**Interview with Bree-Arne Manley and Liz Wright**

Liz

This is a Women with Disabilities Victoria podcast.

We acknowledge that these podcasts were recorded on the traditional lands of the First Nations Peoples of this country. We acknowledge their Elders, past, present, and emerging. We acknowledge that sovereignty has never been ceded, and that this is, and always will be, Aboriginal land.

From the Outskirts is a series of podcasts featuring women with disabilities who live and work in regional Victoria.

I’m Liz Wright, a disability activist and advocate. I’m also the Manager of Community Inclusion and Women’s Empowerment at Women with Disabilities Victoria.

All the interviews were recorded in each person’s home or workplace, so from time to time there is unexpected background noise.

We hope you enjoy.

Bree-Arne Manley is a musician, rock-climber and mum. She’s a self-proclaimed Aussie MS Warrior and lives a fierce and fascinating life.

Please be aware there is some swearing in this episode.

Bree-Arne

Hey, I'm Bree-Arne Manley, and we're talking from the Wadawurrung Country.

Liz

Oh, well, it's so great to meet you. I went down a rabbit hole of watching your YouTubes…

(laughter)

Liz

And a lot of them made me laugh out loud. How’s it all going? Like, you know, you're living here…How long have you lived here?

Bree-Arne

I've lived here for a good 13 years now, I think, since being together with Lachlan.

Liz

Where did you come from?

Bree-Arne

Clifton Springs. Ten minutes away.

Liz

Yeah. OK. So, would you know Sarah Carroll?

Bree-Arne

Yes.

Liz

And Chris Wilson, before he died…yeah…

Bree-Arne

Yes.

Liz

So, I imagine this is kind of a tight music scene around here?

Bree-Arne

It is. Actually, that photo up there was taken by Chris Wilson.

Liz

Oh, really?

Bree-Arne

Yes. He felt sorry for me when I was busking outside the supermarket in a competition, and he came and put a blanket on me, and made me look like a hobo.

(laughter)

Liz

You'll have to describe what else…what's on the photo?

Bree-Arne

It's me busking outside the supermarket. So, there's a bunch of shopping trolleys behind me, and I'm all rugged up in my reggae beanie, and I've got my hood up, and he's got a chequered blanket…orange, dirty looking dog blanket looking thing on…across my lap. He probably didn't have a dog. Probably…It didn't smell like dog.

Liz

No.

Bree-Arne

So…

(laughter)

Liz

So, you've been playing music for a long time?

Bree-Arne

I have, yeah.

Liz

Since a child?

Bree-Arne

My mum used to teach guitar and piano. And one day she heard me tinkering on the piano of something that she just taught one of her students. I was three.

Liz

So, you had a natural affinity towards music and stuff anyway.

Bree-Arne

Yeah.

Liz

So, you've played for many, many years?

Bree-Arne

Yeah, I'm 37 now and the only thing…about six or seven years ago, after Daniel, my second son, was born, my hands started getting really weak. And well, after my first son Jayden was born, I couldn't feel them at all. But they came back. I just did a lot of practice and now it's a real struggle to get my strumming hand going.

Liz

So, did you have MS before you had both your children?

Bree-Arne

I did.

Liz

So, was there a lot of talk around you about should you or shouldn't you have a child?

Bree-Arne

Uh, actually, no. I was quite independent, and I was going to be the boss of that, so…

Liz

Yeah, great.

Bree-Arne

So, I deliberately took myself off my medication after a couple of years in after being diagnosed, because I knew that I wanted a family. I didn't want anything to sabotage that for me. So, I thought, my body is my temple, and I just did all the natural stuff and, you know, probably should’ve come off sugar a little bit earlier, but...

Liz

I can't contribute to the coming of sugar conversation bit because, yeah, I've had a bit of sugar lately…

(laughter)

Bree-Arne

Well, I was just in the supermarket, and I was really jealous… I love eating marshmallows and stuff like that. Real natural, naturally sweet tooth. I think.

Liz

So, sugar helps… not having sugar, sorry.

Bree-Arne

Yeah, well, sugar is an inflammatory, so, it would help everyone to come off it, really. But it's doing things like that, that I just want to contribute to my being healthy and trying to get the best out of my body as I can.

Liz

You're really fit and well known for being a rock climber and people think it's like an amazing feat that you can do that. But I, I think it's great and I think it's amazing. But I also know it's hard work. It's not like the clouds opened and someone's elevated you up there. You work hard at doing that sort of stuff because you enjoy it.

Bree-Arne

Yeah, absolutely. There's nothing like getting to the top of a rock-climbing wall and just going: Hey, I did it! And I did it from my wheelchair. I got out of it and climbed up a wall.

