Living with COVID is like living with a chronic condition

It has been some time now, since the beginning of my “health-bump”. Frankly, I'm surprised at how long it is taking me to adjust, given that I had confidently estimated 3-6 months to settle back into health. How destabilizing it has been not to know much about this disease - not even enough clues to help me decide if I’m an optimist or a pessimist. Too often, I find myself in an unseen puddle of sticky numbness, immobile for long periods.

Becoming aware that the experts themselves are learning as we go. I feel adrift. I don’t know how to get better. I don’t know how to preserve the health I have. I don’t know anyone else who has this experience. My little boat is adrift.

It has been some time now, eight years since the second emergency room visit and extended hospital stay. Eight years, close to nine, if I’m honest. My rare autoimmune disorder may still be a mystery, but my physical health is managed using protocols of “nearby conditions”. In English, this means I’m mostly okay. I pass as healthy enough – with my secret daily medication minimizing my physical symptoms. I have had a few scary months here and there, called “flares” for dramatic effect. For me, learning to live with this chronic condition continues to be more difficult **psychologically** than physically, as evidenced by the number of Brene Brown workshops I’ve attended, and attempts at finding a psychotherapist. Both the hospital stays and the subsequent years have been filled with empty hours, unable to make sense of the unknown. Unknowable, unsolvable, despite filling volumes of journals with a fountain pen and jeweled tones of ink.

The pandemic has made many of us feel uncertain, anxious, and frustrated by a lack of control. This is familiar to me, and yet, a destabilizing experience for those around me. Living with COVID is like living with a chronic illness…watch out for the next flare up – just like the next variant.

In January 2020, I was living in China when we learned of a virus outbreak in Wuhan. We were out of the country as cases escalated, and decided not to return to our home in Shenzhen. We danced an uncomfortable response to the question - have you been in China in the last 14 days? No, we reply with flat expressions, not meeting the gaze. In fact, it was 15 days ago. As it appears this truth might prevent us from getting a room in any guest house or hotel, we told ourselves we were technically honest. Over the next six months, we move through four countries seeking safe haven. So much felt familiar: telling half-truths, feeling unsafe, unsure, unable to return “home”.

Stranded, I try to care for myself and my family. I’m anxious, distractible, but discover the soothing power of Korean romance dramas on Netflix, and bowls of soup. I start making bread (like everyone else, I later learn) hoping that the metaphor of “the yeast is the boss” will help me accept the lack of control I’m feeling.

Being in lockdown feels the same as having a chronic condition: it is up to me to find ways to feel calm, feel safe, feel connected, feel possibility. Being careful with COVID precautions, I face these empty hours again. ~~What day is it? I experience time differently - it’s the longest shortest time. It’s next month already?~~ My little boat is adrift. But now – you’re in the boat next to me. I expect some comfort in the fact we’re in it together, but I can’t see your face, nor you, mine. Our masks and my secret medicine can prevent problems - but also prevent connection. Safe, but alone. A trade-off that gets tired over the years that lay ahead..

While I didn't wish it on the world, now everyone knows what uncertainty feels like. Additionally, people hear about us – the "immunocompromised" – and it's not cause for shame or rejection.. I flirt with the idea of sharing this part of my identity with more people… then quickly shake my head. What was I thinking? There is much stigma around "weakness". No super-hero whirls her cape while saying "Wait a sec, I've got to take my meds". ~~…. Hang on… my meds!~~

~~This leads to a whirl of activity to refill my daily medications. My medications are in China, my doctor is in Canada. The fact that it is dangerous to stop taking this medication is a constant hum in my brain as I see my supply dwindling. Rounds of brainstorming on skype calls across time zones to kind neighbours, pharmacists and doctors eventually pans out – pills in a couriered package arrive - we can now wait three months for passenger flights to resume.~~

Seasons pass, spring 2021. The world has shifted again, with the promise of vaccines for many of us. Another point of uncertainty for immunocompromised people. What is the data on side-effects? Is it safe for the immunocompromised? My doctor and specialists are silent on this. I ask and I ask – including Dr Google. Multiple times. Better to ask my neighbour – a psychiatrist at a large hospital. He tells me the unusual brain and lung complications he is seeing after mild cases of COVD are scarier than any rare side-effect of the vaccine he has heard of. Take the vaccine, he says. I do. We all do – and yet… we're in another lockdown.

Now January 2022. When I hear how COVID has made people feel - depressed, anxious and alone, choose your own adventure --- my mouth forms a wry half smile… Welcome to a taste of lived-experience in chronic condition-land.

But there's always hope, right? I"m getting comfortable with being uncomfortable – and maybe you are too. Or is this just toxic positivity? Again. Unknown. **Given our new knowledge and shared experiences in this pandemic, perhaps we can hope for an increase in empathy for each other across the board.**

Could this pave the way for those of us managing chronic conditions to feel included and understood? With more empathy all round - who else could we include and understand?

And so, when you notice someone making tentative moves, taking the risk to share their story - please dust off the empathy you've gained from your lived experience of the pandemic. It might just be me trying to be brave and share my truth. Cheer me on. …but wait – gotta take my meds first.

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