

Seizing Life, episode 68
Living and Thriving with Epilepsy
Guest: Jon Sadler
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy.
- Kelly Cervantes: 00:18 Today, I'm happy to welcome counselor and author Jon Sadler to the podcast. Jon has lived with epilepsy for more than 50 years since his first seizure at the age of four. After decades of living with seizures and medications, Jon underwent brain surgery in his mid-forties. That surgery ultimately set him on a new career path to becoming a licensed professional counselor.
- Kelly Cervantes: 00:40 Today he mentors and counsels both epilepsy patients and caregivers. Jon is also the author of several books on epilepsy. He is here today to discuss his experiences and share his unique perspective as both an epilepsy patient and a counselor to fellow patients and caregivers.
- Kelly Cervantes: 00:57 Jon, thank you so much for joining us today. Let's begin with your personal story. Tell us how epilepsy first entered your life?
- Jon Sadler: 01:07 It was in 1963. I was four years old and had a very high fever. The fever came down during the night so my parents weren't aware that I was even sick when I went to bed. Early in the next morning, my mother had gone grocery shopping and my older sister, I'm the youngest of four, one of my sisters came in to check on me and she saw me in a kneeling position. She knew something was wrong.
- Jon Sadler: 01:37 Of course, she went and got a thermometer to check my temperature. She slid it into my mouth, and being in a seizure, I just broke it off, and the mercury, fortunately, came out of my mouth along with all the glass because of the position I was in. When my mother got home, this was back before cell phones and all that, my sister told her what happened and my mother grabbed me and took me off to the hospital.
- Jon Sadler: 02:05 I was in a seizure for about six to eight hours.
- Kelly Cervantes: 02:08 Oh, my gosh.
- Jon Sadler: 02:11 My parents were told that the doctors didn't know what I would be like when I came out of it. My mother was really excited that, when I woke up and looked at her, the first thing I said to her was, "Mommy, I'm hungry."

Jon Sadler: 02:27 She just lept out of her chair. She just was so excited that I responded that way.

Kelly Cervantes: 02:33 I imagine. Knowing what we know about seizures now, to have been in a seizure for six to eight hours, was there brain damage that they suspected? You woke up and you started talking, that's remarkable.

Jon Sadler: 02:50 They thought there would be some significant damage. As we know today, sometimes children can have seizures from just having a fever, but it's not epilepsy. However, for me at the time, they took me to another hospital and did an EEG, and they saw that there was something out of sync, and they said, "Okay, we've got to treat this as epilepsy." They put me on Phenobarbital.

Kelly Cervantes: 03:14 You're diagnosed with epilepsy, then at the age of four, what was the rest of your journey like? They start you on Phenobarbital. Were you able to get control of your seizures during childhood?

Jon Sadler: 03:26 Actually, we did. Basically, they put me on phenobarbital, and my siblings called me the little old man, because I was slow to respond to questions or to discussions. My personality was wiped out. I wasn't the vibrant running around little kid anymore. For four years, I always kept on phenobarbital.

Jon Sadler: 03:51 After that, the doctor said, "Look, he hasn't had any more seizures. It was what they considered seizures; they took me off of it. I actually went about nine years without losing consciousness again. I went to college. I did grade school and everything, go off to college, got on a sailing team, was in a horrific boat accident, and knocked unconscious for a while.

Jon Sadler: 04:17 Back in 1978, we didn't treat any... Concussions weren't that big a deal. The person still talked and walked and all that. They were fine. They didn't do any treatment or anything for me, and a few weeks later I started having more déjà vu and auras. They didn't know what it was or anything, and a year later I had a grand mal seizure while taking an exam.

Jon Sadler: 04:41 When everything changed, now it was back. I go back to see the neurologist, and basically the neurologist said, "Well, it's a freak thing. Don't worry about it. I'm putting you on Dilantin.

Kelly Cervantes: 04:51 Even though you had a history of seizures?

