Episode 4: A Personal Journey with Epilepsy

Please note: This transcript has been lightly edited for clarity, flow, and readability.

Welcome to our podcast Epilepsy Uncovered where Kayla, Brooke and Bella, three occupational therapy students, bringing to you a special series focused on shining a light on epilepsy. In honour of being November, which is Epilepsy Awareness Month, join us as we explore four different topics over the next four weeks. Whether you're living with epilepsy, supporting someone you know, or simply just curious to learn more, this series is for you. So, sit back, relax and enjoy.

Kia ora and welcome back to the Epilepsy Awareness Month podcast. This is episode number four and our last episode for November 2025. Today we're talking about epilepsy, of course, but not from a medical textbook. Instead, it is through the lens of a personal story. We are honoured to be joined by David, who is here to share his story.

So, welcome David. So glad to have you join us here today.
You're most welcome. Thank you for having me along. It's a pleasure.

So, to start off with, can you briefly introduce yourself to all the listeners out there?
Well, as you've already said, I'm David Nicholls. I've had epilepsy since; I was about two years old or something along those lines. I’ve never been able to drive. I've got a couple of kids of my own. I'm in my fifties now, so that is a long, long time. I've done many things across my life, including working in NGOs across that time since I was in my teens. So, you know, I've been all over the place.
Awesome.

We know that you also work with Esther at Epilepsy Waikato Charitable Trust. Can you tell us a bit about your role and what that means for you?
I do, my role has been many and varied. I actually started off there as one of the trustees. I was one of the founding ones and then I took a bit of a break and came back as the administrator for the trust, part-time. Then they asked me to also help out with selling the alarms. So now I do both roles and effectively I’m full time.

So, David, can you tell us a little bit about your story with epilepsy?
I think my first seizure was probably so long ago that I couldn't even remember. It would have been way back when I was a toddler. That would have been back when my parents were trying to figure out what was going on. Funny enough, my dad was actually a doctor. So I did have the privilege and benefit of at least having parents who worked in the medical field so they were able to call upon various other people who had an inkling of what might have been happening. However, it did take a little while back in those days to get things sorted out and I ended up under a paediatric doctor for a while. Pretty much it has continued through the decades. going through the public health system with various neurologists. Unfortunately Waikato back in those days, well, New Zealand as a whole really didn't have much luck with neurologists mainly because we're a small country. So I went through a slew of neurologists, all trying to figure out the various different reasons why I might have epilepsy, what might be causing it, how to treat it. I'm one of those drug resistant or therapy resistant people with epilepsy. So it just makes life more difficult and also, I

consider myself in a bit of a privileged position, both being male and also being white. Also coming from a family with a medical background. You know, I have a bit of an Advantage there feeling like I can talk back to medical professionals and go hang on a minute, listen to me please.

That's important.

It is actually; it's something I try and talk to everyone I come into contact with about because they don't call it a medical practice for nothing. They are all still practising medicine, if you will. Not that I don't have respect for medical practitioners, but they are all still learning, no matter what.

Well, that's me and Kayla at the moment. are third year OT students. So, this is why we're actually doing the podcast to be able to learn more about epilepsy ourselves and to hear those lived experiences. So cool to have you on the podcast with us, David.

Thank you. It's a pleasure to be here.

So, I had a bit of a question around with your dad being a doctor and being able to, suppose, get you on the path to diagnosis a lot quicker. I suppose when you first had your first seizure, you probably weren't even aware of being a toddler. What was that like for your parents? Have they ever talked to you about kind of witnessing your seizures or um how they kind of even started to think about what could be epilepsy?

They've never really spoken to me directly about it, but I can certainly infer what it was like for my parents from the way they've reacted over the years. I can certainly say it made them more concerned for my wellbeing. They were definitely more protective. Although they certainly, well my mum was trying to both be protective and allow me to do my own thing at the same time. At times it was still frustrating because I felt like she was holding me back. I could certainly tell that they had those moments where they were quite nervous, shall we say about things I was trying to do or what they wanted me to do, but they were still trying to let me do my thing.

I think that's totally understandable. It's such a tricky thing about how much freedom do you give your child, and you also want to keep them safe. So, I think that's a really tricky thing.

