March 12, 2025

Long Covid - The short Version

Imagine that one morning you wake up with the flu but for the next two years it never goes away. That's exactly my experience with Long Covid.

On March 26th, 2023, six months after my previous immunization, I came down with Covid that is still with me. Since then I have been sleeping my life away, currently 12 hours a day, which is an improvement over 15 hours a day last year. I get up about 6 am and on a good day can get busy grocery shopping, housecleaning, or moderate exercise (pick only one). I'm out of gas around 11 am and asleep from noon until 3 pm. Out of gas means all functions stop and if I don't lay down immediately I'm likely to fall on my face. For the first time in my life I can sleep on my back with the curtains open and the sun in my face. It's more like passing out. The remainder of the day is mostly spent horizontal. I cannot push activity past noon without consequences. I have driven off I-5 into the median after falling asleep. I have fallen on my face hiking up the trail from the beach when I pushed too hard. I have to carefully meter out physical exertion, but even then what works one day does not necessarily work the next. Basically I limit my excursions to my zip code unless someone drives me. With such limitations I have joined the hidden population of those with Long Covid who have no choice but to withdraw from society. I don't expect anyone to adhere to my schedule. As a result friendships have withered and I see no help for that. Art projects, house, car, and yard maintenance have all been put aside for a long time now.

However this is not just about excessive sleeping and extreme fatigue. There are many documented symptoms that go along with Long Covid and I have most of them to varying degrees. Primary is PEM. For the curious I have listed my symptoms below.

Intermittent alerts from my phone are so unwelcome for much of the day that I usually have my phone set on silent mode. Even the constant buzzing can be so annoying that I also turn off notifications from Messages. One for two I can handle but there are spurts where there are as many 30 in an hour. Of course I don't want to wake up to see that the most recent message was just an emoji. I often forget to turn my settings back on and, in any case, coming into a group texting chat hours after the fact is hardly useful. So it goes. It's better for me to miss out on the chat than repeatedly have my sleep interrupted.

Note 1 - CDC Symptoms

This list of symptoms has been copied from the CDC website because, with the recent government cuts, I have no confidence that this information will remain available.

People with Long COVID can have a wide variety of symptoms that can range from mild to severe and may be similar to symptoms from other illnesses. Symptoms can last weeks, months, or years after COVID-19 illness and can emerge, persist, resolve, and reemerge over different lengths of time. Long COVID may not affect everyone the same way. Some people can experience health problems from different types and combinations of symptoms that may:

- Be difficult to recognize or diagnose
- Require comprehensive care
- Result in disability

Fatigue, brain fog, and post-exertional malaise (PEM) are commonly reported symptoms, but more than 200 Long COVID symptoms have been identified.
Other commonly reported symptoms (not a comprehensive list):

General symptoms
- Tiredness or fatigue that interferes with daily life
- Symptoms that get worse after physical or mental effort
- Fever

Respiratory and heart symptoms
- Difficulty breathing or shortness of breath
- Coughing
- Chest pain
- Fast-beating or pounding heart (also known as heart palpitations)

Neurological symptoms
- Difficulty thinking or concentrating (sometimes referred to as "brain fog")
- Headaches

- Sleep problems
- Dizziness when you stand up (lightheadedness)
- Pins-and-needles feelings
- Change in smell or taste
- Depression or anxiety

Digestive Symptoms
- Diarrhea
- Stomach pain
- Constipation

Other symptoms
- Joint or muscle pain
- Rash
- Changes in menstrual cycles

Some people with Long COVID have symptoms that are hard to explain or difficult to manage. There is no laboratory test that can determine if your unexplained symptoms are due to Long COVID. People with these unexplained symptoms may sometimes even be misunderstood or experience stigma. This can result in a delay in diagnosis and receiving the appropriate care or treatment. Long COVID treatment is focused on managing symptoms, reducing their impact on daily activities, and improving your quality of life.