Jon Sadler: 04:54 Even though I had childhood history, they said, "Don't worry about it," and six months later I was in another classroom, and I looked at the student sit next to me, and I said "Goodbye," because I felt the aura coming on, and I woke up in the infirmary again, like I did the first time.

Jon Sadler: 05:12 The second time, I saw a really good neurologist who said, "Look, you have epilepsy. That's what you have. You're going to be on medication the rest of your life. This is what you have to do to take the medication. If you don't take it, you're going to have more seizures." That was an eye opener for me, and really hard to deal with, because I lost my license, I had to sell my car, all kinds of things went on. I was pretty depressed about it all.

Kelly Cervantes: 05:40 I want to ask you about that. You are in your early twenties, young adult, making your way in the world, and all of a sudden you have this resurgence and this responsibility of your epilepsy. What were those social ramifications? Did you experience or feel stigma at that point?

Jon Sadler: 06:03 Oh yes, big time. One of the things my dad told me was, he said, "Never tell anyone you have epilepsy."

Kelly Cervantes: 06:10 Uh. Why do you think he gave you that advice?

Jon Sadler: 06:15 Because in his generation, and even in that whole timeframe, if employers found out you had epilepsy, you lost your job.

Jon Sadler: 06:25 Anyway, I was pretty much kept quiet about it and took my medications, followed what the doctors told me, got sleep, ate regularly, stayed hydrated, just basically followed rules. We had my seizures pretty much under control.

Jon Sadler: 06:43 In the meantime, I got a job working for the Navy, and getting through the physical was the most difficult part because the doctor there told me that I was a freak, and I would never be allowed to do anything more than sharpen pencils.

Kelly Cervantes: 06:56 That brings tears to my eyes.

Jon Sadler: 06:58 That's the stigma. You wonder why I would keep quiet about it for... I never mentioned it to people unless I had to.

Kelly Cervantes: 07:05 I'm so sorry that you experienced that.

Jon Sadler: 07:10 What happened in the same day was I met my supervisor and I told him, "Look, I'm leaving. I'm not working here because this is

what the doctor told me." He said, "Well, the doctor can set one set of rules, but I'm your supervisor, and I'm going to set another set of rules. I want you to meet Mark."

- Jon Sadler: 07:27 Mark was another employer of his, who also had epilepsy. Mark pulled me out of a really dark time in my life. There were times that I thought of suicide. There were times I was just like... The stigma that I was carrying was too much. Meeting Mark was like, "Wow, okay. I've got someone who can associate with me, and help me out with medications, and finding doctors, and making sure we cover each other." It took a whole lot of stress off, and stress being a key trigger to seizures was a big help.
- Kelly Cervantes: 08:03 Having a community can be everything, and having someone to relate to. I want to come back to that a little bit later in your story.
- Brandon: 08:15 Hi, this is Brandon from Cure Epilepsy. Did you know that 1 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: 08:35 In your forties, you decided to undergo brain surgery. It's a big decision to undergo, as an adult. It's a big decision to do regardless, but especially as an adult, when you're established.
- Jon Sadler: 08:55 Not only established, but I had two sons. I was married, had two boys, and they actually helped me make that decision. They didn't want me to have the surgery. There were times, like my oldest at the age of two, recognized my seizures. Some of his first words were "Uh-oh, daddy," when I clap my hands trying to kill a fly, because in my partial seizures, I would do this. Those were some of his first words. That was like, whoa.
- Jon Sadler: 09:27 Then another time when he was older, he was about 13, I was driving him back from a scout camp, and had a seizure while driving. When I came out of the seizure, I was so happy I had my foot on the brake. Then as my peripheral vision came back, I realized it wasn't my foot, it was his.
- Kelly Cervantes: 09:49 Oh my gosh.
- Jon Sadler: 09:50 Had we gone another hundred feet, we would have plowed into some trees and stuff at the end of the road. He had no seatbelt on. I was like, "Wow, I really have to take care... I was taking care of myself as best I could. My neurologist worked with me,

they helped me out. Some new medications were coming along out of a breakthrough seizure. He put me on Dilantin plus another medication.