Especially as kids, as they grow up and especially as they go into the puberty years, once they hit the areas around eight- to ten-year-old mark and then go into their teens because that's when they don't want to be different from their friends and they start rebelling. They want to be able to go out and get drunk and do whatever. I guess I was a bit of an outlier. I'd already grown up with epilepsy and handling my own meds and understanding what repercussions would likely to be, but I knew enough other people to know what they were likely to want to do and all that kind of thing. So, I could kind of understand. It’s funny, I was always a kid that would go to my friend's parties and kind of drink water and hang out in the corner and still have fun but know still but be participating in those parties where all my mates were like certainly in the teen years lying under a chair and opening a cask of wine into their mouth and then sleeping the night under the lemon tree which is a story I know one of my friends will not like me admitting to.

We'll cut that bit out.

No. No, no, no. Don't, don't because it'll be too much fun to watch them squirm.

Talking about how it impacted you in relation to your peers, did you ever feel quite different from your peers then? Like they couldn't quite understand kind

of what it was like for you and you had to sort of grow up a little bit faster because of having epilepsy.
I definitely had a good chunk of teasing through school. I remember primary school was not a fun time. You know, was one of that group of kids that would be on the edge and because I was on so many drugs, my memories were pretty hazy. My coordination was pretty bad. I'd participate in sports and that would be a crap experience, right?
That would be hard.
Yeah. So, you know, I got a lot of teasing for not being great at sports. I've got some good friends who also now have disabilities and understand. But back then, they were very much able-bodied and ran around like nut jobs and drove cars like hoons when they were in their teens and you know, did all those things that teenagers do. And I didn't really get to participate and that's, you know, that's what happens. It's just part of life.
Thanks for sharing that little bit of insight about especially what primary school was like.

Could you kind of tell us what epilepsy has impacted, how it has impacted your daily routines or any other activities you enjoy doing?
Well, believe it or not, I've tried not to let it impact my daily routines to a point. So, from the age of 11, I did an early morning paper run. So, I was just amazingly fit for many years. I also used to tramp. Our family used to go off bushwalking. I cycled everywhere because I'm not allowed to drive I had too many seizures. When cell phones became a thing, I actually got a cell phone that had voice dialling. So, voice recognition and dialling as a safety function. So, it was one of those Nokia bricks, but you know, it was built solid. and could handle any kind of crash; in fact, one time I did have a seizure out on a country road in the middle, almost in the middle of the night, coming back from a girlfriend's place and literally used the phone on a country road to dial. I dragged myself across the road to someone's house and went I need to get some help, please. I've done all sorts of stuff like that. I've tried really hard not to allow my epilepsy to, 'define me' while also trying to be as sensible as I possibly can. I'd desperately love to ride on a roller coaster and love to go climbing, cliffs or abseiling, but I know that having a seizure up a cliff would not be a good thing.
No, certainly not.

In terms of the impact it has in terms of not being able to drive, can you talk to us a little bit about that, David?
There are a lot of times when I'd really love to be able to be a second driver in the household, for one thing because, driving can be super stressful. I know that my partner and I really dislike going to Auckland because of course the roads there and the drivers there are insane. There are a lot of other times when that would be really handy, like back when our kids were young being able to drive at a time when my partner was sick or whatever would be great. However, on the other side of that coin, there are things like total mobility where you can take taxis for half price. Not everyone is in a town in New Zealand that has the ability to do that though. But for me, the half price taxis have been a good side benefit.
Oh, that's awesome.
And free buses through that same scheme has been great. I would say in some ways it doesn't quite or completely make up for the lack of being able to drive.
Especially in those teenage years, you know, when you're turned 16, you get to go

sit your test and then go drive and that sort of thing. It's an experience that I suppose you didn't get because of that.
Although on the flip side of that, having cycled for decades and seen the insane driving, quite frankly, these days I do not want to drive.
Some crazy drivers out there.

