**“DSP Denied”**

**Guest: Mereani Qalovakawasa**

**Host: Pauline Vetuna**

**Transcript by Leilani Fuimaono**

MEREANI: Hi everyone. My name's Mereani Qalovakawasa. I am 28 years old and I'm Fijian. Born and raised in Brisbane and now living down in Melbourne and living life (or at least trying to) -- life as a chronic ill adult. which has been very interesting, especially in the last five and a half years. I'm interested in arts. I really enjoy dancing and spending time on the internet watching makeup videos. That's a little bit about me.

PAULINE: You're listening to DSP Denied. In this program you will hear a conversation about what happens when your disability isn't recognized as a disability by the state, but your disability reduces your capacity to work in a capitalist system.

MEREANI: I'm working at Muji, which is a Japanese store.

PAULINE: So retail.

MEREANI: Retail life, which is also very interesting because there's a lot of physical work involved as well. Working in a big space. We're coming up to a few busy seasons, which is Christmas season and the school holidays, and that's another big challenge coming around for me. Certain shopping centers have their own sales. I work at Chadstone shopping center, which is the largest. I'm enjoying it, but a little bit nervous about the next few months coming up.

PAULINE: With the physical workload and all of that. That brings us to my next question, which is the chronic illnesses you live with.

MEREANI: Yes. I was 12 years old when I was diagnosed with lupus. Systemic lupus erythematosus, and it's basically a condition... I guess to put it simply, it's like when your immune system attacks your own body and mine affects the entire system. It can affect any part of the body because it's the immune system, which is from the blood, and your blood is like everywhere in your body.

So all your major organs, all the cells can be affected, and for me, my condition mainly affects my kidneys. It's been nearly 15 and a half years now, and I think I'm feeling quite sentimental about my whole journey with lupus, and I've had many ups and downs.

I think I'm enjoying the place where I am right now with my condition and I'm feeling good about the future. That doesn't mean to say that my condition will always good, but just feeling good about how I've come to live with it.

PAULINE: As we've discussed before, living with a chronic illness disability is quite expensive. I was wondering if you could talk a little bit about all of the things that you need in order to be able to function in a society, all of the medications, different treatments that you've had to have over the years. Can you talk a little bit about that?

MEREANI: I guess I grew up with my family taking care of me, and not really knowing anything about the costs around it because I was really supported by my parents. So I moved out for the first time five years, yeah, nearly five years ago and moved interstate for the first time.

So I really threw myself out there. But the thing is, I was in a period of remission then, and then four months into my move became unwell. Then that started this whole thing of a big flare with my condition and this whole experience of learning to deal with my condition as an adult, and then how to take care of myself.

That's meant a lot of appointments and visits to Centrelink, and a lot of appointments and visits to my doctors and being... I think I got really desperate for support and help from different communities or if there are different programs.

I've come across a few and they've really helped me out. But yeah, it's really exhausting. I used to go into Centrelink by myself and try and ask for help. I'm just on the newstart program, which is minimal help. There were many phone calls to Mum and Dad, many messages to my brother. Like, "I need some help."

For me, I’d just graduated and moved interstate and was quite ambitious about starting life. I'd been through a lot of health obstacles growing up, and I was ready to live and be free and take charge of my life. You don't expect four months into your big move that you're going to flare up. I really had to calm my pride down because I was like, "Oh but I'm supposed to be out here doing my thing."

I felt really bad about calling my parents and asking for help, because I'm not living there anymore and I wanted to be independent but you know, unfortunately that's what I had to do because I'm not really getting any help.

PAULINE: Well that's the thing. I think all of the things that you wanted were reasonable things that people graduating into adulthood want to do. What I want to talk about too, is the lack of support, because why are you, as someone who lives with a chronic illness and disability, on Newstart.

MEREANI: On Newstart.

PAULINE: Let's talk about that.

MEREANI: Yes. Basically I don't meet the requirements or I'm “not sick enough” for the DSP, their disability support pension program.

PAULINE: Can I just pause for a second, because... The not sick enough thing, talk about how it's impacted your capacity to work? Your chronic illness.

MEREANI: Well during my flare, the many years afterwards in recovery, I basically just spent most of my time at home. I had to be really thorough in organizing my time. If I had to go to hospital and have treatment it meant that I would be home sick, nauseous, sleepy, unable to get out of bed for a good two, three, four days. For me, I wanted to keep my space as neat as possible and make sure I had like some food, just simple things.

