Seizing Life, episode 88
A Post-Traumatic Epilepsy Journey: Diagnosis Acceptance Leads to Career Helping Others
Guest: Mark DeFee
(transcript)

Kelly Cervantes:	00:01	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 Mark Defee to the podcast. Mark experienced his first seizure 25 years ago, while in high school, after an initial epilepsy diagnosis, he was subsequently diagnosed with post traumatic epilepsy, resulting from multiple concussions suffered while playing high school football. Despite the diagnosis, mark was never told to stop playing football. Now a therapist, husband, and father to two young children, Mark is here to tell us about his epilepsy journey and how he learned to accept his diagnosis. Mark, thank you so much for joining us today. To get things going, why don't you start off by telling us about when you had your first seizure, the circumstances around it and how you were eventually diagnosed?
Mark DeFee:	01:04	Absolutely. And thank you for having me today. This is really an honor. And I was diagnosed when I was 17 years old and it was a few weeks before my senior year in high school. I was actually at a gas station and I went inside to pay for gas, back when that was more of a thing, and I was standing in line. And the last thing I remember was looking down kind of at all the candy in front of me, and then waking up in this dark room, truly something out of a movie, a single bulb above my head, the contents of my wallet spread out on a table with these three strange guys staring at me.
Mark DeFee:	01:43	Truly, I thought I had been kidnapped. There was no other kind of explanation, because I was groggy, I was bleeding from my mouth. I couldn't remember anything. They asked me where I was and I thought I was at a store I had been at hours ago with my mom. And they were just like, "No, that's not even close." And luckily one of the men was a nurse and he was the one who kind of jumped in behind me in line and got everybody back. It was a grand mal seizure or tonic-clonic seizure. And after I stopped seizing, they picked me up, took me to the back room to kind of get me out of the way of all the onlookers. They had opened up my wallet trying to find a number to call. And so a few minutes later my parents came bursting in the door.
Mark DeFee:	02:26	And it was just scary. I had no idea what was going on. And I remember the nurse asking me, "Have you ever had a seizure?" And at that time, I didn't even know what that was. And he said, "Do you have epilepsy?" And again, "What are you talking

about?" And my parents came, we went to the emergency room, they explained a little bit more about what a grand mal seizure was and said, "There's not a lot we can do if he's not having a seizure right now." So they sent me home and my parents and I were kind of terrified, like, "What do you mean we're going home? This thing just happened."

Mark DeFee: 03:01 And a few days later I was at a neurologist office and had a self-induced seizure. So I was having an EEG that sleep deprived and make you look at the Strobe lights, hyperventilate yourself. And it was a hyperventilation that got me. And so when I came too, he said, I now met the medical criteria to be diagnosed with epilepsy because there was brain activity on the EEG when I started seizing. And so that kind of kicked off this entirely new life for me that at the time I had no idea what was in store in terms of changes. I just thought I was getting a diagnosis that would require me to take a couple pills and go on with my day. But as you know, that's not the case with epilepsy.

Kelly Cervantes: 03:47 Yeah. I think so many people come into this disease sort of assuming that, right? That you can just take a couple pills and be fine and not realizing A, that one third of people are drug resistant, but B, even if you are one of those people that can find control through current treatments, it can take a while to find the treatment that works. You sort of hinted at it before, but what did you or your parents, what was your knowledge of epilepsy at the time?

Mark DeFee: 04:18 Nothing, even after I was diagnosed, we never found anybody who even knew somebody with epilepsy, because that was a key piece. And yeah, we didn't know anything about this disorder and I was never around a group of other people with epilepsy until my mid twenties.

Kelly Cervantes: 04:36 So what did the doctor tell you? So he says, "Okay, you have epilepsy." What sort of information did he give you? What treatment plan did he start you on?

Mark DeFee: 04:49 Medication, and it took a lot of time to not only find the one that worked, but find the right dosage, because I'd fall asleep in math class, that type stuff. But at that appointment, the conversation really revolved around a few different things of what my life needed to be based on. And I was 17, I didn't really care or take him that seriously. But he said things like, eight hours of sleep, every night, no deviation, medication as you're supposed to, I know it might not feel good or might not feel like it's working. You can't deviate without medical guidance. You

