

Seizing Life, episode 111
Sharing Epilepsy Diagnosis After Decades Leads to Climbing for Research
Guest: Carmen Zannier
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.

Today on Seizing Life, Carmen Zannier joins us to share her 34-year epilepsy journey and discuss her passion for mountain climbing, how she manages her health with this challenging hobby, and how climbing has inspired her to be public about her diagnosis and raise funds for epilepsy research with CURE Epilepsy strategic partner Epilepsy Canada. Carmen, thank you so much for joining us today. To kick things off, let's just get a bit of history. Tell us about how epilepsy first entered your life.

Carmen Zannier: For sure. Thanks. So I was about 10 years old and the first time I had a seizure, I was getting ready for a friend to come over to study. We were going to study social studies together. This was a big deal because I wasn't really allowed to study with friends at the time. My parents were teachers and so they're very like, study time is study time and friend time is friend time. So anyways, I was hanging out in the front foyer at my parents' house and my friend was coming up the steps and that's when I first had my first seizure. It was only in my head, it was not an outward facing seizure and it felt a lot, like I was floating. It was very much like an out of body experience, like I was floating up towards the ceiling further and further away. So it was a very strange feeling. I had never felt anything like that before.

Kelly Cervantes: I've heard of people having seizures like that where they have experience like that, but I don't think I've ever actually spoken to someone who has had these out of body seizure experiences and I can't even imagine how disorienting and especially, I mean, at any age, but particularly as a child, how scary that must have been. What was your reaction when it was over, and did you tell your parents about it?

Carmen Zannier: Yeah, I definitely did tell them because it was scary, your heart races and it was just so unlike anything I'd ever experienced before. So that night, I told them in a way that was more inquisitive than anything. I'm sure I was tired afterwards because that's typically what would happen, but I don't remember in that first instance if I was tired. I just remember being kind of weirded out I had never experienced anything like that. And so I told them, and that probably got them a little bit more on alert because it wasn't anything that they had heard of before either.

Kelly Cervantes: Now, a few weeks after that first out of body seizure, I understand that you had a more visible seizure. Tell us about that.

Carmen Zannier: Yeah. It was in March and we were coming home from March break, so we were driving back from Florida and I had like an outward facing of totally visible seizure in the back seat of the car. And so, had a seatbelt on and everything was

fine. From the driving perspective, I wasn't driving, I was too young. But yeah, my sister would've been sitting next to me and quite frightening for them. So we got home and got to a doctors and then ultimately to a neurologist, and that's where everything fell out from there, getting treatment.

Kelly Cervantes: Yeah. So it sounds like your diagnostic journey to an epilepsy diagnosis seems like it was actually relatively smooth, which is pretty fortunate.

Carmen Zannier: Yeah. I think I was lucky, the gap between that first time and my friend coming over to study and having that experience, and then the first outward seizure was small. I don't remember the exact amount of time, but it wasn't significant. And then I did have more outward facing seizures for a period of maybe about six weeks I think it was. We got them under control relatively quickly, so that was fortunate, I consider myself lucky. I know that that is not the experience that a lot of people have. I went in the rest of that school year until June was rocky, but I was fortunate to be able to get things as under control as they could be.

Kelly Cervantes: So you're taking this medication, the more outward facing seizures are being controlled by the medication, but you were still having the out of body seizures. Were you having them during school? How was that affecting your school here and your social life?

Carmen Zannier: Yeah. So I think in my experience, I was in a position where a lot of what I would experience, I could hide from people. And I think that it was a blessing and a curse because I would deal with it by myself and I didn't know really how to deal with it. So when I was left tired, suddenly I was very, very tired, it was sort of on me to manage. So I think socially, I've had highs and lows as I've been managing the need for sleep and the need for balance in my life. And if it was came down to studying, I know that I always had to have a very focused environment for studying, and I always had to do a lot to for memory work, so take a lot of notes. There were just extra things that I would put in place and learn to put in place over the course of the years to manage what I was keeping from everybody else.

Kelly Cervantes: So did you tell your teachers or your friends about your diagnosis?

