Episode One: Epilepsy 101 Busting Myths and sharing facts.

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 to our first episode of the Epilepsy Awareness Month podcast. This episode is all about understanding what Epilepsy really is, breaking down some of the common myths and sharing facts to help reduce stigma and raise awareness. Today we're joined by Esther, who is the Epilepsy advisor for Epilepsy Waikato Charitable Trust.

As the others have said I am Esther and I am the Epilepsy advisor at Epilepsy Waikato Charitable Trust. We'll talk a little bit more about EWCT in our next podcast, but today yeah let's break down a little bit more about Epilepsy and have a chat more generally around that first word of our organisation.

So Esther, to begin, what exactly is Epilepsy?
What is Epilepsy you ask? So, Epilepsy is a tendency to experience recurrent, unprovoked seizures. So if we break down the definition a little more, it being a tendency to experience recurrent, so recurrent meaning again and again and again, unprovoked basically means that there's not, you know, you don't have an illness that's brought it on or you haven't whacked your head and it's brought on a seizure straight away. So those are provoking factors for seizures. There's a bunch of others as well.

And what about who can it affect?
It can affect absolutely anyone, a person of any age, any gender, any ethnicity, anybody can be affected by Epilepsy because as we know, it's not just the person who has the condition that may have struggles but the broader group around them and so in my role I support the person but also the community around them.

So when it comes to causes or risk factors for developing Epilepsy, can you talk to us a little bit more about that Esther and sort of clarify what that even means?
So, there are a number of causes for Epilepsy. Genetics is one and it's one that people know of and it's one that has been focused on in the past around Epilepsy. I talk a little bit about the history of Epilepsy in some of my talks as well and a sad fact is that in the US, not that long ago between the 1920s and 1970s I believe it was. There was actually enforced sterilisation of people in the US who had epilepsy because they thought that genetics was the main cause but it is only one of a raft of causes for epilepsy and there are a lot of co-morbidities that can come along with epilepsy so for instance if you suffer from a stroke or a brain injury then that could lead to epilepsy. There's also a bi-directional relationship between Alzheimer's and Epilepsy. If you get Alzheimer's more likely to get Epilepsy, if you have Epilepsy more likely to get Alzheimer's and a bi-directional relationship between autism and ADHD and Epilepsy as well. So, you can see how age kind of comes into some of these ideas around the brain and causes for Epilepsy. So, as you can see there are a whole a whole raft of different causes out there; but most of the time we actually don't know what's caused someone's Epilepsy so that can be the case as well.

So, is there a most common onset age or can it, is it quite hard to define when the most common would be considering all those different factors?

In terms of age I guess that's the one demographic you could say that you can kind of set apart from the others so although any ethnicity, any gender, any age, with age it can be more so in the period before you're two years old or older than 65 that you can be more likely and that's just because of brain changes as your ageing growing up and as your brain degenerating when you're getting a little older as well and so that can make it more likely and some of those causes that I just mentioned before, slightly more likely to happen at those time periods in your life.
Awesome, well I've already learnt so much and were only what; two minutes into this, this is great Esther.

So, another question I had Esther was actually around are there different types of epilepsy?
There are actually 25 different epilepsy syndromes so some of the people that we support will be diagnosed with a particular epilepsy syndrome.
So even within the different syndromes themselves I know it can also be that there's different seizure types as well.
Yes, absolutely loads of different seizure types so yeah there's 25 epilepsy syndromes and at least 20 different epileptic seizure types so people could be having the same epileptic seizure type and be experiencing it completely differently or they may have different epileptic seizure types to the other person.

Wow so it looks like epilepsy can look very different for everyone and it's a journey for sure.
Yeah actually that's a good point to mention we actually talk about epilepsy as a spectrum disorder as well and what we mean by that is you know there could be two people, they could be friends, there could be two people who have epilepsy who are friends, experience it completely differently so do they have different seizure types?
Do, have they developed epilepsy at different ages and then therefore it's had different impacts on their life, one friend might have had it since they were born so and it's you know their seizures have affected what life has been like at school for them whereas their friend that they've gained in adulthood maybe only was diagnosed with epilepsy later in life, how do they have those impacts, is the ability to drive impacted, is their ability to be employed impacted, are they experiencing seizures less or more regularly than their friend who has epilepsy as well so yeah it can look completely different for different people.

