incredibly vital topic.
Tom Stanton:	00:53	Thanks for having me here. I'm really excited to talk about it.
Kelly Cervantes:	00:56	Tell us about Danny.
Tom Stanton:	00:58	Danny is the reason that we're here in the epilepsy community. Danny was my nephew, my brother Mike's third of four children. Danny had an older sister Mary-Grace, an older brother John, then Danny, and his younger brother Tommy. They are an incredibly close family. Danny grew up on the Northwest Side of Chicago in the Edgebrook neighborhood. He was just a great kid – really funny, lively, ran around everywhere with his older brother John, his best friend. It's hard to think of the family even today without Danny being a part of it, but he was just the mayor of his block. He had friends who were adult neighbors, his brothers' crew, and kids his age. He was just a great kid. He loved sports, and he loved to act. He was in a play-acting class one day a week.
Kelly Cervantes:	01:54	I love it.
Tom Stanton:	01:55	He was a really, really lively, funny kid.
Kelly Cervantes:	01:59	When was he diagnosed with epilepsy?
Tom Stanton:	02:02	He had his first seizure around age two, and, like with a lot of families, it totally came out of nowhere. His parents were frightened. All of Danny's seizures happened while he was sleeping. With that first seizure, it was a mad rush to the

hospital, to the ER. Like a lot of families we've come to know, they left feeling really uncertain about what had just happened. They wondered what was next, what resources did they have? At that point, Danny was not put on medication. He was just sent home, and the doctors said, "Sometimes this happens. It could be a one-off situation."

Kelly Cervantes:	02:40	Until it isn't.
Tom Stanton:	02:41	Until it isn't. He had his next seizure about six months later. Then, over the course of about two and a half years, he had four seizures that his parents witnessed, all during sleep. Four is a relatively low number, but, looking back now, they always wondered if there were some that they had missed. You know, Danny spent a lot of time sleeping with his mom and dad in their room, which is pretty common. The fear of missing a seizure, or having your child be alone during that vulnerable state when everybody is asleep, is really scary. He slept with them for a period. After the second seizure, he was put on medication and went back into his own room.
Tom Stanton:	03:22	There was this constant process of bed checks and Mom and Dad taking turns. They never really got any rest or peace at night. Let's fast forward for Danny to December of 2009. He had gone to the doctor on a Tuesday morning, and, by all accounts, was on a good path. They had increased his medication level slightly due to weight gain, but basically the message was, "You're heading in a good direction. Stay on this path." They left there feeling really hopeful. Then, four days later on a Saturday morning, his mom went into his room ... Danny shared a bunkbed with his older brother John ... she went in to check on him in the morning, and he was gone.
Tom Stanton:	04:09	It was a morning I'll never forget. At the time, I was coaching high school basketball, and we had a really early morning practice that day. I remember leaving practice at about 8 o'clock, and I had maybe four or five missed calls from my brother Mike. I thought, "That's really unusual for this time of the day on a Saturday." Finally, we talked, and all he could spit out was, "Danny's gone."
Tom Stanton:	04:39	It was just ... Excuse me. It was a moment that we'll never forget. I know what struck me about that message was just the finality of it. You know, there was no turning back, there was no fixing it. We have a really strong family, and we obviously rallied around as much as we could, just to be present. I think that's the biggest thing when tragedy strikes, just to be present.

Whether you know what to say or not, just to be there. That's what we tried to do.

- Tom Stanton: 05:11 It has since launched a movement that Mike and Mariann started that we're really proud of, coming in on 10 years now with the Danny Did Foundation. With Danny, and with a lot of parents we met, they had never heard of the risk of SUDEP. That was a huge blind spot for them, to not know this was one possible outcome. As parents, we're responsible for our kids, and, if we're not empowered with all the information we need, we can't mitigate those risks.
- Kelly Cervantes: 05:44 We came into the epilepsy community only two, two and half years ago. Our family has already benefited from the incredible work that Danny Did has done. With the awareness raised by CURE as well, we were aware of SUDEP very early on. On behalf of all the other families, we're so incredibly grateful for all the work that you guys have done. What exactly is SUDEP?
- Tom Stanton: 06:13 The acronym stands for "sudden unexpected death in epilepsy." What causes it, and why it happens to certain people and not others, is really still being studied. Typically, a case of SUDEP occurs after a seizure that happens during sleep. Oftentimes, when there's a case of SUDEP, a person is found in bed in the morning, like Danny was. There's usually an autopsy that rules out other causes of death. Within epilepsy, there are certain types of mortality that affect our community. SUDEP is this unknown cause for people with epilepsy that is still being studied. We are still trying to figure out what the mechanisms are. Is it something to do with the heart? Is it something to do with the brain? Is it something to do with respiration?
- Tom Stanton: 06:58 I think, as a layperson who's been trying to stay as informed as I can over the last 10 years, ultimately it's probably some combination thereof. It might be slightly different for every person that is struck by it. But finding out exactly what causes this, how we can find benchmarks or things that will help us reduce the risk, is really important. That's why research done by CURE and others in our community is vital to keep pressing and finding out what exactly causes these deaths.
- Kelly Cervantes: 07:31 There are a couple things that come to my mind immediately, and one is that I don't think the general public realizes that people can die from seizures. I don't think that is common knowledge. I think this is an incredible message that needs to get out into the public, that this is a life-threatening condition. The other piece of this, from coming within the community, is I remember sitting across from Adelaide's neurologist after she

