

Seizing Life, episode 138
The Sudden and Life Altering Impact of Adult-Onset Epilepsy
Guest: Jon Tuteur
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes, and this is Seizing Life, a monthly podcast produced by Cure Epilepsy. This month I'm happy to welcome Jon Tuteur to the podcast. Jon was a busy professional in the prime of his life when suddenly at the age of 30, he began experiencing seizures. He has written a memoir about his journey with adult-onset epilepsy entitled *Seizing Today, Discovering Purpose, and Authenticity in a Life-Changing Diagnosis*, Jon is here to share his epilepsy journey, discuss how it impacted his life, and ultimately led him to undergo brain surgery. Jon, thank you so much for joining us today. To start things off, why don't you share a little bit of what life was like for you before epilepsy, BE, if you will.

Jon Tuteur: Thanks so much for having me, Kelly. I really appreciate it. Life before epilepsy, pretty normal life. The one thing I like to share with people, I'm a triplet, so that makes things a little bit interesting. I have an older brother as well, so life was a little chaotic growing up, but otherwise just a pretty normal life. Workwise, I was very much a workaholic. I don't think anyone in my life would disagree with that. I was usually working 60 to 80 hours a week, sometimes more, but, yeah, pretty normal life.

Kelly Cervantes: And then talk to us about how epilepsy entered your life.

Jon Tuteur: So my first seizure, which I didn't know what it was at the time, I was working late at night in my apartment in Washington DC and woke up, slumped over in my chair, just confused. And, again, just really didn't know what happened. I just wrote it off as exhaustion, got into bed, fell asleep, woke up the next morning, didn't really think much of it. And then that next day, I was at my client's site in Arlington, Virginia and meeting with a client, and the next thing I know, I'm waking up in an ER.

The way he described it to me and to the hospital staff, "Jon's eyes rolled back in his head, his head hit the desk, he fell to the floor and shook a little bit." So at that point, the ER doctor did not diagnose me with anything. It was, "We're not really sure." So just continued on with life as normal. And then about a month later, I was in Ottawa, Canada for another work meeting at the American Embassy, and I'm in a big conference room with about 10 other people, and the next thing I know, I'm waking up in another ER this time in Canada with a doctor who very tersely diagnosed me with epilepsy, prescribed Dilantin, and left the room very quickly without me even being able to ask any questions or anything. It was quite frightening. Long story, but that's how it first entered my life.

Kelly Cervantes: I wish that people came to an epilepsy diagnosis in a less traumatic way, but there seems to be a pattern here. I'm so sorry that that was your experience. I suppose medically it's two seizures before you received the epilepsy diagnosis. It sounds like you may have had several. You have this diagnosis, you're in a

foreign country, albeit Canada, you come home, and I'm assuming you start looking for a neurologist.

Jon Tuteur: Yeah, my triplet brother had a good friend whose dad was a doctor in DC, and he recommended three neurologists. And so I went on the neurologist tour and found someone that I just felt really comfortable with, a woman. And at that point, it wasn't 100% clear because she put me through an EEG. The ER in Canada did as well, but for a very long time, I never had a seizure while I was hooked up to an EEG. And I even had the take-home EEG. And I know this is a common theme also, right? It's when we want to have a seizure, we don't, when we don't want to, we do.

So they didn't know my seizure onset zone, but she gave me three options for medication; Lamictal, Depakote, and Keppra, and walked me through the side effects. And it was a pretty easy decision. Depakote, the main side effect that I remember, and I know there are others, but it was hair loss, which at 30 years old and single, I wasn't too excited about. Keppra, the moodiness, that wasn't all that thrilling. And Lamictal was relatively new at the time and pretty benign. The side effects were nothing major, so it was an easy one, and it worked for quite some time.

Kelly Cervantes: And I think you brought up that you were 30 years old when epilepsy entered your life. And I think that's a really important fact to take note of because I think a lot of times the common thought is that epilepsy will enter someone's life as a child or perhaps as a result of a traumatic brain injury, but people don't realize that it can just pop up in your life literally any day.

Jon Tuteur: Yeah, complete shock to me too. And whenever I talk about it, people just always assume, "Oh, you were born with it," or "You've had it your whole life." No. Yeah, 30 years old, out of absolutely nowhere, I've never had a TBI, and I've never even had a concussion. And to this day, we still don't know. And that's hard too. When you're diagnosed with something like this, you want to know, and the uncertainty is a really difficult emotion. I just want to know.