Absolutely so it's really important that people get to know a bit more about what epilepsy is and to understand that so we can make it so that there's more access to that information and getting people diagnosed quicker if they do have epilepsy as well.
Yeah definitely it's it's definitely one of those disorders, some people might call it a disease, some people might call it a condition, some people might call it a disability, there's a whole lot of different names you could use but yeah I guess there's a lot of misconceptions about epilepsy and a lot that's unknown even to doctors and so I think that more focus needs to be placed on epilepsy and I would really like to you know when, I love my role but when I eventually move on from my role I would really like to be able to walk away from it knowing that you know I'd made a difference in that epilepsy was more talked about there was more awareness of it that some of these misconceptions are a thing of the past and not something that's continued and will continue through to the future.
Yeah, that's a really important mission that you're on and we're so lucky to have a role like yours within our community.

Right, so should we get into busting some myths today?
Absolutely yeah no I love busting myths well I'll put on my beret, and I'll get my fake moustache out and I'll act like I'm on myth busters. Here we go!

Alright so, the first one we've got for you Esther is that we have heard is that epilepsy is rare.
Epilepsy is actually not that rare. 1 in 100 people will be diagnosed with epilepsy so person as i said before a person of any age, any gender, any ethnicity anybody can be diagnosed with epilepsy. Uh statistically that number stands at 1 in 100 but it could be 2 in 100 because diagnosis is actually quite hard so yeah so, those numbers are just a bit of a ballpark figure, I guess. But if we look at 1 in 100 and there's about five million people in New Zealand now then we are looking at about 50,000 New Zealanders that will be diagnosed with epilepsy. So, often when I meet people in my role especially when I'm giving talks or I'm at expos and a person comes up to me and you know they don't know anything about epilepsy and they're you know learning some things there and I say to them do you know someone with epilepsy have you seen a seizure and they say you sort of see their face thinking about it for a while and they're like oh I don't think I do know someone with epilepsy and I say do you know a hundred people? Oh yeah I know a hundred people okay well one of them probably has epilepsy you may just have not seen them have a seizure or they may not have disclosed to you that they have epilepsy they may be embarrassed they may fear that there's going to be that stigma in prejudice towards them or they haven't had seizures in a while so they don't think they need to tell you but it is more common than people believe and I think the fact that people think that that myth is out there that it's actually quite rare is I think related to the stigma and fear in prejudice that there are around that there is a round epilepsy?
Yeah, for sure in those numbers just really show how important it is that everyone learns about epilepsy and is aware of what it is and ways that they can help those people around them.
Yeah, absolutely that numbers so much more common than I was expecting one in a hundred New Zealanders these facts have been really great. Esther let's move on to the next myth.

So, another common myth is that all seizures look the same would you like to share a little bit on your thoughts about that?
Yeah definitely let's go into that so not all seizures look the same so mentioned before how there's at least 20 different epileptic seizure types when a person has an epileptic seizure their behaviour can be affected so they may start crying they may start laughing they may become incontinent they may have some interesting movements you may see them convulsing you may see them stiffening you may see them dropping it could can also affect their sensation so a person who's having an epileptic seizure may have their sense of smell affected they may smell things that aren't there they may taste things that aren't there they may hear things differently their site could be impacted but also epileptic seizures can result in an alteration in consciousness so actually that's another myth that is out there is that a person does lose consciousness when they have a seizure but you can have consciousness when you're having an epileptic seizure some seizure types you know retain consciousness and I've heard for some people that they sort of go in and out of consciousness during seizures as well so there's another myth to kind of go along with that one if I talk a little more generally to different types of seizures the most well-known one so I can flick off some you guys can learn some terminology here so tonic clonic seizures one seizure type that most people if they're aware of epilepsy are aware of tonic clonic even if they don't know the name it used to be called grand mal which basically just means big seizure so not very descriptive if we go to tonic clonic and what that to terminology means tonic means stiffening clonic means jerking so it's a seizure where you stiffen and then you jerk it is probably the most likely seizure type that people will be aware of in the media because it can have that big impact people call it and there's a reason it was called the big seizure other types that people may be aware of for example an absent seizure which is where a person can look vacant for a number of seconds there is also a tonic seizure so you're just having the stiffening with that one a clonic seizure there's an a tonic seizure which means that a person will drop they'll lose control of their muscles and drop there is myoclonic myo meaning muscle clonic meaning jerks a little jerks of the muscles a person not losing consciousness there so those are all generalised what we call generalised types of epileptic seizures which means they're happening in both sites of the brain simultaneously but there's also focal types of seizures which are happening in

one lobe of the brain so we've got four different lobes and you can experience a seizure in any of those four lobes and within those four lobes can have awareness or could have impaired awareness during a seizure and depending where it's happening and whether you have awareness they can look completely different as well all the parts of our brain are responsible for different things and so if you're having a seizure in one of those four lobes whatever that part of the brain is responsible for may show up and how your seizure shows to a person who's observing it.

