8. The Future Is Disabled

**Pauline**

You're listening to The Future Is Disabled. A program for 3CR's 2022 Disability Day broadcast on the connections between Long COVID and ME/CFS, and what it is like to be a multiply marginalised disabled person with ME/CFS. Before we get into that, you're going to hear a track from June Jones. This one is called Trauma Girls

**June Jones**

I felt my body spit my soul out / Now I'm empty as a single rubber glove / I know I overreacted / I feel ashamed, I am an apprehended dog / I was struck down by history, dragged back to the past / I wanna roll around the smoke and dust / Here come the trauma girls / The spend time in the corner girls / That can’t remember what a world like this was meant to offer girls like this / Here come the trauma girls / The spend time in the corner girls / That can’t remember what a world like this was meant to offer girls and / I felt my body spit my soul out / I understand if you don’t love me anymore / I never told you I was crazy / Nor was I subtle with the padlock on the door

Because I’m not a chill girl or a goer with the flow / Because I’m kind of always on fire and any cool is just for show / Here come the trauma girls / The spend time in the corner girls / That can’t remember what a world like this was meant to offer girls / Here come the trauma girls / The spend time in the corner girls / That can’t remember what a world like this was meant to offer girls and / Here come the trauma girls / The spend time in the corner girls / That can’t remember what a world like this was meant to offer girls like this and / Here come the trauma girls / The spend time in the corner girls / That can’t remember what a world like this was meant to offer girls and / Here come the trauma girls / The spend time in the corner girls / That can’t remember what a world like this was meant to offer girls like and

**Pauline**

The experiences of people living with ME/CFS can offer us insights on a future where increased rates of disability as the result of long COVID look likely. Emerge Australia is a national organisation providing education, advocacy, research and support services for people living with my myalgic encephalomyelitis/chronic fatigue syndrome, otherwise known as ME/CFS.

**Pauline**

There are more than 250,000 people in Australia living with the condition. The impacts of ME/CFS can be disabling. It is estimated that 25% of people living with the condition are house bound or bed bound. With many people living with these conditions unable to work or participate in community life. In March this year, Emerge Australia released an official statement on the close links between ME/CFS and long COVID.

Scientific studies indicate that the most frequent shared symptoms of people with long COVID and people with ME/CFS: Post-exertional malaise or PEM, cognitive difficulties and fatigue. Much research on both ME/CFS and long COVID are desperately needed and many of those living with ME/CFS continue to sound the alarm on the completely inadequate and sometimes dangerous medical advice, often given to ME/CFS patients. So in this program, we're going to be hearing from someone who has been living with ME for a number of years now. I'll let them introduce themselves.

**Alex**

Yeah, so I'll go by Alex. I am a disabled person with Myalgic Encephalomyelitis, or what gets called chronic fatigue syndrome. I am quite impaired by that. And, yes, obviously, I identify as disabled. I'm also queer, trans, an artist, and have been a sex worker as well. Yeah.

**Pauline**

So Alex, I connected with you in the place where I connect with a lot of chronically ill and disabled people, which is online. And I also came across an ongoing fundraising page for your literal day to day survival as someone with ME, who is not able to access the National Disability Insurance Scheme to help with the costs of that daily survival. So to begin with, could you tell us about ME? What it is and the impact this has on your day to day life?

**Alex**

Yeah, sure. So it's called My yogic encephalomyelitis. So basically, that word means, inflammation, brain inflammation. And it's a multi-system illness that has no formal testing for diagnosis. So it's diagnosed by ruling out a lot of other conditions as the cause of the main symptom. The hallmark symptom of ME is post-exertional malaise, which is ongoing fatigue. After an event of exerting yourself past a certain point of your capacity. So for different people with different levels of severity, their ability to exert themselves is different. For people with mild ME/CFS. They might, after doing some exercise, they might be stuck in bed for a few days after.

**Alex**

So it really depends on your severity. For severe people with ME/CFS, past their capacity can be things like tolerating noise, and light for too long or even at all. There are people that have to basically spend most of their time in a quiet, dark room. In bed resting with headphones on to block out any noise. Obviously, with each person is different. They don't know exactly what causes at the moment, there's different research happening. But because it has been a highly stigmatised and poorly understood, illness that just gets blamed on laziness or being unfit.

**Alex**

There hasn't been really funding that goes into it to research it. Yeah, so there's a lot of different aspects of this illness as well as some patients turn out to have connective tissue issues happening where it's degenerated their connective tissue. There's a lot of co-morbid conditions. Like people with ME/CFS might also have Postural Orthostatic Tachycardia Syndrome, which is when you are upright, you experience tachycardia, fast heart rate, as well as other dysautonomias. There's a lot of systems in the body that are impacted by ME/CFS. But we haven't really got the solid confirmation.