- Jon Sadler: 10:17 Finally, the doctor said, "We're out of medications." My doctor finally said, "You need to go to Jons Hopkins," so I went over to Jons Hopkins and my internal medicine doctor had me have an MRI of my head. The first day, I walked in and showed it to the doctor there, Dr. Kraus looked at and said, "There's the location. We know where your seizures are coming from."
- Kelly Cervantes: 10:43 That must've been a bittersweet moment, because here you know that you are eligible for surgery, but that also means, oh my gosh, you're eligible for surgery.
- Jon Sadler: 10:54 Right. He gave me a whole list of ways we could treat it, and got more medications, and all that. I was like, "No, let's head toward surgery."
- Jon Sadler: 11:04 The big question then was what was the surgery going to do to me? They said, "Look, it's so much damage in that part of your brain, we don't think you need to worry about it." I had the surgery done, and the day after Dr. Kraus came into my room and he said, "Jon, what's a hundred minus seven?" I looked at him and I said, "What's a hundred... You know I'm an engineer?" Okay, so I'm like, "Fine," I said, "This number just appeared in my mind." I said "92."
- Jon Sadler: 11:37 I said, "No, no, no, that's not right." It took me a little while and I got to 93, and then he goes, "minus seven." I'm like, "I have no idea." My memory was still there, but having taken out the hippocampus on the left side, that was like the RAM in a computer. That was the RAM that accessed the information in the front of my head. My mind now had to track a whole new way to get there.
- Kelly Cervantes: 12:04 So the information was still there, you just had to find the new road to get there?
- Jon Sadler: 12:09 That's it.
- Kelly Cervantes: 12:09 So how long did that take for you to recover those lost abilities?
- Jon Sadler: 12:18 A total of nine years.
- Kelly Cervantes: 12:20 Wow.

Jon Sadler: 12:21 Fortunately, where I work, they had a big evaluation that had to be done on a project, and that involved all the numbers, and everything. And they said, "Jon, we don't care how long it takes you, but you go do it." What would have taken somebody three weeks took me three months. But, the more I was doing it, the more I was learning, the more I was rewiring my brain.

Jon Sadler: 12:45 The biggest thing that happened to me though, is I started meeting other people with epilepsy. Initially, it was a little one-on-one thing. People hear about what I've been through, and they came and got in touch with me. What really inspired me, it was about four years after the surgery, was a fellow that I met through work who had a four year old son who had a lot of the same surgery and medications I'd been on, with intractable seizures.

Jon Sadler: 13:15 He looked at me. I sat there and he tells me his son has epilepsy. It was over a minute we sat on the phone before I told him that I did too, because I was in this argument with myself. Should I tell him? No I shouldn't. Yes, I can.

Jon Sadler: 13:31 When I did, I didn't realize how much hope I inspired in that person. Back in my college days, I was going to University of Rhode Island and saw the word "Hope" on the state seal, that's what pulled me through all of that. Then being able to turn around and give hope to somebody else, my whole world just flipped over. I no longer had to be quiet and silent about my seizures.

Kelly Cervantes: 13:54 Which has to have been so liberating and very easily leads me into my next question here, which is, I understand that during this recovery process, you also decided that you were going to get a Master's degree in Counseling, which seems like the most daunting thing, while you're in recovery, while you have this job, while you have a young family. It sounds like you were inspired to move in this other direction. Tell us about that.

Jon Sadler: 14:28 Well, I would just mention, talking to this person with a child with epilepsy, he got back to me many times thanking me, and then he'd tell me things about his son had a seizure at a swimming pool, and I said, "Sunglasses might help because of the reflection of the light in the pool probably triggered the seizures."

Jon Sadler: 14:47 I didn't realize how much I knew but then could share with other. My counselor said to me, he said, "Jon, you ought to consider becoming a pastoral counselor. And I was like, "What's that?" Anyway, I looked into it, and it seemed to fit me really

well. I applied to Loyola University and I wasn't sure that I'd get in or not, but to make a long story short, I got in.

