

Seizing Life, episode 77
SUDEP: What To Know and What To Do
Guest: Dr. Elizabeth Donner
October 20, 2021

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. This week on seizing life, we return to a difficult but important topic within the epilepsy community, SUDEP, or Sudden Unexpected Death in Epilepsy. Wednesday, October 20th is SUDEP Action Day, a day for raising awareness and education about this most devastating outcome of epilepsy.
- Kelly Cervantes: 00:37 While SUDEP may be a somber topic, I hope that my discussion with Dr. Elizabeth Donner will provide epilepsy patients and their families with information and options to consider. Dr. Donner is a child neurologist and the director of the comprehensive epilepsy program at the hospital for sick children and professor and Michael Bahen chair of epilepsy research at the University of Toronto, where she also leads a program focused on identifying those most at risk for SUDEP. Dr. Donner has been at the forefront of SUDEP research and awareness for over two decades and I'm honored to welcome her to the podcast to share her knowledge and insights.
- Kelly Cervantes: 01:16 Dr. Donner, thank you so much for joining us today. I think to start the episode off, I would love, some people, maybe this is the first time they're hearing the term "SUDEP," others may have a general idea of what it is, but maybe they don't know what it stands for, or don't really know what the word means. Can you just start us off with the basics?
- Dr. Elizabeth Donner: 01:40 Thank you, Kelly. For sure, that's obviously a good place to start this difficult conversation. "SUDEP" stands for "Sudden Unexpected Death in Epilepsy," and just like it sounds from its name, it's really the death of a person with epilepsy when that death is unexpected and unexplained, particularly when there's been an autopsy or a postmortem examination and we can't really figure out what the cause of death is, so SUDEP isn't really so much a cause of death as it is a category of death.
- Kelly Cervantes: 02:11 Okay.
- Dr. Elizabeth Donner: 02:13 Make sense?
- Kelly Cervantes: 02:14 That makes a lot more sense. Also, of course, it can't be a simple answer because epilepsy in itself, there is nothing simple about it, so I sort of expect some mystery and complication.

- Dr. Elizabeth Donner: 02:27 Absolutely. I often explain to people that epilepsy is like an umbrella disorder where lots of different things cause people to have epilepsy. That's probably going to be true for SUDEP, too. There's probably going to be a lot of things that result in that category of death that we call "SUDEP."
- Kelly Cervantes: 02:43 All right, so clearly, we don't know a lot about SUDEP still, but we have learned so much in the last 20 years. There's been a lot of research and a lot of focus on SUDEP. If you can, outline for us what is known, for example, how common SUDEP is, when SUDEP is most likely to occur, and perhaps who is most at risk?
- Dr. Elizabeth Donner: 03:10 Those are great questions because those are some of the really important things that we've learned, I'd say in the last 20 to 30 years, and I've been working in the field since about 1999. Since that time, there's been tremendous growth in our understanding of how common SUDEP is and what some of the risk factors are for SUDEP. Starting out with how common SUDEP is, we can see now with a fair bit of confidence that about one with SUDEP will die out of a thousand people per year, so if you follow a thousand people living with epilepsy for one year, one of those people will die in that year of SUDEP.
- Dr. Elizabeth Donner: 03:52 That is when we consider people with all different types of epilepsy, and right off the top, we talked about how variable epilepsy is, and we know some people have very frequent seizures, some people have less frequent seizures, and so among those one in 1,000 people that die of SUDEP, what is it that puts that one person at risk? At this point, we understand that the most important risk factor for SUDEP is the presence and frequency of what we doctors call "generalized tonic-clonic seizures." Those are the seizures, some of your listeners might know, but others might have called them "grand mal seizures." They're really those whole body-shaking seizures, and we know that the more generalized tonic-chronic seizures a person has per year, the more at risk of SUDEP they are. That's a really important way factor because it tells us what we can do to reduce our risk and that's reduce the frequency of those seizures.
- Kelly Cervantes: 04:46 Now, is there a certain time of day that SUDEP is more likely to occur as well?
- Dr. Elizabeth Donner: 04:53 There is. There's actually a typical SUDEP scenario. As mixed or heterogeneous as the underlying causes of SUDEP may be, there is a classic picture, and that is the person being found in bed in the morning dead, most often in the face-down, or what we call "prone position." That leads us to recognize that have

having seizures at night, and some people might call them "nocturnal seizures," puts people more at risk of SUDEP. It's also possible that being alone or unattended or unmonitored throughout the night may increase the risk of SUDEP. That's been a very tricky risk factor to tease out and also something that carries a lot of weight with it, I know that for people who are listening, to recognize that we may reduce the risk of SUDEP for our loved ones if they are being monitored overnight in some way.

