

You think you have long COVID: What now?

April 19 2023, by Frank Otto



Frantz Dickerson, at far left, recently with his sister, Ngyra, and her husband, David, boating in the San Diego Bay. Credit: Dickerson family

In September 2020, Frantz Dickerson caught COVID-19.

Initially, Dickerson dealt mainly with exhaustion, but his wife, a nurse, eventually measured his [blood oxygen levels](#) and found them low:

Normal readings find between 100% and 95% of oxygen in a person's blood, but Dickerson was below 90%. So it was off to the hospital.

He spent three days there until his [oxygen levels](#) went up. By mid-October, Dickerson felt like he'd recovered from his "main issues" and was ready to go back to work as an elevator sales and repair representative.

But when he returned to work, he noticed some difficult lingering issues, especially tied to exhaustion and brain fog.

"My brain was like a 10-lane highway before COVID, and, suddenly, it was a two-lane road with a traffic jam," Dickerson recalled.

He'd discuss a project at his boss' desk, then walk back to his own desk and totally forget what they'd talked about.

"I was drinking four 32-ounce coffees to stay mentally acute and it just wasn't working," Dickerson said. "There were a lot of intricacies that I was continuing to miss, and I was wondering, 'What is going on?'"

Dickerson's story is not uncommon. Since COVID-19 became the world's most far-reaching modern pandemic, long COVID has affected a significant number of people: As of January 2023, a survey from the Kaiser Family Foundation showed that 28% of the people it surveyed either have had long COVID or still have it.

This crisis spurred the creation of a collection of long COVID clinics. The Penn Medicine Post-COVID Assessment and Recovery Clinic was among the first, established at the tail end of COVID's first wave in late spring 2020. Benjamin Abramoff, MD, an assistant professor of Physical Medicine and Rehabilitation in the Perelman School of Medicine at the University of Pennsylvania, became an expert in long

COVID and leads the Penn Medicine clinic.

And while Dickerson was eventually able to get help from Penn Medicine's team and others, some patients have difficulty determining where and how to get care. Because long COVID, in many ways, remains mysterious, recognition of it and determining the right treatments can remain difficult. For many patients, it can be a difficult journey from the first step to the last, and that includes just assessing, at the beginning, what's happening with your own body.

So you think you have long COVID. Here's your first step

Self-identification is an important initial step. COVID-19 takes a while to clear from your system and can leave some symptoms that will linger. But are they long COVID?

"I think the World Health Organization definition of long COVID is a pretty good place to start: New or worsening of symptoms three months after COVID infection with symptoms lasting at least two months, without any other explanation," said Abramoff.

Common symptoms include persistent fatigue, difficulty breathing, insomnia, and "[brain fog](#)," which can be tied to memory issues. Other symptoms range from [mental health](#) (feelings of depression and anxiety) to the physical (joint pain, headaches, and gastrointestinal issues). A person who experiences these symptoms for several months following their COVID infection should go to a primary care doctor, Abramoff said.

"Long COVID is often a diagnosis of exclusion," Abramoff said. "So visiting your primary care doctor is important because that will help

eliminate other potential causes of ongoing symptoms and they can initiate some treatment approaches."

If symptoms persist, it's possible that the doctor may refer patients to a specialized long COVID clinic, like Penn Medicine's.

Recovery takes time

Often, people go to the doctor expecting a rapid resolution to their illness. You have strep throat, you go to the doctor, get your antibiotic, and then you're feeling a lot better in a day or two.

But long COVID isn't one of these situations for most people.

"Once individuals have had symptoms for several months, recovery tends to occur slowly and incrementally," Abramoff said. "Recovery varies widely. While some people improve over the first few months, there are some people who take months and years to get better. There are still people who got sick with COVID in 2020 who have residual symptoms."

Something Abramoff and colleagues have noticed in patients is that the severity of the initial infection appears to influence the subsequent severity or persistence of long COVID symptoms. Put simply: The sicker someone was, the more likely they are to have a worse time with long COVID.

It's part of the reason why preventive measures like vaccines and their boosters, as well as antiviral treatments like Paxlovid, are so key.

No one-size-fits-all treatment

Because we still don't totally understand the underlying mechanisms of COVID, each person's treatment for long COVID can be different because it is dictated by their individual symptoms.

These treatments range from occupational and physical therapies to medications and even self-management strategies. So one patient may benefit from receiving medication for joint pain, another undergoes a therapy program to increase endurance, and someone else may just get help in planning their day so that they aren't overwhelmed by fatigue.

"One of the challenges of treating long COVID is that it presents differently in each patient, so every patient is treated individually," Abramoff said. "So we focus on treating symptoms and working to improve day-to-day quality of life and function."

Remember: Most do recover

A frustrating aspect of recovery from long COVID—but one that's important to remember—is that it may not be a strictly linear process. Fatigue, for example, is often the most difficult symptom to overcome.

"The typical course of long COVID tends to include fluctuations with good days and bad days," Abramoff said. "Certain patients also have triggers that can worsen symptoms as well, which could include overexertion, whether that comes from exercise or mental or emotional sources. New illnesses can also cause problems."

Despite these ups and downs, the numbers indicate that most patients recover. A study out of Israel showed that the majority of patients who had long COVID after a mild infection recovered within a year, and the Kaiser Family Foundation survey found that the rate people reported experiencing long COVID steadily fell from 19% in June 2022 to 11% in January 2023.

There are also investigations underway for different medications to treat long COVID patients, "particularly antivirals," according to Abramoff.

"As the underlying causes of long COVID are better understood—including changes to the immune system of patients with COVID—more treatments directed at the underlying causes will likely emerge," he said.

Reopening the highway

Dickerson is one of the more extraordinary cases of recovery. Today, he feels as if he's totally recovered. In fact, he feels his body—and especially his brain—are functioning even better than they did before COVID. The 10-lane highway that had been reduced to two lanes is now opened all the way back up. And, these days, it behaves a little more like the Autobahn than the Schuylkill Expressway at rush hour.

"It feels like I have a couple extra lanes on the highway now," he said.

But it was a grueling road back. More than half a year after he first got sick, in the summer of 2021, Dickerson finally got clarity once he had a neuro-psychological exam. It provided a path forward for treatment.

He had to leave work for seven months and enrolled in cognitive rehabilitation. He also joined a long COVID support group.

At the urging of his therapist, he also picked the guitar back up, something he hadn't done for a long time—even before COVID—as part of a therapeutic strategy to retrain his brain and build calming moments into his day.

He also changed jobs, returning to work at a new job that was fully remote, allowing for him to better pace for himself, crucial to his

recovery.

Dickerson's story is remarkable, according to Abramoff, as many patients who suffered severe COVID symptoms like he did tend to have difficulty returning to 100 percent. But while it is difficult to keep track of, Abramoff said that the majority of his patients do experience a recovery.

And with advances in treatments and understanding of the condition, he hopes that a recovery like Dickerson's will be that of every long COVID patient.

Provided by University of Pennsylvania

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