

CENTERING OUR VOICES

LIVING WITH A COMPROMISED IMMUNE SYSTEM THROUGH THE PANDEMIC



CHRISTINE

BENDIGO RESIDENT

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My name's Christine, and I've been living in Bendigo for just over three years. I moved here from Melbourne where I lived for a long time. I'm in my early sixties and have some complex health issues, I'm immunosuppressed following a transplant I had six years ago following a couple of years of various treatment including cancer treatment.

Prior to the transplant I worked in senior management in community and public health and I have sole parented a son who was a teenager at the time I was really sick. Post transplant, because of the complications I've never returned to work. I moved up here because I'd lost my income and had to sell my house in Melbourne and Bendigo had more affordable housing.

I didn't have networks in this area so I was a bit naïve in thinking, oh well, you can just uproot and go up there and everything will be good but I guess I was also assuming I still could muster some capacity to re-establish. I'd been here for a year and then Covid came along, and I'd started to make some inroads into the community. I'm also a writer, a poet, and I was very involved in the spoken word community in Melbourne, and I'd had ideas about being part of something here as well, but that didn't happen.

Having immunosuppression already, once I wrapped my head around what Covid meant and what it was, I was quite used to taking precautions for my own safety and protection. I became completely isolated and in the first year of Covid I was still needing procedures in Melbourne every three months, I was having a lot of medical to-ing and fro-ing, then the requirement for that stopped.

Day to day for me, particularly in Covid, means that I have developed a lot of social phobia. That includes some friends who know me and who've known my situation, and I'm very mindful and respectful of that. However, unless you have that yourself, you don't think through all the detail of it – what's their social network and their social network's social network, and all the rest of it. The day to day experience of being immunosuppressed means maintaining a very socially isolated existence.

I have a handful of medication for breakfast and that affects me in all sorts of ways. The side effects from that also complicate my health. I've just developed breast cancer for example, and that's probably because of immunosuppression. I've struggled to find meaning, now that I'm in this situation.

The places I'll go include the supermarket and I'll be one of three or four people in the supermarket with masks on still. As the restrictions have relaxed it makes us more vulnerable, so that's disappointing. There's a fatigue that comes with that, on top of the fatigue I live with anyway on top of my medical conditions. It certainly impacts mental health, if I'm around other people at all I'm wearing a mask, I still sanitise and wipe down my shopping trolley and all the rest of it. I go to places when it's not likely to be busy. I walk my dog without a mask, I go in the bush. Fortunately I'm located with bush at the end of my street. I just steer clear of people.

The physicality of it all is that the immunosuppression that I'm on gives me brain fog and fatigue. I don't sleep, I have terrible insomnia, I have restless leg syndrome through the night which is horrendous. I have osteoarthritis and tendonitis, so it feels like accelerated ageing – I feel thirty years older than I kind of am.

A couple of things that would help me feel safer around Coronavirus, would be if it could just disappear, that would be great – I'd feel safer then. I think if there was a greater sense of social responsibility would help too. The whole dismissiveness of underlying health conditions as a term, as a blanket term, "oh well, people who died had underlying health conditions" – it is so dismissive.

What brings me the most joy? Joy can be a bit hard to find sometimes so I do seek it in the bush, birds, and bees, and plants, and my dog, and my son. There's a strong protective factor, I want to stick around for my kid. They give me joy, although my son now lives in Sydney. Joy is in the small things – trying to find something small like the lorikeet out the window there, those sorts of things bring me joy.

As a transplant recipient, and with that comes immunosuppression – the two go hand in hand – it's fraught territory, it really is. On the one hand you're very lucky to have had a donated organ, to be on the waiting list in the first place, and then been successful in getting a transplant organ. I'm very mindful that with that comes, in my case for the type of transplant I had, it means someone has died and there's a grieving family, that there's huge loss that's happened somewhere and in the midst of that loss, a family has made a really difficult decision so that other people who are dying, as I was, can not die.