Carmen Zannier: In the early years, yes. Over time, I stopped. I think over time you learn the goods and the bads of disclosing, and so I also would dig my heels in more that I could handle it myself. And so, over time I told fewer and fewer people.

Kelly Cervantes: Can you talk about memory issues all of these things that I think a lot of people with epilepsy struggle with, be it from the seizures or the side effects from the medications? Did you have any sort of IEP or accommodations throughout school or college?

Carmen Zannier: So I did not. So this was in the '90s and I think there were probably different programs by different names at the time, but I did not. After the first diagnosis, I had a really supportive teacher and a supportive set of friends to get me to the end of that school year, so March till June. I still think back to a couple of things that some friends did, and they probably don't know what an impact they made. And that teacher that I had was very supportive. I know he was on the phone with my parents at the time, talking to them about how I was doing and getting me to the end of the school year successfully.

So I think the school system was strong for me with the programs that existed. And this would've been late '80s, early '90s. And then throughout high school, it was more a matter of taking the time that I needed to study and I probably wasn't the most popular person, I probably had to go home and get some sleep and study a little bit more or go home and get some sleep to just enjoy the social time that I did have a little bit more than other people. So I still had a friend network, but it was probably smaller than it might have otherwise been.

Kelly Cervantes: And as you left school and moved into the professional world, how did your epilepsy affect you then, did you let your employers know?

Carmen Zannier: Yes. At times, I did, and at times, I didn't. I think, again, I was fortunate I was in a position where I didn't necessarily have to disclose because I wasn't in a spot where I was still having outward facing seizures that were out of my control. And I think that I was lucky to be in that position. I did in some scenarios choose to disclose because I wanted to do right by the people around me. And I remember one time actually disclosing to my boss, very nice man, I liked him and I remember leaving and thinking, I'm not sure what I achieved there. And I think if I had to do that moment over again, I think I would disclose, but I would also ask for some sort of provisions in return, not necessarily of him, but of the larger system.

When people are disclosing, they're sharing I think a big part of themselves, and they're doing it with the hope that if there's an emergency, everybody can be as empowered and as set up for success for that emergency as they can be. So I think if I had to do that moment over again, I would say, "Hey, let's get some first aid training in. Let's get some education going." I'm not an expert at all in the area of disclosure, and I think there's probably a lot of legal components there that I don't know anything about, but to me, there needs to be a trade-off there if people are disclosing that there's also provisions for supporting them. And I think first aid training is useful for so many things beyond only like epilepsy for sure, and then so many other scenarios too.

Kelly Cervantes: Yeah, I think that that's incredible advice for anyone who is facing a moment of disclosure.

Brandon: Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over \$90 million to fund more than 280 epilepsy research grants in 17 countries.

Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.

Kelly Cervantes: I'm just personally curious, you talk about the difference between the outward facing and the more internal seizures. What would someone see when they were looking at you when you were having those more out of body seizures or the internal seizures? What might someone notice, is it more like an absence seizure where you're just sort of staring off into space?

Carmen Zannier: No. So no one's ever noticed them. My dad caught it once, so he would be the closest expert anyone's ever had for living with me with these things. And he caught it once in all of these years because my eyes changed a little bit and he saw me just get tired right in front of him. But nobody else ever saw any of them. And I can carry on a conversation during them. So I remember math class in grade school going on and just feeling like I was up in the ceilings while we were doing fractions, which is a very weird experience. So I don't think about fractions ever without thinking about being in the ceiling of a math class. So it was parallel universes kind of thing.

Kelly Cervantes: Epilepsy is so wild.

Carmen Zannier: Yeah.

Kelly Cervantes: Just like it's bonkers. Carmen, I wonder, you mentioned earlier that you told fewer and fewer people about your diagnosis as time went on. Was that because of stigma you experienced or stigma you were afraid that you would experience?

Carmen Zannier: Yeah. I think it's a little bit of both, and I think it's also about what we internalize. So I think there's definitely stigma attached to epilepsy, and I think there's that coming from the outside world and having to, whatever, fields, the jokes or just deal with having had a seizure in public and people telling you about what happened after it happened. So I think there's a stigma of epilepsy from the outside world, but I think also part of my struggle was my own internal understanding of what it meant for me, how it changed my world, so did it change who I was, and did it change what I was capable of?

