Episode Two: Living Well, Diagnosis, Treatment and Tools.

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.

Welcome back to Epilepsy Uncovered. In today's episode, we will explore how epilepsy is diagnosed, treatment options, and what supports are available, also discussing tools and technologies out there. Today, we are joined by Esther and David from Epilepsy Waikato Charitable Trust. Thank you for coming in.

So, to start us off, kind of recapping episode one, first we kind of talked about… what epilepsy is and what this looks like and some stats. So today I wanted to focus a bit more on the diagnosis process. Can you walk us through what getting diagnosed looks like?
Yeah, sure. There are a few different ways, a few different tests that doctors can use to try and diagnose epilepsy. So back in episode one, we talked about how epilepsy is a tendency to experience recurrent, unprovoked seizures recurrent meaning again and again. So, in terms of diagnosing it, often that recurrent part will come into that and they'll want to be putting those tests into place after a person has been having several. If a person has one, they might do an ECG to see if there's a problem with their heart that's causing their seizures but if they're having recurrent, then they might do an EEG, which is an electroencephalogram and it involves this little thing being put on their head and it's got these little nodules and what it does is that little sticky bits on their head, they record their brain waves so that's one of the ones they use. And then there's a couple of others, a CT or an MRI, which are like a brain scan, and they can pick up things sort of inside their brain, not so much focused on the brain waves, but is there like some sort of brain tumour or is there something that can show up on a scan? Sometimes they might do blood tests as well, particularly if they think that maybe the person has an epilepsy syndrome and it might be one that's caused by genetics so, that's one way as well, that's a bit of an extra and then alongside that, they'll be looking at the details that somebody's been able to record of the person's seizure visually or if they've been able to write down some notes around the person's seizures and they'll use that alongside those tests. It's almost like a bit of a diagnosis tool in itself but not one of those tools can be used on its own. It'll always be some sort of combination of those different methods.
Awesome, Thank you for sharing. There's a lot of different techniques and going on to say how the person has to record their seizures and we'll touch on those seizure diaries later on in the episode.

Who diagnoses someone with epilepsy?
Now, it depends on the person's age. So, it'll either be a neurologist making a diagnosis if the person is above 17, 18, so an adult. Under that age, 17 and under, it would likely be a paediatrician. Sometimes paediatricians at Waikato Hospital, so specifically where we are, we don't have any paediatric neurologists at Waikato. So sometimes paediatricians here at Waikato might reach out to a paediatric neurologist

up at Starship in Auckland. And people like EEG technicians will obviously be involved in the process. They won't be making the diagnosis, or an MRI technician, if they've been involved in the testing, they're a part of the process, but not the diagnosis per se. Yeah, so it can be bit of a combination. It can depend on how complicated the epilepsy is as well I guess you could say.

I understand this can be a really scary time for people experiencing epilepsy or their surrounding whānau. What kind of supports are out there to help during this time?
Yeah, there's a lot of different supports, I guess to be honest, not enough supports. It depends what part of their life you're looking at. So, if it's their mental health, then is there free counselling sessions that they can get put in place through the GP? Is there a school counsellor? Some schools have social workers. They call them SWIS (social workers in schools) and sometimes they are involved in that process If we're looking more so at their physical health, then having a good GP, having a good pharmacist, they're really important to be able to maintain good health around their seizures and whether their treatment's working, also just more generally because they are, know, GPs are general practitioners so they're looking a little bit more fully at the process and then I guess there's also supports out there around things like emotional health, I guess you could say, and looking into different social services that could be helpful, whether that's through housing, finances, employment, education. Different people can get involved in different facets of the person's life.