PAULINE: And you live alone too.

MEREANI: And I live alone. And also because I didn't really want to... It takes a lot of effort to find a new place and friends, and when I was right in the middle of that flare up, I don't really want to be out there. You just don't have that energy to look for a new place and then move and organize all of that.

PAULINE: And then with you, I know you've said before that the place that you're in now, while it's not ideal, is close to everything you need medically.

MEREANI: Yes it is. It is. But also in a suburb that has gone through a lot of changes in the last five years and the rent has gone up many times over the last five years. So it is quite expensive, and I've had trouble over the last five years paying for my rent and then also having to pay for my treatments and medical things.

So it's been really expensive. I think I'd save a lot if I'd have moved out, but it's just a really convenient place for me. And also when I'm unwell and have been really unwell, the pharmacy is one street away, my local supermarket is one street away, and if I lived elsewhere I think I'd be really struggling. There would be no way that I'd be able to live on my own. I'd definitely have to move back with my parents.

PAULINE: And you don't drive and you don't have a car.

MEREANI: Yeah. I've got my license, but that was another thing. When I did get my license, I was told that I had to pay $250 for my doctor to fill out a form that says I'm able to drive for the Victoria Transport Department. So I was like, "Wow, I never had this in Queensland." But then they sent me one again for another year. Do I have to-

PAULINE: Do it every year? It's going to be every year.

MEREANI: Yeah, but it costs $250. I asked my doctor and she was like, "That costs $250." I was like, "What? I don't know about these things." I'm already in a not very good financial place, so do I have to pay $250 a year just to say that I have a condition but I'm still able to drive?

PAULINE: Going back to treatment, because I'm still angry at that. You're not sick enough to be eligible for the disability support pension. You already said it's extremely expensive to live the way that you need to because where you live, everything that you need medically is accessible to you and it's particularly important because you live alone.

You don't have anyone to physically support you and get those things for you. We've talked before about pill shaming. I remember one of the first conversations we had was about people saying... The helpful advice people give to people with chronic illnesses about, "Just do yoga. Just to try other things." Obviously many people with chronic illnesses, including lupus, need a pill regime. Could you talk a little bit about yours and also the cost?

MEREANI: Yes. Well, first of all, I have tried yoga and it was expensive. That's all I can say. It was expensive. No.

PAULINE: Yeah, stop telling sick people to do yoga, please.

MEREANI: I mean, look, unless you want to pay for it, then okay, I'll do it. Feel free. I think that's my thing when it comes to like unhelpful advice. I'm like, "Well if you want to pay for me then okay, I'm willing to give anything a shot."

I guess with my medication I actually started filming a lot of videos because I was at home a lot. I would take videos of me taking my medication and I had to to do injections and that was another thing.

I was a bit nervous to take some of my meds alone so I would film them and then put them up on my Instagram. I think especially at that time, I was on many different things for different parts of my body that were affected by some of the treatment that I was taking.

Some of them cost a lot. Some of them were covered by government. Some of them were only partially covered by government. I remember one time I had to go and see the women's... The IVF clinic, and I was told that the first two treatments would be covered and then not knowing that at the end of July that changes and only one treatment is covered.

My doctor didn't tell me, and so I remember going in to the pharmacy and the lady was like, "Oh, unfortunately we're not covering this one so you'll have to pay the $310," and I remember that was the worst day because I missed the train and was late for an appointment, lost my folder of all my medical files, was late for that next appointment, at the Women's, and then told that, "Oh yeah, you have to pay $310." I think I had maybe like $60 in my bank account because I still was attempting to go to work in the city at my retail job at that time.

That was paying for my Myki fare, paying for my food. If I can't make food at home, I'd buy food, so that's another expense as well. You need work clothes and things like that. My wardrobe was still very much a Queensland wardrobe, and experiencing winter for the first time, I had to buy a whole bunch of warmer clothes and sometimes you just don't have enough energy to wash your bed linen. I don't know, it's just a basic thing of living at home. And I wanted to feel okay in my body, at least try to feel comfortable. I remember having to pay for so many other things and then not having the money to pay for that injection, which is $310. Then I was like, "Excuse me, can I just like have a moment?” I was like “Ahhh!”, crying.