had her first seizure, and the neurologist not being able to tell us why, not being able to give us a defined treatment, and how frustrating that was.

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| Kelly Cervantes: | 08:10 | Being on the other side of that and finding out that your child has lost his/her life to this and not being able to understand why they were taken. It's shocking in this day and age that we understand so little. To that end, what research is being done? What advancements are being made?  |
| Tom Stanton:     | 08:33 | Over the last 10 years, there's been a big increase in research around SUDEP. We can go way back to the '90s when CURE was funding grants around SUDEP. They were one of the only organizations really in that space. Thankfully, more has happened, and there's some progress. There's something called the Center for SUDEP Research, which is a 14-site trial that started in 2013 I believe it ends in 2019. It is funded by a \$27 million grant from the National Institute of Health. For epilepsy, this is a big deal. It is not everything we need. There's more that we need in terms of funding at the federal level, but this is one of the biggest grants for SUDEP research. |
| Tom Stanton:     | 09:21 | A doctor by the name of Sam Lhatoo has been heading up that study with several other researchers. That's ongoing and, hopefully, we'll put out some important information that we can really communicate to families. Research is important, but, at the end of the day, we need to have a conversation between a doctor and a patient that says, "Hey, Kelly, here's what we found out based on this research. Here's what you can do and what we can do for better treatments for Adelaide." We need to make that full-loop connection.  |
| Kelly Cervantes: | 09:53 | Are you finding that happening more and more? Are doctors having those conversations with their patients?  |
| Tom Stanton:     | 09:58 | I wish I could say it was happening more, honestly. I think, at some levels, at the specialist level, for epileptologists, it is a more common thing. There have been a lot of studies regarding the number of parents who want to hear about the risk of SUDEP. Obviously, it's a lot to digest, but, typically, it's in the 90-98% range of parents who do want to be informed. As a parent, I can certainly appreciate wanting to know that such a serious outcome is possible for my child.  |
| Tom Stanton:     | 10:31 | If you look into other disease states, like cancer or other things that have death as a possible outcome, it's common practice for the provider to say, "Here's the prognosis, and this is the range of possible outcomes." That's what patients, parents, and   |

caregivers within the epilepsy community deserve. That honesty. A really big part of what the Danny Did Foundation has faced as a challenge is improving that communication between providers or caregivers and adult patients about this risk. Typically, surveys show that about 30% of doctors do communicate the risk.

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| Tom Stanton:     | 11:10 | That percentage will increase within certain populations who are at higher risk for SUDEP, such as those with Gervais Syndrome or Lennox-Gastaut Syndrome. For kids like Danny, who are controlled, it's typically still not mentioned by a doctor. That's where the work from advocacy groups like the Epilepsy Foundation, the Danny Did Foundation, and CURE, bringing that message directly to families and patients, is critical.   |
| Kelly Cervantes: | 11:38 | Let's bring that message to families. Who is at the highest risk for SUDEP?  |
| Tom Stanton:     | 11:42 | The two highest risks for SUDEP are uncontrolled seizures and tonic-clonic seizures. People with refractory epilepsy are at heightened risk. Danny had tonic-clonic seizures during sleep, which put him at high risk. His seizures were not uncontrolled, but they occurred during sleep and were convulsive in nature. Those are the two biggest risk factors. We think about how we can mitigate or lessen risk. Controlling seizures is number one.  |
| Tom Stanton:     | 12:16 | I always say that awareness and education are simple ways that we, collectively as a community, can try to mitigate or lessen this risk. Letting people know, like you said, that seizures can be fatal. It's not necessarily something that we want to shout from the mountaintops to Mom or Dad, who just faced their first seizure, but it's got to be within that safety conversation when we're talking about issues to be aware of related to bathing, or when you're at the pool swimming, or when you're exercising. If your child is old enough to drive. There's this whole range of risk and safety issues that we talk about, and our position at Danny Did is to couch the SUDEP conversation into that safety talk. We can't leave that risk out of the conversation anymore. It's just too much of a blind spot for parents or patients to have. It's not fair to them. |
| Kelly Cervantes: | 13:17 | What else can parents, caregivers, or patients do, aside from obviously being aware and trying to get seizure control? For some people, this is not going to happen. What else can they do?  |
| Tom Stanton:     | 13:35 | A big thing is treatment adherence, making sure you're staying on top of whatever treatment is for you. Most commonly, that's  |

medication. This can be a motivator for a child who is going off to college and might be thinking, "Okay, my lifestyle's going to change. I'm not having the same structure I had." Knowing about the risk of SUDEP can be a very real motivator.