- Brandon: 05:58 Hi. This is Brandon from CURE Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide currently live with epilepsy. For more than 20 years, CURE Epilepsy has funded cutting-edge, patient-focused research. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.
- Kelly Cervantes: 06:21 We don't understand a lot about the mechanisms of SUDEP, but do we know anything about what happens in the body when SUDEP occurs?
- Dr. Elizabeth Donner: 06:31 Yeah, there's been some really, really nice studies looking at that. People have worked hard to collect information about people who have died of SUDEP when they've been on monitors, so for example, in our epilepsy monitoring units, places in the hospital where people are admitted with EKG monitors, EEG monitors, breathing monitors, and most often, in those cases, people have SUDEP following a big convulsive seizure, those generalized tonic-clonic seizures, like I mentioned, and we see changes in that post-seizure period, so not during the seizure, but after the seizure, we see changes in their heart rate and breathing that eventually reduce until the patient dies. What was noted in some of those studies is that if somebody stimulates the person after their seizure, and that doesn't have to be a nursing level of stimulation, but if someone goes to them in attends to them after the seizure, then that reduces the chance of them dying.
- Kelly Cervantes: 07:41 Okay, so I want to take that little nugget of information and go back to what we were talking about with some of the conditions that make SUDEP more likely and talk about the ways that SUDEP can potentially be prevented. I know that there is a lot of nuance here and I really do want to dive into that because I think you brought up an incredibly important point, where there can be a lot of guilt for the caregivers of someone with epilepsy when this happens, so I want to spend a little bit of time here because obviously, the number one goal is to prevent

SUDEP from occurring, so what do we do? How do we make that happen?

Dr. Elizabeth Donner: 08:23

Well, first, if I can talk about that guilt for a moment, I think it's really important for people to know that the majority of times, SUDEP deaths are not witnessed and the people who die are alone, but there are cases reported in the medical literature, and many cases actually that I know of personally through my work in this field where someone has actually been with the person when they died of SUDEP. SUDEP does not always follow a generalized convulsive seizure, like what I described. I described to you the classic case, but it doesn't always follow a seizure, and sometimes it's witnessed, and even in the presence of a witness, it was not possible to save the person's life. I think it's really important to recognize that because nobody should feel guilty that they lost a loved one of something so tragic and I just want to make that really clear.

Kelly Cervantes: 09:12

I appreciate that. I had no idea that people had passed away from SUDEP in a hospital, in an EMU. That was new to me, to know that that is possible, that even in a hospital setting where they're connected to a pulse ox and to all of these other things and that death still couldn't be prevented, I mean, that was honestly a little shocking for me to hear.

Dr. Elizabeth Donner: 09:37

Yeah, I think it's shocking for most of us to hear and it's scary and we need to recognize that it's scary. But at the same time, I think the hesitancy to talk about SUDEP for many years has been related to people's feelings, like, "There's nothing we can do, and if there's nothing we can do, why bother to talk about it?" That's a whole other conversation because I think people with epilepsy or people living with people with epilepsy in their family have the right to know all the risks of their disorder the same way we do for heart disease and cancer and these more common illnesses. But the important message that I want to put through today is that, in fact, there are things to do to reduce your SUDEP risk. Those really have to do with actively managing epilepsy.

Dr. Elizabeth Donner: 10:24

Now, I tell people that and they say, "Well, duh, I already do that." Doctors say, "Yeah, I already try to have my patients have as few seizures as possible," and that kind of thing. But I think it's really important that people understand that when they're trying to have as few seizures as possible, when they're really doing that active epilepsy management, that they are not just trying not to have a seizure at the grocery store or trying to keep their driver's license or trying for their child not to have a seizure at school, they're actually working to reduce the risk of

death and save lives. Let's talk for a minute what that active epilepsy management would look like, right?

Kelly Cervantes: 11:01

Perfect, yes.

Dr. Elizabeth Donner: 11:03

That means working with your healthcare provider to have as few seizures as possible. That means taking medications when they're prescribed, how they're prescribed. It means figuring out what the seizure triggers are. I know not everybody can do that, but a lot of people can figure out their seizure triggers, and if you know your triggers, maybe you can avoid them or be aware of your risk when that comes.