Then once someone has been diagnosed, what are the main types of treatments?
Yeah, there's a couple so, there's two that are more well known than the others one of them is anti-seizure medication or used to be called anti-epileptic drugs. But they changed the name because the drugs aren't actually working to stop the epilepsy, they're just working to try and stop or control the seizures. So, they're now called ASMs, anti-seizure medication, and they control seizures in about 70% of people with epilepsy. There's about 20 something different anti-seizure medications. That controlling may not be all of their seizures, or it might mean that they might still have a similar amount, but maybe their seizures are shorter. For the people that this medication works for, they may also be on more than one anti-seizure medication. And there's a 30% of people with epilepsy that anti-seizure medication just doesn't work at all. It doesn't shorten the seizures; it doesn't stop the seizures or make it so there's less of them. So that 30%, they have intractable epilepsy or medication resistant epilepsy. So, there's a couple of other options out there for them, not that they're so well known. And even the 70% who the medication works to control their seizures; the side effects of the medication can just be awful. Every anti-seizure medication has side effects. I even hear some people who don't have medication resistant epilepsy say, well, I'd rather have more seizures, still be on my medication, but be on less medication, because I just really don't like the side effects we've talked quite in depth about that portion. If we move to the 30% that do have medication resistant epilepsy, sometimes brain surgery is an option depending on if doctors can tell where the seizures are coming from, which is why it's really important to note down what we're seeing for them to do EEGs, to do all the right kind of testing. Sometimes they can remove a whole lobe of your brain, they might remove a part of a lobe, they may sever the connection between both sides of your brain. Sometimes they use lasers and all sorts. So brain surgery can sometimes be

an option. And then there are two that aren't as well known. One is the ketogenic diet, which has been around for about 100 years. It was actually the original treatment for epilepsy. So, if anyone listening has heard of the keto diet, it's the same thing. It was originally the treatment for epilepsy, but as you can see, it's helpful for other things out there as well and it's basically a diet that's low in carbs, has adequate protein, and has high fats. The fats convert into ketones and then the ketones have an anti-epileptic effect. So yeah, that one's been around for quite a while, but a lot of people don't know about it because when medication came in, it sorts of went out of fashion because it can be quite restrictive. There are a few different versions of the ketogenic diet but the most restrictive one is the one that has the most impact in terms of controlling seizures.
Only recently has Waikato Hospital had someone trained on the ketogenic diet to help people with intractable epilepsy, but only for children, not for adults with intractable epilepsy. Then the fourth treatment option is the vagal nerve stimulator so, that basically is a pacemaker for your brain, involves a little unit being placed under your skin next to your chest, and then there's a wire that comes up from that unit, from that generator up around your left vagus nerve. And what the generator does is it sends regular pulses through that wire up to your brain to try and control seizures at a regular pace, but also people who do get fitted with this get a magnet that they can put over the generator if they feel a seizure coming on to try and control it. Also, an added bonus of the vagal nerve stimulator, the VNS, is that it can have a positive impact on a person's mental health as well. It's shown that in the statistics that it can have that impact. So, as well as the possibility to control seizures or lessen seizures for a person with medication resistant epilepsy, it could also have a positive impact on their mental health, which is really cool.

We know of a handful of people that have been fitted with a vagal nerve stimulator in New Zealand, but the type of funding or the ways that they've been able to get that has been through the hospital that they get it done, having the money to be able to fund it, the family sometimes just funding it privately and it's a massive cost. Or the other option is sometimes local politicians might be able to support that person getting that funding to get that done.
Totally, there are so many different treatment options out there.

Going back to the medication, I had a bit of a question. Do medication dosages change over time? Does someone become, say, more medication resistant?
That's a really good question, and I guess the simple answer to that is yes. So usually, a person's put on a medication and what happens is they say start low, go slow. So, they'll be put on a smaller amount, and it'll get increased over time. Now once it gets to that dose where it should theoretically be controlling their seizures and if it is, then they'll be kept on that until anything is noticed that is changing. If the side effects become super untenable or if the person says, well I've been having seizures, I've been having breakthrough seizures but I haven't been changing anything with my medication, I've been controlling my seizure triggers as much as I can that may show that that medication isn't working for that person any more, that their brains become used to it. Maybe their seizures have changed over time, because that can happen too and certain medications work to control different types of seizures. So, some medications are good for focal and for generalised seizures. Some are more so just for generalised or just for focal. So, there can be a few different reasons as to why medication dosages might change or the medication in

general or whether maybe a medication gets added. I've heard of a couple of our members even who have been on a handful of medications, and they don't know whether they're in the right to say, hey, can I have a medication review or whether doctors know best and that's the reason they're on so many medications so it can be quite confusing.
It's really good to know that there are other options, not just medication being the one stop fixes all kind of thing. Yeah, and I think it's really important to think about someone's mental health and emotional wellbeing going through all these changes.

