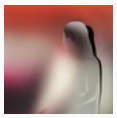
MORE FROM COVID-19: FIVE YEARS LATER

Long COVID Showed Me the Bottom of American Health Care
REBECCA NAGLE



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COVID-19: FIVE YEARS LATER

Long COVID Showed Me the Bottom of American Health Care

Access to clinics has only gotten patchier as attention to the disease has faded.

By Rebecca Nagle

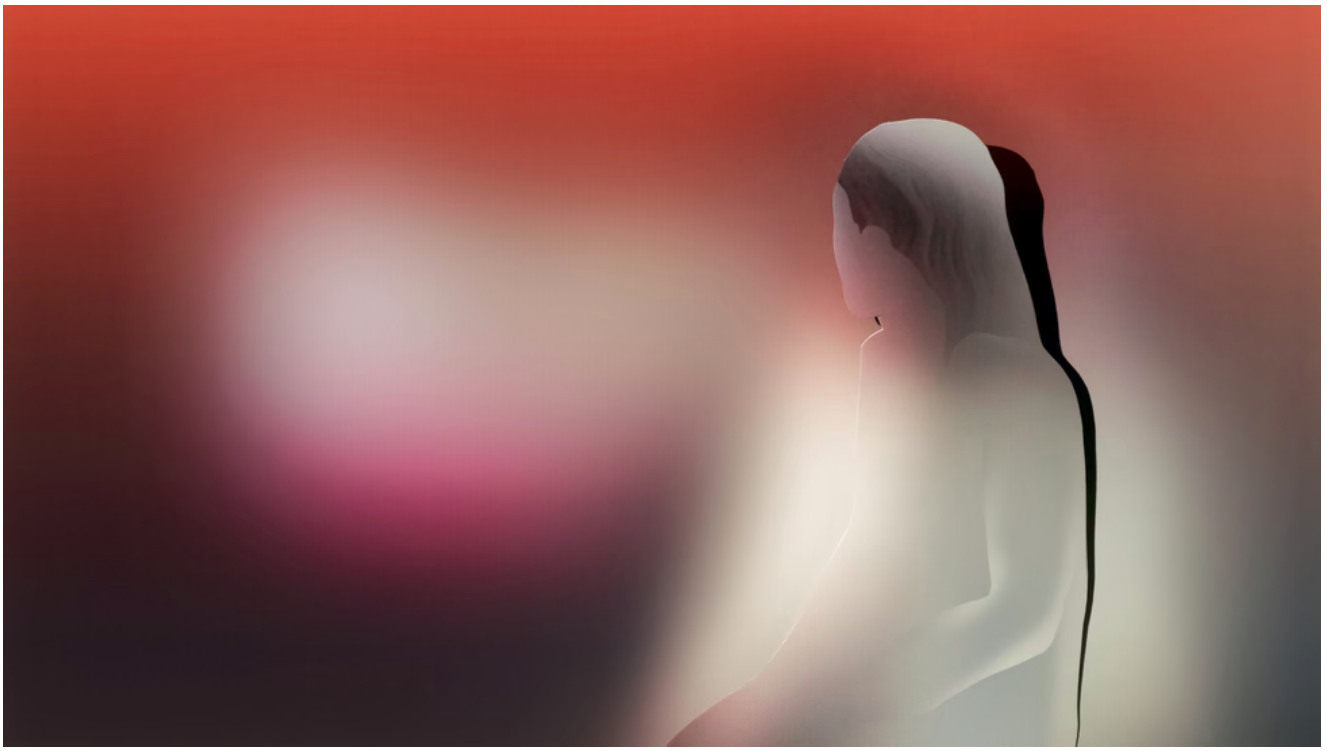

Photo illustration by Ina Jang

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My house was dark. Tinfoil covered the windows. The only light I could tolerate came from dimmable red bulbs. Ten weeks before, I had tested positive for COVID. On week three of my infection, I went to the emergency room with a debilitating migraine. On my third trip to the ER, I was hospitalized for seven days. I came home to a changed life. All the clichés about headaches are true—a pile of bricks on the head, a vise grip on the temples, an axe through the skull. The pain altered my consciousness. Trying to move or access a thought was like trying to see past a flashlight shining in my eyes.

It was 2024—a point at which most people in America considered the pandemic long since over. But it wasn't for me.

