

Seizing Life, episode 67
After SUDEP: A Journey of Grief and Hope
Guest: Geoff Applegate
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a bi-weekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:18 This week, I welcome Geoff Applegate to the podcast to discuss a difficult but important topic, the grieving process after the loss of a loved one. Geoff's fiancée, Zsatara, passed away in August of 2020 from sudden unexpected death in epilepsy, or SUDEP. Geoff is here to talk about how he and the couple's young son, Nathaniel, are coping with the loss, what has helped him move through the grieving process, and how he's honoring Zsatara's memory by telling her story and raising awareness of epilepsy and SUDEP. Geoff, thank you so much for joining us today. I want to start off by asking you about Zsatara. Tell us about your fiancé and how you guys met.
- Geoff Applegate: 01:03 So we actually met on an online dating app. We went out, started with texting and talking on the phone, and eventually met up. The first day we met, we were together for about four or five hours just talking. That connection was there, immediately. She was like no one else I had ever met. Right away, I don't talk this way, but the kind soul, you could just tell the kind person that she was. She was just such a positive person, someone that I needed in my life at that time, the perfect person for me. I say we complemented each other so well. We were very similar, but very different. I had been through some rough relationships. She had been through a couple. I didn't want to fully jump into one. Especially, I didn't want to jump and have move in with me. Within two months, she was living with me, and it was great. I'm so glad that we found each other, just by chance, on a dating app.
- Kelly Cervantes: 02:13 I love the way that you talked about her and your love for each other. At what point in your relationship did she tell you about her epilepsy?
- Geoff Applegate: 02:26 I guess the first few times we talked would have been when she told me. I would have been like, "Oh." I only knew seizures were when people shake, that's all I knew of them. So, I wouldn't say freaked out, maybe weird. I don't know, weirded out, freaked out, kind of the same answer, but I just remember being like, "Okay, that's something that stands out to me." I didn't really know how to react to it. I've never been around an epileptic person. I just didn't know how epilepsy works. I didn't know what triggers were and things, I was completely new to it.

Geoff Applegate: 03:02 I don't think I knew how to take it. I think over time she would talk to me about it, but I just remember initially kind of being like, "Oh, is this something..." Maybe even like, "Is this something I have to look out for? Is this maybe something that maybe would cause me to not want to date this person because of complications or things that could happen in the future?" Ultimately, it had no effect. We got to the relationship, but it was something that was on my mind a little bit, of just, "What's this mean for the future?"

Kelly Cervantes: 03:38 Yeah. I guess, how did she explain it to you? Did she teach you what to look out for when she had seizures?

Geoff Applegate: 03:47 Yeah. So, she told me what triggers her seizures, it was more reading than anything else. Again, the only thing I knew was people shake and people get them from watching Japanese videos, like anime and stuff, and lights, and all that. So, I remember asking about that and she said, "No, that doesn't do it for me. It's reading." So, she would explain the triggers and she would explain to me some things in the past, some of her seizures that were pretty bad and told me about them. She taught me the things I needed to do. I remember her showing me some seizures on YouTube and stuff, so she tried to educate me a lot on epilepsy.

Kelly Cervantes: 04:34 Did she ever talk to you about SUDEP, or do you know if that's something that she was even aware of?

Geoff Applegate: 04:40 For me, I never even knew what SUDEP was. Even after she died, I got a phone call and I talked to someone, and they said she died from a seizure. They said SUDEP and I was like, "What's that?" I had never heard of it. I had never heard of her talk of it. Do I think that she knew of it? We never talked about her dying, specifically, just from a seizure. I can't say for sure if she knew about SUDEP. I've been to some of her doctors' appointments with her and doctors never talked about it.

Geoff Applegate: 05:18 I can say that I know her biggest fear was what ended up happening, dying alone. Anytime I would leave, she would never say... It was a thing with her, "It's not goodbye, it's I love you." She would always say, "I love you," and if I said goodbye, "Oh no, I love you. I love you." So, I think that that also played into, if I leave and something happens, at least the last words were "I love you," which ended up really taking place. I can't say no, that she didn't know what it was, but we never had a discussion about it, and she never told me was afraid of dying, specifically just from a seizure.

Kelly Cervantes: 06:01 Geoff, I'd love to know how epilepsy affected your personal lives and her professional life, if it did. For starters, I know that you have a son together. What was that experience like, when she was pregnant and afterwards?

Geoff Applegate: 06:19 I wouldn't say it caused a lot of day-to-day stuff with us. If we wanted to do something, it wasn't a hinder in that way. After Nathaniel was born, I'd say her epilepsy caused fears, somewhat. I had a fear of... I work overnight. I used to work overnight, 10:00 at night to 6:00 in the morning, and it was an hour drive each way to work. So, I would have to leave an hour early, and then I work. I would always be afraid that she would maybe be holding the baby and have a seizure. Luckily, it never happened. She was a hairstylist, which was her dream, and she was good at it. She went to work every day and didn't let epilepsy stop in any way in life. She didn't let the epilepsy beat her on a daily basis. When it comes to epilepsy, yes, she may have passed because of SUDEP and a seizure, but she still beat it. She didn't let it beat her, mindset wise.