Liz

Did you do rock climbing before you had MS?

Bree-Arne

Every now and then. It was something I always wanted to get into. But I didn't have the right crowd around me to do it, like I'm doing it now.

Liz

The kids like rock climbing, too?

Bree-Arne

They do. It's a treat for them to come and they do some climbing, but that they get to play on the phone for a little bit while mummy's doing her wall…

Liz

Yeah.

Bree-Arne

And I take a little bit longer than what they do so…

Liz

So, they've got a bit of time to kill.

(laughter)

Bree-Arne

Yeah. And then they get the like caramello and their big jumbo snake.

Liz

Do you go…you go to the same place regularly?

Bree-Arne

Yes.

Liz

So, have people stopped staring?

Bree-Arne

Ohhh…?

Liz

And by that I don't necessarily mean maliciously. I mean curiously.

Bree-Arne

Well, I don't think I notice it as much. Because for starters, I can't see that far away. And every now and then I might hear someone go: Wow, she's so strong. Or: Look at her do that. Or: I didn't know you could do that from a wheelchair.

Liz

Yeah, that's great. That's so good.

Bree-Arne

Yeah.

Liz

With your music, like we're sitting in a room that's full of gear. Are you playing regularly… or irregularly because of COVID?

Bree-Arne

No, I'm trying to play more often because I really want my hands back and I couldn't pick up my guitar for a few years because I was too scared, I wasn’t going to be able to play it the way that I used to.

And I used to…I spend hours and hours perfecting my craft and writing songs, and it just was devastating to not be able to play them as well anymore. But I can still play them. I'm still making music. I'm writing an album at the moment.

Liz

Do you record at home?

Bree-Arne

Yeah. This is a recording studio which… explains all the recording equipment.

Liz

Yeah, I can see all of that, but I just wasn’t sure if… like when you're going to do an album, are you going to branch out into a bigger space with other people or are you going to do a solo acoustic?

Bree-Arne

No. Well, actually the great thing about branching out with other people is they can always record it in their own studio and then bring the stems, the tracks, back here. Then I can add it to mine. And I have someone who helps me with production because I can't see very well, and she helps me blend it all in.

Liz

So, with the not seeing so well, is that a thing from MS?

Bree-Arne

Yes.

Liz

So, everybody I have interviewed with MS, everything is different.

Bree-Arne

Yeah.

Liz

So, I was with a friend, a woman yesterday, and she was talking how she used to play the tin whistle, play the harmonica, and she really, really, really misses it. But her eyesight's OK at this stage, but her hands are deteriorating quite quickly. She's a lot older than you. So, your eyesight is affected. And how is that?

Bree-Arne

Well.

Liz

Isn’t it the optic…what’s it called?

Bree-Arne

Optic neuritis. The optic nerve. I've just been to the optometrist recently who's just checked my nerves with a special machine, and he has said because I've had so much deterioration in there, it is like looking through the eyes of an 85-year-old at 37. So, I'm just happy I can still see my photos.

Liz

So how does how does that manifest? And my curiosity is as someone…I have Stargardts, so that manifests in a certain way. So, does it mean reduced length of vision like you can't see the kids down the road? Or is it about writing or…?

Bree-Arne

OK, like I can see that there is person there. I can see a lot of the detail. I can see your scarf is the same colour as my pants. But there might be a patch missing every now and then.

Liz

That’s very much like Stargardts.

Bree-Arne

Yeah.

Liz

Which is like macular degeneration.

Bree-Arne

Well, I definitely wouldn't be able to read writing from me to you away, so that’s about a metre and a half away, but…

Liz

We're kindred spirits here.

Bree-Arne

Yeah.

Liz

Because that's exactly the same sort of manifestation. Yeah.

Bree-Arne

Yeah. It's just I can see the larger details, but some of the finer ones are missing.

So, every now and then, if I'm out and Lachlan’s meeting me somewhere, and I'll see someone walking past similar shape, like I never go to grab them, or say something to them that I would normally say to my husband, because every now and then it turns out it's not him.

(laughter)

Liz

I know, I know, I know. It's kind of funny. I've got a younger sister who doesn't have anything wrong with her eyesight. One of her favourite tricks is meeting me somewhere and walking straight past to see if I'll ever pick her out. And I often do, because it's the familiarisation as you were saying of their shape or their you know, that they're wearing their hat that they always wear or, you know, their gait, you know, the way they walk.

Bree-Arne

Yeah…their…the hooded jumper.

Liz

Yeah, exactly. That sort of stuff. Some people think it's mean, but I always think it's hilarious.

(laughter)

Bree-Arne

Oh, yeah. It just drives me nuts because when we're at school, they've all got school uniforms, exactly the same one. I nearly reached out to grab a kid yesterday, and I was like: You're not Daniel. Yeah, you're not my son. Move along. You’re not mine.

