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Covid: 5 Years Later panel
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The Art of Tolerating the Intolerable

I've had covid once, in June 2022, while vaxxed and fully boosted. It was a "mild" case, because I never needed hospitalization. But, to make a long story short, that single infection has disabled me.

I've gone from being a healthy, active runner and swimmer to a much smaller life. My main limitations are balance problems and profound, ongoing fatigue, although the full list of symptoms is much longer. I would compare the fatigue to how I felt, in the before-times, in the day or two after running a marathon. In my experience, the fatigue after a half-marathon is no comparison – what I feel daily now is that post-marathon fundamentally empty physical battery. But with long covid the battery never recharges.

I am enrolled in the NIH long covid study¹ and have participated in one clinical trial (with another in the works). But there really isn't any treatment. There are some existing medications and treatments that can alleviate some symptoms, in some cases. For me, the most useful intervention has been getting contacts that aren't corrective but help my eyes coordinate – they've helped with balance, improved my ability to deal with cognitive load, and reduced my vomiting (from as many as 17 times a day at its worst).

But for me and for many other people dealing with long covid (especially the chronic-fatigue flavor of long covid), the only really effective coping technique is pacing. Pacing means controlling energy expenditure. Sometimes we use metaphors like "staying within your energy envelope" or "spoon" theory. Put more bluntly, it's a lot like permanent lockdown. I rarely leave the house. I'm constantly calculating whether I can afford to spend the energy to go to my kid's basketball game, attend a parent-teacher conference, take a shower, or work sitting up vs reclining. If something unexpected comes up, I know I'll need to cut back in another area. Working full time, exercising, and socializing are all things of the past. This fall, I'll be teaching online for the first time since the spring of 2020 (when we all taught online), primarily because navigating CU's physical campus is just too physically taxing.

The benefit of pacing is that it has mostly eliminated the days when I have to crawl to get to the bathroom or when I can't lift my hands due to fatigue. The cost of pacing is that I often

¹ <https://recovercovid.org/>.

feel like I'm looking out at the world from behind a clear glass wall – I can see it all, but I can no longer touch it. I'm no longer part of the wider world.

Frankly, I'm almost certainly overextending myself just by joining this panel. I'll pay a price for this event in the next day or two, if I'm lucky, and for longer if I'm not. But I so appreciated Dr. Ho's invitation, and I feel an obligation to speak for the many other long haulers who are in worse shape. The latest numbers suggest that 8-10% of Americans have had some form of long covid.² But we rarely see them. Being too ill to leave the house or even leave the bed means that many people with long covid are quite literally invisible to the wider world. The less we see these people in public spaces, the more comfortable we feel not using masks and not keeping our germs at home. And the more people don't mask and go to work and play while sick, the less able long haulers are to use these public spaces. It's a vicious cycle.

The world looks very different from a wheelchair. I've also found that the world looks differently at people in wheelchairs – we become a strange combination of hyper-visible and invisible. CU facilities are almost all technically ADA-compliant, but the ADA is a very low bar, and there's no enforcement, with the exception of disabled people filing complaints and going through the courts. As you can imagine, not many of us have the extra energy to do this. One of the most surprising things I've noticed since becoming disabled is how many people park in ADA spots without ADA tags or placards. I want to be clear I'm not talking about people with invisible disabilities, just people who don't have placards. In this situation, I ask people (politely, I hope) if they have a placard, and only once has someone had one that they just forgot to hang. The rest of the time, they have told me, "Oh, sorry, I'm just here for a minute."

I've found is that it's not so much that things get better as time goes on, as that one's ability to tolerate the intolerable improves. Art helps build tolerance. I mostly lean on beading and cross-stitch. When I cross-stitch, I gravitate towards trees, branches, and vines, lemons, apricots, and plums, which I think is reaching out for the nature I can't really access anymore and the foods I can no longer eat. The finished products are satisfying, but what really buoys me day to day is the unfinished work, the process, the meditative rhythm of needlework. And probably my favorite part is the discard jar, with its layers of craps, knots, tangles, and frayed ends. Everything in the jar is messy, broken, unusable and still, somehow, beautiful.

² Dr. Sarah Jolley, CU Anschutz, <https://www.cpr.org/show-episode/long-covid-the-ongoing-battle>.