

Seizing Life, episode 74
One Family, Two Different Epilepsy Diagnoses
Guests: Mary and Tom Nugent

- Kelly Cervantes: 00:02 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 Mary and Tom Nugent to the podcast. Mary and Tom are the parents of three boys, Jack, Quinn, and Will, two of whom were diagnosed with epilepsy at a young age. Mary and Tom are here today to talk about the challenges of raising two children with epilepsy, the varying impact that epilepsy has had on their two sons, and how it has affected our entire family.
- Kelly Cervantes: 00:43 Mary, Tom, thank you so much for joining us today. I want to start off by learning about your amazing family and your three incredible sons.
- Tom Nugent: 00:56 Well, we have three boys, Kelly. Jack, Quinn, and Will, Jack is 26 years old and he actually started his new job as a neurologist at the University of Chicago.
- Kelly Cervantes: 01:11 That's amazing.
- Tom Nugent: 01:13 It is.
- Mary Nugent: 01:13 We're very proud.
- Tom Nugent: 01:15 Yeah, very proud of him. So he finished medical school at St. Louis University School of Medicine back in May, and then just started at the University of Chicago. Then our son, Quinn, is about to turn 24 years old. Right now he's doing some work with the Western Special Needs in our recreation district. He's a part-time camp counselor. He's not quite sure what he is going to end up getting into. We are encouraging him to maybe consider that as a career. He has a lot of empathy for special needs kids, and a lot of that has to do with our family and his youngest brother. So our youngest is Will, who's 18. Both Quinn and Will have epilepsy. Will is very much impacted by epilepsy. He was able to go to school, so it's been great. He's been, right now, transitioning from high school to kind of a transition program, but still able to engage with a lot of his schoolmates and teachers and counselors from the last few years.
- Kelly Cervantes: 02:17 Well, you have, it sounds like, three incredible boys on your hands, or men, I should say, at this point. So I want to learn more. You mentioned that Quinn and Will both have epilepsy. How did epilepsy enter your lives?

- Mary Nugent: 02:33 Well, it's funny because the word "epilepsy" kind of wasn't talked about when Will was diagnosed. So 2003, when he was about four months old, he started having some twitches and some jerks. They weren't very noticeable. You'd have to really be looking at him to see it. So as he was progressing, we kept seeing a little more and more of those jerks, and turns, and odd behavior. About four months old, five months old, we mentioned that to his pediatrician, and the pediatrician just kind of said, "Eh, I don't really see anything here." As time went by, we kept seeing more and more. I was his caregiver, so his brothers were at school, his dad was at work, I was the one seeing this. But again, if you weren't looking directly at him, you might miss it.
- Mary Nugent: 03:27 By the time he was about nine months old, I had mentioned to the pediatrician again. I'm like, "There is something wrong here. He's not quite reaching his milestones. He's not quite there. There's something up." And again, the pediatrician kind of said, "Eh, he's kind of making his milestones. He's kind of there." But I said, "I don't know." Within three weeks, Will started having multiple, multiple events, that were more and more noticeable. I took him into the pediatrician, and on the same table that he sat three weeks before, the pediatrician looked at him and goes, "Oh my gosh, he's having seizures." So, that's where it began, but he was also developmentally delayed a little bit. He was also very high tone, he was off, so there was other things. So we kind of called it a seizure disorder until we could find out what it was.
- Kelly Cervantes: 04:22 Was infantile spasms ever mentioned to you or hypsarrhythmia?
- Mary Nugent: 04:25 Well, there were all sorts. There was infantile spasms, they looked at Angelman syndrome. They looked at all these kind of different syndromes thinking, "Okay, does he fit those?" Bits and pieces kind of fit, but it wasn't quite that. We kind of landed on Lennox-Gastau syndrome. That is the closest we could get to an actual diagnosis for him. He has these multiple seizure types, he's developmentally delayed, he has some autistic features, so that's kind of where he landed, even though it's not the perfect diagnosis for him.
- Kelly Cervantes: 05:03 Right. So that is Will, your youngest, but that is not your only child to be diagnosed with epilepsy. Your son, Quinn, was also diagnosed. What was that diagnostic journey like?
- Tom Nugent: 05:17 Yeah, that was a little bit different because starting when he was, it was nine months, he had a febrile seizure. This was,

again, Mary was home with him first time that it ever happened. So obviously seeing that, this is obviously before Will was born, so obviously that concerned us, that freaked us out quite a bit to see him going into a grand mal seizure. We took him to the hospital. They checked him out and was like, "All right." He did have a fever that day, so we kind of chalked it up to, and his doctors kind of chalked it up to, a febrile seizure. He had another one of those a few years later when he was just at four years old. We had him checked out and just, "Hey, nothing underlying, no issues with him. Just, once again, it was probably a febrile seizure. Just keep an eye on him." It was nothing where we thought that this would continue.

