

CENTERING OUR VOICES

LIVING WITH A COMPROMISED
IMMUNE SYSTEM THROUGH THE
PANDEMIC



EMMA

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My name is Emma, I'm a person with Multiple Sclerosis. MS is an autoimmune disease where your immunity thinks your brain and your spinal cord are bad when you become ill and attack it. So you end up with debilitating symptoms that stick with you forever. It's different for everybody but for me I have pins and needles, pain in my legs and my feet, and I have numbness and pins and needles in my hands, and I experience fatigue, anxiety, and on occasion depression because having a brain that is damaged is not good on lots of levels.

The medication I take makes me immunocompromised. This medication helps keep my MS in check but it makes me highly vulnerable to all sorts of illnesses, primarily chest infections and colds and things. Covid for me is high risk. I'm triple vaccinated with Pfizer. I'm a parent to a three-and-a-half-year-old and I have a husband who works full time. I work casually as a counsellor and I've just finished my psychology undergrad degree last year. I'm 37, and I have two dogs.

I woke up with my MS symptoms in the same year that Coronavirus joined us. So if you're going to have an autoimmune disease, I don't recommend getting it in the middle of a pandemic! It is terrifying. I woke up in October 2020 with the pins and needles in my feet that I thought would go away, and it's spread throughout my body. I spent some time in hospital and a few investigations later got my diagnosis.

I've been learning a lot since then about what MS actually is – generally, but more importantly what it means for me. How to live with it in a pandemic at the same time – it's been highly challenging to say the least.

Accessing support has been hard. I'm based in Bendigo and as we know in Regional areas, we don't have a team of specialists on staff here. When I end up in Bendigo Hospital no one in Emergency understands what MS is or how to treat it. But I've recently had to find a psychiatrist just to help me manage my anxiety and how that effects my MS symptoms. That was very hard, I ended up having to see someone over Zoom from Geelong. At times when I needed to see my neurologist in Melbourne, it's a full day. I'm in a position where I'm not working regularly every day, but if I was I would have to take that time off work, go down to Melbourne, see my neurologist, have all the stress and anxiety of exposures that go along with being in a city, and the energy and effort of a full day as well is quite taxing.

At different stages throughout the pandemic we've had varying degrees of isolation, whether it was mandated or self-imposed as they started to lift the mandate. There have been periods of loneliness - not always in the physical sense, as I definitely rethink catching up with friends. I have my own safety to consider so I'll ask things like "can we sit outside?" and maybe we'll go to a park instead. It's been challenging and I've needed a lot of brain power, extra energy needed to process and weigh up the pros and cons of different decisions.

Especially having a toddler to consider and wanting her to thrive. When we were in mandated lockdowns seeing how that affected her from an enrichment perspective - her social enrichment and her learning and growth. I've been considering her needs in amongst it all as well. When I take her to a playground, I wear a mask, I have the hand sanitiser, I'm being as safe as I practically can, keeping distance from people. But then I have this tiny little germ "bringer homer", just running around, potentially wreaking havoc on all those careful things I've put in place. I've had to accept that if Covid comes into the home we'd just have to find a way to cope and manage.

My friends and family have been really important to help me get through the pandemic. Also my toddler - just having her to focus on as well, and her needs to consider.

Health providers are definitely putting out different advice to people, especially people with immunocompromised systems. I think probably they just don't know enough yet, because we haven't lived with Covid for long enough, and we don't have the data to tell us how it's going to go for any individual person. Autoimmune is so complex and individual to each person, there's no real telling how an illness like Covid's going to go in a body like that. I have been told conflicting things.

One neurologist I was seeing was a bit more blasé about spending time with unvaccinated people and around Christmas time having family members who are actively anti vax, that was difficult. I was really trying to find an answer about how I protect myself and manage those relationships.

The MS Support Australia have really awesome nurses who will give you a call and have a chat, they said don't go anywhere near an unvaccinated person in an enclosed environment, do keep yourself safe.

As different variants of Covid come out and their impact on different people, there's different messaging – like you don't need to be so stressed because this strain of Covid is not as deadly as the other variants, but there's still that real risk and anxiety. Just because I don't end up dead, I could end up without the function of my legs or my hand, or go blind or whatever. There's quite a lot of unknown and anxiety around what will happen to my body once I get it.

Some advice for anyone who was previously healthy and wakes up to find themselves with Long Covid would be, be kind to yourself. Rest. Make no apology for what you ended to get up in the day – if that means that you need to rest, then do that. It's extremely difficult to go from able bodied to struck down as I've kind of learned in the last couple of years. The hardest part has been being kind to myself when I've been fatigued, or my body's not functioning the way I want it to, just having people around who are supportive and kind. No one will understand exactly how it feels or what you're going through unless they're in the same boat as you. Try not to stress about that. Be in it with yourself – advocate for yourself, seek all the help that you think you can have for yourself, because it's a rough road to be on.

Some advice for people who think Covid might not be a big deal, who are just looking forward to getting the masks off and the restrictions all eased and back to life as normal: unfortunately our world will never be pre-Covid again, from what I can see. The measures the government have put in place at times have been extreme and been highly impactful on a whole heap of people for a whole heap of reasons. The reasons for those restrictions and advice and everything was to keep the majority of the population as safe as possible for as long as possible. So we know Covid is highly infectious, we know that people are getting Long Covid, which is debilitating. We also know that there's a lot we don't know yet about how Long Covid and the disease itself may impact on our brains and our immune systems for years to come. In the light of all of that, and in considering there are vulnerable members still in your community, the elderly, people with compromised immune systems, the disabled, wearing a mask and practicing safe hygiene – with sanitiser and washing your hands – all aid in not just protecting yourself but protecting those who are vulnerable in the community. So I think that the government has sort of forced everybody for a long time, but now it's up to you. Do you want to be part of the community in understanding that there are risks, not just for yourself but those around you. How do you do your small bit to protect and help the vulnerable in this time?