And so I think I struggled a lot with that second set of questions. And the first set, the external factors and worrying about the stigma from the outside world, that's for sure a thing, we need to work on that through education, and we need to fight that and train people and educate and have systems in place to better support people. But I think also that second set of questions was what was really key for me, how did it change who I was, and did it change what I was capable of? And I think I spent a lot of time on those questions over the years. A lot of time, because it's been about three decades just over.

Kelly Cervantes: Which sort of perfectly leads me into my next question. What eventually made you decide to become public with your diagnosis?

Carmen Zannier: I think, to be honest, I think I just got old. So I wish that I could-

Kelly Cervantes: I love that answer so very much. It's just so honest. I'm like, at some point we just stop caring what other people think, that barrier just starts to come down and we settle into ourselves. And I think there's so much honesty in that, but please go on.

Carmen Zannier: Yes, it's true. I had just turned 40 and it was a casual comment from my dad because I said something about being tired and he was like, "Well, don't forget, you need the extra sleep." My mom had passed away a few months before, so you think your life tweaks then too. And so suddenly I was just like, "What am I doing?" I'm having the same argument with myself for over 30 years for, at that point it was like 30 and just a bit, it's been about 34 since. And I think I was just done arguing with myself. And so yeah, it was time to start doing something to help the wider program and the wider need for more research, more funding a cure for epilepsy.

Kelly Cervantes: And you decided to do that in a big way, which I want to get to. You had been taken up climbing, which is just dangerous, especially if you're like, I don't know, having active seizures. I'm trying to wrap my head around this. Explain how you first got involved in climbing.

Carmen Zannier: Yeah. I'm originally from Ontario and I moved to Alberta, Canada where the Canadian Rockies are. And I lived in Calgary for 10 years. And there's just a great social network, great way to meet people is to go out on day hikes. There's a lot of different small groups and communities that do that where you can meet new people. And I didn't know much about hiking, and I got into it through the University of Calgary's Outdoor Program Center, a fantastic program that I believe is still 15 or so years later is still running strong.

And hiking just sort of grew and evolved. It went from doing a single simple day hike up to multi-day trips, really around the world. And it just feels so good to be out walking in the mountains. There's nothing that feels better than that to me. And as my skills developed, I started to take on more and more mountains. There's one mountain called Big Sister as you're driving from Calgary to Banff, and that was probably a pivot point for me. It's a bit of a scramble, it's a bit of a harder one, and I felt good doing it. And I think at that point, I knew I was onto something. From a hobby perspective, it was developing into more.

Kelly Cervantes: And are there any sort of security or safety precautions that you take above and beyond what the average person might do?

Carmen Zannier: From a gear perspective, there is not. So it's critical that I am just staying balanced and staying healthy when I am doing these trips. And as those became

multi-day trips, the lead up to the trip, I am really careful with just lifestyle stuff. So getting lots of sleep and staying balanced on any kind of food and drink intake. And then when I'm on a trip, if it's a multi-day trip, I'm the first one to go to bed, and I do stay just really well-organized to keep everything the stress down. So I make sure that when I'm packing, everything is exceptionally well-organized, and I think there's an element of not adding stress to an already high stress environment. But mostly I just go to bed early a lot.

Kelly Cervantes: I think that's good advice for all of us at some point.

Carmen Zannier: Yeah.

Kelly Cervantes: We're all much safer when we're well-rested.

Carmen Zannier: We're well-rested. Yes.

Kelly Cervantes: Now, tell us about your most recent climb to Mount Vinson, and how you decided to raise money for Epilepsy Canada through that climb.

Carmen Zannier: Yeah. So I wanted to go big, I guess, after 30 years of not talking about something, it's time to get loud. So I climbed down Vinson with a company based out of Colorado Mountain Professionals, they're wonderful organization. And I had gone with them on past trips, and so I emailed them to see if I was skilled enough for Mount Vinson. And the answer came back yes, which was wonderful. And I emailed Epilepsy Canada, and I just said, "Hey, I'm going to do this. How about we put some branding on it for epilepsy and see what we can do to make the most of it for finding a cure for epilepsy?" Epilepsy Canada in particular, what I liked about them is that their mandate is to find a cure, so research for a cure, and I think support programs are absolutely critical. But after 30 years, I wanted to be big, I'm like, "Let's find a cure for this. Let's get some money and let's do a really awesome location and crazy mountain." So it became Mount Vinson.