And for a person who's actually having a seizure that must be quite a scary thing at first to not know sort of what's going on especially if you're sort of going between being conscious and not being conscious?
Yeah definitely and actually that's a bit of a side point that I can mention is some people who have epilepsy experience what's called an aura and that's like a warning that a bigger seizure is going to happen afterwards or that's how they at least used to describe it it's now seen as a type of seizure within itself one of those focal seizures that I was just mentioning before one with awareness so that person is aware of what's happening to them hence why they know that it's a warning about having a bigger seizure afterwards and so some people do get that and that could be quite uncomfortable but it also can give that person that little bit of time that they may be able to make themselves safer if it's to go into a bigger you know more convulsive seizure. I've met people who have had seizures where they're aware and had seizures where they don't have awareness and they have talked to me about being more fearful around the ones where they do have awareness because at least when they lose their awareness they don't know what's going on and and when they lose their awareness it can be often more likely for the people around them to be scarier for them than the person experiencing the seizure so it's again it's different for every person and that's why we talk about it as a spectrum disorder.

That makes me think of another misconception that I've heard which is that flashing lights cause seizures for everyone.
I like talking about this one I'm a bit of an avid gamer and so turn on the PlayStation one of the first messages that comes up is photosensitive epilepsy and I don't have a giggle it's not funny but I read it and I think interesting how I always see this particular seizure trigger come up and when I meet people in my job and I'm talking about triggers and talking about epilepsy and they talk about flashing lights and I say well yeah that is one of the seizure triggers so there are a number different seizure triggers out there and seizure triggers basically make it more likely for a person with epilepsy to have a seizure they lower the seizure threshold and so flashing lights is one of them but it's only five percent of people with epilepsy that flashing lights is a trigger for and that might not even be things like strobe lights it could be light between trees it could be light reflecting off water things like that but there's a number of other seizure triggers that are common for people so things like not taking your medication not having enough sleep or being sleep deprived which is kind of a negative cycle that one because you can have seizures during your sleep too missed meals, stress, physical or emotional it could be sometimes it can be certain types of music for people or certain size of text in a book it could be patterns it could so things like even optical illusions I guess might trigger someone's seizure is a whole bunch of different things out there if you're too cold, if you're too hot, are you overstimulated sometimes you know electronic screens and things like that might trigger someone's seizures so there's a whole bunch of different things out there and that's just a few of them so definitely not just the flashing lights and yeah no only a small proportion of people with epilepsy who that is a trigger for.
That's so good that we could debunk that one such useful information.

Another one around seizures is that you should put something in someone's mouth during a seizure can you tell us a little bit about that Esther and why that's probably not the best idea.
Yeah definitely, again I hear this one a lot still and particularly when I'm seeing people who are of an older age bracket that that was something that was talked about quite a bit when they were growing

up and they were witnessing people having seizures is I know we need to put a spoon in their mouth or you know should we be putting our fingers and don't put anything in a person's mouth when they're having a seizure they were scared so the reason they did that is they thought the person was going to swallow their tongue which actually cannot happen it's anchored in your mouth you're not going to swallow your tongue so there's no need to put something in someone's mouth when they're having a seizure if you do then you may injure them you may get injured and it's just not necessary so definitely don't be putting anything in someone's mouth when they're having a seizure. If they have something in their mouth already like if they're eating and then they experience a seizure while they're eating then you just try and get what's ever in their mouth out but not to be putting anything in their mouth if there's nothing in there
That is one that is a really harmful misconception so good that we could debunk that one as well.