**Pauline**

So the fundraiser that I mentioned at top, the fundraiser notes and updates have mentioned how you have been rejected from the NDIS, multiple times. Could you tell us about what the process of applying has been like for you? And what justifications for the repeated rejections have been?

**Alex**

Yeah, so I've applied for the NDIS, five times. And I'm currently in the process of, I don't know if it's called an appeal, if you're at the Administrative Appeals Tribunal with your NDIS case. But I'm in that process, and I've been there for over six months now. I have no lawyer. So I was rejected from any legal aid. And I've only just had an advocate, I've only just made it to the top of an advocate waiting list to try and help me. There's this main problem that keeps coming up, where they will say that my condition is to be dealt with through the medical system, not NDIS.

**Alex**

I submitted my internal review information to legal aid with my application. And regardless of what I explained to them, they rejected on the basis that my condition is to be dealt with through the medical system. Obviously, NDIS, well it might not be obvious, but NDIS tend to deal with impairments, not conditions themselves. So if you have impairment caused by a particular condition, they will deal with that.

**Alex**

But you need to prove that you are fully treated and stabilised as well. As well as fully diagnosed and that the condition is permanent. Like lifelong. I'm pretty sure. So lots of questions come up on permanency of the condition. But that's why I was rejected from Legal aid. I can't afford to pay for a lawyer myself. So just didn't do anything. I just went through to the case conferences with the AAT, I forget what they're called. And the NDIS is lawyer. So basically, I had to just talk to this lawyer and have the AAT person? On the phone by myself. Which is really stressful. Because I don't know. I don't know stuff.

**Pauline**

Yeah, that sounds absolutely horrible. So what are your other options for financial support, given the NDIS will not assist you? And if you tried to access those, have you been successful or not?

**Alex**

I tried to access aged care. I'm not at the age where aged care is usually given. Aged care is for over 65s. But in certain cases where you don't have any other support aged care is supposed to be the last resort. So I had an aged care assessment team come and assess me in my home. And they were saying, the level of care that we could give you with aged care is not enough. You'd need NDIS. We don't want young people getting on to aged care when it's not appropriate. So that was maybe eight months ago, maybe. And I don't have any other support like other than fundraising.

**Alex**

So other support that I've tried to get through RDNS. I forget exactly what the name of the package or program is. I think it only goes for three months. But it's for people that don't have NDIS or other options. But they weren't able to support me either.

Aged care had said, you really need an OT assessment. You really need an OT assessment to provide more evidence for NDIS. But also, OTs are very expensive, and they're not covered by Medicare. There is a rebate. But for a report for NDIS. It's 10 hours of work that the OT needs to do. So I've been quoted the out of pocket expenses would be $1,200 or so.

**Alex**

You know, where do you get that money? If you can't really work? You know, I'm on the disability pension, finally. I've only been on it for a few years. But that's not enough. Most of my expenses are way higher than the pension. How can you afford out of pocket expenses? So basically, they were saying, well, RDNS should be able to provide that for you. And they were saying, we'll talk to RDNS. I don't think they really did. And I called them up a few weeks later. And I was like, "Hey, I'm just really wanting to know, this is aged care. Can you support me?".

**Alex**

And they just kept saying no. And then they gave me another number. Ability First Australia. and I'm not really sure exactly what happened with them. But they were basically like "No, we support people at risk of being put into aged care". But for some reason, I'm never severe enough. Like I'm mostly bedridden, I can get out of bed a bit, I use a powered wheelchair, and I can go out of the house. Only a little bit. At most, a couple of hours a week. But it's still all past my capacity. Basically I'm forced to do like a lot of things because I don't have the help to do it.

**Alex**

But it all makes me worse every time I'm pushing past that capacity. So basically, that's still not enough for them. But I think because with ME/CFS. Technically if you do something, and it makes you worse, that's not in your capacity, right? So I think they see, because you get up out of bed and you have that shower, because you have hung in, in a week, yhey see that as not bad enough. But you're gonna be in bed for ages after you have that shower, that one shower.

**Alex**

And, you know, years go by that you're without support, you just keep getting worse. So it never seems urgent enough. But it's been urgent for me almost four years now. I used to be a much milder with my symptoms, and it would be just attributed to other chronic health conditions that I have. It took me a long time to have any formal diagnosis.