Complications
Some people, especially those who had severe COVID-19, may experience multi-organ effects or autoimmune conditions lasting weeks, months, or even years after COVID-19 illness. Multi-organ effects can involve many body systems, including the heart, lungs, kidneys, skin, and brain. Symptoms for many of these multi-organ complications are similar to commonly reported Long COVID symptoms. As a result of these effects, people who have had COVID-19 may be more likely to develop new or worsening of health conditions such as:
- Diabetes
- Heart Conditions
- Blood clots
- Neurological conditions

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Note 2 - Post-exertional Malaise (from Wikipedia)

Post-exertional malaise (PEM), sometimes referred to as post-exertional symptom exacerbation (PESE)[1] or post-exertional neuroimmune exhaustion (PENE),[2] is a worsening of symptoms that occurs after minimal exertion. It is the hallmark symptom of myalgic encephalomyelitis/chronic fatigue syndrome (ME/ CFS) and common in long COVID and fibromyalgia.[3][1] PEM is often severe enough to be disabling, and is triggered by ordinary activities that healthy people tolerate. Typically, it begins 12–48 hours after the activity that triggers it, and lasts for days, but this is highly variable and may persist much longer.[4][5][6]

Management of PEM is symptom-based, and patients are recommended to pace their activities to avoid triggering PEM.

Symptoms

Fatigue is often prominent in PEM symptoms, but it is "more than fatigue following a stressor".[6] Other symptoms that may occur during PEM include cognitive impairment, flu-like symptoms, pain, weakness, and trouble sleeping.[6] [4] Though typically cast as a worsening of existing symptoms, patients may experience some symptoms exclusively during PEM.[6] Patients often describe PEM as a "crash", "relapse", or "setback".[6] Symptoms typically begin 12–48 hours after the triggering activity,[5] but may be immediate, or delayed up to 7 days.[6] PEM lasts "usually a day or longer",[11] but can span hours, days, weeks, or months.[6][12] PEM involves an exacerbation of symptoms, or the appearance of new symptoms, which are often severe enough to impact a person's functioning.[13]

Triggers

PEM is triggered by "minimal"[5] physical or mental activities that were previously tolerated, and that healthy people tolerate, like attending a social event, grocery shopping, or even taking a shower.[4] Sensory overload,[13] emotional distress, injury, sleep deprivation, infections, and spending too long standing or sitting up are other potential triggers.[6] The resulting symptoms are disproportionate to the triggering activity and are often debilitating, potentially rendering someone housebound

or bedbound until they recover.[11][6][14][4]

Variability

The level of activity that triggers PEM, as well as the symptoms, vary from person to person, and within individuals over time.[6] Due to this variability, affected people may be unable to predict what will trigger it.[4] This variable, relapsing-remitting pattern can cause one's abilities to fluctuate from one day to the next.[1]

Management

Main article: Chronic fatigue syndrome treatment

There is no treatment or cure for PEM. Pacing, a management strategy in which someone plans their activities to stay within their limits, may help avoid triggering PEM.[26] Physical therapy for people with long COVID must be modified to avoid triggering PEM in susceptible patients.[27]

Note 3 - How I experience Long Covid

- I experience almost all of the symptoms in the CDC list above to varying degrees(excluding menstrual cycle disruption of course), so there is no need to discuss them all or we would be here all day.
- As previously mentioned I sleep and rest an enormous amount. The good side of this is having the opportunity to read an extraordinary number of books, mostly novels. Thank goodness for the King County Library's extensive collection and for ebooks that saves driving to the library.
- PEM rules my life. Practically speaking I have to be very careful if I want to avoid a flu-like crash. If I have an afternoon appointment I rest through the morning with the hope I will get through it OK. At the beginning even the most innocuous task, like sweeping the walkway would leave me with excruciatingly sore muscles for way longer than is normal. I was an athlete for decades and I know sore muscles. PEM is on a whole different level. Fortunately I don't experience the sore muscle thing much anymore, just the crushing fatigue, nausea, and dizziness. On one particular group trike ride I allowed myself to be pressured into riding too far. I came home and decided to take a short rest on the couch at 4 pm before I made dinner. When I woke up I was momentarily confused by seeing the rising sun. Imagine my surprise to find I had slept straight through to 6 the next

morning. I got up to shower and eat, and went back to bed for another 24 hours. That's right, 38 hours! Going on that ride was a bad choice and I'm much more careful now.

