

# Q&A: Specialists answer questions about long COVID

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Long COVID, the condition where symptoms that surface after recovering from COVID-19 linger for weeks, months, or even years, is still a mystery to doctors and researchers.

The symptoms, such as [chronic pain](#), brain fog, shortness of breath, [chest pain](#), and intense fatigue, can be debilitating. Severe cases of long COVID can even affect the body's organs. But imaging tests don't always show the origins of those symptoms. And we still don't know why only some people develop the condition or why others can get it after a mild COVID-19 infection.

Research has offered some insights but not enough to provide a solid understanding of how long COVID progresses in the body. That knowledge will be essential to developing treatments.

"There is no one pill or strategy that helps everybody," says neurologist Lindsay McAlpine, MD, director of the Yale NeuroCovid Clinic and one of many Yale Medicine specialists who care for long COVID patients. But there is a growing understanding that people experience the condition in different ways, leading to an individualized approach to treating their symptoms.

Personalized care is the focus of the Yale New Haven Long COVID Multidisciplinary Care Center, which launched in spring 2023 and is directed by internist Lisa Sanders, MD. Although Yale Medicine has been caring for long COVID patients since the pandemic began, the new centralized program adds a multidisciplinary approach: Patients are evaluated and, if necessary, referred to cardiologists, neurologists, pulmonologists, rheumatologists, and other specialists who have experience treating the condition. The program also offers on-site physical therapy and social work services—the latter because long COVID can affect relationships, finances, job security, and quality of life.

Specialists in long COVID answered questions about what we now know about the condition and what we can do about it.

## 1. How is long COVID defined?

The World Health Organization (WHO) [defines long COVID](#) as "the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation."

The Centers for Disease Control and Prevention (CDC) adds that long COVID includes a wide range of ongoing health problems that can last weeks, months, or years. The condition can affect any part of the body, and serious cases may affect multiple body systems, including the heart, lungs, kidneys, skin, and brain.

Each patient is different. Not everyone with long COVID has had a severe case of COVID-19. Some acquired the condition after a mild case, and others may have developed symptoms but never tested positive for COVID-19. "We usually call those patients 'presumed COVID,'" says Yale Medicine pulmonologist Denyse Lutchmansingh, MBBS, associate director of the Winchester Center for Lung Disease.

## 2. What are researchers learning about long COVID?

Akiko Iwasaki, Ph.D., a Yale School of Medicine immunobiologist, leads multiple studies investigating the pathobiology of long COVID. Iwasaki says research has shown that long COVID is not a single disease.

She also lists four hypotheses on her laboratory website that could explain long COVID's initiation and progression:

- After a person has COVID-19, a persistent virus or remnants of it cause chronic inflammation and ongoing symptoms.
- The body's disease-fighting B and T cells trigger an immune

response—and subsequent inflammation—in a process called autoimmunity. The stimulus that triggers this occurs continuously in the body, making it difficult to pinpoint and shut down.

- Latent (or dormant) viruses inside an individual reactivate. (Every person carries multiple viruses that are dormant. Under certain circumstances, they can be reactivated.)
- Chronic changes occur in the body after the acute inflammatory response (COVID-19 infection). Inflammation in one tissue can damage other tissues.

"Our research thus far has shown hints of all of these," Iwasaki says. "It's also possible that these things can happen in sequence. You may start with a persistent virus that then leads to the reactivation of latent viruses, leading to inflammation. It's also possible that some people have only one of these things going on while others have all of them."

### **3. Isn't long COVID on the decline?**

In the U.S., the [Household Pulse Survey](#), an ongoing survey conducted by the Census Bureau and National Center for Health Statistics, suggests that the incidence of long COVID may be decreasing. The percentage of participants who had COVID-19 and reported having new or continuing COVID-19 symptoms (when they responded to the survey) dropped to 11% in January 2023 from 19% in June 2022.