Liz

Tell me about the school thing? I hated primary school when my daughter was there. I found it very difficult with the eyesight thing because people think if you don't have a cane or a dog or even though you're a wheelchair user, people still don't identify themselves as they walk up to you, often. And I'd be like: I know who you are.

Bree-Arne

I've got the best way of dealing with that. Everyone comes as ‘mate’. How you going? How you going buddy? I haven't seen you in a while.

(laughter)

Liz

Yeah, Yeah, good. Very good response.

Bree-Arne

And then after they've left, I say: Lachlan who was that?

Liz

Yeah. Yeah.

Bree-Arne

And quite often he'll go: I have no idea.

(laughter)

Liz

So, are both your boys at school?

Bree-Arne

They are now, yeah.

Liz

So, is the littlest...how old's the youngest?

Bree-Arne

Six. He's just had a birthday, so I had to think about that for a second.

Liz

When's your next gig?

Bree-Arne

I haven't…

Liz

Nothing planned?

Bree-Arne

I haven't planned anything. I'm really trying to finish this album off.

Liz

Yeah.

Bree-Arne

And I had it to do list at the start of the year. With all these crazy things on there, and the stupider they are, that Lachlan says they are, then the more I want to do them. So yeah, I've ticked them most off my list, but I’ve got to climb the You Yangs.

Liz

Oh, that would be awesome.

Bree-Arne

I think I'm going to have to Batec that one and then just climb the stairs at the end.

Liz

Oh, my God. Yeah, you're a braver woman than me.

Before we started this recording, we talked about how you've just joined a committee recently, you know, an access and inclusion committee. What do you hope to achieve from being involved in that committee?

Bree-Arne

I really want to be someone that they could use for information and experience to say: Well, this isn’t accessible, this isn't very good. We can see you as, you still get around alright and are really fit, and they will look at us differently, not just something to be swept under the rug.

For example, I tried to climb the lighthouse up here a few years ago. The poor guy didn't know what to do with me. He saw me get out of my chair and walk over to the stairs and said: Oh, look, sorry, I'm going to have to say no. I thought…

Liz

So, he said no to you?

Bree-Arne

Yes. He goes, I feel really bad, but I'll give you some vouchers to the Queenscliff Boat Museum.

Liz

Oh, the marina?

Bree-Arne

Yes. And I went: I'm not a tourist! I'm not interested in going and looking and stuff. I live here. I wanted to climb every lighthouse in Victoria…

Liz

Yeah.

Bree-Arne

I said: I’ve climbed Cape Otway lighthouse, and he said: Oh sorry. I don't know what that is.

Liz

So, are you doing like bum climbing? Like, you know… just putting yourself up on the rail.

Bree-Arne

Yeah.

Liz

Yeah, yeah. OK.

Bree-Arne

And it actually put a spanner in the works so bad I didn't even put my videos together that I wanted to do that anymore.

Liz

You should be able to do that.

Bree-Arne

Yeah, well, that's actually one of the things that we're bringing up in the…

Liz

In the committee.

Bree-Arne

In the committee.

Bree-Arne

But there’s like, so much to get to.

Liz

There is so much to get to because there's so much that's just exclusive and excluding of people with disability.

Like, you know, even though people, you know, Queenscliff has some beautiful old buildings, blah blah blah heritage overlay, there's still ways and means of being able to change buildings to make them accessible so that you could go as an adult on your own into, like one of the pubs and have a beer or, you know, if that was your cup of tea…

Bree-Arne

It wasn't even just that. Daniel was in kinder down there last year.

Liz

Yeah.

Bree-Arne

And he went for an excursion to the beach, and I was going to climb down the stairs and get to them. But then I thought, no, I'll go and get us a hot chocolate and a snack and then bring it back to them. He'll love it.

And then I go around the corner to the cafe and it's like, oh they've just got…it's like they had a middle finger up to anyone who is in a wheelchair because, every where’s got a step or multiple stairs and I could get up the stairs, but then what am I going to do?

Liz

Yeah. How are you going to get down holding everything?

Bree-Arne

Yeah. I'm going to have to, like, bounce off all the tables and all the people in there.

If you're not in that situation, you don't think about it when you're that age and able to do it. There's no reason why they would go: Oh, this person has no access to this, but I do, so…

Liz

Whatever.

Bree-Arne

Yeah.

(Music playing)

Liz

To find out more about Women with Disabilities Victoria go to: wdv.org.au

Liz

Yeah. What are your goals for the rest of this year?