Tom Nugent: 06:11 Until he was about nine years old, we really had a very serious issue with him. He had just come back from a baseball practice, was just eating dinner. I was making dinner for him, and right before I called him over to eat, his older brother says, "Something's wrong with Quinn." He had just thrown up on the couch. I pulled him out of that room, put him in the bathroom, went to go clean up, checked on him, and he's in the bathroom, having a full on grand mal seizure. It was a very serious one. It lasted about three minutes. We brought him over, we're very close to Central DuPage Hospital, we brought him over there. About an hour later, as they were kind of doing some more tests, he had a very serious, about a 25 minute seizure.

Tom Nugent: 07:04 It was just really difficult, just being outside of his room at the hospital, when he's having this seizure. It's one of those things you see on a TV, where people are rushing in and trying to stop this seizure. It was just, I can't tell you how difficult it was, Kelly, just being out there as this is all happening. They really had to give him some really heavy duty medication to kind of stop the seizure, knocked him out for a few days, stayed in the hospital. After that, it was apparent that, "Hey, something's up. This is not febrile seizures." About that time, it was confirmed, "Hey, Quinn, he also has epilepsy."

Kelly Cervantes: 07:40 So now you have two children with epilepsy. What is going through your mind?

Tom Nugent: 07:45 Yeah, that was very, very difficult, because at the time, with Will, we were really struggling with him. We were trying the ketogenic diet with him. We were having a little bit of trouble with him eating, keeping up with that, and his seizures were increasing, and it was just... I remember sitting up in my room, just thinking, "How can we deal with this? We're struggling with William. There's no way we're going to be able to handle this,

with two kids with epilepsy." So that kind of initial realization was extremely difficult. I don't know what you have.

- Mary Nugent: 08:21 Oh, yeah. It was. It was just what the future was. Quinn was an unknown. At this point, we kind of knew what we were dealing with, with Will, even though that was changing monthly, weekly, daily, sometimes, the way his seizures were presenting. So now we're faced with Quinn. What is this outcome going to be, and what is his life going to be? Because his life was different. He was engaged in school, he was engaged in sports, he was engaged with friends. So that was a hard reality, that his reality was changing, his day to day life was going to change, and we were going to have to deal with that, and deal with the child that knew what epilepsy was because he watched his brother.
- Kelly Cervantes: 09:12 You bring up this sort of incredible, intricate path I think you both walked, where with Will you were mourning the idea of what his life was going to be and what it could have been, had the seizures not taken that idealized future away from him, but with Quinn, he was living it. He was living that life, and so that fear, that grief, that worry of losing the life that he was already living, just sort of... It hits that much harder.
- Brandon: 09:47 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: 10:07 How are both boys doing today? Were you able to find treatments that could bring them seizure control?
- Mary Nugent: 10:16 Well, Will, he's been on multiple medications. I think we're count 17, 18 at this point, with different variations of dosages, combinations, timing. We did the ketogenic diet, and then when that failed, we did the Atkins diet, the modified Atkins. We tried the VNS, that was a complete failure for Will. So back in 2011, we decided to do the corpus callosotomy, to have that split of his...
- Kelly Cervantes: 10:52 The separation of the two hemispheres, right.
- Mary Nugent: 10:53 The two hemispheres, correct. So those were done, and he did fabulous. So it was during Christmas break that we had it done, and he progressed very well. We got out of the hospital in two weeks and he was doing great. He even went back to school in

January, back to his class in January. At that point, all these tiny seizures that he had had for so long, that were hundreds and hundreds daily, of these eye blinks and these tiny jerks, they stopped. Will looked at the world in a different view. He saw the world, it wasn't being turned off every second when he had those eye flutters or those jerks. He went to school and the teachers all said he just looked at their faces like it was the first time he could really see them, and his classmates, and his room at school, his classroom, and he was just looking around and we saw this and it was wonderful.