Well kind of leading on to that. So, we understand that some people with epilepsy can drive if they're medicated and some people can't. Could you kind of tell us about how frequent your seizures are and what type you have?
Yeah. So, I have a little mixture of seizures to start with I have full on what used to be called grand mal or these days they're specified as tonic clonic. But I also have a few mixtures chucked in there. So, I have myoclonic jerks and they're constant little twitches down my left side of my body. My head might jerk, my arm will go, my leg will go. It's kind of annoying because it's just this constant twitch and it ramps up the tautness of all the muscles up the left side of my body. Back when I was younger, it used to be, I'd go to the pictures, it used to be quite violent. I'd go to the movie theatres with friends and they'd go, what, what? And I'd be going, what are you talking about? And they'd be going, you nudged me. And I'd be like, what? And it would have been a Myoclonic jerk. It does change sometimes over time. Depending on medications, the brain's a weird thing so at the moment, I'm having seizures every few weeks, often in couplets or groups of about two or three. But the brain being what it is, it's kind of weird. What happens is sometimes when you go onto a new medication or get a change in regime, the brain will go oh, here's something different and, this medication is now working and doing its thing. So the brain will go, I'm now not having any seizures. And then over time, the brain will figure out kind of, well, especially in someone like me, it will figure out how to get round that new barrier that's stopping it from having seizures. And then you'll go back to having more frequent seizures.
Right.

So is that sort of the journey that you went with medications? It was like trying one and then it would kind of work for a little bit and then all of sudden the seizures would be back?
In part. So, I've had, I've gone through pretty much every medication there is in New Zealand. I'm even on the ketogenic diet, a really strict medical version of it. Certain neurologists do not like calling it the ketogenic diet. They like to call it the metabolic diet simply because the diet industry or weight loss industry has hijacked it for weight loss. But if you're doing it for something like epilepsy, or diabetes. It works for all sorts of things. You should be doing it in conjunction with your doctor and a dietician and your neurologist. I try and keep the carbohydrate intake down to about five grams per meal, which is really low but that's why you do it in conjunction with neurologists, dieticians and doctors because you have to keep an eye on things, including your weight very specifically.

In terms of school, David, can you tell us a little bit about how having epilepsy kind of affected your daily life at school and what that was like?
Quite frankly, big time, especially by the time it got to high school. At that point in time, my neurologist was basically taking the tactic of giving me one drug and then going that didn't work, let's add another drug and then let's add another drug and see if that works and then let's add another drug and so I can't even remember how

many drugs I was on at time. I was basically a zombie through most of high school, I can't even remember a lot of it.

Do you think if you'd had kind of more support from your teachers and your peers or people had just known about it a bit more that it might have been a bit of a different story for you going through primary school and going through high school and those challenges.
I think so. I mean, part of the story is still how many drugs I was on. I mean, that's a difficult one in itself because you can't change the neurologist at the time and you can't necessarily blame them for doing the thing they know to do. But I certainly think it might have made a difference with more support for and from the teachers of the time. But once again, it's all about knowledge. These days actually, I have a friend or two who are teachers and they've actually asked me to have a chat with students they teach who have epilepsy. As a kind of ‘peer’, you know, who are going through puberty and you know, starting to act out and all that kind of thing.
That's really cool. Being able to like to communicate with someone.

My dad has epilepsy and back when he was younger, he had the absent seizures. So it wasn't so much the convulsing, but he always felt so alone, and he always, felt different and he never had anyone to talk to. So, I think that's really cool, incorporating that and being able to kind of meet with other people and speak about something.
It's quite difficult too, when you have absence, because it's pegged as daydreaming quite often.
Yeah, he found that. To someone witnessing it, you would just assume, if you had no idea what epilepsy was or that it was even a seizure, then you would just be like, they're just, zoning out every now and again.
I mean, the crazy thing is there are thousands of different styles of seizures as well so someone might be doing something that you wouldn't think of as a typical seizure and it's actually a seizure. People have psychotic breaks as a seizure. There are weird, weird types of seizures out there.