		need to limit your alcohol intake as much as possible and you need to reduce the stress in your life.
Mark DeFee:	05:32	And he gave these kind of matter-of-factly like, "Okay, now go out and do them." And I just kind of sat there, like, "I'm about to be a senior in high school. There was no way I'm doing any of these." And I thought I was invincible at the time. And so it took a while to really hone in exactly how to create a life that was not just filled with fear.
Kelly Cervantes:	05:57	Right. So you're 17 years old, going into your senior year of high school, trying to figure out your own life and who you are, you play high school football and you've had three concussions. How long did it take for someone to connect those two? The epilepsy and the concussions.
Mark DeFee:	06:19	They connected it pretty early. I had actually had two by then. And when they saw the brain activity on the EEG and saw that came from the left side of my brain, the abnormal electrical activity, that's when they kind of said, "Well, that's where you had had both the concussions. So obviously we can't be definitive because it feels like nothing's definitive in epilepsy, but our best guess is it came from these concussions." So they connected it really quickly, but no medical professional ever said, "You need to stop playing football." And I actually had my third concussion after being diagnosed. And I think I missed maybe a few days of practice. I certainly didn't miss a game because where I went to high school football was a big deal. And that was just part of it.
Kelly Cervantes:	07:11	No one tells you not to play football. You have a third concussion.
Mark DeFee:	07:15	They always said, "It's up to you if you want to keep playing." And I was like, "I'm a 17 year old kid, been working for this since I was in fifth grade. What do you think? I'm going to say?"
Kelly Cervantes:	07:24	It's shocking. Thankfully concussion protocols have come a long way and I hope parents and students sort of listen to your story and take heed in it and learning from this and understanding why all these protocols that we have now are so important. You're diagnosed during high school at a time where your social life is the most important thing going on in your world. How did your diagnosis affect you? Was it so that you shared with your friends at school? Did it affect you academically?

Mark DeFee:	08:07	Yeah, definitely had to share it. In Texas, when you have a seizure, your license is taken away for six months. So I remember driving to registration with my mom, that was fun and kind of every one then finding out for the first time, because registration truly was like a week after getting diagnosed. And so we had to begin informing teachers and football coaches and all that. And we just hadn't done that yet. We figured we'd do it at registration. And so in the cafeteria, I could almost see this wave of people finding out because when they didn't know, they treated me like the old Mark, coming up, "Hey, I love senior year, there's going to be so much fun, blah, blah, blah."
Mark DeFee:	08:50	When they did find out, they stood a little bit further away. They talked in a softer voice. "Hey, how you doing?" So you could tell that they were immediately seeing me as more fragile. And again, I'm not going to stop playing football. No one wanted that. But they definitely saw me as someone that they had to walk on eggshells around because they didn't didn't want to be the thing that caused a seizure and they certainly didn't want to see one and it felt lonely, but I also couldn't really blame them. I didn't know anyone else with epilepsy. It scared the heck out of me to see that. So I wasn't angry or frustrated, but it did change everything for me.
Brandon:	09:37	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:	09:57	So you mentioned that it took you a while to get to a dosage of your medication that both worked for your quality of life so that you weren't falling asleep in math class, but was also helping your seizures. So Mark, were you able to gain some sense of seizure control once you found this balance of the medication and finding that right dosage so that you weren't falling asleep in math class, but you were hopefully able to control some of these seizures?
Mark DeFee:	10:28	Yeah, I was and I feel very grateful for that. As you know, epilepsy is a spectrum and I'm very fortunate to be on the well controlled side. And so it was really when I deviated from all the medical requirements or recommendations that I really got in trouble. At first, as we were dialing it in, I would have seizures. They were always at the house. And so I've never had anybody see a full blown tonic-clonic seizure, except my family. I've kind