Some days, I couldn't stop crying. It was more than despair at my circumstance: Long COVID can dysregulate mood and has been linked with depression. And the disease hijacked my stress-response system, leaving my body in a constant state of alarm. Any unexpected sound, even getting a text message, would set off a jolt of panic through my body, the same sensation as slamming on the brakes while driving. I lost my ability to cope. I broke a window in my house. I put a hole in the wall.

Researchers know more about long COVID than they once did, but it is still hard to define. The clearest consensus is that it's a complex collection of symptoms that can affect almost every organ system in the body. Theories of why COVID can linger abound, and include ongoing inflammation, the virus never fully going away, and tissue damage. Many scientists agree that multiple factors likely contribute. Meanwhile, doctors are still struggling to treat the disease; less than half of doctors know how to diagnose long COVID and even fewer—28 percent—report knowing how to treat it, according to one 2023 survey. Long-COVID patients are still reporting that medical professionals don't believe them, and though in some cases patients' self-diagnosis might be off the mark, the reality is that many people living with long COVID simply aren't getting the care they need.

In my case, that person who was in mind-numbing pain, unable to read, unable to write, unable to Google things or look at screens, unable to drive, drained by talking on the phone, spiraling in despair, and barely able to leave the house had to navigate the American health-care system. That I needed care for long COVID only made my predicament worse. From hearing chronically ill and disabled people speak about their experiences, I knew that to be sick in this country is a hell unto itself. But knowing something is true and experiencing it are different. I know that the Grand Canyon is deep, but I have never seen it with my own eyes. For our health-care system, I have been to the bottom.

According to the latest federal survey as of September 2024, more

than one in 20 adults in the United States had long COVID—defined as symptoms that last longer than three months. (The survey does not ask about the severity of symptoms.) Vaccines may help protect against the disease, but getting COVID still means risking long COVID. The coronavirus can leave patients with blood clots, brain dysfunction, organ damage, immune problems, and more; about a quarter of people with the disease report that it significantly disrupts their ability to perform daily activities. There are no FDA-approved medications to treat long COVID. Many medical institutions created specialty clinics to see patients with the disease, but much of what even the best clinics can offer is symptom management. Pinning down recovery rates from long COVID has been difficult, but according to several studies, after two years, the majority of people living with long COVID had not fully recovered.

Three months into my illness, I had been treated for migraines and a concussion—COVID's impact can mirror a traumatic brain injury—but not long COVID. The tribe that I belong to, Cherokee Nation, runs the largest outpatient facility of any tribe in the U.S., but my primary-care provider there told me she didn't know how to treat long COVID. I was referred to my tribe's specialty clinic for rare and infectious diseases. When I managed to get that appointment, however, the provider told me he knew how to treat only pulmonary long-COVID symptoms (which many long-COVID patients don't have). Nowhere in Indian Health Services, the treaty-based federal program that serves 2.8 million Native Americans nationwide, is there a long-COVID clinic. (An IHS spokesperson said the Biden administration would have needed to set up such a clinic.)

I started looking outside Indian Health Services and found a long-COVID clinic an hour's drive from my house. When I called, I learned the clinic had shut down. The state where I live, Oklahoma, does not have a long-COVID clinic. My dad found one in Arkansas. Like many long-COVID clinics, it required that patients apply to get in. But after I submitted all the paperwork, I didn't hear back.

I realized that to access care, I would need to travel. At the time, I was unable to drive, and my symptoms limited how much time I spent outside my house. When I called the Cleveland Clinic, I was transferred four times until I was accidentally forwarded to the customer-satisfaction survey. I spoke with one receptionist who told me her clinic didn't take patients from out of state, and another who warned that traveling to her clinic probably wouldn't be worth the time and money. (A spokesperson for the Cleveland Clinic wrote that patients should be able to make an appointment without a referral, and that the clinic and its staff "strive to provide patients with timely access to scheduling and care.")

In my first telehealth appointment with a nationally recognized COVID

clinic, the doctor wouldn't discuss her recommendations but said I could read them in the patient visit notes. When I explained that my symptoms made reading impossible, she asked me if someone could read the notes for me. Later, my mom read me a copied-and-pasted list of healthy-lifestyle information, such as the benefits of taking a daily probiotic and the importance of getting enough sleep. The list included the doctor's favorite bedtime teas. I told my mom to stop reading.