When it comes to what sort of first aid should we do for someone that's having a seizure, what does that look like Esther?
That's an interesting question as well it can look a little different depending on what type of seizure they're having and so I often get asked if I can provide first-aid training to groups around seizures and I say well yeah I can talk a little more generally around first-aid for seizures but what would be a really good idea is if we can have a chat about the types of seizures or the types of symptoms at least of what this person is experiencing when they have a seizure see if we can figure out what type they're having and then from there be able to know what kind of procedures to put in place so I guess if we're looking more generally at first-aid the one the myth we just talked about not putting something in someone's mouth not restraining the person as well or shouting at them or anything like that you know making sure that there's a safe space when they have a seizure or that you're creating that safe space if they don't have that awareness you know we don't want them to walk into something or you know walk onto a busy road or something like that so what kind of measures can we put in place. Let them have their seizure don't try and control them when they have a seizure just be there you know to look after them and be there when they come out and you know be helpful when they come out things to keep in mind are how long the seizure is going for so we don't want epileptic seizures going longer than five minutes that would be a time to put emergency procedures in place like calling 111 if or if the person has an emergency and or if the person has an emergency contact to call them so for some people as well actually that's something I can mention is some people that I do see they say even though I'm having you know if I have this seizure and it goes five minutes or I have a cluster of seizures or you know one of my seizures closely follows the next one sometimes people with epilepsy don't want to be taken to hospital sometimes that it stresses them out and triggers other further seizures so for some people it is calling that emergency contact and them you know if it's a family member that's been with them is they've grown up with epilepsy then they know what these seizures are like for this person they know what's helpful for them when they come out of a seizure so sometimes it might not be calling emergency services sometimes it might be calling them just to say hey this has happened you know can you make a record of it and I just want your advice on what you think about what I'm seeing especially if you haven't seen that seizure before also haven't seen that person have a seizure you come across someone in the street you think they might be experiencing a seizure it's good to just get little bit of advice sometimes it might be a good idea to put a pillow or your hands or a jacket or something under their head as well just so they're not hitting their head on the ground so that's something that we talk about as well yeah those are some other thoughts are on first aid.
So just stick with someone and be there to support them and whatever what way that looks like or what you know them or if you don't know there's some really simple things you can just do.
Yeah definitely.

So, another common myth that comes up often is that if you have epilepsy, you should avoid sports or physical activity now what are your thoughts on that one.

Yes I do hear this and I do quite a bit of work with schools so it can be quite relevant in that space you know PE is quite a common thing that kids do at school with as adults sometimes they hear about it less often because you know we're less involved in that kind of world when we've got work and what have you going on a social life and all that sort of thing but yeah particularly in that school space I guess I do hear things like you know we've got this child who has epilepsy in our class or at our school you know should we be sure we should be watching them more and the pool should we be watching them in the playground you know should they be wearing a helmet should they be allowed up heights and you know we definitely want that that kid to feel safe but we also, well the person doing sports or whatever it is we want them to be safe but we don't want them to be you know helicoptered over and wrapped in cotton wool you know we want them to be able to experience life as similar as possible to a person who doesn't have epilepsy. I mean any of us can have a seizure at any time so then they'd be putting those same measures in place for everyone if that was the case but I guess what I'm trying to say is definitely have in place measures around things like places where they might be doing physical activity where they're at a height or in a pool if it's things like you know can people with epilepsy play contact sports or something a bit more specific like that then we actually have a fact sheet on our website around epilepsy and sport and exercise and that sort of thing and we have a bit of a traffic light system on our fact sheet so some sports probably not a good idea for people with epilepsy to play they fit within the red light then we have the orange light where yes you know you can play the sport but you might have to put in a few more sort of accommodations in place and then we have the sports that are under the green light where you can play these sports just like anybody else would these are probably the most safest sports for you to play.

And to add on to that point Esther as well a person that has epilepsy is so much more than just being an epileptic and labelling them as that you know like it's something that they have but that doesn't mean that they can't play sports they can't do this they can't live a normal life as well.

Yeah labels can be in this is a conversation I hear in many different areas labels can be helpful they can also be harmful we prefer to talk about it you know if we're talking about someone who has epilepsy we don't we don't call them epileptics we call them person who has epilepsy yeah epilepsy is only a part of their lives only a part of you know day-to-day and who they are and what they're able to do.

I think we're all absolutely looking forward to having you back on another episode with us that will be coming up next week as you talk more about your role and epilepsy Waikato Charitable Trust. It's been so cool to have you on the podcast Esther we so appreciate that so Ngā mihi nui and I think we'll call that a wrap. Awesome and listeners ka keti anō we'll see you next time.