- Jon Sadler: 15:11 My first class was in Humanities. The professor was an older gentleman. I failed the first exam because of my memory issues. He got these fill in the blank questions. I couldn't... I could give you the first letter to the answer, but I couldn't spell out the rest of the word.
- Jon Sadler: 15:32 Another fellow student made sure I told the professor everything that was going on, and he immediately said, "Well, we're not going to count that exam. What do we need to do?" I said, "Don't give me a multiple choice of ABCD. Give me a whole list of words. You can put 20, 30, 40 words on there, and I'll find them, and I'll know the answer. I'll recognize it."
- Jon Sadler: 15:55 So what he did was, for everybody in the next exam, he had 9 to 10 words to fill in the blanks. Some of them were very similar, but I managed to get a B on the exam. What really got me, though, was what inspired this man to help me so much? It wasn't until the very last class that he shared with everybody about how his mother had epilepsy, and how it inspired him to become a pastoral counselor.
- Kelly Cervantes: 16:26 Oh, my word, it's amazing once you start sharing your story, just how many people you find out are also affected by epilepsy and maybe aren't sharing their story because they're nervous too.
- Kelly Cervantes: 16:43 Now you counsel people with epilepsy, I wonder having been through counseling yourself, having this degree, being a person with epilepsy, and I understand that you've also been a caregiver of someone with epilepsy, what are some of the common themes that you find coming up as you're talking to people?
- Jon Sadler: 17:08 I go between being a mentor and a counselor. A lot of people who are living with epilepsy, I'm more of a mentor. People who are caregivers, more as a counselor, trying to help them understand it. E.
- Jon Sadler: 17:25 Epilepsy can turn your world upside down, but ask questions. Make sure that if the medication is making you feel worse than having a seizure, make sure you tell the doctor and you're going to change it. Sometimes you may have to find another doctor. The biggest thing that I try to do is inspire hope. One of the things I learned as a mentor and a counselor, is hope now, for me, stands for Helping Other People with Epilepsy.

Kelly Cervantes: 17:54 I love that.

Jon Sadler: 17:57 The biggest thing that I like, in Facebook and all, is people are sharing their stories, or asking questions, and the responses they can get. We're not in the battle alone anymore. I was very isolated for most of my life, and then I was able to come out and say, "Yes, now I can help other people."

Kelly Cervantes: 18:16 I certainly have a love-hate relationship with social media, but building community and finding that we're not alone on whatever our life journey and circumstances may be, certainly is powerful and strengthening.

Kelly Cervantes: 18:34 Jon, I want to know, how are you doing today? You've had brain surgery, you've been on and off medication for a majority of your life. Are your seizures controlled? How are you feeling?

Jon Sadler: 18:49 I'm actually doing really well with the seizures. I have not lost consciousness in over 14 years.

Kelly Cervantes: 18:54 Woo Hoo!

Jon Sadler: 18:54 Yes! I'll tell you, the first few years I was having several auras a day after the surgery. The surgeon said he wished he'd taken out just another quarter inch, it would have taken all of it out. Anyway, with time, as my brain healed and rewired and all, I only have very brief auras, maybe less than 10 seconds, maybe up to 30 seconds, about three or four times a year.

Jon Sadler: 19:27 One of the things that I'm going through right now is learning about the long-term effects of some of the medications I've been on. I have some liver damage. We're going to be doing some surgery and all soon, I'll probably... We're not sure exactly what it all is, but I have tumors in my liver now. That's going to be an adventure I'm on for the next six months, at least.

Kelly Cervantes: 19:57 I'm so, so sorry to hear that. Please know that we are thinking of you as you embark on this next journey. I think it's another sign for all of us of how imperative research is, so that we can move past these medications that potentially have these long term side effects and can cause significant damage. Thank you for sharing that with us. I do genuinely hope that you're able to find answers and find health.

Jon Sadler: 20:31 That's the reason right there when I look at the research and all that's being done.