I wanted to talk about what does stress and anxiety and mood changes do in relation to epilepsy.
A large proportion of people who have epilepsy will have some sort of mood disorder as well, whether that's anxiety, whether it's depression. For some people, their seizures or their epilepsy might have so much of an impact that it might be suicidal tendencies, sadly. It might be behavioural challenges that they face. Some people with epilepsy have agoraphobia and they just can't leave the house. I think in terms of mental health, there's a few different areas where we can look into that there'll always be, I guess, that side of epilepsy as it’s a disorder that affects the brain. And when we think about mood disorders, it's also things that are going on in our brain in a different facet or in a different area of the brain, perhaps, or maybe even within the same area and that might be why some people with epilepsy do suffer more from certain mental health conditions. It may be the medication itself that's having an impact on their mood for example, the anti-seizure medication that's called Levetiracetam, or most people know of it as Keppra, that's the brand name. Some people talk about having like a Keppra rage. So, if you have a mood disorder or you're more prone to having a mood disorder, then being put on an anti-seizure medication like that's not the best choice because it's just going to possibly have even more of an impact on that. So, I think there's there's a part that we won't ever be able to control depending on where it's happening in the brain or with the treatments, how much they're being offered, the different types of treatments that might have an impact on that mental health. I think in terms of societally, I think if we are able to remove the stigma or some of the stigma around epilepsy and the prejudice around it, I think that will help with the mental health of people who have epilepsy because they'll feel understood and that people will be educated around what they're experiencing, at least to a degree.
That's so interesting. I didn't know how much medication could affect mood.

Moving on to some different questions. What are some of the tools, technologies that can help a person manage their epilepsy day to day?
Well, you've got things like personal alarms, you've got fall monitors, you've got all sorts of other things, seizure diaries, which aren't exactly a technology, but some people use apps for those. We've got a book, a paper version of that.

Could you tell us a little bit more about the seizure diaries?
The seizure diaries are pretty simple. The paper versions are pretty much ah a page where you record your seizure, your seizure type, what time, what medications you're on, try and include your triggers. So, what you think might be setting off your seizure and any other relevant facts. And the idea is so that you can kind of try and see a pattern. And that's something you can hand over to your neurologist or your

GP. The idea there is so that you can try and improve outcomes for your medication, either to have less medication or to have a better medication regime.
I think going into like doctors' offices, it can be quite overwhelming presenting all the information and you often forget things. I think that's quite a good idea to have somewhere where it is all written down.

Could you kind of talk to about what seizure alarms are?
Seizure alarms. In fact, I've got one on my hip. It's not one we sell. It's a fall monitor and GPS tracker. But the ones we sell are things like the SAMi camera, which is a nighttime camera system that tracks movement and sound then within that threshold, if it detects something outside that, then it will send an alarm to a base station, essentially is an iPad that then sounds the alert for parents or caregivers. And the other ones we have are things like or used to have was a night watch, which is something similar. It's a band kind of thing. There's a new version coming that detects heart rate and movement and blood pressure, I believe from memory. There are also things like a watch type system that can be worn that also detects falls. But the one thing with watches is that they're not as reliable. We found the SAMi is very popular.
It's fantastic in not only picking up seizures when they're happening and alerting the person's family members to the seizures but also getting that video record so then, the family can show those videos to doctors to say here, this is what the camera's picking up. Can you tell me a little bit more around this? Have we got the right treatment in place? Is this a seizure type that we weren't yet aware of and that kind of thing?
It's fascinating what technology can do these days.