A FEW MONTHS into the pandemic, some patients reported that their symptoms weren't going away. Through their advocacy, long COVID got its name. By 2022, hundreds of long-COVID clinics had opened across the country. There is no standard for what kind of care these clinics provide: Some are multidisciplinary teams, but many are one specialist or one nurse practitioner. This patchwork system of care has only deteriorated as attention on the disease has dwindled.

Many of the long-COVID clinics that popped up during the pandemic have closed. As part of my reporting for this story, I compiled a list of 171 clinics, drawing from the Survivor Corps website, a patient-led resource-and-advocacy group, and from searching online for long-COVID clinics by state. I then called each clinic to verify which ones were still operating. Of those, 79 were still open and accepting new patients, five were not accepting new patients or outside referrals, 61 had closed, and 15 were unreachable after two attempts. Eleven more were advertised as long-COVID clinics but don't have a medical doctor or nurse on staff; they provide services such as speech or occupational therapy. (My assistant Sydney Anderson and intern Cheyenne McNeil, who have been helping me work through my illness, contributed to this reporting.)

Based on the list we assembled, 22 states have no long-COVID clinics accepting new patients. Given COVID rates in those states, we estimated that almost 3 million people who *currently* have long COVID reside there. Because of insurance policies, licensing and telehealth laws, and the cost of travel, not having a nearby clinic can easily mean that patients won't access care. Of the long-COVID clinics that are still open, some have wait lists, do not accept outside referrals, do not take insurance, treat only specific long-COVID symptoms, or do not take patients from outside of their geographical area.

Getting in touch with the long-COVID clinics that are still open is another barrier. I spoke with operators who had never heard of their institution's long-COVID clinic; I got transferred to the office that schedules COVID tests; I got transferred to disconnected lines; I called numbers that rang and rang and rang and rang. One day, I spent two hours on the phone and spoke with only three people who could provide information. When I called Yale New Haven Health System's clinic, one of the most well-known in the country, I got transferred to a disconnected line. I called back and got transferred to the customer-satisfaction survey. I called a third time and left a message. I called a

fourth time, trying a different number, and spoke with a receptionist who said the clinic was closed. (The clinic is still open; in a statement, Yale New Haven Health said that the phone number for the long-COVID clinic is on its website, that the volume of calls the clinic receives is very high, and that it had not previously heard of patients having difficulty accessing the clinic.)

If you are healthy, this might all sound like the familiar nightmare of customer service to which we have all become accustomed. But for people who are sick, it is a wall that stands between them and the care they need. When you are sick, you look at that wall and think, *I am not well enough to climb it*.

The closure of long-COVID clinics in recent years has affected patients who need care. I talked with people who, like me, have been living with long COVID later in the pandemic. Ryan Parker lives in Portland, Oregon; is a member of the Northern Cheyenne tribe; and used to work in philanthropy. Like many people with long COVID, Parker tried to work through his illness. He told me he returned from one work trip so sick that he couldn't get out of bed for a month. Last fall, the long-COVID clinic that was treating him closed. Because of the disease, Maeve Sherry has been disabled and unable to work for three years. They found a long-COVID clinic in Great Falls, Montana, three hours from where they lived at the time, but it closed in December of 2023, they said. There are now no long-COVID clinics in Montana. When Myisha Hill was still struggling to do household chores, take care of her kids, and even talk weeks after a COVID infection, she looked up the long-COVID clinic near where she lives in Las Vegas, she told me. But it, too, had closed. There are now no long-COVID clinics in Nevada.

A spokesperson for the University Medical Center of Southern Nevada wrote that the clinic closed "amid low demand." Other clinics echoed this response, saying they suspended operations after patient numbers dwindled. A few clinics also stated that they now refer long-COVID patients to primary care. Several spokespeople told me as a reporter that their clinics were still open, but when I called as a patient, I was told the clinic was closed. And even when clinics are open, patients still face barriers: I spoke with people with long COVID who told me they couldn't access care because a clinic didn't take their insurance, their doctor didn't send a referral, or the clinic rejected them as a patient.

The alternative to enrolling in a clinic is to try to see a regular neurologist or cardiologist. But many specialists have lengthy wait times, and long-COVID patients are twice as likely as the general public to report that this is why they can't get care. Parker, for instance, is trying to see a specialist for myalgic encephalomyelitis/chronic fatigue syndrome, a form of debilitating fatigue that is common with long COVID. The first available appointment is nine months out.