

THANK YOU COVID

Things are a bit different for me. As most of Melbourne emerges from lockdown I still find myself in one, in fact I've been in one for near on two decades now.

Disability can do this.

The year 2020 was still particularly hard though, I mean I had all my normal rigmarole and drama, yet without doubt the reins were pulled even tighter. And double that tightness because I live in a care facility, so the truth is that I lived a hell not many people can imagine.

But before I get into my tale of redemption and partial emergence, I'll give you the backstory.

I'm a quadriplegic who has a tracheostomy and is ventilator dependant, and after this obvious disaster occurred in my early 20's I found myself being thrown around amongst several hospitals.

Then as my health slowly stabilised, and upon realising that my medical needs were too great to live at home, the next logical step was that I had to move into care.

This was the beginning of my locked down life.

I was a young charismatic man, a bit of a brat actually, regardless, I had countless restrictions placed upon me. I was breathing through an apparatus, social isolation became my normal, invasive medical procedures and testing followed, then there was no choice but to work from home. My health was quite unpredictable too so participating in the community as I would have liked just wasn't possible.

I wouldn't even go shopping for essentials, healthy family members would home-deliver.

Only on the rare occasion would I go out - always wearing my Sunday best, I looked very strange at the Bunnings. By the same token, it also felt like people didn't want to come near me in case they caught my illness. They would always stay at six feet.

After some time I basically never bothered to leave my friendly mess, it was just too hard. So, my daily wear went plaid pyjama classic. Absolutely gorgeous. Then friends wouldn't visit, I think they were dealing with their own lives (or could smell me from their homes), nevertheless all my social activity moved online. What's more I'd now discovered the wonders of online shopping.

For year's this was my life, only popping out into the community for essential services. Doctor's appointments, bottle shop runs, etc, plus my hair was out of freaking control. Without doubt I was living in a bubble, it was only my care staff who were my close contacts.

It was certainly a sheltered way of living that not many people knew about or understood.

Then when Covid and its subsequent lockdowns came about (apart from thinking woohoo piece of cake I've totally got this), as it turns out I was in one of the most vulnerable segments of the community. And being so at risk to this virus I went into an extra hard lockdown. The few civil liberties that I did have were stolen away. Then as the rest of the community relished in 2 hours of exercise per day, I had none. My nursing home had become a prison.

At this time it was strange to hear everyone online whinging about their predicament, even whinging about how they could only drive within 5 kilometres of their home. Well in my case, I literally wasn't allowed to leave the site, in fact because of several staff coming in contact with Covid patients (because they also worked in hospitals), on numerous occasions I was locked in my bedroom. I wasn't allowed more than 5 metres from my bed. All in the name of safety.

Each morning I'd watch the Premier's press conference to see the developments and if any new restrictions had been enacted, then I'd read the email from the care home manager to see their new rules as well. This is why I kept saying I was in a double lockdown. Then there was the added complexity of things like my family not being able to visit, yet my care staff were free to roam as they pleased. Trust was pushed. Especially when regular staff were forced to take leave and complete strangers took over my care.

I can only compare this level of lack of control with disability itself. You are that forced into a corner yet you still have to somehow make it work.

No matter the anguish, the personal pain, the mental trauma – life must go on.

There is no value in letting social isolation hold you down.

And it was great to see this play out in the general community. After becoming familiar with images of naked streets and barren bars, to hear the Premier's final announcement that we were coming out of lockdown brought a tear to eye. I experienced it alone by myself in my room. What I was doing was living vicariously through everybody else. Then to see everybody on television celebrating it was pure elation, almost as if an incurable paralysis had been conquered. Everybody was able to get up and walk again and return to their old lives.

To me the Premier's words resonated like that of a Doctor – you're cured!

However, unlike the rest of Melbourne I wasn't quite so lucky. My reality was that I was still fighting to be allowed visitor's, actually my hard lockdown continued for another 4 weeks. I was still living on the frontline. The rules of the public weren't good enough for me, I'm always one step behind. And management always hangs on to control for as long as they can.

But after 9 months in total lockdown, not even once moving beyond the letterbox, finally management gave me the key to my cell. Accompanied by a staff member I was allowed to go out for a drive in my disability van, however I was still not allowed to get out. It felt like throwing a dog a ball but you keep holding onto the leash. Nevertheless, with great nervousness and anxiety I went out that day, a memorable experience to say the least. It was strange seeing people again, particularly who weren't wearing blue hospital gowns.

Assimilation was the exact antidote that I needed. For the first time in almost a year I felt human again.

This was the second time in my life that I'd felt this exact same feeling. The first was near on two decades earlier when I managed to leave hospital, only back then my leash wasn't being stuck in a van rather a wheelchair. Admittedly, both felt like a barrier to connection.

Only this time around, it now feels like there's a lot more relatability and empathy toward circumstances out of our control. Everybody now knows what it feels like to be stuck and lose freedoms. People have tasted my life. Plus, there is now more relatability toward creative living and making the most of what we've got, which ironically has been my plight for years.

So as awful and unfortunate as Covid was (and still is in many parts of the world), oddly enough I feel that most people understand me better now. Most people can relate to this life of partial lockdown that I live day in and day out, even if just a little bit. And for this I am grateful.

For all the bad in the world it seems that there is always some good.