		of evolved over the years, the type of seizures I have. And so it became more apparent.
Mark DeFee:	11:08	But early on, when I chose to lean into my new diagnosis and everything, I did pretty well, but there or were moments where not sleeping, I would have a seizure in the middle of the night, because I came home after a football game and then went and drank with friends because I was an idiot at 17. So I would wake up in the morning realizing I'd had a seizure, that type of stuff. But I've never of those people who've had it multiple times in a day. I worked with a lady one time who had 80 seizures a day. And if she forgot to put her helmet on before she stood up, she could really harm herself. And so I feel very grateful, I've never been through that and that compared to a lot of people, I was able to get controlled pretty quickly.
Kelly Cervantes:	12:01	And then you went to college.
Mark DeFee:	12:04	Yes.
Kelly Cervantes:	12:05	And you talk about the doctor saying, "Low stress, don't drink alcohol, get lots of sleep." And those are all things that just for the average college student get thrown out the window. So tell us about that process. How did you choose which university to attend and what were those early years of college like for you?
Mark DeFee:	12:27	Yeah. Sorry. You saw me adjusting my chair because this is a part of my life that I looked back on just going like, "What are you do doing?" But I remember the summer before college, my neurologist, my parents sat me down and gave me this big talk about how I needed to take this seriously and all that. And I agreed. "Yeah, absolutely. Yeah, I'm going to be on my own for the first time and I've been newly diagnosed." And so my ultimate response to that was, I went and joined a fraternity. So I couldn't think of a better way to say, "I don't believe you." Or, "This isn't happening to me. I'm invincible." Still that mindset of not being willing to accept it.
Mark DeFee:	13:05	And I ended up going to Texas Tech and I enjoyed it. I grew up a lot in West Texas because my grandparents and the extended family lived there. But looking back on it, I'm not sure I would've gone to school there if I didn't have family there. For me, it was important to be somewhere where I could call someone who knew, because for me keeping this under wraps was important. Obviously when I joined a fraternity or started pledging, I didn't tell them anything. I never went to the school asking for accommodation, because for me it was one of those, if people don't need to know, I'm not going to tell them until absolutely

have to. And because of that mindset, it didn't take very long before I had to tell them because I had another seizure, I had to give my license up again, all that, but in my mind, if I just ignored it, then everything would go away.

Kelly Cervantes: 14:01 I understand that your roommate freshman year moved out. And so you had a dorm room to yourself and you're in a fraternity and you're having nighttime seizure, reading that and knowing what we know now about SUDEP, I feel very lucky to be talking to you.

Mark DeFee: 14:29 Yes. I feel very lucky to be talking to you.

Kelly Cervantes: 14:32 It's terrifying to read that and to know how scary that can be. And I wonder your thoughts looking back on that now, and you sort of talked about that, but you changed your mindset at some point during college, from living dangerously with your diagnosis to taking it more seriously. When did that shift occur?

Mark DeFee: 15:02 And I think it occurred junior year. I would say it would probably have occurred faster if someone had ever once brought up the term SUDEP. Again, I didn't even find that out until I was in my mid 20s. Again, we saw so many neurologists in Dallas and no one once told me that there's a chance I might not wake up someday. And it took me a little bit of time in my 20s to wrap my head around that. Because it felt like a new kind of blow from epilepsy. Another punch to the face of, "Oh, this is out there. This has been out there this whole time?"

Mark DeFee: 15:38 So I think that would've maybe helped me grow up more, but it was about my junior year that I really started paying attention. And part of that was because in the spring semester I went on a study abroad program and so getting ready for it I had to kind of get my mind right that no one's going to be there on this study abroad to help me. It was a trip around the world on a shift called Semester at Sea. But I only had one friend that I really knew, he knew about it, but again, I kind of kept it under wraps. And so to do this really amazing thing, I had to grow up a little bit.

Mark DeFee: 16:16 And then on that study abroad, just seeing how much of the world does struggle. I kind of sat there going, "Mark, what are you doing? You've been in this pity party mode and yeah, you have epilepsy and it stinks, but there's a lot more going on in this world that I think people could claim to have a rougher time than you. So you should probably just grow up."

Mark DeFee:	16:39	And it was when I got back to Tech that I was walking through the psychology building, because I was a psychology major and I saw a volunteer position for the Lubbock Rape Crisis Center. They needed a pair of professional counselor. They were looking specifically for men because you'd be shocked how many men call there about sexual assault? And for whatever reason, I was just like, "This sounds like something I can help with." And that led the foundation to realize that putting myself out there for other people allowed me to turn and my brain off. So I wasn't thinking about my epilepsy just 24/7. And now I know, going to graduate school, learning about positive psychology and everything. The fact that you help someone else can help increase your happiness, reduce that seizure frequency. And so I felt like I kind of stumbled upon that myself, but once I started doing more of it, it just clicked that this is a way for me to keep my life in perspective while also maintaining that healthy lifestyle that's required.
Kelly Cervantes:	17:48	So what were the changes that you made to your lifestyle specifically?
Mark DeFee:	17:55	Yeah. This is going to sound weird, but I actually had two jobs in my senior year and I volunteered at both the rape crisis center as well as St. Andrew's Youth Group. [inaudible 00:18:08] as church. And for me, I structured my day in a way where I could still be around my friends, but also pay my way in college. That was a very big thing for me after Semester at Sea. And so I actually had a job as a bouncer at night and it sounds so counterintuitive because I didn't go to bed till 3:00 AM, but I structured my day where I would go to sleep and then sleep till 11:00 or noon, take afternoon classes and then go to my first job, which was a YMCA kind of daycare thing. And then go have dinner, go to my second job.
Mark DeFee:	18:49	And my whole thought process was, from 8:00 AM, till class, no, one's really doing anything anyway. So I'll sleep then so I can still be out with my friends at night, but I won't be drinking because I'll be working. And so in my mind, I came up with this great idea, it worked pretty well. There are sometimes where I was just too exhausted to do anything, but my whole goal was to help more, pay my own way and still find a way to be around my friends, but not drinking and putting myself at risk.
Kelly Cervantes:	19:22	I think it's a genius solution actually. You find this way to still be social, you find the balance in your life that works for you and I admire that, in your 21 year old self, finding a way to make a schedule that worked for you and for your epilepsy because you got to a point where you realized you couldn't ignore it. And