- Mary Nugent: 11:58 So the corpus callosotomy did help, it took away that part of his seizure activity, those small little seizures that blocked out his world. So that was great, but six months later, we started having seizures again.
- Tom Nugent: 12:17 So he does still probably have about two or three a day, just kind of shorter, maybe 10, 15 seconds, with his seizures. But yeah, that's been pretty consistent for about the last four or five years. With Quinn on the other hand, once we started, after that big episode he had, we started with him with Lamictal. He's been very compliant as he's gotten older. We obviously would make sure, when he was younger, he took his medications, but he's been really good. As he's gotten to be older, he got to be an adult, and he's still on Lamictal. He did have a couple of seizures his freshman year in high school. I think a lot of that was driven by something new, getting up much earlier, not sleeping as well, a little bit of stress with that. But since that point, he's not had any seizures. He's still staying on that medication, so we're still on Lamictal, we'll kind of let him determine that course, whether he wants to stay on that or maybe wean from that at some point.
- Tom Nugent: 13:15 But yeah, Quinn's had about, I think, eight total seizures, but obviously I think either he's grown out of that, which is potentially the case, or the Lamictal is certainly helping.
- Kelly Cervantes: 13:27 Your family is in such a unique position to speak on epilepsy because epilepsy affects people so differently. Here, in your little microcosm of a family, you have these varied ends of how epilepsy has affected two different members of your family. The effects of how it has impacted Will's life are pretty clear because it has had such a significant impact on him intellectually. But how has having epilepsy impacted Quinn? I guess you sort of touched on it, but how has Will's epilepsy affected Quinn as well?

- Mary Nugent: 14:10 That has been a tough battle, and it's getting better. The battle's getting better, but Quinn, number one, is Will's biggest protector. Quinn, he is there for his brother all the time. He's his biggest protector. But Quinn has had a lot of anxiety over this. So we ran into a lot of problems when Quinn was younger. One, him understanding what was going on with his brother, but also the chaos that surrounds a child that has a seizure. When we're calling the paramedics and ambulances are coming, and mom and dad are kind of screaming at each other to try to get things in order because, "You need to call 911. You need to watch him." So it's chaos, and Quinn did not do well with the chaos. We would have to calm him down and it was a lot.
- Mary Nugent: 15:04 It was stressful on us, we're trying to care for Will who's having a seizure, and then we've got to go calm our 10, 11, 12 year old because he's freaking out over his brother. But that has gotten much better over the years. Quinn has learned to deal with it, he's learned that he needs to just walk away from the situation, take himself out of it, so he's grown in a big way.
- Kelly Cervantes: 15:31 I think that the growth piece of it is all you can really hope for, because it is hard. It is hard to see someone that you love enduring a seizure. I cannot imagine how much more difficult that is when you, yourself, have epilepsy and have had a seizure yourself, and then watching someone else go through that and it's someone that you love. We sort of touched on this briefly, but I wonder, were you ever able to find a cause for Quinn's epilepsy? Have you done genetic testing? Did anything there bring you any answers?
- Mary Nugent: 16:08 We did do genetic testing. We had originally done it with Will early on, when he was about three or four. A couple years ago, probably about two years ago, we kind of thought, "Things have changed. There's more information out there. They're finding more and more." So we were told, "Let's go do it again." We talked to our doctor and he said this was a good idea. We'd never had Quinn tested previously, but since Quinn has been impacted by epilepsy and seizures, the doctor thought this would be the thing to do, so we needed to do that. So we did have testing, and there is a gene they have gotten from me that does have epilepsy, autism, schizophrenia, some other things, that they had both gotten from me. So both boys carry that gene, and then Will also carries some de novo genes that aren't related to, that he did not get from his family.
- Kelly Cervantes: 17:08 So maybe there's some answers in there, and maybe that leads to better treatments down the road, more focused treatments, one can only hope. Another issue that we've discussed a lot on

this podcast, and we've mentioned a little bit today, the impact of the siblings. Here you have three sons, two of them have epilepsy. How did it affect your eldest son?

- Tom Nugent: 17:40 Well, it had a significant impact on him. I do say that, I think, in a positive way. What's really interesting with Jack is how he dealt with this. He was much more calmer when we dealt with some of these seizure issues with both of his brothers. Just for example, when Quinn had some of these major seizures and we'd have to call 911, we tell Jack, "Hey, wait at the door so you can kind of flag down the people who are in the ambulance coming to help your brothers." He was always very calm about that. He said, "All right, dad. I'll go ahead and do that." So I think he's much more calmer, but also very understanding, and I think he was very curious about these issues.
- Tom Nugent: 18:26 I think it was his sophomore year in high school when he started expressing an interest in getting into the medical profession. He actually got a chance to go kind of spend a day as a neurologist, and that was with Will's neurologist who invited him down to kind of spend a day with him, just see what that is like. Jack came back from that and just said, "This is what I want to do." He just came back with such a focus. "I want to do this." All of a sudden his grades really improved in high school, and he's done very well, obviously, in undergraduate level and then obviously in medical school, but definitely an impact on his choice of career terms of what we've dealt with as a family, with his two brothers.
- Kelly Cervantes: 19:14 Absolutely. Well, we need all the neurologists that we can get. The ones that have personal experience with it, all the better. So we are so excited to have Dr. Jack on the epilepsy team, for sure. I wonder how having two sons with epilepsy has affected you as parents, has affected your relationship? Because you absolutely grow immensely as a person, but there's a cost to that growth, too.
- Mary Nugent: 19:51 There is. As a family, I see it as a lot of our things are split. We don't spend as much time as a group of five. A lot of times it's a group of three. Tom's taking the other, especially growing up, taking the other boys and doing other stuff with them and I would be back with Will, or vice versa. So there was a lot of times where it wasn't this full on family of five, kind of doing stuff together.
- Kelly Cervantes: 20:18 Oh, my husband and I called that the divide and conquer.
- Mary Nugent: 20:21 Yes, yes.