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| Kelly Cervantes: | 13:59 | I want to point out you saying that a person going off to college can be affected by SUDEP. Danny was a child, but SUDEP can affect anybody and everybody, regardless of their age. This is not just a pediatric risk, but also a risk for adults as well.   |
| Tom Stanton:     | 14:20 | Exactly. Unfortunately, we've met many spouses who have lost their spouse or adult sibling to SUDEP. It's not an age-specific risk. It can occur in kids as well as the elderly. Treatment adherence is really important, whatever that means for your loved one, to stay on top of that. We think early intervention during a seizure is really important. Danny, like I said, only had nocturnal seizures. We are considering monitoring options that can alert Mom or Dad, or a caregiver or spouse, that a seizure is ongoing, especially during sleep. Just having someone present in the room can be a big advantage for the person seizing. |
| Tom Stanton:     | 15:02 | Maybe the person's airway is wedged into a pillow, or maybe they've fallen out of bed. Maybe you find them unresponsive. You've got an opportunity to act. Whether or not Danny would be alive if his parents used a monitoring device, we'll never know. But certainly they would have loved to have that chance to be there and to take every opportunity to get to him as quickly as possible. We're big advocates for monitoring and alerting systems that can enable early intervention when a seizure happens.   |
| Kelly Cervantes: | 15:36 | Where could someone find these monitoring devices? I know seizures can be silent, and you're not necessarily going to hear something. So a typical baby monitor may not work. What options are out there, and how can someone find them?   |
| Tom Stanton:     | 15:54 | Over the last 10 years, there's been a lot of activity in this space. Devices and technologies related to epilepsy have really evolved over time. One of the functions that Danny Did is to help walk families or adult patients through what's out there, from basic movement monitors to wristwatches that can monitor for movement or skin perspiration. There are systems that look at heart-rate variance. You really have to align the system with the type of seizure that your loved one is facing.  |
| Tom Stanton:     | 16:29 | A big part of what we do is simply helping families set expectations. They come to us very excited about a certain system. We try to help them talk and think through their  |

expectations. Does this align with our reality? Are these seizures designed to be captured or alerted to by this system? Initially, it's monitoring, but then you want a system that alerts. Ultimately, what would be great is something that can have that closed loop and have an intervention built in. There's a therapy that's delivered, and maybe you even suppress the seizure.

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| Tom Stanton:     | 17:08 | There are implanted systems like VNS that are designed to do that, but, in the wearable space, external devices are not there yet. We spend a lot of time tracking what's in the pipeline, what's coming along. All of these things are pieces that we can help with as a foundation, as advocates, to help let our community know what's out there and walk through what are the best options for them.   |
| Kelly Cervantes: | 17:36 | Are statistics available to you? Can you see that, within the last 10 years, there has been a reduction in the number of SUDEP deaths? With the awareness that has been raised, with the devices, are we seeing a decline?   |
| Tom Stanton:     | 17:54 | I would say statistics within SUDEP are really tricky. One primary reason is because a lot of coroners and medical examiners don't know what SUDEP is. At the time of death, they're not necessarily captured as a case of SUDEP, so our numbers, we think, are always underestimated. There's an effort at New York University led by Dr. Orrin Devinsky called the North American SUDEP Registry, and Danny Did is a partner to that. CURE is also a partner to that. It's basically trying to capture every case of SUDEP to record the history. What happened before? What was this person's volume or journey with seizures? In addition, they try to collect brain tissue, if the timing allows. It's a really critical piece of research to try to get a more accurate count on how often this happens. The accepted numbers that are used currently are 1 in 1000 people with controlled seizures will die from SUDEP. That probability increases to 1 in 150 people with uncontrolled seizures. |
| Kelly Cervantes: | 19:10 | Oh my word.  |
| Tom Stanton:     | 19:11 | It's a huge difference. That talking point is really important for our community to be aware of. It's a lot to digest, and it's frightening, frankly, to think about.  |
| Kelly Cervantes: | 19:22 | I wasn't aware that the statistics were that high.   |
| Tom Stanton:     | 19:25 | There was a new guideline put out in 2017 from the American Academy of Neurology, in partnership with the American   |

Epilepsy Society. For the first time ever, they put out a practice guideline on SUDEP. Let's say there are 4-, 5-, 6000 neurologists out there. They are, in theory, going to adhere to these practice guidelines. So, for the first time, there is a recommendation that they talk with all patients about the risk of SUDEP.