		then you graduate and you go on to have a 20 year career mental health, corporate mental health. Tell us about that journey and what you learned over those years.
Mark DeFee:	20:00	I realized helping people is what I enjoyed. I liked talking through kind of difficult moments. And so I realized counseling is where I wanted to be. And it was my second year in graduate school that I realized the workplace is where I wanted to focus. And I had this idea that if you could change the workplace, you could change the world because of that ripple effect. And so I leaned into that and got into a field called Employee Assistance Programs or EAPs where we truly focus on creating mentally healthy workplaces through personal and professional development. And part of that played into my story.
Mark DeFee:	20:40	So my first five and a half years in my career, I was a consultant for companies, but a lot of it was crisis intervention. And you'd be surprised how many employees in this country on a daily basis are in crisis at work. And so it was a moment for me to connect with people who literally had the means in their hands to take their own life, guns, knives, cars, pills, whatever, it was something that everyone around me was like, "Isn't this causing you tons of stress. Are you going to be able to handle this? This sounds like I would just be freaking out." And for me I was like, "It's actually one of the best parts of my day, because I can just focus on somebody and one thing and know that I'm making a huge impact."
Mark DeFee:	21:25	And from there I went into of sales and account management, got out of the clinical side and really enjoyed that because then I could put strategies together for large scale promotions of EAP within companies and do a lot of trainings and put programs together for coaching. And it kind of took off from there, but everything I do now, I try and wrap in that I have epilepsy, so I can create that connection, but also say, this isn't stuff I just studied and practiced in my career. I've been doing this stuff for 25 years now since I was diagnosed. And it all started from this watershed moment in my life that led me a direction I wasn't expecting.
Kelly Cervantes:	22:09	So as you're disclosing your epilepsy diagnosis, using it to connect with the people that you're helping, how was that information received both by patients, by employers, colleagues, coworkers, how did you navigate that in the corporate work and by as opposed to in your previous schooling environment?

Mark DeFee:	22:33	Yeah. I don't know if my route is the right one for everybody. I felt more empowered because it had been some time since I had had a tonic-chronic seizure and I'm well controlled. And so people didn't see that side of me and I kind of saw it more as a, "Hey, I'm still beating you at sales. And I have this thing to carry with me. I have to fly in a day early and go sleep for 10 hours before a presentation. Whereas you fly in that morning, you go home that night and I'm at that hotel room after that presentation because I need to sleep before I get on a flight."
Mark DeFee:	23:10	And so I kind of took it more as a chip on my shoulder and it pushed me harder. And because of that, I don't think people really felt like they needed to provide that much accommodation. My direct bosses, they knew everything, a lot of other people didn't and they just kind of said, "Do what you need to do." And so I felt very fortunate that the people I had to tell really supported me, but a lot of other people just never saw that side. And so it was something to share with them and help them kind of better understand where I was coming from, but I never really experienced that stigma because I want to control the messaging of when I tell people and how much I tell people and who, because I need to trust them I guess, but if I'm really going to tell them how on a daily basis, I can feel my eye flicker because my medication is stopping a seizure, that type stuff. Try not to tell too many people, but I just did.
Kelly Cervantes:	24:16	But I think people are better off for knowing that. They're not witnessing it, but there are all of these side effects that are all of these things that you're battling on a daily basis. You said that your seizures are well controlled, but I kind of want to needle into that a little bit because that doesn't mean that you're not having seizures, it's that they are well controlled in a life, seizure, balance, that you are comfortable managing. So how often are you having seizures? How is your epilepsy affecting your day-to-day life?
Mark DeFee:	24:56	So I've kind of pivoted, I have a lot more kind of focal seizures where I'll kind of stare off, but the biggest impact is what my epileptologist calls just an extended aura, because I'll have these moments, hours where I can't think very clearly and my body's exhausted. I never go into really a type of seizure. I cannot get out of that until I go sleep for eight, 10 hours. And so like, I'll start feeling bad on a flight, barely get off it, slide into an Uber where luckily I don't have to tell them where we're going and I just fall asleep in the backseat and then kind of slide into a hotel room. And so it is impactful, but not in the way I wake up after a seizure, the way I did as a child, or as a teenager, but that still impacts me quite a bit. I don't know if I'd fully say they