Kelly Cervantes: And it's so hard to, how do you treat something? How do you find the right medication if you don't know what's causing the seizures? And so many people think that epilepsy is the diagnosis, but it's really the symptom of something else. And it can drive you crazy if you really dwell on it. And then you come to realize that a majority of the people with epilepsy don't know why they have seizures. So you started on Lamictal, and how did that work for you?

Jon Tuteur: Lamictal was great. Again, I really didn't experience side effects at all. I did not feel different at all, and it controlled my seizures for the most part for a number of years. So overall, Lamictal was phenomenal. Unfortunately as is the case with a lot of medication, the efficacy can wear off, and that's what happened in this case.

Kelly Cervantes: So tell us about the kind of seizures that you were having. Obviously, it sounds like the big seizures you had in the beginning were classic tonic-clonics, but that wasn't the only seizure type you experienced.

Jon Tuteur: I've kept pretty detailed track of my seizures. I've had over 500 seizures. The majority of them have actually been what's called focal aware seizures. I have had a number of tonic-clonic seizures, what people commonly know as grand mal seizures, but the vast majority are focal aware seizures. And that was another thing that was so fascinating to me as I started doing more research and asking more questions, and I think this is true for most people. They think of epilepsy, they think of grand mal or tonic-clonic seizures, someone loses consciousness, falls to the ground, shakes, makes some weird noises, whatever, that's one of as you know over 30 seizure types that was just shocking to me. And so focal aware seizures is the vast majority of mine.

Kelly Cervantes: Can you explain to people what a focal aware seizure looks like and what it feels like?

Jon Tuteur: Yeah, and this is one of the things that I know we're going to get to my book later, but one of the things that I write about, because I think it's somewhat shocking and surprising because I don't think it's what people would think of. And I want people to be able to understand it and to as much as they can walk in my shoes or anyone else's shoes who's going through this. A focal aware seizure, so the aware part, you're conscious the whole time, you're awake, you don't lose consciousness. So I could be having a focal-aware seizure right now and having a conversation with you, and you wouldn't know it unless I told you. Now, would I be extremely coherent? Maybe not. But I've been in that situation. I've had conversations at work with people while I'm having a focal-aware seizure. So for me, there's three stages.

The first stage is there's this awful smell, and I describe it in detail in the book. I will spare you of that here. It's very hard to describe other than to say it's nauseating. Then I get really sweaty, particularly on my hairline, but in other places. And then the way I describe it is it's like there's a movie playing in my head. And some doctors would say, "Oh, it's déjà vu." A lot of people talk about the aura. That's the aura, right? It's déjà vu. As I started doing more research, I don't think déjà vu is the right term, at least for me. I think it's really what I would call a flashback. It's a scene from my life that has happened previously that I'm reliving. It's so interesting and strange at the same time.

Kelly Cervantes: It's terribly disorienting.

Jon Tuteur: Yeah, disorienting too. And it's the same 10 or so scenes that would play over and over again. It's really strange. And the other thing about my focal aware seizures, different from my tonic-clonic seizures is the focal aware seizures in a lot of cases would cluster. And so what I mean by that, I'd have one, and then over the next week or so, I'd have many, many more. And this is not the scientific term by any means, but I call them aftershocks. So the first one is the

most intense, and then the five to 10 that happen over the next week or so are less intense, but still have the smell, the aura, and the nausea and the sweating.

Kelly Cervantes: Thank you so much for that description. I think that is going to help so many people better understand what their loved one or what a friend or someone that they don't even know yet what they're experiencing.

Brandon: Hi, this is Brandon from Cure Epilepsy. Do you have questions about seizures, medications, treatments, or other areas of epilepsy? Cure Epilepsy's new video series Epilepsy Explained provides answers to help you better understand the basics of epilepsy. Each month, a different expert offers short, easily understandable answers to questions from our community about a particular area of epilepsy. Doctors and researchers who are leaders in their field will cover questions about seizures, diagnosing epilepsy, medications, surgery, and many more topics. New episodes of Epilepsy Explained will be available on Cure Epilepsy's website and YouTube channel on the third Wednesday of every month. Now, back to Seizing Life.

Kelly Cervantes: You mentioned that Lamictal worked for a while and then the seizures came back. Tell us about that time period and the next steps you took.