Bree-Arne

Oh, I'm still…

Liz

With the album? You've got that you’re working on…

Bree-Arne

I'm working on an album called Good Grief. So, it's all the stages of grief that have gone through my MS and I'm writing a song for each one. I've got to finish my Nan's documentary I've been working on it for four years. She died, but I filmed her secretly for two years before she died. I've got heaps of art projects…

Liz

You're writing the album Good Grief, which is around, you know, the stages of grief.

Bree-Arne

I've got a song for each of those.

Liz

I really can't wait to hear this. I think it will be amazing.

Bree-Arne

Yeah, well, I really wanted this to be an album where people could listen to it and hear their own pain in it as well. Because that one of denial, I wrote a song when I was 19, based on everything I was feeling now called Mr. Sinister. And recently I've just added to it and added my voice into it now. So, I've got me now, and me then and then I’ve mixed them both together.

Liz

Oh my God, that sounds great.

Liz

You rock climb twice a week minimum?

Bree-Arne

Yeah.

Liz

In the school holidays, do the kids climb more than twice a week.

Bree-Arne

No.

Liz

Well, you just all go together.

Bree-Arne

No, I usually pick which one wants to go.

Liz

Oh OK.

Bree-Arne

So, who's come rock climbing tonight? And I'll be doing that when I go to pick them up later because they don't just rock climb in school holidays.

Liz

Oh, no, no, I know. I mean, I know you're doing it after school, but I just mean all year round.

Bree-Arne

Oh yeah. All your round and if they don't want to go one day then I'll just go on my own. More climbing time for me.

Liz

So, did I hear you correctly earlier say you got MS at 19?

Bree-Arne

Yes.

Liz

So, what were your tell-tale signs, besides…it was hands stuff first wasn’t it?

Bree-Arne

No, it was my eyes first. I thought I was getting a migraine, so I had an aura. So, I reached from my migraine medicine. I never got the headache. I just didn't know what was going on.

So, because the doctor sent me to an optometrist, who sent me to an eye specialist who sent me to another eye specialist who sent me to an eye specialist at the hospital, who sent me to the neurologist, who then sent me for three MRI’s. And then he went on holidays and said: If you get anything different, then to go into the hospital in emergency and they will be able to sort you out. And I did that.

And the woman, she wasn't even facing me. She was facing her desk and typing something. Now she was really ubrupt and she just turned, and she just said: Uh, we think it's MS.

Liz

Yeah Great. Great, great delivery.

Bree-Arne

After nine months, I was like: Hey, grrrrrr, really? Sometimes you get really good ones and sometimes you get really bad ones.

Liz

That’s true.

Bree-Arne

When it came to my diagnosis, I just had all bad ones except for my GP up at the doctor's in Drysdale and maybe one of the eye specialists, who was an old fella. He wasn’t abrupt, he was just so, so.

Liz

So, you got a diagnosis then what did you do?

Bree-Arne

Went straight into denial. Well, they, they put me on medication, and I thought: I don't need that. I feel fine. And I just had a shot every night. I hated it. I felt like I had those cold flu symptoms they get with Betaferon for years. Every now and then I forgot do it or I was just trying to be young, and I was drunk, and I was taking a while I was smashed, and it was…yeah…just…

When I finally was coming out of that stage and just went, I don’t want this because I want to have a family and I've heard that some people haven’t, and they become sterile…

Liz

Yeah.

Bree-Arne

I just went, No. I would rather family. And I took myself off everything.

I just remember being so angry at people who didn't understand my disability. People are using disabled toilets, people using disabled car parks who weren’t disabled.

And then I learned my lesson one day because I was…I didn't even mean to…I was staring at this young fella. He came into a disabled car park, and I didn't notice that I was staring, but I noticed he was staring at me right back. And then his carer went to the boot of the car and got out his wheelchair, and I sort of felt like an absolute dropkick at that stage and I just went: All right, something needs to change.

And I just let it all go. I let it all wash off me like water off a duck's back. If someone was in a disabled car park, I didn't care. If someone was in the disabled toilets, just say g’day, how are you going? All that stuff. And it was this huge, enormous release off my shoulders, off my chest, off my weight. I didn't have to worry about it anymore. It was something less that I was stressed about.

I reckon it's all about positivity and bringing something good to this table of life that nobody else can, or that because we're all put on here for a reason and we're all like, MS, different. There's no two people with the same symptoms at the same time. It's like that with everybody. Nobody is the same person. You can't reproduce the same person. They have similar qualities, they have similar looks, but they're not they're not the same.

Liz

No way. And I think that's a lovely way to end today. I have to say, thank you so much.

Bree-Arne

The pleasure is mine.

(Music playing)

Liz

You can keep up with Bree-Arne’s adventures at: YouTube.com/brees4music