So how can these tools support safety, independence and peace of mind for both individuals and their families?
Essentially for something like the SAMi and the nightwatch type stuff, it means parents often feel like they are so nervous, they need the children sleeping in the bed with them. So that's the most immediate benefit. They feel like they can have the children sleeping in their own bed and then they suddenly get more sleep themselves. So that's the most immediate benefit, right? Plus, they get the bonus thing with the SAMi where they get a video of any seizures happening that they can go, here look, here's some footage of the seizures that are happening. And the neurologist can then look at that and go, oh, actually, it's not just that type of seizure, it's this type of seizure too, and then that one chucked on top or actually it's not that type of seizure it's this type of seizure. So, you know, you've got all that kind of thing thrown in. The other thing is there are a couple of other different monitors like the epihunter, which is a headband that takes an EEG that you can just walk around with it has a little thing that goes on the hip and it just has a battery and it takes an EEG as you walk around during the day and it stores that information, you can give that over to the neurologist. There are all sorts of stuff like that.
That's fascinating. I never would have thought of that.
Can I add something there?
Go ahead.
Sometimes parents and staff at schools find that the epihunter could be helpful in terms of like absence seizures specifically, they say to me, how do I tell if this child's just having a daydream or are they having an absence seizure and they're so sure what can I look out for and if for that particular child there's not much of a difference

between what a daydream and what an absence seizure might look for them, something like the epihunter could help in being able to monitor those brain waves if they are having an absence seizure as opposed to a daydream.
That's really interesting.

Do you think there's any barriers for people trying to access these different types of technologies?
The biggest barrier would be money.
100%, It's a hard one.

Could you roughly speak on maybe some of the costs?
Well, in terms of money, the costs aren't what I'd call enormous, unless it's for something like the Nightwatch, which once again currently isn't available here any more until the new version comes out, which was round about three grand. Essentially if you didn't have enough money to get these things, funding through the ministries or ACC is almost non-existent as you have to meet very specific criteria. You're looking at around $1,000 for something like the SAMi camera or the Epihunter is on a subscription basis. So I can't even give you a specific number on that because of that particular reason.
Definitely and epilepsy is an ongoing condition. It's not going to stop. So, paying that subscription can really add up.
And even some of the software that's available for smartwatches, they make it a subscription because it's an ongoing way of making money on an ongoing condition. Which is pretty annoying in my view.

Do you think there's any other barriers to accessing these things?
Awareness and the way epilepsy is classed officially in government agencies.
Sometimes it's not classed as a disability even or sometimes as a specific type of disability and then one organisation says, well we don't fund for that type of disability, we only fund for physical disability or we only fund for this particular type of disability and tries to find that grey space where they can put your epilepsy so that they don't have to fund it for that person.
The term episodic event comes to mind which is how they get around it.

In terms of within the community, what sort of resources are available in terms of maybe apps or information to help people be more educated on the topic, that sort of thing?
We've got a website. It's www.ewct.org.nz and there's a ton of information on there aside from those sorts of things online, we do have books alongside our seizure diary, we've also got a book called Understanding and Managing Epilepsy, which was written by our previous epilepsy advisor, Maria Lowe. Then we've also got a couple of kids books, Ariana and Jack and Ben's Buddies, which are helpful in reducing stigma around epilepsy. We've got a quick and easy read that just very basically breaks down epilepsy into its simplest terms; there's a few different resources out there that people can access to learn more.
I know some of those resources are also starting to be translated into Te Reo Māori as well, Esther.
Yes, so our kids' books are already in Te Reo Māori. So, Ariana and Jack and Ben's buddies are both in Te Reo Māori. We are in the process of translating our quick and easy read into Te Reo alongside a bunch of other languages.

Awesome. That's so cool.

So we've talked quite a bit about lots of different things here. What do you think is sort of the most crucial thing or what would you like people to take away from today?
I say, you you're the expert on your own health. You're the expert on what you're experiencing. Don't let people tell you what you're experiencing. Really put your foot down and know your worth.
That's such an important message for all our listeners to take away.

Thank you so much Esther and David for featuring on the podcast Ngā Mihi Nui. And listeners, tune in next week as we hear about Esther's role with Epilepsy Waikato Charitable Trust and all the incredible mahi they do within our community. Ka kite anō!