Kelly Cervantes:	20:37	Absolutely.
Kelly Cervantes:	20:39	So often epilepsy is referred to as an invisible disease. Not just because many times the seizures can't be seen, but also just not talked about. There is even so much not known within the epilepsy patient community. So many questions out there that even folks with epilepsy who are caregiving of people with epilepsy, they just don't have the information.
Kelly Cervantes:	21:07	What can those of us in the epilepsy community do to change this?
Jon Sadler:	21:13	That's pretty hard because you're talking about trying to change whole communities and move from... I used to live in Baltimore, now I live down here in North Carolina on the Eastern side, the Eastern shore and all. On the Eastern shore, people don't talk about epilepsy. Just trying to get people to come out, "Yeah, I have it," and that's all you get. It'd be better if there'd be more community interaction of some kind that we could get going with this.
Jon Sadler:	21:44	One of the things that I try to do to help people, is write a couple books about it. The first one I wrote is called, Weathering the Storms. It's to help educate people. The subtitle is, Living With and Understanding Epilepsy.
Jon Sadler:	22:01	Yes, it's got a big piece of my personal story in it, but I use it a lot, like the counselor, I start off with information about epilepsy, and then I finish it up with a section about the caregivers. I had a parent that I help out, I mentioned earlier, who had a child who had all these seizures, and she helped me put together a caregiver program.
Jon Sadler:	22:27	Based on my experience of being a caregiver, I wrote another book, it's fictionalized, and it's called, In the Midst of the Storms, A Story of Trauma, Faith, and Hope. It's all fictionalized. It flows very nicely, there's a whole storyline to it.
Jon Sadler:	22:47	The main piece of it is a person who's dealing with PTSD of being a caregiver. That's the Post-Traumatic Stress Disorder of being a caregiver. Things I learned personally being the caregiver of my next door neighbor. He started having simple seizures, simple partial seizures. Eventually over 18 months, they had grand mal seizures several times a week. Yeah, it's pretty hard. It can be pretty trying. The more we can educate the caregivers, the better things can be.

Kelly Cervantes: 23:23 I think the education piece is just so important and empowering. Taking that outside of the epilepsy community, what is the public perception about epilepsy that you would like to see changed?

Jon Sadler: 23:40 Well, that's pretty hard in a lot of ways. Overall, I think within a community setting, if there's a child in the neighborhood who has epilepsy, then it should be discussed with everybody in the community so people aren't scared of it. As long as they know what to do, that can be a huge help.

Jon Sadler: 24:04 I mentioned the parent that I helped with a child who had all those seizures in a short period of time, and she helped me, and we worked with each other in educating the teachers of the school what to do if her child had a seizure. The more we can educate the community and make epilepsy a... At least talk about seizures and make that a topic that's easy to talk about and people aren't afraid of it, that would be the greatest thing we could do.

Kelly Cervantes: 24:34 I couldn't agree with you more. It's actually such simple, on paper anyway, simple advice and simple steps that we can take, just talking about it and educating people. It's something that everybody can do within the community to teach their neighbors, to teach their community, and then hope that that message spreads outward and outward by word of mouth. We can someday relinquish and defeat this stigma.

Kelly Cervantes: 25:03 Jon, I am just so honored to have been able to speak to you. You are a wealth of information and the work that you are doing to bring hope to this community, to our community, it's really beautiful. While I wish that you were not a part of this epilepsy club, we sure are happy and proud to have you as a member. Thank you so much for joining us today, and for all that you do for us.

Jon Sadler: 25:34 Thank you for the opportunity.

Kelly Cervantes: 25:39 Thank you, Jon, for sharing your personal experiences with epilepsy, and your insights as a counselor. As Jon noted, epilepsy doesn't just affect the person diagnosed. It impacts that person's family, friends, and community in numerous ways.

Kelly Cervantes: 25:55 As an organization founded by mothers of children with epilepsy, Cure Epilepsy has always understood the multiple impacts of a diagnosis. That's why we are dedicated to patient focused research, which we know is the best way to discover

new therapies, and cures, that will bring relief to both patients and their families.

Kelly Cervantes: 26:14 Please help us continue to fund epilepsy research by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

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