Jon Tuteur: So that time period was really marked by a lot of stress, significant increase in stress. So I had started a new job that was extremely stressful for a variety of reasons. We had moved to a new house, which we were renovating, my wife's pride and joy, she's incredible at that, but can be stressful. And she was trying to get pregnant, and that was challenging. And so we were going through IVF. So just a lot of stress, and that I think was a big contributing factor. Interestingly enough, while I was in the hospital for one of my surgeries at Johns Hopkins, one of the neurologists really pushed back on my notion that stress is a trigger. And he very forcefully told me, "There's no scientific evidence to prove that stress is a trigger," which I still find fascinating because I don't think I've met anyone yet with epilepsy where stress isn't a trigger. So when I have more time, I really want to do a research study around this because stress is a trigger for so many different things.

Kelly Cervantes: Yeah, I'd be curious. Yeah, maybe it's stress causes sleep deprivation because we absolutely know that sleep deprivation can cause stress. Regardless, your seizures come back, there is a lot going on in your life, what was your neurologist's treatment?

Jon Tuteur: So that was the difficult part. It was a lot of trial and error. I really felt like a lab rat during those days, and it was, "Wow, this is our best approach. We'll increase your Lamictal. That didn't work? Okay, let's add this. Oh, that didn't work. Let's try vitamin D. That didn't work?" It didn't really feel like there was a whole lot of rhyme or reason to it. And, of course, now after doing the research and talking with so many people, that's not that uncommon. It's just hard to believe that in 2024, we still don't know enough about the brain or epilepsy, which is why a cure is so important and funding for finding a cure for epilepsy.

Kelly Cervantes: Jon, you're doing my job for me. I love it.

Jon Tuteur: It was really, really difficult to be on that hamster wheel, if you will. And then I actually switched to a different neurologist because I needed something different. And I went to Johns Hopkins, and the first thing that this neurologist prescribed for me after I described everything to him, he wanted me to go to the epilepsy monitoring unit for a week long EEG. And I had never done that. I've had countless EEGs, but never been in the hospital for a week. And part of why I think he prescribed that is I was describing to him the pattern of my seizures. I was analyzing the data, and I noticed that my seizures were occurring, and this is still interesting to me, and I don't have all the answers, but my seizures were occurring approximately every 25 to 35 days. So it was almost like a woman's menstruation cycle.

And as I was describing this to him, I see him processing it, but he didn't really say much. And I tried to do some research on it. Certainly we know that women's menstruation cycles can impact their seizures, but there isn't much on men from that standpoint. But he said, "Since you know approximately when your seizures will occur, we can time your visit so that you can have a seizure while you're in the hospital." And it worked out perfectly. I had a number of seizures while in the hospital for that week long EEG.

Kelly Cervantes: And were they able to then collect enough data to tell you what they recommended?

Jon Tuteur: Oh, Kelly, I so wish they did. But, again, as you know, it's not as simple as that. The data was "inconclusive," which was a word that I heard way too many times. So I had to have a PET scan. I had a neuropsychology evaluation, which I spend some time writing about as well. If you haven't had one, don't get one. I liken it to taking the SATs again, which was not a fun experience the first time around. It's an over four hour examination of your various executive functions and memory and math. I remember walking out of Johns Hopkins after that just being so incredibly exhausted.

And then speaking of inconclusive, so we thought, well, PET scan, neuropsychology evaluation, data from week-long EEG, as well as CT scans and all kinds of other things, that should give us the data we need to determine your seizure onset zone. And then my neurologist, after reading the neuropsychology evaluation paperwork or report told me those same words again, "It's still inconclusive. There is one other test that we can do, but it's quite invasive." Okay, tell me more, Doc. It's called a stereo EEG or an SEEG. What we do is we drill holes in your head, and we thread the electrodes through the holes and implant them in your brain. I was like, "Wait, did you say drill holes?"

So that certainly was quite frightening, but at the same time, I was having uncontrolled seizures. And around that time because it wasn't you have to do this, it was still my decision. And around that time, we were on a vacation with our family and another family, and my older daughter who was three or four at

the time, three I think, saw me have a tonic-clonic seizure in my sleep. And that actually was pretty common for me. Thankfully, most of my tonic-clonic seizures happen while I was sleeping. And at that age, she freaked out. My wife happened to be there, and she kept saying, "Tell daddy to stop. Tell daddy to stop. Tell daddy to stop." She's watching as I'm shaking and making the snapping noise with my tongue and just uncontrollable. And certainly I'm not responding to her because I'm unconscious. And then as my wife is telling me the story, and I see how sad my three-year-old is, I have to do something different. So that got me over the fear of having 14 holes drilled in my head,

Kelly Cervantes: Amazing what kids will force us to do for ourselves and for them. So you get the SEEG, you have the drills, you have the holes drilled in your head, and then what?