Kelly Cervantes: And for the folks who don't know where Mount Vinson is, can you share where it is exactly?

Carmen Zannier: Sure. Story. Yes. Mount Vinson is on Antarctica. It is the highest mountain on Antarctica. So we flew from Chile to Union Glacier Camp, Union Glacier Station on Antarctica, and then flew inland from there to base camp, and then you hiked from base camp to ultimately the summit. It was incredible. Antarctica is gorgeous, we should absolutely protect it. And the climb itself was stunning because there's sun a lot. And then as soon as the sun goes away, of course, very cold. It was like extreme temperatures. And the sun's out, it's beautiful, and then it goes behind the mountain because it doesn't ever go down at this time of year, but it goes behind the mountain, it gets cold quick.

Kelly Cervantes: Was there anything in particular that you had to do differently for this particular climb than you had done for previous climbs?

Carmen Zannier: I had to pee into a pee bottle for the first time ever.

Kelly Cervantes: Oh, lovely.

Carmen Zannier: So I used the Shewee for the first time. So I think guys have done this no problem. But I had never done it for climbing before, and that was definitely a new experience, but I don't know if that's what you meant. Mostly it's a lot of self-care because anything that happens down there is sort of 10 times worse because there's just very little support system. And so you don't want to get too sweaty when you're walking because then you'll get wet, and that really matters. If you were hiking in Kilimanjaro and you're sweating a lot, you're probably going to dry out pretty quick because it's pretty warm there, and that's not the case for Antarctica. So you want to be really careful with your body temperature control. You want to be really careful with your eyewear because it's exceptionally bright and that can damage your eyes. We put on sunscreen at every single stop, so there was a lot of elements of self-care to prevent any injuries from happening. You don't want to get to frostbite for any reason at all.

Kelly Cervantes: Wow. That is absolutely incredible. And I'm sure just like this amazing once in a lifetime experience, and then how incredible that you got to do that and raise money for epilepsy research. How much money did you end up raising?

Carmen Zannier: We raised \$26,000 Canadian.

Kelly Cervantes: That's incredible.

Carmen Zannier: Yeah. I start crying every time I say it. I can't believe it. People were so supportive and I'm so grateful for it. We started out and I had no idea where we would land. I just had no idea. And I was blown away by the support from everybody, my family and friends, and also just strangers. I got notes from complete strangers that talked about their experiences with epilepsy, and it was just wonderful, I just so much appreciate it.

Kelly Cervantes: It's an amazing thing to raise that money, it's an amazing thing, obviously, to do the climb, but perhaps the biggest piece of it is that it was the first time that you shared your story publicly. And so I can only imagine all of the emotion tied into that. So now that you have gone public with your story, what does the future hold for you for climbing and fundraising?

Carmen Zannier: I would like to keep going. I would like to climb more and raise more. I had climbed different mountains before, but the combination on this one was just undeniably fulfilling. And so, I just want to keep going with that. I'm doing very, very early thinking and early planning about what might come next, but I just want to keep going down this path. It's been really rewarding.

Kelly Cervantes: And to that end, I wonder, you didn't share your story for 30 years, and now that you have, how are you feeling about having it be public, having it out there? How does it make you feel?

Carmen Zannier: It's like a cliché, it's just really freeing or liberating. I feel like a cliché because I definitely was a cynic and definitely was closed off in the past. And so, it's as empowering and freeing as they talk about of being when you just hit acceptance and you're just like, "Yep, this is it. I have this disease and I manage it, and now I move forward from there." I wish I had gotten there faster for sure. I don't recommend the path that I took to anyone because it is just as liberating as everybody always describes these sorts of things to be. There's fear. Sure. I think there always will be an apprehension, but the benefits outweigh that.

