

CENTERING OUR VOICES

LIVING WITH A COMPROMISED IMMUNE
SYSTEM THROUGH THE PANDEMIC



MELISSA, 52

CASTLEMAINE, VICTORIA

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Melissa is 52 years of age and lives in Castlemaine. This is her experience of living with compromised immunity through the pandemic:

I was born here, moved away for many years then came back. I've got a progressive disability – a spinal cord injury – and I have a compromised immune system. I'm single, I'm disabled, I'm human. I've got a couple of kids.

During the first year of the pandemic my daughter was in year twelve, so it was a very disrupted year for her. We also had the understanding that it would be very easy for her to bring Covid home through her attendance. I also have an immune compromised daughter in law and my daughter herself is immune compromised.

It was pretty tricky. I basically knew that I had no control, so I just did my best. I didn't really go out. I knew it would probably kill me because my autoimmune system cannot handle two different things. My mast cells don't recognise me, so any virus or illness that's introduced to my system, my immune system will completely overreact and start attacking me. I end up with either anaphylaxis or tunnelling cavernous wounds.

It was easy to just disappear - no one noticed how unwell you were, or how much you were struggling. No one would come and do face to face services. The first year my daughter was here, but the second year of the pandemic she'd moved out. I'm literally alone with two cats and going a little bit bonkers. I think the thing that's going to be hardest for me is reengaging with community.

It's only the last couple of months that I've really said to myself: you are really isolated. I have a mum that rings me at 9 am to see if I'm dead every day, and that's about it. I could go not seeing someone for months on end. I think it helped me hide my mental health state, so I could disappear. No one would say "you know I don't think Melissa's left the house for six months". Because we're all told not to leave the house. There was a weird safety in that, because I could pretend that I couldn't leave the house.

I've just had phone consultations for two years basically. I've only been into the doctors a couple of times and as soon as they decide you don't have Covid, that's the end of the discussion. I don't believe people's chronic illnesses have really been managed very well, because the hospital and GP's have been overwhelmed with testing and vaxxing. There's not a lot of room for "hey I've got this weird rash" or "I've got this weird pain". I've gone months without face to face conversation, or even a phone call that went more than five minutes. It was certificate, prescriptions, see you later. If someone is developing or having a change in their condition, to get it dealt with has been incredibly difficult.

My mum was in hospital for eight months with a thigh break, my daughter was hospitalised as well, so I was trying to manage all these people in hospital via the phone. I think I got a couple of visits in on mental health grounds with my mother - it was very difficult to manage myself and my family members with disabilities as well at the time. It was just really a big mess to be honest - to try and figure out what people needed and how to get it to them.

Vaccination was really simple for me. I got the 'flu a few years ago, and it almost killed me. It escalated into a life-threatening wound that took three years to get under control. I knew one hundred per cent. It was simple - if I get Covid, I'm dead. If I take the vaccine, I might be dead. I knew the stats, I knew that six billion people had been vaccinated, I knew in Australia there'd been nine deaths directly linked to Astra Zeneca.

I saw two doctors before I went and got vaccinated. It was forty minutes discussion of whether or not they were prepared to give it to me. And I just said, if I get Covid I'm dead, and this vaccine might effect me. So I made it that simple. I didn't have to think about it and I didn't have to stress about it. I was eligible for Pfizer and the first dose I was flat out for ten days - I couldn't sit up, I was that weak, and I had severe headaches. But the second dose - nothing. No reaction whatsoever.

I've got asthma and I have chronic sinusitis, so I have difficulty breathing at the best of times. I knew my immune system would freak out and rip my lungs to pieces, cos that's what it does. Vaccination was an easy choice. I didn't have to worry about it. I just did it.

I haven't got a tattoo on my head that says I have no immune system, or that my spinal cord is crushed, like a lot of people like their disabled people to be in a wheelchair, and you can't see an autoimmune disorder. You're not going to know who is at risk - you could be standing next to someone who could be killed by anything entering their system.

There seem to be two types of people, the ones who say this is like a cold – “it only effects the old and sick, let it rip”. They believe “if you got some sunshine and took vitamin blah blah, you'll find you've got a natural immune system”. That really stood out to me, this constant message that it only effects the old and sick. That we're disposable. What about kids on chemo? This attitude that absolutely reeks of eugenics – “we'll just get rid of the weak”.

The second type of person is really caring and well meaning, but they don't actually ask us what we need, or what would actually help.

Not all disabled people are sweet little angels – some of them are feisty. And if you didn't have your feisty ones that speak up for the community, they would let us all die because it would save the government a hell of a lot in their budget.

I've been fighting for my life for quite a few years. When they treated my neck I was on high dose steroids and I went into kidney failure. At times I've had pain levels where I wish I could die, but I'm a clinger. I've been told that people like me who suffer chronic illness and pain would find death a blessing. I went hang about, I'm not here because I'm this pathetic weak creature that is just waiting to die. I don't care if I'm a head on a stick – I'll watch telly.

I don't need much. I'm someone who marvels at the light in late afternoon, when it comes across the Australian sky in orange and pink, that's my jam. I'm very good at stopping for a moment and noticing absolute beauty. Just having a moment of low pain when the sky looks nice - that stuff feeds me. I don't need a big life anymore. I've learned what I can and can't do and that's good enough for me. I don't need to go and climb mountains or win an award or be famous. I just want a comfy couch and a big telly, and to chat to someone occasionally.

I still have enjoyment in my simple life. Just because we're “not contributing to society in a meaningful manner”, according to the ableists, it doesn't mean we're disposable. We're smart - we're a very diverse community.

The world has been quite an ugly place the last few years. I think it started with Trump's election, when there was that time where it was ok to be a bigot, it was ok to be racist, it was ok to be homophobic, it was ok to be transphobic, all these things suddenly were ok and everyone was living via social media. So you connect but suddenly to call people out on this behaviour wasn't ok. You were being a "snowflake".

Australians like to get around the rules, they like to be cheeky, but that cheeky attitude ended up being dangerous and causing clusters when we had no vaccine. Now we've got a vaccine - just use it. We really do need to be up around the 95% to protect people. At 95% the 95 can probably carry the 5 that won't or can't.

People need to slow down and really ask themselves "Why am I anti vax? I've had every other vaccination in my life, why am I not taking this one?" People want to believe that they are in control of their lives. When you're frightened, it's easier to believe a conspiracy theory than accept the realisation that there's this really nasty bug out there that we can't control, and that is going to take out a certain percentage of the population.