Jon Tuteur: So they expect that I would have a number of seizures, and so that they could then triangulate all the data and say, "Okay, this is your seizure onset zone." They had a hypothesis. They were fairly certain it was in my temporal lobe, but they certainly weren't going to recommend an actual surgery to either ablate or cut or remove that part of my brain without knowing for sure. It was supposed to be a week-long stay. One week goes by, no seizures. And during this period, I'm doing 24-hour sleep deprivation. Two weeks go by, same thing. And I had planned to just take a week off and go back to work, and so I'm having to adjust all that. And I'll never forget this, Kelly, if you can indulge me for just a minute, the attending neurologist walks into my room one day after two or so weeks, and all the residents are there, and it's probably four or five of them, and she says to me, "So what are your triggers besides sleep deprivation?" I said, "Well, hot showers." That actually has caused a number of seizures for me.

But at this point, I've got wires coming out of the back of my head connected to the EEG machine, so shower was not an option. And then I was thinking about it some more, and I sort of sheepishly said, "Alcohol," and she looks at me very seriously and she said, "Oh, we can do that." And she looks down the line at her residents, and she says, "Hey, Laura, tell Jon his options." And in my head, I'm like, "Okay, they're just messing with me. This isn't real, right?" She starts out, she says, "Well, we have this Sherry dessert wine. We have Bud Ice, and we have Jack Daniels."

I'm still like, "This isn't real, right? This is a joke." I said, "I'll take some Jack." So that evening, Jack Daniels shows up in one of those orange translucent bottles with the white cap, the childproof cap like you'd have prescription cough syrup for your kids, that kind of thing. And I still have a couple of the bottles because I had to keep them just so people-

Kelly Cervantes: Yes, you did.

Jon Tuteur: ... would believe me. And it says my name with Jack Daniels. The only issue was it was just a very, very small amount. It really was not going to be enough to trigger a seizure, but at least I could make a little bit of a little cocktail at night to

entertain me. So two weeks go by, three weeks, and they're saying to me, "Okay, you need to just stay for another week." And at that point, I was like, "Guys, I can't. I've paused my life for three weeks. My wife is home with our two young kids." And so they said, "Okay, no problem. We can induce a seizure with electrical stimulation." And I don't remember at the time being particularly fearful of that, but I think as I processed it, that had something to do with what happened next. So the morning of the electrical stimulation, I had a seizure right as my neurologist was walking into my room, so no electrical stimulation. They read the EEG data, and it confirmed the hypothesis, and I was out of there before breaking the record for longest stay at the Johns Hopkins Epilepsy Monitoring Unit.

Kelly Cervantes: Well, I'm glad that you finally had your seizure first and last time I'll say that. So they're able to determine where the seizures are originating from and suggest surgery. Walk us through what that looks like, what the surgery experience was like for you as well as post-surgery.

Jon Tuteur: Yeah, so it was my temporal lobe, my non-dominant hippocampus, which is as they told me, an ideal location for laser ablation surgery, which is still a relatively new procedure and a lot less invasive and a much shorter recovery period than a temporal lobectomy, which was the other surgery. Essentially, they really open your skull and cut out that part of your brain. The laser ablation surgery, they drilled another hole in the back of my head, so a total of 15 holes for those of you who are counting, and then threaded laser fibers through that hole and literally burned my non-dominant hippocampus. It was a four plus hour procedure. I remember my neurosurgeons were walking me through everything that would happen. It was certainly extremely frightening. A lot of people in my life were like, "You're crazy." But, again, I just always thought back to my daughter seeing me have a seizure, and I couldn't do that again.

I wake up as I'm being put onto a gurney and being wheeled back to my room at the Epilepsy Monitoring Unit at Hopkins, and as I'm on the gurney, I'm having a seizure, and then another and another and another. I had about 10 seizures in a short period of time, focal aware seizures. And you can imagine, I was like, "What is going on?" I just had surgery to eliminate seizures, and now I just had a cluster of 10 of them after waking up right after. It's like, "What in the world is going on? What have I done?" Finally, the neurosurgeon comes in and he says to me, "This is actually fairly common. We're just poking around in there. We're messing around. Things can happen, and I know it sounds really strange, but when we get in there, just this kind of thing can happen. Now, if it continues to happen, that's a problem, but I'm fairly certain that this is going to be an isolated thing."

