First she had heart palpitations, a bad headache, a spike in blood pressure. Then came tingling and numbness in her foot and hand, along with crushing fatigue. Some days, 53-year-old Susan Jeansonne, MD, could not keep her eyes open past 5 PM.

Yet her electrocardiogram, blood counts, and basic laboratory results all looked fine. So “I just kind of went on about my business,” said Jeansonne, a pediatrician who offers home-based care in Kingsport, Tennessee, recalling her January 2022 symptoms in a recent interview with JAMA.

But before long, things got worse. Vacationing with family that March at Universal Orlando in Florida, Jeansonne—a self-proclaimed gym rat who hikes and farms and lives with 3 big dogs on 77 acres—could barely walk. “It felt like I couldn’t quite make my toe push off,” she said. Coming home with a severe headache and stiff neck, she wondered if she had meningitis, or maybe Lyme disease.

While awaiting Lyme titers, Jeansonne started a course of doxycycline, then had a routine surgery that had been postponed due to the COVID-19 pandemic. For 2 weeks, she did “pretty much nothing” while recovering at home. “I felt great,” she said. Returning to work, though, “everything came back almost exponentially”—the numbness, the tingling, the palpitations—and then the brain fog started. Jeansonne struggled to get through her continuing medical education work. “I told my husband, something’s really wrong,” she said.

She saw a neurologist, then a neurosurgeon. After undergoing brain and spine imaging, nerve conduction studies, and a lumbar puncture—a huge workup that “tested me for everything”—Jeansonne was sent home to rest. The headache went away. Her hands stopped hurting. Her blood pressure normalized. “For 48 hours, I felt really good,” she said. None of those procedures showed anything concerning.

Yet as Jeansonne resumed seeing patients, her symptoms returned and intensified. By June, she no longer felt safe driving and had to cut her daily schedule from 6 to 8 patient visits to just 1 a day, or none. Even a light 15-minute gym workout was too much: tingling and headaches would develop a few hours later, forcing her to cancel the rest of the day. “We were so stumped,” she said.

Jeansonne went back to the neurosurgeon. “I don’t know what’s going on,” he said. “You probably have something related to COVID.”

In December 2021, about a month before the initial episode of disabling symptoms, Jeansonne had come down with a mild illness—a sore throat, backache, headache, and 100°F fever. But after a day of rest, she felt better. Test results for respiratory syncytial virus, influenza, and COVID-19 all were negative. Later, though, a polymerase chain reaction, or PCR, test for COVID-19 would read positive.

No Road Map

The US Centers for Disease Control and Prevention (CDC) has logged more than 104 million COVID-19 cases in the US as of late April. And according to the most recent Household Pulse Survey data, collected by the CDC’s National Center for Health Statistics, more than 11% of adults who ever had COVID-19 currently have symptoms that have lasted at least 3 months. That means millions of people are likely living with post–COVID-19 condition, also known as long COVID.

One puzzling aspect of post–COVID-19 condition is that it can develop “in a stuttering fashion, or in a delayed way, so it becomes a little difficult to connect it to the infection,” said Lucinda Bateman, MD, an internist and founder of the nonprofit Bateman Horne Center, a clinic combined with a research and education organization in Salt Lake City, Utah, that focuses on chronic, complex disorders including long COVID.

Another challenge is the inability to clearly measure the condition. “We don’t really have specific tests—something that could say, ‘Oh, you have long COVID,’” Bateman said. Plus, she noted, it can be hard to link symptoms in different organs to the same original process, especially because primary care physicians “work on a very pressured calendar,” so they have limited time with each patient.
People with long COVID “feel we are not listening to them,” said Ana Palacio, MD, MPH, an internal medicine specialist at the University of Miami Miller School of Medicine. Yet at the same time, physicians “feel frustrated that they do not have the resources and the information and the time to deal with this.”

Since the 1980s, Palacio noted, the practice of medicine has shifted away from relying on a physician’s experiences and gut feelings toward a more systematic approach where illnesses are diagnosed and treated with standard protocols based on evidence.

Physicians are “trained to tackle a couple of issues per visit and to use evidence-based approaches and to use codes to get their health system reimbursed,” Palacio said in an interview. And to “make things systematic,” she added, “we are trained in cardiology, gastroenterology, pulmonary—the organ systems are separate.”

Yet long COVID generally affects multiple areas of the body and can manifest with many simultaneous symptoms. At the Post-COVID-19 Program at UT Health in Austin, patients present with a median of 18 new symptoms, according to clinical data that will be presented at the Society of General Internal Medicine conference this month.

Given long COVID’s heterogeneous nature and lack of clear diagnostics, the UT Health team faced a steep learning curve when patients started coming to the post-COVID-19 clinic early in the pandemic. “I never received any formal training about pathophysiology, mechanisms of dysfunction, let alone treatment” for postviral conditions, said W. Michael Brode, MD, an internal medicine specialist and the clinic’s medical director. “There’s no road map.”