Dr. Elizabeth Donner: 11:26

For some people, when it's feasible, it means using a device overnight or during the day to identify when seizures occur. We know that those seizure-detection devices, and there's quite a few on the market now, we know that there's no evidence that they actually save lives, per se, but based on what I said earlier, that attending to a person after they've had a seizure may reduce their risk of SUDEP, you can't do that unless you know they had a seizure, so using even something as simple as a baby monitor, like a video or auditory baby monitor in a patient's room, in a person's room so that someone who lives with them can go to them after a seizure is a very, very important part of this.

Dr. Elizabeth Donner: 12:08

I have to say as a caveat, I'm really lucky. I'm a pediatric neurologist. I work with children and families and all my patients live with caring adults, but I know that a lot of people living with epilepsy aren't living in a place where there's someone with them who could respond to a device, and so we have to keep that in mind as well.

Dr. Elizabeth Donner: 12:26

The last piece I want to talk about active epilepsy management is about recognizing when seizures are drug-resistant and people are having seizures despite being on optimal medical therapy. For those people, we need to figure out if surgery is an option to treat their epilepsy.

Kelly Cervantes: 12:43

Absolutely. When I first came into the epilepsy community five, six years ago now, surgery, it wasn't talked about quite as much as it is now. I do feel like really just within the last few years, there has been this push to make surgery another one of these treatment options, and so I have appreciated that. That doesn't mean that surgery is accessible for everyone.

- Dr. Elizabeth Donner: 13:13 It's not accessible for everyone. It depends on your jurisdiction, where you live, funding. It's also not an opportunity for everybody. Not every type of epilepsy is treatable by surgery. If it was, we'd probably not have to be here as much as we are talking about epilepsy, but everybody who has drug-resistant seizures should look at what other options are available. You mentioned diet therapy. That's also a great option. I treat lots of kids with the ketogenic diet for epilepsy, another important thing to consider.
- Kelly Cervantes: 13:41 Now, one thing that you sort of touched on before was that there does seem to be this reticence among providers to discuss SUDEP. I couldn't even begin to keep track of the number of patients or caregivers that I have spoken to, many, unfortunately, who lost a child to SUDEP or others who are early on in their journey that SUDEP has never been mentioned to them. I would like to think that this is changing, but it's a tricky conversation, but I agree with you, that it is one that she should be had with every patient with epilepsy. Where does that reticence come from?
- Dr. Elizabeth Donner: 14:20 Yeah. As I mentioned before, I really think that the reticence of physicians and healthcare providers to talk to people living with epilepsy and their families about SUDEP has come from a kind of historical paternalistic medicine culture where people think they want to protect their patients and they felt there was nothing to do to reduce risk, and so we've been working for decades now advocating for SUDEP discussion among patients and people living with epilepsy in their families.
- Dr. Elizabeth Donner: 14:58 Rather than scolding, I think the approach is to teach doctors and other healthcare providers that there's something you can do about SUDEP. In fact, we completed a study where we actually surveyed child neurologists living in the US and Canada about their practices talking about SUDEP with families of kids with epilepsy and we found out some interesting things. First of all, most child neurologists are not talking to all of their patients about SUDEP, but when you ask them, or when you look at why or what are the circumstances under which child neurologists speak with their patients with epilepsy about SUDEP, there's two important factors. One, if they've lost a child in their practice in the past and the other, if they have better knowledge of SUDEP, so educating doctors and nurses and other healthcare providers about SUDEP, I think, is the way to get them to talk about it.
- Kelly Cervantes: 15:53 Well, and I can only imagine, you talk about seizure management. The fewer seizures you're having, the less likely

SUDEP is to occur, and knowing what those triggers are. I'm just envisioning the 18-to-25-year-old, who's going off to college or living away from home, and they're like, "Oh, well, if I forget to take my med, I'm going to have a seizure, and that sucks," but knowing that the stakes are higher, not that you want to scare someone into taking care of themselves, but I do think that it's important information that every patient should or caregiver should have at their fingertips and be aware of those dangers because one in 1,000 patients, I mean, that's-

Dr. Elizabeth Donner: 16:41

Not as rare as we'd like.

Kelly Cervantes: 16:43

... No, not at all. But I mean, that statistic is, you think of how many epilepsy patients are just in a single practice in a single hospital.