And then I take a whole bunch of other medications that you just get from the pharmacy. They're 20 bucks, but sometimes I don't have... I've got money, but it's not enough to spread out over all of the medical expenses, and I'm thinking like, "Hmm, how am I going to share all this out?"

I don't know, I'm okay with taking my medications now. I'm okay with it. I've found that over the years it's gone up and gone down and I used to get a bit upset. Like, "Oh, my medications gone up again." But that's just the nature of my condition, and that it fluctuates. So my medications will increase and decrease over time as well. Sometimes it's like, "Oh, you take too much medication." I'm like, "Well, you know, I'm okay with it. Maybe for you."

PAULINE: You need it.

MEREANI: I need it.

PAULINE: Please mind your business. With that $300 injection situation. What did you do?

MEREANI: They told me to go upstairs and talk to the doctor and the nurse, and then the nurse came down and he was just talking to the pharmacist and having a chat. They decided to honor what the other doctor had originally told me, that the first two would be covered.

I think that they could tell that I was having a really, really bad day, because also my folder of medical documents was still missing with all my information. Sometimes you’ve got to put on the tears or something. But no, I mean...

PAULINE: They come anyway.

MEREANI: Yeah! They come anyway. There's no need to... Because that's just how it is. That's just how it is. You think, "Oh no, will I have to..." Because my condition is an invisible condition and sometimes you feel like, "Oh no, maybe I need to show them," because they don't believe...

But I think I've also tried to tell myself, in this time that I don't need to, because I don't want to feed into that idea as well of, “This is what sick looks like and if I put this sick show on then they will believe me and then I will get…”. But I'm trying to be a bit more, "Well no, this is just how it is and I'm still deserving of help, so help me.

PAULINE: The problem is state agencies don't necessarily.

MEREANI: They don't, no.

PAULINE: You talked about documentation. That's awful. I can't believe that happened to you, losing that. But also how important documentation is to the whole process of trying to get help from anyone in regards to disability. This brings us back to Newstart. Because you're on Newstart, another disability support pension. Can you talk a little bit more about why you were rejected from the DSP?

MEREANI: I've been on Newstart and met up with my support worker that I had just come across and asked me if I'd like to apply for DSP. I thought, "I'm probably not the person that would be able to apply for that." But she encouraged me and said, "No, your condition..." My condition, first of all, is a lifelong condition, and there's no cure but there is maintenance, and because of that, apply for it.

So I'm like, "Okay, let's apply for it." And we all thought because my condition is a chronic condition, it's a lifelong condition, that I would get approved anyway because I'll have it for the rest of my life. So when we filled out the forms, we got all the documents, some of the evidence from supporting doctors. We sent them in.

The rejection letter that I received from them told me that, "We acknowledge your lupus side." So that's awarded 10 points. You need 20 points to be approved of DSP. Then we also talked about how the condition affects my mental health. We had supporting evidence for that as well.

But their explanation was, "We could not..." I think it was something like, "Oh, we could not verify the details from this doctor or this specialist," and therefore I couldn't be awarded any points for that. I guess the wording is really important and they're super, super picky.

If you don't word it in a certain way, then you won't get awarded any points. You won't get approved. I guess that the wording that my psychologist had put in, I actually gave in a wrong document. That document was meant for an NDIS, and I thought that would be okay. I thought that would be okay.

Like, "Oh, it's the same thing. We're asking for support." I guess what she had written had given the impression that “Oh, my condition is going to get better if I keep taking these appointments with her”. So they wrote, "The condition will improve and therefore it's not fully treated and stabilized... So if it's going to improve then you can't be awarded any points at all.

You've only got 10 points for your lupus. The 10 points overall does not meet the 20 to be awarded DSP."

So unfortunately that means I'm rejected. So we thought, "Well, surely I should be awarded something because it's affecting me and I do need support, the money to pay for my appointments."

We ended up going to appeal that decision because we just thought that was ridiculous. I did the appeal this year, which was intense. That was a whole other process.

PAULINE: Oh my goodness. The recognition of mental health too as a disability, it's really difficult. And also, like you said, there's a relationship between your permanent disability, your permanent chronic illness, and your mental health.

It is a permanent thing that you're going to have to deal with on an ongoing basis, and do self care for and seek treatment for. You just mentioned the NDIS, a whole other thing. Can you talk about your experience trying to apply for that?