And thankfully it was, but that was really, really scary. He told me before the surgery plan to take two weeks off from work, and my response to him was, "How about one?" And neurosurgeons don't really have a sense of humor, at least mine didn't, and he said to me, "You're going to be on a very heavy dose of steroids and other medication. You're going to probably have trouble sleeping."

The recovery in the hospital was a couple of days. I'm back home. It's been probably about two or three weeks, and I just still feel awful. I am more fatigued and exhausted than I had ever been in my life. And he told me two weeks, I was expecting one, we're now at three. What's going on here?

So he readmitted me to do some more tests. Thankfully, everything looked good with my brain. They worry about swelling, they worry about bleeding. They worry about a variety of things, but everything looked good. They did a whole blood panel and saw that my iron levels were low, so they gave me iron through an IV, but nothing really, really changed. Then my neurosurgeon says to me, You know, I just had two patients recently that had very similar procedures to you with an SEEG and laser ablation surgery within a month of each other, and it really took them about a year until they felt back to normal." I was like, "Well, that would've been helpful information before." Here I was preparing myself for two weeks. So anyway, it really was every bit of a year, Kelly, before I started to feel quote-unquote normal again.

Kelly Cervantes: Wow. And so how is your epilepsy today? Long-term, knocking on all things wood, did the surgery work?

Jon Tuteur: Yes, thankfully it did. I have only had one seizure since the surgery, which is coming up on, I guess, about two and a half years now, and that was really only because I forgot to take my medication, so proof that the medication is working. I really hoped that eventually I could be completely medication free. As you know, the medications don't have the most fun side effects, but they're working. We've weaned down a little bit, but at this point we've agreed let's just keep it where it is. Everything is mostly good, so, yes, thankfully the surgeries seem to have worked really well.

Kelly Cervantes: That infamous quality of life balance, which brings me to what I am actually most excited to talk to you about, which is your book. It's about to come out very soon, and I cannot wait to read it. The more epilepsy literature that we can get out into the world, the better. I think your story is so compelling, especially because you were diagnosed as an adult, you have an entirely different viewpoint. Your experience it's so valuable, I think, to getting the grander population to understand epilepsy and our community.

Jon Tuteur: Yeah, I appreciate you saying that. Let me start by saying, writing a book was never on my bucket list. This was not, "Okay, someday I'm definitely..." No, that was never a thing. But I was in the hospital for over 40 days and nights, and the mind tends to wander when that happens, and I started documenting all of the crazy things that had happened in the 14 or 15 years since I was diagnosed. And when I got out of the hospital, I went to see a good friend who's in the literary world, and I ran the idea by him. He loved it. He then introduced me to a bunch of other people in the literary world, and off we went. But writing a book, as you know, is quite the endeavor two and a half years later. Yes, it should be out this summer. June, July is what my publisher is telling me, but I won't get an official date for at least a few more weeks, but somewhere in that June, July timeframe.

Kelly Cervantes: Well, congratulations. Tell us the full name of the book with subtitle.

Jon Tuteur: So the book title is Seizing Today, Discovering Purpose and Authenticity in a Life-Changing Diagnosis. It'll be available in your typical Amazon, Barnes, &, Noble, etc, etc. All those places.

Kelly Cervantes: Amazing. Well, everyone needs to make sure that they go out, that they get their copy. I know that I cannot wait to read it. Thank you, thank you, Jon, and best of luck to you.

Jon Tuteur: Thanks, Kelly. Really appreciate it.

Kelly Cervantes: Thank you, Jon, for sharing your experiences with us. Jon's story is a reminder that epilepsy can affect anyone at any age. One in 26 Americans will develop epilepsy in their lifetime, and like Jon, 50% of those diagnosed cannot find a cause for their epilepsy. This is why Cure Epilepsy has been funding groundbreaking research for more than 20 years. We aim to uncover the secrets of epilepsy, discover new therapies to improve the lives of those living with epilepsy, and ultimately find a cure. If you would like to help us achieve our goal of a world without epilepsy, please visit cureepilepsy.org/donate. Thank you.

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