		were seizures, but it's definitely related to my epilepsy. And I wouldn't be having these moments if it hadn't been for my diagnosis.
Kelly Cervantes:	26:10	Right. So tell me how you found CURE Epilepsy.
Mark DeFee:	26:17	It's kind of funny, I was starting a coaching program for epilepsy titled The Seizing Life Coaching Program. So I was like, "Hey, maybe I should check out to see if this name's taken yet."
Kelly Cervantes:	26:28	I love it.
Mark DeFee:	26:29	And so I found the Seizing Life podcast and then found CURE, and then I found more about what CURE was doing.
Kelly Cervantes:	26:37	Brilliant. And I understand that you have been helping in some capacity with our post-traumatic epilepsy program.
Mark DeFee:	26:46	Yeah. They asked me to just kind of provide my thoughts on what life would be like if I had been able to be informed earlier about my susceptibility to being diagnosed with epilepsy because of my concussions and my thoughts are I really enjoyed high school football, but if someone after my first concussion had said, "You look like you're on track to be diagnosed with epilepsy if you keep this up." Or, "There are biomarkers telling us you're at risk here." I think I would've said, "Okay, I'm done." But that wasn't available then. And so I was just really excited to be able to add my perspective, because if that treatment or those diagnostic tools become available, I think it really can change lives.
Kelly Cervantes:	27:37	Absolutely. And what I appreciate is when you can take that experience and help give back to these research programs, to hopefully help someone who could have the opportunity to make that decision that you weren't given. What would you tell someone who is newly diagnosed with epilepsy?
Mark DeFee:	27:59	God, I think I would stop and acknowledge, "Hey, this is going to change it everything. And it's going to take some time for you to wrap your head around it. And it's not a straight line. There will be days where you're feeling really good. And then there will be weeks where you're just so angry that this had occurred and wondering why you. So there will be moments where it gets tough and it gets dark, but other people have been able to get to that other side, if you're working hard on yourself and accepting where we are now or where you are now, I truly think

		you can find a life of fulfillment and happiness within our new boundaries."
Mark DeFee:	28:44	Everyone says, "Well, you can do anything you want if you put your mind to it." It's not the case. I can't go to the moon or go even on a deep sea diving or anything like that. But I still have found a life that is very meaningful. And so you can't too. It just, it takes some time, it takes focusing on the right things, but it starts with that acceptance that for the large majority of us, this isn't going away. And so once you wrap your head around that, you can begin that cognitive process of, "What do I want my life to be like?" Instead of just sitting here saying, "This is unfair and why me? Poor me." Yeah. That's part of it. And if you're in that place, nothing's wrong with you. This is part of the process, but you need to be working towards a moment where you can stop and start asking yourself, "What do I want life to be like now?" And moving towards that.
Kelly Cervantes:	29:44	Those are incredibly wise words. Mark, thank you so, so much for sharing your insights, your story with all of us.
Mark DeFee:	29:55	Of course.
Kelly Cervantes:	29:55	And helping our community through your profession. It's really remarkable and we appreciate all that you do.
Mark DeFee:	30:04	Well, thank you. I greatly appreciate being on here and having a conversation with you.
Kelly Cervantes:	30:12	Thank you, Mark, for sharing your epilepsy journey with us and for your support of CURE Epilepsy and our efforts to prevent post-traumatic epilepsy. Post-traumatic epilepsy is a priority research area for CURE Epilepsy and features a multicenter multi-investigator research team focused on better understanding the underlying causes of PTE, so we can prevent it from ever happening. To support this important work, please visit cureepilepsy.org/donate. Through research there is hope. Thank you.
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to epilepsy and any other medical conditions be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.