- Activity is limited to a span between 7 am and 11. Not many want to accompany me under those limits but it's not like I have a choice. Fortunately I have a neighbor who is an early bird so we sometimes take her dog on a hike starting at 7:30.
- Another issue is A-fib which started with the Covid. Yes, I've experienced it previously but only when my thyroid medication was out of whack. My A-fib is controlled with medication and I'm happy to report I've now reduced my dose to 1/4 of the prescribed amount. That's a hopeful sign. And no, I do not have an underlying coronary issue. I've had a full workup and deemed to be healthier than average for my age.
- Headaches, migraines, ocular migraines, light sensitivity, and sound sensitivity; talk about an unpleasant way to ruin a whole day, or two days. The ocular migraines are just odd, only last a few minutes, and are maybe like a drug induced psychedelic trip. They show up as shimmering zig-zag patterns that start on the periphery and slowly move across my field of vision. It's not a driving problem because I have plenty of warning to pull over before I temporarily cannot see straight ahead. In any case they have become less frequent. For the day or two that the standard migraines last I'm totally worthless while hiding out under my couch blanket with the lights off and the stereo turned down low. Forget trying to read.
- Reading the CDC list of symptoms in many cases does not convey what the experience is really like. Take "neurological conditions" for example. What does that even mean? For one I assume they are talking about neuropathic pains (pins and needles) like diabetics experience. Yes, I have that issue and no, my blood sugar is normal and not the cause. There's more to that kind of neuropathy though. I sometimes feel like I have electrified panty hose pulled over my head that causes itching and burning. It's so annoying at night that it interrupts my sleep.
- The on-again off again nature of Long Covid and PEM is frustrating. I take each day as it comes never knowing how things will go. Some mornings I feel pretty good and other times I simply go back to bed for the rest of the day. As I write this I just spent two days on the couch with congested ears, dizziness, and nauseous if I tried to stand up. Suddenly around dinner time

it all just disappeared. I even felt good enough to perform light resistance training. I had been wondering if I was coming down with a virus, but nope, it was just the same old stuff.

- I went camping last September and it took many days to get the truck loaded. I planned my route to the North Cascades carefully and stuck to the mountains so that I could pull over and sleep when necessary. It took me three days to get to my destination which in normal times is a one day drive. With all my prep it was a good trip and I didn't fall off the rimrock and break ribs like last time. If I get overextended when out hiking, I get woozy and my balance becomes precarious. I now carry folding trekking poles in my daypack at all times.
- I have taken flack a couple times after group outings because I did not hang around and socialize afterward. Wondering if I'm going to vomit in the parking lot and getting so dizzy I know I need to get on the road home pronto precludes drawn-out socializing. It hardly motivates me to engage in activities that start too late, end even later, and force me to drive too far. Sorry, but I have learned not to put myself in risky situations. It would be natural for you assume that, in my excessively fatigued state, I might spend considerable time watching TV. Nope, I don't need it. With such a short amount of time each day to be productive I don't want to devote any of it on such a time wasting device. I don't subscribe to any streaming services either, although I do have Amazon Prime that comes with my membership. I don't find much compelling content there however. I have never been a consumer of TV news broadcasts but I do have a digital subscription to the New York Times and the Atlantic. That's enough to keep me up to date with today's deluge of depressing news.
- There is one giant piece of good news. After much research (I have the time and scientific/nutrition training) I have cured most of my severe food intolerances that have bedeviled me for decades. I could not touch any amount of dairy for forty years without fear of a trip to urgent care. Now most of my intolerances have been completely gone for about a year. What it took to effect that change was rigorous and would add too much to an already lengthy story. Look for more about that later.

Final Thoughts

Recent publications from the scientific community postulate that this virus likely damages **small nerve fibers** (possibly through inflammation) resulting in a

host of potential problems. Obviously neuropathy is one result, but so is A-Fib, balance issues, and endocrine driven problems like diabetes that rely on *small nerve fibers*.