The team decided early on that they would just “start seeing patients and figure it out—let’s hear the story. Let’s see what the patterns are. And take it from there,” Brode said in an interview. Over time, they noticed a handful of symptoms over and over again. “Almost everybody has fatigue, brain fog, neurocognitive impairment, and postexertional malaise,” the latter being a worsening of symptoms for days or even weeks after physical or mental exertion, Brode said. “Having seen lots of these patients, it’s always the similarities that strike me more than ‘This is 50 different symptoms unrelated to each other.’”

Whole-Patient Care
Despite the time pressure of typical primary care appointments, Bateman thinks general physicians are well positioned to deliver supportive care for patients with long COVID. “You might need specialists to help screen for specific problems,” she said, but “they’re just looking at their slice. They’re not really managing the whole patient the way we do in primary care.”

Patients often have to wait months to see a specialist or visit a specialty clinic. Last July, as Jeansonne’s condition continued to deteriorate, she called the post-COVID-19 clinics at Vanderbilt University Medical Center and Johns Hopkins Medicine. At both places, “it would be a 3- to 6-month wait,” she said.

Out of desperation, Jeansonne asked for help on a Facebook group for physician mothers. Someone tagged psychiatrist Monica Verduzco-Gutierrez, MD, chair of rehabilitation medicine at the Long School of Medicine at UT Health San Antonio. Verduzco-Gutierrez raised the possibility of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) with orthostatic intolerance and suggested resources at the Bateman Home Center.

After watching several of the center’s videos and downloading its guidance for ME/CFS-related postexertional malaise, Jeansonne started drinking electrolyte fluids and wearing compression socks. She paced her activity, lying down for a 15-minute break every few hours and not answering evening calls. She downloaded an exercise protocol developed for postural orthostatic tachycardia syndrome (POTS) and began a graded program of horizontal exercise. After 6 months on this regimen, Jeansonne has resumed seeing patients 4½ days a week. She rejoined the YMCA, has normal blood pressure, and rarely gets a headache.

There are not enough long COVID specialty clinics to meet patient need, Ziyad Al-Aly, MD, chief of research and education service at the Veterans Affairs (VA) St Louis Health Care System, said in an interview. “We’re going to have to figure out a way to make sure the larger community of physician assistants, nurse practitioners, and primary care clinicians is educated to recognize and treat [long COVID].”

There’s also an urgent need for research. Last August, the US Department of Health and Human Services launched a research action plan for long COVID that includes the National Institutes of Health-funded Researching COVID to Enhance Recovery, or RECOVER, Initiative. Some have criticized RECOVER as inadequate and slow—to the extent that its principal investigators recently published a Call to Action urging Congress to include $37.5 million in fiscal year 2024 to speed research and disseminate learnings to other physicians.

The first RECOVER clinical trials are expected to launch in the coming months, a spokesperson from the National Heart, Lung, and Blood Institute told JAMA in an email, and will evaluate multiple interventions focused on 5 symptom types: viral persistence, autonomic dysfunction, sleep disturbances,
cognitive dysfunction, and exercise intolerance or fatigue. Details of the interventions will appear on ClinicalTrials.gov once finalized, the spokesperson said.

Until results from those and other clinical trials arrive, guidance on managing long COVID in patients is available from the CDC, the VA, and the American Academy of Physical Medicine and Rehabilitation.

Experts interviewed for this story offered some basic guidance for primary care physicians:

- **Believe the patient.** "Say it out loud. They need to hear it," Palacio said of patients with long COVID symptoms, who are often not believed. If their physician says, "I believe you, and I will work with you to try to make you better even though I know very little about this," stress levels go down.

- **Go beyond symptoms.** Physicians are accustomed to checking off symptoms, but it's also important to ask, "How often do these occur?" and "How do they affect your ability to carry out normal daily activities?" Bateman said. "When you can't perform physically and cognitively, it starts to really be disabling."

- **Address fatigue.** "If patients stop exerting themselves, they start to feel better. It's as simple as that," Brode said. Physicians should discuss with patients what they can honestly do in their daily activities.

- **Look to familiar conditions.** According to the CDC, long COVID can share symptoms with ME/CFS, fibromyalgia, posttreatment Lyme disease syndrome, dysautonomia, and mast cell activation syndrome. Approaches to managing these conditions can help some patients with long COVID. For example, POTS can be alleviated with fluids, compression garments, and graded horizontal exercise.

Primary care physicians "should be willing to think outside the box and use their medical training to provide sensible, supportive care," Bateman said.

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**Disclaimer:** Dr Palacio’s views do not represent those of the VA Health System.

**Note:** Source references are available through embedded hyperlinks in the article text online.