Dr. Elizabeth Donner: 16:51

Yeah. I love your example of the kid going off to university because I use that example all the time when I talk. Actually, when I present to physicians about SUDEP, I have a slide and on it are opportunities to talk about SUDEP, and one of them is that times of lifestyle changes, like going off to university. Another one is maybe moving in with a partner and getting married and talking to your partner about risk and how to reduce risk and how to stay safe with your epilepsy, so there are key points in a epilepsy trajectory when there are good opportunities to talk about SUDEP. Another one is the situation we talked about before, when we're identifying that someone should be evaluated for surgery. One of the reasons to evaluate people for surgery is to reduce seizures and one of the important things about reducing seizures is reducing risk of death. We just need to call it. We just need to say it.

Kelly Cervantes: 17:44

Yeah, I couldn't agree more. I know we have this statistic, the one in 1,000. However, it has only been recent research that has given us that statistic, and I know that that's actually some of the research that you did with, I believe it was a CURE-funded grant in 2009. Can you tell us a little bit about the research that you have done in SUDEP and efforts to get better reporting on it?

Dr. Elizabeth Donner: 18:13

Absolutely. Thank you. Yeah, I was super lucky to be funded by CURE when I was still relatively junior in my research career. That really launched me into a whole SUDEP research program that's been ongoing now for more than a decade. One of the things I did with the CURE funds was I established a Canadian pediatric SUDEP registry. We worked for a lot of years to develop collaborators across the country of Canada, where I

live, to identify all the cases we could find of SUDEP in children under the age of 18.

Dr. Elizabeth Donner: 18:56

I really felt from work that I had done way back when I was a resident, starting when I was a resident, I started that in 1999, I started some studies looking at SUDEP in children because I had had the experience that people felt that SUDEP didn't happen to kids and I knew that wasn't true, but I needed to find a way to show it, so I started by digging through charts and records in the coroner's offices, provincial offices, looking for cases.

Dr. Elizabeth Donner: 19:24

I realized the best way to understand the risk of SUDEP in children was to work of people across the country, so we worked hard and we partnered with the Canadian Pediatric Epilepsy Network, and we identified collaborators across the country to report cases of SUDEP in children to us, and over time, we developed very strong partners in the province of Ontario, where I live. What that allowed us to do was to gather every pediatric SUDEP case in the province of Ontario over two years.

Dr. Elizabeth Donner: 19:55

Now, previously, it was believed that the risk of SUDEP in children was 0.2 per thousand, so almost 10 times less the risk of SUDEP in adults. I knew that wasn't true because I knew we hadn't been finding all the cases, so what we did is we meticulously looked for pediatric cases of SUDEP in the province of Ontario over two years, and then we just did the math. It turns out that SUDEP is as common in children as it is in adults, one per 1,000 children living with epilepsy. At the same time, some colleagues in Sweden showed the same thing in some very high-quality Swedish data, and so I think we can say with a lot of confidence that SUDEP is as common in children as it is in adults, and I actually should point out that there are some very high-quality studies in some select groups, like patients with drug-resistant epilepsy and patients with other specific forms of epilepsy that demonstrate that the rates are actually higher in those groups.

Kelly Cervantes: 20:55

We are just so grateful for the research that you have done into this field. I'm wondering, I know that you are based out of Canada, but in the work that you've done and in speaking with your American colleagues, is SUDEP considered a cause of death? Is it recorded in the United States in a similar way to how it is in Canada?

Dr. Elizabeth Donner: 21:17

That is a very complicated question. There's no mandatory reporting of SUDEP in Canada or in different provinces of Canada. That's the same for the US, but there are certain states

in the US where actually families and grassroots advocacy has been successful to make SUDEP reporting mandatory in those states, which has been an amazing example of advocacy from the bottom up.