Brandon: 07:27 Hi, this is Brandon from CURE Epilepsy. Did you know that one in 26 Americans will develop epilepsy in their lifetime? For more than 20 years, CURE Epilepsy has funded cutting edge, patient-focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: 07:47 If you can, can you please tell us the circumstances around her passing?

Geoff Applegate: 07:53 Yeah. She had to work Saturday and Sunday. I had the weekend off and she wanted me to take my son to my parents in Boston. We lived in New Hampshire. Again, about an hour drive. So, I went and picked him up in the morning, she went to work. I'm coming in, she's leaving. "Okay, I'll see you later." "Okay, love you." She takes off to work. So, I was jumping in the shower, and she called back right away, five minutes after she left, and she was like, "You're still going to take him?" I said, "Yeah, I'm going to take him." She was like, "Okay. Well, when are you going to be home?", and she sounded sad. I said, "I'll be home Sunday, when you get out of work, so that way when you come home, we can just..." We were going to watch NeverEnding Story that Sunday night. I went to my parents and that night she never called when she got off work. Which was kind of strange, but I thought maybe she was just tired and fell asleep, so I didn't call her or anything.

Geoff Applegate: 08:51 The next morning, she also didn't call and I thought... She was late a lot, so I was like, "Okay, maybe she just woke up late.

She'll call me once she gets a chance." At about 9:30, I got a phone call from her work, and they were asking me, "Hey, have you seen Zsatara?" I said, "No, I'm not home. I'm at Boston." So, when I called her, it went straight to voicemail. So, I was like, "Oh, she never woke up because her battery died overnight. That's what it is, simple as that." Her boss was also her best friend, they did a wellness check. So, I ended up calling the police too, just to check in with them, and they said, "Okay, we're trying to get in the house. Is there another way in?" I said, "Yeah, head around the back. It's usually unlocked," and they said, "Okay, we'll call you back."

Geoff Applegate: 09:36 So I'm expecting a call back, and then about 20 minutes passed. Within that 20 minutes, I'm sitting there going, "Oh, it's going to be more than oversleeping." I did mention to the police that she was epileptic, that it's possible she had a seizure, but I didn't think. So about 20 minutes passed, and they called back and said, "Yeah, we got in the house, and she was in the bathroom." I said, "Oh, good. Good, good." Then that's when they said she was deceased. Immediately, the only thing I could think of was a seizure, but I still didn't think that a seizure is what killed her. I thought maybe she fell and hit her head or something. So, the medical examiner, later that day, called me. Of course, I had to ask, "Had I been there, would I have been able to save her or anything?" They said, "No, when the seizure happened is when she died." The first thing I did was look at my son, thinking, "Oh, man. How am I going to tell this little boy he's never going to see his mother again?"

Kelly Cervantes: 10:38 Thank you so much for sharing that with us, and I'm so sorry for you, and your son, and Zsatara's family's loss. It's not fair, and it sucks. You mentioned your son, and how you looked at him and you weren't sure how to tell him. I've sort of been in a similar situation, except instead of my son's mother, it was his sister. How did you share that news with him? How old was he at the time? How did you walk through that with your son?

Geoff Applegate: 11:21 He just turned five Saturday, May 1st. So, he was four, a little over four and a half at the time. He had no concept of death. When I told him, it kind of was like... My parents were there and Zsatara's mother was there, and I wanted to do it as a family. She passed on a Sunday, we waited until Thursday. I told him, "Mummy is here in your heart. She's right here. Anytime you put your hand here and you feel it, that's mummy." I didn't want to go the heaven route because he wasn't going to understand it completely. Plus, something I've learned, you spend so much time, "What am I going to tell him? What am I going to tell him?", and, for my son, anyway, he was four. He

had no concept of it. It really didn't matter what you're telling him because 20 seconds later, "Where's the Ghostbusters?", or whatever toy he wants to play with. It's just not going to sit with him, but it actually did because he still feels [inaudible 00:12:35], "Mummy's here, mummy's here."

- Geoff Applegate: 12:37 So it didn't stick with him at that time, but long-term, it has. He's now since learned about heaven. When the time was right, we taught him about heaven and Jesus. He asks about her a lot, especially this weekend. Last weekend was his birthday, this weekend was Mother's Day, and the day before that was my father's birthday. You could just sense he was off. He knew something, "Everyone's here but not mummy." He does ask her about her a lot, and I just let him think whatever he wants. I try not force her down his throat, not everything has to be, "Mummy, mummy," but I definitely do talk about her a lot and try to keep her memory alive. I think there's a line, and there can be unhealthy and healthy. I try not to be obsessive and unhealthy. I feel like I've done a pretty decent job, not in a braggadocios way.
- Kelly Cervantes: 13:41 I think you're doing a wonderful job. I think you are doing an... You were tasked with an unimaginable conversation and it's not just one conversation, right? It's all of the follow-up questions. I just have to say, I think you're doing an amazing, amazing job.
- Geoff Applegate: 14:05 Thank you.
- Kelly Cervantes: 14:05 As you went through the weeks and months following, I know you said that it took you some time to adjust. I'm sure you were in shock, in many ways. Are there certain things that people did or said that helped you in your grieving journey more than others? Also, I know that this is still actually quite fresh, you're not even one year into your grief journey yet, but what are the things that people have said that were truly helpful?
- Geoff Applegate: 14:38 So I have a couple people that I talk to. I tend to get aggravated with the, not towards anyone, but when someone says like, "Well, at least she's not in pain now." I don't want to hear the same stuff. I do like when someone just is honest and says, "I don't know what to say." The Epilepsy Foundation of New England reached out to me, and they hooked me up with another gentleman, Matt, who, his fiancé, same situation. I believe it was about four months before their wedding she passed from SUDEP. So, it was someone that, kind of like an AA sponsor, he kind of was the person I could go to for questions. We still talk. That's been a person, and I just recently met