The supplement **SAMe** has been promoted as a cure, but clinical trials don't support this idea. It may, however, improve some symptoms. I gave it a good solid try in September of 2023 and I saw enough improvement that I could take a long camping trip. I found I could for once stay up all day, and since daylight that time of year is 12 hours, I could slide into bed at 6:30 and get up 12 hours later. I was happy with that turn of events. But it didn't last. Part way through the trip I started getting horrible abdominal pains (a known SAMe side effect) on par with passing a kidney stone. I stopped the supplement and the pains immediately ceased. Sigh. Retrying a month later yielded immediate resumption of crippling pain, so SAMe is out for me.

If you remember this was the same trip where a piece of rimrock broke underneath me pitching me into a ravine where I landed on a pointed basalt boulder breaking two ribs and banging my head. Did Long Covid's affect on balance play a part in this? In any case, it was not a good situation because the area has no cellular coverage and my satellite communicator was in the truck. I knew my ribs were broken but I pretty much hurt all over. I carefully felt around for other injuries and found nothing more than a few cuts and scratches. It's a good thing I didn't break a leg or I would have been in serious trouble. I carefully got up and holding my left arm against my side went in search of my new hat that had blown downhill. Then it was time to pick up the game trail in the bottom of the ravine and slowly shuffle my way back to the truck. I knew my trip had just come to a sudden end and I just wanted to get home pronto. I had planned to break up the return trip into two more nights on the road to make sure I didn't suffer a long Covid metabolism crash but that was out the window. I always carry some Hydrocodone in my first aid kit but I couldn't take that and still drive, so Tylenol would have to do. I had a full tank of gas so I just needed to endure the rugged 4x4 drive out of the canyon and find some chips and a large coke to sip on to keep me awake and fed during the drive. It's tricky driving and eating with just one arm, but it all worked out. Arriving home I headed straight for the couch where I stayed for three days. Having a backrest was very helpful seeing as I could only sleep on my good side. The truck didn't get unloaded for many days and I really didn't care.

I did not seek medical help for my ribs. I broke ribs several years previously and

the only thing they did was confirm what I already knew with X-rays and then offer pain pills. However the day after this last event I woke up with a really annoying floater in my left eye, the side that banged the rock. After careful questioning, the Ophthalmology Dept. decided I was probably OK to delay coming in and gave advice on what to watch for that could turn into an emergency. Eventually I went in and was referred to a retina specialist who told me I had just experienced a vitreous detachment which is common in those over 65. The only persistent issue is that damn floater to which I have mostly learned to ignore.

Another idea in the scientific community is that Long Covid could possibly be damaging mitochondria functionality which might explain the fatigue and that certainly would make sense considering that mitochondria shift into anaerobic metabolism when over stressed thus creating lactic acid. Too much lactic acid is what creates sore muscles. The supplement **CoQ10** has been studied as a possible treatment to improve mitochondria functioning but no positive results have been found in clinical trials. I tried this supplement before the research results were known to me and concluded it was useless for anything but draining money out of my wallet.

Currently **there is no cure for Long Covid** so I just have to hope that it will eventually go away. Some symptoms can be treated with varying degrees of success, but that is an ongoing process, not a cure. I am aware that residual effects may linger forever. Not being able to work on my art projects, travel, go kayaking, and socialize with friends is a big disappointment. However I have adapted and become good at living in my own head. I get to read, write, and process images on my computer. I have a nice state park one block from the house that is full of trails. It's a major reason I bought this house and I'm thankful for everything this location has provided, first for Holly and now as an convenient place to get fresh air, exercise and lug around a camera. With limited energy I'm now patient enough to slow down to search for small things to photograph. I immersed myself into the nerdy and techy world of **focus stacking photography** to better capture images of tiny subjects. Most of my stacks consist of 100 to 300 images processed by computer to yield one single photo with improved depth of field. Here are camellia flower and slime mold examples. I take these kind of photos for my own gratification, not because non-photographer viewers care very much.

If you got this far, **thanks for reading these somewhat** digressive descriptions.

Let me know if you find anything unclear or that needs to be expanded.