- Kelly Cervantes: 21:47 I have to say, I have a dear friend whose son passed away from SUDEP and she actually had to argue and fight. She was actually a doctor and she had to fight with the medical examiner to get the cause of death listed as SUDEP. I hear stories like that, and it just makes me so nervous that it's one in a thousand, but what if the numbers are higher, and we just don't know? Would that help urge people to donate or urge governments to focus more money and effort into this sort of research? Because these numbers still aren't solidified. To that end, where do you see SUDEP research moving forward in the future?
- Dr. Elizabeth Donner: 22:32 I think that we're talking about one in 1,000, and I know that when I talk about frequent generalized tonic-clonic seizures as being the most important risk factor, or nocturnal seizures, there's all sorts of people who have nocturnal generalized convulsions who aren't dying of SUDEP, thankfully, but what is it about the person that dies of SUDEP that puts them at that extra risk? We're still working to find that out.
- Dr. Elizabeth Donner: 23:03 What we really need now are the identification of something called "biomarkers." A biomarker is like a clue, something about the person that's a clue that they're at higher risk. That could be something that you see on MRI, it could be something that you see on an EEG recording, it could be something about their seizures, or their genes. There are some possible SUDEP biomarkers that are being identified now. There's really amazing science going on looking at those issues. When we can identify who is at the most, most risk and use biomarkers to do that, I think we're going to be able to apply really strong preventative strategies and do proper experimental trials to figure out how to really prevent death.
- Kelly Cervantes: 23:52 I see biomarkers being something that a lot of researchers are focusing efforts on, whether it's SUDEP or just general epilepsy research and the importance of those biomarkers. Is there a connection between SUDEP and perhaps cardiac arrhythmias? Are we seeing any connection there? Is that a biomarker?
- Dr. Elizabeth Donner: 24:18 That's a good question. Kelly, remember off the top, we talked about how SUDEP is going to be mixed, it's heterogeneous, not all SUDEPs are going to be the same, and it's just really a category of death, right? There's some nice work that's been done in animal models and in some cell lines when researchers

just work with cells, looking at certain genetic mutations that predispose people to heart problems that also may predispose to epilepsy and increase the risk of sudden death, so that is a really big area of exploration right now. I think we will find over time that some SUDEP deaths are related to genetic cardiac arrhythmia genes that also predispose to epilepsy. It's actually a very exciting story on a very sad backdrop, so I temper my enthusiasm by the tragedy of SUDEP, but it's really exciting to see progress being made in that way.

Kelly Cervantes: 25:16

Absolutely, I-

Dr. Elizabeth Donner: 25:17

Kelly, I have to tell you, CURE has been the biggest mover and shaker in this field over decades that I'm aware of. All the research that we're talking about, CURE was there at the beginning, funding people like me and basic scientists. It's been unbelievable and so important.

Kelly Cervantes: 25:36

... Yeah, it is one of the things that I am so incredibly proud of to be a part of this organization because of how they have moved the ball forward and the amount of SUDEP research that is being done today because young investigators like yourself were funded 10, 15, 20 years ago.

Kelly Cervantes: 25:56

I do want to leave patients and caregivers with a bit of actionable hope to recap because this is a heavy subject and it is absolutely terrifying to think that this is a risk factor, that death is a risk factor, so just to recap and to give people hope, what are the things, what are the actions that they can take to limit risk to themselves and to their loved ones?

Dr. Elizabeth Donner: 26:27

You remember we talked about active epilepsy management, having as few seizures as possible, when possible, using a monitor overnight to monitor for seizures, that can be something as simple as a baby monitor, working with your healthcare provider to identify triggers when seizures are drug-resistant, looking into surgery or other kinds of treatments. If I can, I'm going to put one more little job on top of people living with epilepsy and their caregivers, which is to talk to their doctors about it because we've discussed lots about how there has been historically a reluctance for physicians to talk about SUDEP. I think it helps to move the ball forward when families show up in the office and say, "I know about this, I heard about this. I want to talk about what it is and what my risk is, or what my child's risk is, and what I can do to modify that risk."

Kelly Cervantes: 27:18

Absolutely. We are our best advocates, and the more information we have, the better we are able to take care of

ourselves and our loved ones. Dr. Donner, thank you so, so much, not just for talking with us today, but for being an epilepsy researcher, for being a neurologist, for fighting this fight alongside your patients. It means the world to our community, to the families, and to the patients to know that we have fighters by our side like you, so thank you so, so much.

Dr. Elizabeth Donner: 27:55

Thank you, Kelly. It really is an honor and I've enjoyed speaking with you today.

Kelly Cervantes: 28:02

Thank you, Dr. Donner, for sharing or knowledge and insights on SUDEP, and thank you for the work that you continue to do around this important area of epilepsy research. For those in the epilepsy community, SUDEP, or Sudden Unexpected Death in Epilepsy, has often been a difficult topic to address. While some healthcare professionals may not wish to bring alarm patients and their families by bringing up the topic of SUDEP, it's as necessary to discuss as it is difficult. Patients and their families can only make informed decisions about care and treatment options if they are given all of the information available. As Dr. Donner noted, CURE Epilepsy has been at the forefront of SUDEP research, and we are committed to continuing that research until we are able to fully understand and prevent SUDEP from ever occurring. We hope you will help us in this effort by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

Legal Disclaimer: 29:10

The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. The information contained herein is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.