My dad's seizure progress had generalised, and I can still remember the time when I was like seven and this was the first time, I had witnessed a seizure, and I was terrified. I had no clue what epilepsy was, it wasn't something we spoke about much or anything I knew about in school either. So, I think providing a little bit of education and just taking away some of that fear for the people around you as well, because it's terrifying or the person, but I guess all those people that surround them as well.
Well, the cutest story I've got for you is with my daughters. I trained them from, I'll say trained them, but I've taught them. It is a form of training, but I basically taught them from a very early age. One, not to go near my drugs. Two, what to do when I had a seizure. I always used to take them up to Crèche. So, I'd be chucking them on a bus, then walking them up the hill to the Crèche in a push chair. And one morning I got one of my daughters up to Crèche and then promptly had a seizure. And so, I woke up with a blankie, a pillow and a cuddly teddy bear. And my daughter telling everyone, “Don’t worry. Daddy's just having a seizure, he has epilepsy”.
That’s such a beautiful story. That's adorable.
It was totally adorable.

Ever since, that's what I woke up with when the kids were young. It'd be like, here's a teddy bear, Dad.
That's so lovely. I'm so glad that you were able to explain that, to your daughters and to have them know in those situations. Some really important conversations to have with family.

In occupational therapy, we often use models to consider our overall health and wellbeing. So, I thought it be a really good time to incorporate Te Whare Tapa Wha and this is the four walls of wellbeing. Have you heard of it?
No, I haven't. I talk about wellbeing with people, but I haven't heard of that.
One of the first walls is Taha Tinana, which is physical health.

So, how does epilepsy affect your physical wellbeing and what helps you to manage the side of things?
In terms of physical wellbeing, it's affected my physical wellbeing in all sorts of ways. I don't often get severe injuries. Usually, it's just tiredness or a couple of bruises. Ever so occasionally there are bad injuries. So, I've damaged my back a couple of decades ago and the knock-on effects of that have been irritating. So, every now and again I have a seizure now and it tweaks my lower back which means I need to go to an osteopath or physio. The seizure I had that damaged my back was particularly bad. I was half on, half off a couch. So basically, I ended up in, lying flat for a week or two, and in massive pain. ACC actually covered that because they don't cover everything for people who have seizures when they damage themselves.
That's an interesting thing to note.
Yeah, it's the same with dental damages. There's all sorts of little bits and pieces where if you're kind of lucky and you have an accident while having a seizure, then that will get covered. But if it's just something like grinding your teeth, perhaps that possibly won't be covered by ACC. It just occasionally I'd do damage to myself. I would imagine I'll be a very wrecked old man by the end of my life.

I've got a very positive outlook on life for someone who has had epilepsy since I was young and been through the various things I've been through; I guess. Sometimes irritates my partner. But the way I put it the other day, was that, in some ways it's a bit of a defence mechanism. Because if I don't have a positive outlook on life, I would just probably be unbelievably depressed.

Actually, that's another one of the walls of Te Whare Tapa Wha is Taha Whanau, which is, family and sort of social well-being. What role has your whanau and support network played in your journey?
Well, certainly my immediate family have played a fairly important one. I have a very supportive partner. My extended family has been pretty supportive over the years. Though my mother and my partner have been the two main supportive people, especially in the last; blimey, 23 years, 24 years my partner has been the mainstay and my kids have been pretty important.
That's great.

In terms of personally, Taha Hinengaro is about mental and emotional health. How do you take care of your mental wellbeing when things get challenging?
That's a good question. As I said, I've developed that sense of having to be an optimist over the years. Looking back, I have, I guess, been through some pretty

tough times, the 90s especially with the socioeconomic times, the way the government went, and the 80s with the changes that were made to welfare and various things like that were pretty tough. So, I had to learn to kind of in a sense compartmentalise things and learn to take myself away from certain situations. So, and give myself some mental time to have a break so that I could process.
Absolutely it’s super important to take that time to process.

Well, David, Ngā Mihi Nui. Thank you so much for sharing a part of your story with us today.
You're welcome. It's been a pleasure.
We so appreciate your vulnerability and spending this time with us. I think for me, a take home message would be that if you are someone living with epilepsy, don't be afraid to share those stories and tell those around you about it.
Definitely. Ask the questions. Have the discussions. Don't be afraid to tell people.

And with that we wrap up the fourth episode of Epilepsy Uncovered. Thank you so much to all the listeners out there for joining us this November for Epilepsy Awareness Month. We hope you've learned something new and be sure to share this podcast with your whanau and friends. Ka kite anō!