Kelly Cervantes:	19:53	My mind is blown that this is just so recent, that these sort of guidelines are just coming out. Epilepsy has been recorded since the beginning of human time.
Tom Stanton:	20:05	Since Biblical times, yes.
Kelly Cervantes:	20:06	And we're just now making recommendations to clinicians to talk to their patients about this.
Tom Stanton:	20:14	I think that really paints the scope of what we've been up against over time. There's been such a hesitation to bring up this topic. The reasons to us don't really matter. The history doesn't really matter. We need to change and adapt and serve our community better. It's really been maddening over the years to see such resistance, but this guideline was a step forward. It would have been written differently, and more strongly, if it had been written by advocates, I think. But for what it is, it's a step forward. So we try to talk about that and leverage that within the medical community, the provider community.
Kelly Cervantes:	20:58	Where do you see the future of SUDEP awareness, advocacy, and research? What is Danny Did's ultimate goal here?
Tom Stanton:	21:07	It all comes back to that point of eliminating seizures. When my brother started the foundation, he had a vision for how a new generation impacted by epilepsy would be treated with a different standard of care. You have your first seizure, go for your doctor's visit, and receive information about the whole range of risks that come with epilepsy. You have a suite of products or interventions that could alert you during a seizure and, hopefully, work to suppress the seizure.
Tom Stanton:	21:41	In other disease states, we see these similar options that are presented to people who are new to a medical challenge. Developing those in epilepsy is where we see this going. It's really important that we encourage companies who have an interest in this space to stick with the research and development, to stay in this world so that the outcomes for our patients become better.



- Tom Stanton: 22:06 The other thing that's so critical, as you know, is the research, just driving that forward. But how does that happen? Primarily through stories. Letting the supporters know, whether they're at the federal level or whether they're private donors, that there are real families impacted. There are people lost. There are lives altered dramatically every day by epilepsy. 1 in 26 Americans will develop epilepsy. This is an astounding figure. So driving that research forward is a major, major factor in getting to the point of curing epilepsy and, ultimately, preventing deaths caused by seizures.
- Kelly Cervantes: 22:45 Where does the name of the organization, Danny Did, come from? I think it's just ... I love the sentiment behind it.
- Tom Stanton: 22:50 When Danny passed, my brother Mike, Danny's dad, wrote his obituary. The last line that he wrote was, "Please go and enjoy your life. Danny did." And that really captures what we try to be about, just that joy for living every day, for taking nothing for granted, for embracing the people around you. Danny was a hugger, and we try to maintain that vibe and aura around the work that we do. To just enjoy today, to enjoy the people around you. Danny did.
- Kelly Cervantes: 23:25 Where can people go to learn more about Danny Did? They've heard your story, they want to learn more, and they want to help.
- Tom Stanton: 23:33 The best way is our website, which is DannyDid.org. We try to speak in really plain language, family to family, parent to parent. Our goal is to digest everything that we take in and then put it out in a way that's really approachable. So DannyDid.org is our website.
- Kelly Cervantes: 23:52 I can say, as a parent, as a caregiver, as an advocate, our family is beyond grateful for all the work that you, Danny's parents, and the rest of the Danny Did family have done to raise the awareness and to be out there, pushing advocacy. This is a tough topic. This is not something that you want to be sitting around talking about every day, but Danny Did is, and it really means the world to the rest of us. Thank you so much for being with us today, for talking about this, for sharing your experience, and for continuing to push awareness of SUDEP out into the world.
- Tom Stanton: 24:34 Thank you. We're happy to have the chance to do it, and, if I could, I just want to say thank you to people like Jeanne Donalty and Gardiner Lapham who were there when Danny died. They were out there at the forefront trying to spread the message of

SUDEP awareness. Thank you to my brother and his wife, for the bravery it took to join that movement and try to advance it. The credit goes to them. It also goes to my colleague, Mary Duffy, who's out there talking to families every day. These are people I really admire and respect for the work that they're doing. And to you, and your family, for having the courage to make your fight public. It means a lot to us and has elevated the whole movement as well. Thank you for that.

Kelly Cervantes:	25:15	Thank you.
Kelly Cervantes:	25:19	The stories you heard today are devastating and a strong reminder of why we cannot relent in the fight against SUDEP. We must battle on by continuing to learn more and educate others. If you have additional questions about the latest research on reducing the risk of SUDEP for someone you love or yourself, subscribe to our research alerts at <a href="https://SeizingLife.org/SUDEP">SeizingLife.org/SUDEP</a> . Finally, if you know someone, or the caregiver of someone, who is at risk of SUDEP, please share this episode with them. Through awareness and education, we can do our part to minimize some of the SUDEP risk factors, one person at a time.
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