another woman, Donna, who her daughter passed to a seizure-related thing.

Geoff Applegate: 15:30 This is another thing, too, is SUDEP is a big thing, but there's other ways people die, too. They have a seizure when they're driving a car or falling into a pool and drowning. So, there's other things, but it's just nice to meet these people. In a way, it's almost like, "Here I am," I feel like... I have all this support with my family, very big family, but they don't exactly know what to say. Here, I have these strangers, who I've never met, that I can talk to. Even if they've died through, for example, Donna, her daughter died. Seizure-related, but not SUDEP, we can still talk and be like, "Wow, there's still so many similarities," even though it's a similar way of dying, but still different. It's nice to have that. I've changed as a person, just the way I think, and I think it's due to certain people that I talk to.

Geoff Applegate: 16:24 I was a very closed person and started to be very... Especially on Facebook, we were closed about our relationship. We didn't go on Facebook and type the "I love you" and all that, we just kept it quiet on Facebook. I became more open on Facebook because I wanted people to see what I was going through. I was getting messages from people from 5th grade and stuff, "I'm thinking about you and your son every day." It's something that motivated me to be better, be a better me. I'm thankful to anyone that's taking a moment to think about me and my son, or Zsatara. You just got to feel the love.

Kelly Cervantes: 17:03 You hit on some incredibly important points there, specifically finding your community and how much that can really help you heal, and that the comments do help, right? That they hit you in a certain way, that love and support, you do feel it and it really does get you through. You commented about sharing on Facebook, and how you are now sharing a lot more, both the grief and about the epilepsy. What motivated you to begin sharing so publicly?

Geoff Applegate: 17:40 I wanted people to see that, "Hey, he's doing okay." Worry about me, feel sad for Nathaniel, you don't have to "worry" worry about me, but this is what I'm going through, this is what I'm doing. Somewhere along the line I felt like, hey, I didn't really have anyone that I could look at as, "This is what he did," or, "This is what she did." So, I felt like I'm not going to document everything on Facebook, but I'm going to document some things, or say this, or take pictures of this or that, and let people see things like, "Okay. Every situation is going to be different, but Geoff did this. Maybe this could work for me."

Everything I've done since Zsatara has passed has been a trial. Some things work, some things don't.

Geoff Applegate: 18:33 For example, me and Nathaniel, we didn't talk about Zsatara for about a month after the funeral and everything. I kept it quiet because I just wasn't sure how to handle it. Then about a month in, I noticed a little bit of an attitude change. Then at bedtime... We did do kissing her picture at bed every night, but we didn't talk about it. I noticed about a month in, I started showing him videos and pictures and stuff, and it changed him. Everything is adapting and learning as you go, every situation is different.

Geoff Applegate: 19:06 I feel like there's no book that I could read that's going to help me. I'm going to do what I'm going to do, what I feel is right. Right or wrong, I'm going to do it. I'll take advice from people, but I just think that you know yourself and your children, in my case, your son, better, and you just do what you think is right. Most of the time, it's probably going to be right. You're going to suffer some setbacks. I've done some things that I know, I'm like, "Okay, this didn't work. I've got to not do this anymore," but just go with your gut and what you feel is right.

Kelly Cervantes: 19:45 Geoff, I connect with so much of what you just said, and I really think it is going to help so many people who are listening today. I just want to wish you and Nathaniel so much love and gentleness, as you navigate this grief journey. We are so fortunate to have you as a part of our community. I know that this is not a club that you ever wished to be a part of, but we are just so grateful. Thank you for sharing your story with us today, and please know that we truly wish you all the best.

Geoff Applegate: 20:25 Thank you. Thanks for having me.

Kelly Cervantes: 20:25 Thank you, Geoff, for sharing such a personal and difficult story, and thank you for speaking up to raise awareness of epilepsy and SUDEP. This is not the first time we've talked about SUDEP on the podcast. It's a difficult topic to discuss, and we know it's probably uncomfortable for many of our listeners to hear. However, we in the epilepsy community need to be willing to have uncomfortable conversations because those conversations will raise the questions that need to be answered, and the answers will come through research. As the leading non-governmental agency committed to funding epilepsy research, we ask you to help us find those answers by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

Brandon:

21:23

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