MEREANI: Yes. I'm glad that I came across my support worker, because I just can't imagine anyone trying to fill out NDIS applications, and even the DSP application was like 32 pages. That's just a lot for someone to fill out on their own.

PAULINE: Can you repeat that? How many pages?

MEREANI: 32 pages.

PAULINE: 32 pages.

MEREANI: Yeah, and you just have to talk about your condition and I feel like that can be really like emotionally-

PAULINE: Triggering.

MEREANI: Yeah. No one wants to spend 32 pages talking about how their life sucks.

PAULINE: You mentioned before about how you didn't want to feed into that thing just for your own wellbeing.

MEREANI: Yeah, of your own wellbeing, right?

PAULINE: Having to ruminate over just how badly it affects you on your day to day life. But you have to, in these bureaucratic processes, in order to get help.

MEREANI: So NDIS, I had help from my support worker and there's this application, which is just a couple of pages. There are, I think, six different categories and you just have to explain how your condition affects some of the different categories.

It may not affect all six, but to be approved you just have to prove that one of them is affected. We filled out the different forms and the different sections that affected my life, and we got a one page letter, maybe a one and a half page letter that said pretty much the same thing.

I was actually surprised that the letter was so short. The rejection letter from Centrelink was quite thorough. The NDIS one was just "your condition isn't fully treated and stabilized."

And another thing is that they believed that my condition would be okay just to be treated by mainstream services, and therefore I'm not able to be approved of NDIS. So that's another thing that I realized.

If they believe that you're okay to be treated with just the regular services, health services that you can just get through your doctor, or your doctor can fill out, you know, a 10 appointment mental health care plan, or I think it's called Alliance Health, which you're able to get five appointments to see some sort of specialist.

If they believe that you're able to go see that and treat your condition, then they won't approve you for NDIS. So pretty much they believe that I would be okay just with the mainstream services.

But the thing is, my condition is a chronic condition and I’ve pretty much exhausted all of those options. 10 appointments to go see a mental health care person, that's not enough. You can use that up within half of the year and then you have to pay full price for the rest of it. It's really annoying. Again, if you don't word things out in a specific way, then they'll say, "Well, you can be treated with the regular programs and you don't need NDIS."

PAULINE: Oh my goodness.

MEREANI: Yeah, you have to be very particular and word things in a way that they will approve of. But I don't know... I don't know...

PAULINE: What that language is.

MEREANI: Yeah. What sort of qualifications do they have to approve who does and doesn't get it?

PAULINE: That's so true, because again, I remember we've talked about this, it appeared from the feedback that you got from them that none of them understood what lupus was.

MEREANI: Yeah. I was like, "Oh, okay."

PAULINE: Are they then qualified to deem it not disabled?

MEREANI: Apparently it depends on who picks up your form and reads it. It's different for every person. One person might decide, "Okay, yep, that's fine with me." And another person's like, "No." Maybe they had a bad day and got stuck in traffic, and they've just decided to reject everyone. If you're in that pile, then that's tough luck for you, which is really, really, unfair.

PAULINE: Yeah. Very unfair.

MEREANI: I don't know. I don't know. I'm not in that room, but it definitely feels like it.

PAULINE: Thinking about what would make your life much more easy (other than simply being granted the DSP and the NDIS) in the process, what could they change that would make it easier for people living with disability and chronic illness?

MEREANI: I think for me, I didn't know any of these programs or the support groups were available for me, and so I really struggled within like the first decade and my family as well. My parents had no idea, we were just out here on our own.

PAULINE: I so relate to that.

MEREANI: That was a really big struggle. That puts a lot of tension on the relationships in the family and not knowing how to express myself and what I needed for help. I think that really was hard for us because we didn't know that we had help that was available for us.

I think when people get diagnosed, it would be nice to be at least given some like, "These are support networks," or be directed in some way that offers support for people.

Because I feel like there was a lot of time that I just spent on my own thinking that this is my own thing going on here, and not knowing that I could have professional help. Navigating all the form writing and calling up different people and...

PAULINE: Support.

MEREANI: Support.

PAULINE: A lot more support. Mereani, thank you so much.

MEREANI: Gosh, thank you. Thank you for having me. There's so much left to be covered and I feel like in my brain I'm thinking about a hundred different things. But what I'm saying, only is just the tip of the iceberg, and I'm sure there are many other people who would like to continue the conversation as well. Thank you again for having me.