

# CENTERING OUR VOICES

LIVING WITH A COMPROMISE IMMUNE  
SYSTEM THROUGH THE PANDEMIC



**TRACE**

CASTLEMAINE RESIDENT

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My name's Trace – I live here on Jaara Country. I am in my late fifties but my spirit feels still very young, hopefully all my life. I work mostly from home in my little studio in the garden and also a lot out in the bush. I was going out into a lot of schools, libraries and festivals doing little workshops but now they've gone onto Zoom. Some are starting to potentially come outdoors again, but I say no to all the indoor ones.

I make children's books and I do work about connection to place in particular, real acknowledgement to First Nations folk and human rights, they're my main things that I work on.

My body's getting older and has some problems but I'm really hanging in there with the play. I dance and I ride a bike – I've gotten an eBike, because I've had a lot of pain with the riding otherwise, and I swim. I work hard to keep my health in as good a shape as I can.

Just before Covid came along, my relationship of ten years ended and my son moved out of home. So I found myself living in the walls on my own, but outside with the community of all creatures. I also live within a lovely community. I think the thing about the play for me is it's a mental health thing, a balance. Especially as I'm living inside the walls on my own.

My health situation I could describe as a messy concoction. I've got colitis and that's caused me to get osteoporosis, and then arthritis, exhaustion, and I'm prone to be anaemic. I also have a thing called upper respiratory resistance disorder. That means every two or three minutes I stop breathing in the night and that's more exhaustion and more for the poor old immune system to kind of feel good in. On top of that I have a cerebral aneurism. I really need to manage the breathing because when I don't breathe for long periods of time, you know when you've been underwater for a long time you feel this blood pressure in your head? I wake up with these drowning dreams from not breathing and the problem is that can put pressure on the aneurism and cause it to burst, so for me that's a life-threatening thing. Because I've got all these things, I'm trying to keep my immunity up and it's hard work to keep doing that, even just a common cold can be pretty complex and completely take me out. I have all that monitored as well as some other things. I get quite a lot of pain during the night as well. I won't bore you with the rest of it. (laughs)

I don't take my health and my life for granted at all. I was already someone who was like that, and life just continues to remind me of the gift of every single day. How am I still bubbly and happy and joyful and grateful and feeling fully alive? Well for a start, I've seen three members of my family die in a moment – actually four, well one went in a coma, so I'm very aware of my mortality always – and our mortality always – and how incredible it is to be alive.

One thing about the colitis is it wakes me up really early. So I get up, I'm a very visual person so I go out and I love seeing the sun rise. I go out in the bush and I take my brekkie and I find my way up some hills. I think just starting the day with that absolute awe and marvelling and seeing the seasons pass, and all the gifts that come in the seasons, you're already setting up your day in that way, even if the rest of the day is so hard. You start well.

Also the other thing for me is my work is really meaningful. It's basically inspiring care for the planet and one another. I could say that I was really isolated in some ways even within a beautiful community and so in the last year, two years, I've become more and more connected with nature and I just feel that really gives me so much joy.

The week that we went into the very first lockdown I had a book launch due that day that it went down, and that was from a three year book project. I had a huge book launch organised and thirty events, and basically a year's income out the door in one strike. And I guess I just pivoted. It was really hard. My son came back for a while and he was really struggling with coming back and he was awake at night and I was awake in the day, so I couldn't really spend time with him, but occasionally there was someone to touch. On that topic of touch I'm still really struggling with that. Much better than before, though it's still a tough one. One thing that happened for me, I started hanging off trees and stuff, stretching off trees and then I started leaning into them and finding that physical connection with another live being, and I call this thing "troga". It inspired a lot of people to get into it! I've got this certain angle of a lean that I love the most and I've written a lot of poems in the last couple of years and there's one about that, I could give you a line or two of it?

Find a tree – a perfect angle  
On which to lean, on which to dangle  
Know that you like roots of tree,  
Are held by core of gravity.  
It's been the same forever past  
Holding all through time so vast.

I'm incredibly privileged in that I've got another contract for a book, and I'm working on that. I'm basically, I can work from home. I did a lot of Zoom sessions in the end, and also I've converted my home. I did a very basic renovation and there's someone in the other half of the house now – cos what am I going to do in a house that three of us lived in? I put the laundry outside, so we all use the same washing machine. We share the vegetable garden, and there's also someone living in the garden in a converted shed type situation. The other thing for me is I have a little room I call the cocoon room. And I can put the heater on there at night. But what I love to do is go outside and find a billy fireplace type thing and have a fire as company for maybe an hour, under the stars, and then just go back to the cocoon room in the winter.

For me I feel like there's this invisible group – there's a very loud group who don't want to be vaccinated and there's a big, big majority who have this kind of health privilege. "Oh well, we'll get Corona, it's inevitable" and they go out and drink in cafes indoors and get on with it. And then there's this whole other lot that I call the invisibles. There's a lot of them and me, laying very low in a lot of situations, feeling this exclusion, because I don't want to be going where people are not wearing masks. So I don't go to places because I don't get invited to places, and you get more and more isolated.