Kelly Cervantes: Yeah. I mean, I can imagine the stress when you talk about stress being one of your big seizure triggers, and that becoming public kind of probably relieved some of that stress of that weight that you're carrying around of having this secret of sorts.

Carmen Zannier: Yeah. Because you just end up having to be confident about it and confident about who you are and just say, "Yes, this is me, and I am still capable of these things." And so yeah, the stress is gone because it feels physically lighter, for sure.

Kelly Cervantes: So in a way, being public with your epilepsy diagnosis has helped your epilepsy in some ways.

Carmen Zannier: Yes, I think it has. And I think that's the part where cynical me for freaking 30 years. Oh, sorry. Yeah, it wasn't the way to go, it really wasn't. It has helped me continue to manage it better and continue to be okay with saying, "Okay, these are the things that I need to get through the day."

Kelly Cervantes: Well, and I wonder how did your friends and your coworkers respond when they learned about it.

Carmen Zannier: Everybody has been very supportive, and no one's been super direct trying to make you answer a thousand hard questions on the spot. Everyone's just been supportive and lots of support on social media and lots of support in-person. And I think the landscape's changed too, there is more support for these things and for being truly authentic in society in general, and that's a good thing. We need to be talking about all aspects of epilepsy, all aspects that a person needs support in.

Kelly Cervantes: Yeah, 100%. And I think there's something to be said about that in how times have changed and progressed. And part of that is the double-edged sword of social media, whereas, I mean, first of all, you were a teenager, but in the '90s or then even in the early 2000s before social media really exploded, there wasn't an accessible global platform for people to share this sort of information.

And so it was very isolating, you didn't understand how many people there were who also had epilepsy. So I think that the times allow for more empathy and for more understanding and more connection. So I wouldn't beat yourself up too bad for not disclosing this in 1999, there's just not enough information out there. It is so much easier to share our stories now because we know we're not alone.

Carmen Zannier: Yep. That's a great point. That's a great point because the people that reached out through different forms that were strangers, it just landed so well, I appreciated it so much. And that never would've happened in the late '90s before those connections existed.

Kelly Cervantes: So what would you like the public to know now about epilepsy that you think is misunderstood or not understood at all?

Carmen Zannier: I think I'd like people to understand that there's a whole person that needs healing, not just a seizure. I think there's the before and after the seizure that's critical, there's during the seizure that it's an exceptionally violent experience for anyone to live. And we have to manage that, we have to treat it, but I think we need people to understand that healing epilepsy is really about healing a whole person. The things that happen in the weeks after a seizure, anything tied to mental health and just the balance that a person needs in order to ward off any triggers that they have. So I would say we have to heal the whole person, not just the seizure.

Kelly Cervantes: Yeah, 100%. I think that's something that we hear over and over again from the people who are diagnosed with epilepsy themselves and from caregivers, that the diagnosis isn't just the seizures, it's the time in between the seizures too, the anticipating the seizures and the recovering from them and all of the ways that it affects the life. And I think we can get really focused on the seizures themselves, but there is so much more as you said so well. I just want to thank you so much for sharing your story, having the bravery to do that, for raising awareness through these incredible climbs that you do, which is just absolutely wild and amazing, and raising money for epilepsy research and for understanding and valuing the important of that research plays in all of this. And so, I just think that you're incredible, and I think that I could probably talk to you all day, but-

Carmen Zannier: Thank you.

Kelly Cervantes: ... I won't, promise I'm going to let you go. Carmen, thank you, thank you, thank you. You have been an absolute delight.

Carmen Zannier: Thank you very much. I really appreciate the opportunity and the platform to share. So thank you so much for everything that you're doing.

Kelly Cervantes: Thank you, Carmen, for sharing your story with us and for raising awareness and funds for epilepsy research. We wish you the best of luck on your future climbs. CURE Epilepsy has been dedicated to funding epilepsy research for 25 years. In that time, we have raised more than \$90 million to support over 280 research projects in 17 countries. This investment in research has resulted in numerous discoveries and advances that are bringing us closer to our ultimate goal, a cure for epilepsy. You can help us achieve that goal by visiting cureepilepsy.org/donate. CURE Epilepsy, inspiring hope and delivering impact. Thank you.

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