- Tom Nugent: 20:23 Exactly.
- Mary Nugent: 20:24 Ours was because we couldn't take Will on some of these adventures that his older brothers could go on. So that was hard. For us, it's stressful. We try to work it hard not to go at each other and get angry. I think we're angry about the situation and sometimes that comes off as we're not getting along together and we're angry at each other, but we try to not do that. But it's stressful because there's a lot of sleepless nights. There's a lot of sleeping in the other room, or sleeping with Will and watching him, and staying, comforting him or caring for him while the other person is sleeping alone and doing that. So we have a lot of separation in that point, but I think as a team, we try to work really hard on caring for our son and doing the best we can for him. It's been a long... It's hard. It's a lot to work on in a relationship when you're impacted by a hard situation.
- Tom Nugent: 21:39 Yeah, and I'll add real quick. Yeah. As an individual, Kelly, I remember there's a commercial out there. I can't remember what it was for, but it was a parent with a young child. The parent was feeling sick and just said, "I can't have a bad day." That's kind of like what it is, with a child with epilepsy. It almost is like they're still a baby. You can't have a bad day because you're going to run into some of these issues. When you kind of either let your guard down or you're not focused on it, something's going to come out and bite you. So what I've learned, is I've just got to be really organized, whether it be in my work life or anything I do outside of work or family, just try to be as organized as I can so I can spend as much time with the family, especially with Will, making sure that he's safe.
- Kelly Cervantes: 22:32 Absolutely. From the outside, for what it's worth, it appears that you guys make an incredible team. I think that is incredible advice. When you are parenting a child with epilepsy, there is so little about the epilepsy that you can control. Focusing on those pieces of your life that you can organize and that you can control, so that you can manage the variables. Is there other nuggets of wisdom that you would care to share with other epilepsy parents who are on this journey also?
- Mary Nugent: 23:08 Well, when they're first on this journey, I think it's listening to you. Your doctor sees your kid every year. Your neurologist, when you get to a neurologist, they see him every six months, maybe four months. Just be strong in what you think your child needs. Research, and talking to your doctor, and making sure that they're listening to you, because again, you are there 24/7 and they're there once a year.

- Kelly Cervantes: 23:43 Yeah, absolutely. You have to trust your gut. I think it's a learning curve because we sort of grow up thinking that doctors know everything, but, especially when it comes to the brain, there's still so much unknown. We do. We have to educate ourselves and advocate for our kiddos.
- Tom Nugent: 24:02 Yeah, and I'd add, to me, it always helps to be part of a community. At times, especially early on in this journey, I felt like we're kind of out here on our own, which is not a great feeling. So I think one of the things I did, too, is I started doing more research, connecting with different groups that are associated with epilepsy, doing as much research as I can to find out about, especially when Will, when we had to make that decision to go through surgery. Medications, you can stop and start those. Brain surgery, that's irreversible. That was a really major decision. I think that's when I really started finding lots of resources, doing research, and definitely staying connected to communities because it's such a hard condition to deal with. I think it's good always to know that there's other people dealing with this. While we've all got different situations, I think it's always very valuable to stay connected just to understand, "Hey, we're not the only ones out there dealing with this. Let's hear from other people," and always maybe draw some information on how people deal with these situations.
- Kelly Cervantes: 25:09 Beautifully said. Thank you both so, so much for joining us today for sharing your experiences and your journeys. I truly believe that our listeners are going to take so much from this conversation today. So I really do appreciate your time. Mary, Tom, thank you.
- Mary Nugent: 25:27 Thank you.
- Tom Nugent: 25:27 Thanks, Kelly.
- Kelly Cervantes: 25:33 Thank you, Mary and Tom, for sharing your epilepsy journey with us. As Mary and Tom's story demonstrates, epilepsy can impact individuals in extremely disparate ways and ripple through families with deep emotional, mental, and physical consequences. CURE Epilepsy was started by mothers who understood the wide ranging impact of epilepsy on their children and families, and who yearned for better treatments, more research, and ultimately, cures. Over 20 years later, we have made great progress in understanding seizures and producing new treatments, but we must continue to push science forward toward finding cures. We hope you will help us advance epilepsy research by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

Legal Disclaimer: [26:30](#)

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