

San Francisco Chronicle
2022-05-07

Millions of people suffer from long COVID.

Why is there still no treatment?

Shelley Hayden of Sonoma has a case of long COVID so serious that her “brain is broken,” she said. The 54-year-old marketing coach asked not to be interrupted in conversation so she wouldn’t lose her train of thought.

Tyler Gustafson of Berkeley recovered from COVID-19 in 2020, then got hit last summer with what felt like a heart attack: deep, aching chest pain. His body tingled. His blood pressure soared. His left side grew numb, and his thinking slowed. Even his vision became distorted. Worst of all, the symptoms never let up, so the management consultant took medical leave. He was 30 years old.

Mysteriously, Gustafson has begun to recover. But Hayden still battles frequent “crashes” that leave her mentally and physically exhausted for days or weeks at a time. Their terrifying, conflicting medical sagas — two among millions of COVID survivors with ongoing symptoms — reveal the still-murky nature of the syndrome that has mystified doctors and caused drug companies to freeze in their tracks, unsure where to direct their treatment investments. Patients say they feel caught in the quicksand.

“The approach to caring for people with long COVID is so bad,” Hayden said. “I’ve been teaching my doctors!”

Recognizing the need to wrestle the problem to the ground faster, President Biden announced on April 5 a [National Research Action Plan on long COVID](#). It’s a public and private collaboration that will build on [Recover](#), a \$1.15 billion initiative from the National Institutes of Health to coordinate long COVID research at sites across the country, including UCSF and Stanford.

In the two years since patients and doctors identified long COVID, researchers around the world have scanned, poked and peered at thousands of people, hoping to uncover anything that might lead to a cure for the persistent symptoms ranging from exhaustion and brain fog to racing heartbeats and loss of smell. They believe that roughly a third of unvaccinated COVID survivors suffer lingering symptoms, and about [half that many](#) patients who were vaccinated.

Scientists are gradually discovering more about the syndrome, said Dr. Steven Deeks, co-principal investigator with UCSF’s research study [LIINC](#), or Long-term Impact of Infection with Novel Coronavirus. LIINC alone has published [18 papers](#), including a small new one [suggesting the COVID drug Paxlovid](#) can ease persistent symptoms.

Researchers point to three likely causes of long COVID: bits of virus that remain hidden in the body, persistent inflammation caused by the coronavirus, and autoimmunity — when the body’s own immune system turns on itself.

These, in turn, wreak havoc in four main ways, Deeks told state lawmakers at a hearing in March. They cause neurological symptoms like confusion, debilitating fatigue, cardiovascular problems, and a unique condition called POTS — postural orthostatic tachycardia syndrome — where the heart races when the sufferer stands up.

Many patients, like Hayden and Gustafson, have overlapping symptoms. Virginia Sen. Tim Kaine, who has long COVID, says his nerves tingle “24-7,” as if his fingers are forever stuck in a glass of Alka-Seltzer. But even diagnosing long COVID is tricky. There are no X-rays to detect it and no blood tests to prove what’s going on, Deeks told the lawmakers. Without that, treatment remains elusive. “I knock on the doors of all the drug companies saying, you guys have got to get involved,” he said. “They say, OK, fine, we’re committed. But how are we gonna basically prove to the FDA that our drug works?”

Dr. Larry Tsai, who heads Genentech’s respiratory and allergy product development, told The Chronicle that clinical trials to see if existing drugs can be repurposed for long COVID “are likely to begin soon.” But new drugs? Not yet, he said. Such trials “await better scientific understanding of the underlying cause” and clearer recognition of who would best respond to them.

Before Gustafson got mild COVID, he ran a few miles daily, hiked, surfed and played guitar. It’s a story many long-haulers tell: They were exceptionally healthy until they weren’t. Then they felt decades older than their years.

“My chest pain — 24/7 for seven months straight — literally felt like I was having a heart attack every moment of the day,” he said. “My heart felt like it would explode out of my chest.” Yet his tests were normal. Except one: his cytokine levels, indicating high inflammation. Gustafson’s doctors at Stanford prescribed steroids and other anti-inflammatories. But it wasn’t until March, after they tried low-dose Naltrexone, a drug used to block the effect of opioids, and colchicine, usually for gout, that he felt relief. Now, with “65% improvement,” he’s back to work, though some days are still bad, he said. “I feel like it’s all a waiting game for everyone.”

Even agreeing on a definition of long COVID took more than a year, but the World Health Organization finally offered one in October. The syndrome occurs “usually three months from the onset of COVID-19,” with symptoms lasting at least two months that “cannot be explained by an alternative diagnosis.” Long COVID affects everyday functioning, can persist from the beginning of COVID infection, and fluctuates over time, the organization concluded after conferring with researchers and patients.

One of those patients was Lisa McCorkell of Oakland, who co-founded the Patient-Led Research Collaborative after getting long COVID. It’s one of several advocacy groups that meet monthly with the U.S. Centers for Disease Control and Prevention. “I don’t think we’d be nearly as far with long COVID if the HIV/AIDS movement hadn’t made inroads” in working with federal agencies, she said. “They knew that the people closest to the pain should be closest to the power.” McCorkell was nearly done with her master’s in public policy in March 2020 when she was hit with classic COVID symptoms: shortness of breath, body aches, and even the swollen

extremities called COVID toes. Later, she developed POTS, the racing heart when standing, and other symptoms that have felt more manageable since she was vaccinated. But, as with most people infected in the earliest days, tests were scarce and she was never diagnosed. “That’s coming back to bite us now,” she said, because research studies require participants to have a COVID diagnosis, as does workers’ compensation. “Making those things contingent on having some sort of test is one thing we’re fighting.”

Among the long COVID treatment trials funded by the federal government include studies of how cannabis, magnetic resonance imaging, and even singing might help. So far, most are small. “It’s a really exciting area of research. However, we need to conduct well-designed and rigorous studies,” said Dr. Lisa Geng, co-director of Stanford’s long COVID clinic. Which gets back to why patients feel so frustrated: “We’re still very much in the process of trying to understand the causes of long COVID,” Geng said.

Like many sufferers, Hayden is impatient for results. “People need help this minute — not six months from now or two years from now. It’s heartbreaking and unfair.” Researchers with UCSF’s LIINC study have collected a lot of data from Hayden, but it isn’t a treatment.

“Her case is pretty severe,” said Dr. Michael Peluso, clinical lead and co-principal investigator of LIINC, where many participants, like Hayden, have “post-exertional malaise.” It basically knocks her flat. She and others compare their experience to the equally mysterious “myalgic encephalomyelitis,” or **chronic fatigue syndrome.**

When she “crashes” every few weeks, she says, “I feel like I’m crawling. It’s hard to stand up. Hard to walk across the room. And you don’t feel rested after sleep” because her joints hurt during the night, she said. And there’s brain fog. She’ll start a word — say, “couch” — and it cuts off as “cou.”

Absent any treatment from doctors, Hayden and other long COVID sufferers turn to each other for remedies. “We all get way better information from peers than doctors right now,” said Hayden, who is a member of a large health maintenance organization. She takes allergy pills day and night, hoping they will reduce inflammation and help with “the whole autoimmune” thing. She takes fish oil and supplements CoQ10 and NADH. Beyond that, she is astonished that people have abandoned masks.

“Don’t you understand?” she asked, directing her message to the public. “You could be disabled for life.”

Nanette Asimov is a San Francisco Chronicle staff writer. Email: nasimov@sfgchronicle.com
Twitter: [@NanetteAsimov](https://twitter.com/NanetteAsimov)