So you're asking how do I fund supports then? It's basically like fundraising has been the main source. A huge chunk of it. Some of it has been accessing, there's a grant called like the DeCoster grant, which disabled people can access to pay for things. It's not very much but it paid for a little bit of my a powered wheelchair two years ago. So I'll try and access little things like that and then I also will try and access artist funding. Like accessing a benevolent artists funds, that have been impacted by unforeseen circumstances and stuff.

But yeah, it's never very much compared to the overall amount that has been fundraised. But yeah, it's so hard because people are so generous and donate a lot, especially other disabled people. Other sex workers, other queer and trans people. And yeah, other multiply marginalised people, they have such a capacity to care. So I find that really hard to accept donations from people that I know, are multiple marginalised, because it's not sustainable.

**Pauline**

Yeah, oh, gosh. That's come up so much in my conversations with people this year about the burnout, and just the fact that it shouldn't be left to multiply marginalised people who are poor, to be taken care of by other multiply marginalised people who are poor. You're totally right. It's not sustainable. It's, yeah.

**Alex**

I read this post somewhere on Instagram, where someone was talking about being a queer person of colour, and that they noticed so much burnout. And it's real, like the burnout is real. They were saying it's because within the community, they've just got such a small wealth of resources that they can't just rely on.

So yeah, I think that's just not sustainable. But it needs to come up from people with more capacity. More privileges coming down, rather than just people that can relate. But I don't know how to, it's hard to know how to reach people to care.

**Alex**

I just always feel bad when it's like other multiply marginalise people, because I know. I know how much they're struggling too. And I don't want them to put me before themselves. Overall the funds never seem enough as well. Like, I just need so much help. I really need daily support.

Yeah, it's just really, really hard. And also, I can't employ someone from a support worker agency and stuff. I can't give the funds to someone I don't have a connection with or a friend of a friend where we have the understanding that I rely on fundraising.

**Alex**

So I will pay you and I'll pay you in full, but it won't be by a certain time. Like, it's just as funds come in, which is so hard. Because people that help me, and they've all been so supportive and great. They helped me, because they're not working full time. They're on jobseeker, which is horrible. Below the poverty line. They're on jobseeker. So yeah, a bit of extra money is helpful for them.

But I can't give them the job security either. So it can't be flexible for them. There's no sick pay. So that is really hard, because I don't have the level of consistency that I need as well. Which is yeah, obviously really hard. Um, basically, I need NDIS.

**Pauline**

You just heard a portion of a longer conversation with Alex detailing some of the extreme hardships of being a multiple marginalized disabled person with ME. To listen to a longer version of that interview, and to the show, keep your eyes on the 3CR webpage for Disability Day 2022 after the broadcast.

**June Jones**

(Extrovert by June Jones feat. Alice Skye) I used to think I was an extrovert but I was just afraid of being alone / Coming off of my Lexapro I can't text or talk on the phone / I wanna, I wanna, I wanna, I really wanna, I wanna, I wanna go home / At a party trying to talk to you but the music is way too loud / And these drugs don't do anything / I don't know why I ever go out / I wanna, I wanna, I really wanna, I wanna, I wanna go home / My brain is grating on the holes in the walls of my skull / The pain is greater than any pleasure I've ever known

**Alice Skye**

I used to push my body beyond all the limits I'd set / Now when my body speaks I try to listen I try to respect / I gotta, I gotta, I gotta, I really gotta, I gotta, I gotta go home

**June Jones**

My brain is grating on the holes in the walls of my skull / The pain is greater than any pleasure I've ever known / I wanna understand the rules of the game that we keep on playing / I don't understand the rules of the game that we keep on playing / I wanna understand the rules of the game that we keep on playing / I don't understand the rules of the game that we keep on playing / My brain is grating on the holes in the walls of my skull / The pain is greater than any pleasure I've ever known / I wanna, I wanna, I wanna, I really wanna, I wanna, I wanna go home / I wanna go home / I wanna, I wanna, I wanna, I really wanna, I wanna, I wanna go home / I wanna go home

**Voiceover**

Have you heard of long COVID? If you or someone you know have had COVID-19, you may still experience symptoms weeks or months later. There are many symptoms of long COVID. But the most frequent are extreme tiredness, shortness of breath and muscle aches and joint pains. Anyone can experience long COVID, including children. You can find information in your language on the health translations website health translations.vic.gov.au Just type on COVID as a keyword.

**Voiceover 2**

A 3CR supporter.

**Voiceover 3**

 3CR community radio 855 AM.