

365 days



I've been in a funk for the past month or so, not really depressed or even numb. Honestly, it feels more like grieving than anything else, that kind of emotional ebb-and-flow as if remembering the bad news all over again.

Along came this week, which was notable for monster exhaustion, the kind that knocks me out, that forces me into bed and in bed I mostly stay.

And, then of course, there's today. Today I've been sick with long Covid for a year. A guy could get the blues.

But the question I've been wanting to ask, and have asked of several people in my life, is this -- do people know I'm not going to get better?

It's a legitimate question, but I should clarify: I am hopeful that I will get better; I just don't expect to anymore.

Mostly because it's been a year, and I'm worse. Objectively and subjectively.

And the implications of that are clear to me, if not set in stone, so I wondered if everyone else had figured that out yet. This won't be over soon. I don't want to be forgotten, but I also don't want anyone looking out the window and waiting.

I haven't accepted anything, just acknowledged it. And I know I can do things. I could meet people for dinner at a favorite restaurant, hang out for a couple of hours. I can clean up, so to speak. But I need a couple of days of doing nothing before, and then who knows how long after? That's the equation I always consider. Is it worth it? Is it worth three weeks of sofa life? So the answer is usually no. I'm just trying to make it through the day here.



I stagger. I mean, sweet Jesus, you should see me try to walk across the room, or outside on the rare occasion (I have cameras outside my home). That there is an ataxic gait, as a neurologist would say. I walk wacky. And they're finding more and more Long Covid patients developing signs of a neurodegenerative disorder an awfully lot like prodromal Parkinson's, as fun as that sounds.

I seem to have an attention span of about 15 seconds, and my short-term memory is shot; if you give me three words to remember after 10 minutes, I'm pretty sure after *five* minutes I won't even recall that you gave them to me.

I can't focus long enough to do things in a sequence; if I go into the kitchen for a sandwich and a glass of water, I'm probably coming back with only one and it might actually be a dishtowel.

I can't focus enough to watch a movie, most of the time; I just don't have the sustained focus that's required to appreciate storytelling. I can listen to music, but again there's a limit. I've lost the capacity to follow a story, it feels like, although it's possible – it just helps if there's a sense of familiarity.

Is that enough? It feels like enough. I feel the need to be as honest as possible, because this is difficult to understand, I know. But it's not all doom and gloom.

I've learned some valuable things, a lot of them based around using routine to calm the chaos.

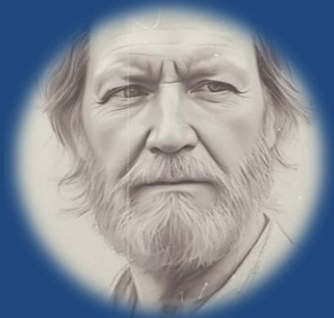
I've learned to prioritize, and I've learned how to say no, both skills long overdue to be learned. Shame and guilt feel like wastes of energy, and speaking of which – energy is what I've learned the most about, and understanding is definitely a comfort.

Because this fatigue is not your father's fatigue. It's a separate beast, and it's indifferent to my will, iron or otherwise. And I know why.

Because medical science knows. Not only is Covid specifically known to increase the risk of dangerous blood clots, but it seems to create micro-clots in small blood vessels, enough to impede the delivery of oxygen to the rest of the body. Like the brain. Like muscles. You get it.

This explains my – and many, many others – low blood oxygen saturation level. It's not *terribly* low on average, just a bit under normal, but it dips into scaryland and I don't know what that means. I don't know if it's causing permanent damage or temporary, or anything more than soreness and brain mushiness.

Now add to this mitochondrial dysfunction: Mitochondria are the little energizer bunny parts of cells that process energy. They grab it from food and sort it and send it off to be utilized, in a way (that's really lame but see mushiness above). When mitochondria start acting weird, it essentially pulls the plug. No juice. Asking me to buckle down and work through the fatigue is like asking me to fly.



This is a battle I can't win; I've had to learn *that*, too. If I run out of energy, I either lie down or my body will lie down for me.

So I guess I'm that guy now, although this is one of the good things, actually. I have to be the steward of my energy, including my time (hence the *saying no* thing). It's taken most of this year to realize that I have to be my own caretaker, because this can be invisible, and so much of it is guessing. Julie and John know most of the signs by now, but even if you're in my presence I imagine it would be hard to tell until, you know, I fell over.

But I will tell you! I've learned how.

I've managed to finish some books and watch a few things (I rented "Asteroid City" and loved it, as I knew I would). It's not all been a bland diet.



Self on a very small scale.

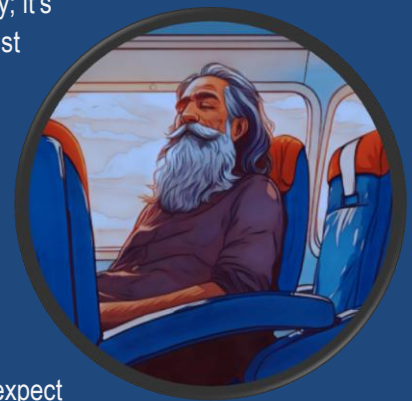
This is life as I enter year #2, such as it is. Small comforts, lots of naps, patience and pacing. I've had a couple of great phone/video conversations, but those have been with old friends and I don't feel as self-conscious if I lose my train of thought (it can be a ghost train at times). Mostly I love getting texts and emails, and a lot of people help me tremendously in keeping my spirits up.

It's a little comical how determined I am to find comfort now. Every few weeks, it seems, I order some other kind of desk organizer or cable/cord thing or you know, stuff that makes my life a tiny bit easier or more fun. It's essentially Treat Yo'

Because everything's small now. And that's your scoop, that's your take-away if you want one. I'm OK, not terrible, not suffering, but life is very small. I'm going to make an attempt to travel next month to visit with family, and I have no idea what to expect. I've made it as easy a trip as I could, but that's new territory; it's either a horrible idea or an enlightening one. But there are a few things in life I'm just not willing to put on hold, and that's also new – I now have some real clarity on what, and who, matters.

I apologize for the length of this; I never know what's going to happen when I try to write this down. And I'm sorry for the darkness of some of this, maybe; again, being as honest as I can is for my sake, not yours.

And for those of you with your hearts in the right place who want to advocate or agitate on my behalf, here's where I am: I don't blame anyone for this, and I don't expect modern medicine to find an answer yesterday. My doctors have been kind and as helpful as they can be, and I'm counting on medical science to help at some point. I'm just not holding my breath. I was unlucky.



I will believe that until I learn otherwise, too. I don't have the energy to point my fingers. Random bad things happen to everyone. It's not a conspiracy.

It's about what I can do, anyway. I'm done waiting for the day when this is over; I'm waiting for the day when I don't think about it. That day I'll definitely let you know. Otherwise, no news is just that. Thanks for reading and caring. Time to get small now.