I've had people tell me "I want to get Corona so then I can go on a holiday because I'm not vaccinated". I try to see their point of view, so I don't just get so upset by it, because to me it feels so deeply disrespectful of what we are grappling with every day in trying to keep ourselves alive basically. Not to get long Covid. Many of us, it would amplify everything and some things and what things, you're dealing with enough already. Your health is everything. I just feel like this lack of understanding and lack of hearing from many who are health privileged. We're not all doing what you're doing, and there's reason for it, and I don't know how long we'll be doing this for but gee we've got to find ways to be able to do it together. I have found this dance that started outdoors, that's been fantastic, to just do something together.

I feel really tender talking about this stuff because I am a lot more privileged in so many ways than a lot of people we're talking about here. I just can't believe that we're not centring these voices, because this is what this is about, it just feels so incredibly rude. It's this lack of humanity for who's in the back – you want to bring them to the front, in the centre, and put the care around them, rather than “oh we can do this now, because we're free”. Actually can we just look at who's in a difficult situation right now, because you're free?

I was wearing the full-on mask on the train, I had to go to Melbourne for some scans, and you kind of feel like the freak in the room and that's not a good thing. There was a moment there for a while where you feel this solidarity - because I would always have to take a mask on the train for years. For a moment there we were all the same and now there's a whole lot of invisible going on and that's not ok. We need to all work together and listen to every voice. “The ones that die are whatever, they were already...” They're humans! Put them at the centre and talk about them.

I was really grateful the other day, I went to a party and I thought I'll go really early and I'll only stay outside and when it gets too much I'll leave. I figure they'll all be inside. It was a beautiful night and people were outside, I felt like I could hold the space and it was fine. I did have to go inside to use the bathroom and it was like, am I going to be a freak in my mask? There was a queue, what do you do? Nobody's got it on their radar – let's make it so we can have a way for everyone. It's invisible for so many.

Accessing care over the last couple of years: I've enjoyed having some things over the phone instead, and being able to stay in my safe zone. Yesterday I had some high-level screening in the city, and it was really edgy for me to do that. I took my P2 mask that I'd been given at a recent blood test. When I got to the hospital entrance, they gave me a brand new one of those things that you can't seem to get. I walked there, there's no way I was getting on a tram after being on the train.

I went to meet a friend before, and she arrived after me so I sat down and started doing some weaving. I took the weaving in with me and found some really good things to weave with in the bush. It was holding me inside this highly clinical space which was even more so now that we're all so masked up, but I kept weaving and I was focused on that. I had a feather in my hair for protection and I decided to really keep, because I've been so connected to nature these days, to keep that strong in me as I went into this environment. It was kind of strange that I was going down to help me and it was putting me at risk by actually going there on the train.

I had a counsellor on the phone and at one point we could go back into the space, and she asked me if I wanted to come back in. I said "No! I feel way better not being in the room with you, sorry!" Seeing some of my health practitioners in social settings where I was definitely not hugging anyone, and they were hugging everyone, do I want to be in the room with them? Because basically if they've hugged all these people it means they're connected to them. It's my vigilance and it's my precious life, and I don't want to get long Covid or worse. I actually don't want to get Covid. To be home alone sick, is really not my idea of what I want to do. It's hard enough as it is.

A friend of mine was offering up an indoor event and I really wanted to go. I said are you aware that there's been 120 cases in our region in the last week? He was like "Oh, really? I didn't know that. Maybe I'll have to think about now that you've said that, thank you". Because now that people are tired of looking at it, and that might not seem many in some ways, but it's around and I know the people.

Some of us eat meals alone all week, and now I've started to invite myself to sit in people's garden and bring my dinner. It would be nice for people to ask me a bit more. I wonder about other people who don't have those connections that I have. How's it working for them?

I saw Community Lunch was on, but I believe it's inside, unless you're unvaccinated. So the people who are health compromised can go and sit out with the unvaccinated people. It's a funny old thing, isn't it?

I feel like I live my best life as I'm living. It's incredible to have that privilege – being able to grow vegetables and make books and dance. I think for me it's more about how I want to live than a bucket list. Just to live well – a simple life's good for me, and just to keep doing the creative work and to keep well. I don't have the urge where I have to go and climb whatever it is. As long as I can still see and have my creativity and my fingers to move I'm probably happy.

I'd just like to say on that that I have an absolutely beautiful life. I really struggle, and I have a really beautiful life.

I sent a friend of mine a photo of my arm with the cannula in it yesterday and next to it the basket I was weaving, and said, you know, we choose what we want to focus on. She wrote back and said it's a perfect example of coping craft. That's a beautiful thing to call it. For me it's even more than just coping though – it's living and it's thriving and it's loving and connecting. Connecting deeply with nature. So many people on the planet are struggling, and to find what we have and what's in our pockets, that we can do to have that coping craft and for that to bring it beyond Covid. I wish that well for everyone – I know there's so many people doing it hard and I feel so grateful that I have creativity. I just really pray for the people who feel isolated and in pain, dealing with significant ill health and hope they have ways to have coping craft and beyond coping.