While there isn't a clear explanation for the decline, Yale Medicine cardiologist Erica Spatz, MD, MHS, tracks long COVID as part of a CDC-funded study called INSPIRE (Innovative Support For Patients with SARS-CoV-2 Infections Registry). "Our data—as well as other data—suggests the incidence of prolonged or emergent symptoms is declining as more people are vaccinated and as we have been seeing milder variants," she says.

At the same time, no one knows exactly how many people have long COVID, although [one study estimates that 65 million people worldwide have the condition](#), and experts say the number is probably much higher. Many cases of COVID-19 likely have not been reported, especially with the increase in rapid testing at home since 2022 (and, thus, decreased reporting of positive infections). And people who had difficulty distinguishing between COVID-19 and colds or similar health issues may not have sought testing or medical advice.

But, doctors are still diagnosing new cases, in addition to caring for patients who developed long COVID at earlier points in the pandemic, adds Dr. Lutchmansingh. "Since 2020, Yale specialists have had over 1,000 referrals for patients with persistent symptoms following COVID-19," she says.

#### **4. Who is getting long COVID?**

Anyone at any age can get long COVID. "I've seen long COVID in every age, including plenty of 20- or 30-somethings who have no history of illness," says Dr. McAlpine.

However, you may be at higher risk if you had a severe COVID-19 illness, especially if you were hospitalized or in intensive care, according to the CDC. Your risk is also higher if you had a chronic disease, such as diabetes, before COVID-19, if you had multisystem inflammatory syndrome, or MIS (a rare but serious condition in which different body parts become inflamed) during or after COVID-19, or if you did not get a COVID-19 vaccine, the CDC says.

In March 2023, a study of 800,000 people published in *Health Affairs* added another possible predictor: People with long COVID were, on average, more likely to be older and women.

## **5. Are new cases of long COVID milder than older ones?**

This can be a difficult question to answer, partly because long COVID data is limited. But Yale Medicine doctors say they have seen a shift as omicron and its milder subvariants have replaced the early alpha and delta variants, as well as the original strain of the virus. "I think about long COVID patients in terms of the years they were infected because they're not all the same," says Dr. Lutchmansingh. "Anecdotally, my patients who were infected in 2021 and 2022 seem to get better faster than those who were first infected in 2020."

While there are new patients who struggle with symptoms, "I don't have as many patients on full-time disability as I did earlier in the pandemic," she says. Disability is a major concern among people with long COVID, to the point where the condition is officially considered a disability under the Americans with Disabilities Act (ADA) and the Affordable Care Act (ACA). A report in 2022 estimated 2 to 4 million Americans were out of work due to long COVID.

## **6. Will I need to see a specialist for my long COVID symptoms?**

It depends on the symptoms. Because there is currently no cure for long COVID, doctors aim to treat the symptoms associated with the condition.

As many as 200 long COVID symptoms were identified in an [international study published in 2021 in \*EClinicalMedicine\*](#) that surveyed more than 3,700 people with long COVID. Many symptoms are sorted into categories by specialty, where treatments are similar to what they would be for non-COVID patients with similar symptoms.

The specialists you may need to see for long COVID include:

**Pulmonologists:** These doctors have played a central role in treating both COVID-19 and long COVID since the early days of the pandemic, when many patients went to the hospital with urgent symptoms, such as low oxygen levels and lung issues. They treat breathing difficulties, sometimes prescribing treatments like an inhaler (a handheld device that delivers a puff of medicine into the lungs). "For some of my long COVID patients with asthma-type symptoms, biologic treatments are making a difference," Dr. Lutchmansingh says.

Exercise may also be beneficial for some patients, she adds. "It's just a different way of exercising than we're accustomed to," she says. While rehabilitation for non-COVID-19 pulmonary patients may involve a push to build muscle and strength, that type of exercise method can worsen symptoms for some long COVID patients. "So, we have to figure out a way to get them to exercise that targets their needs but isn't detrimental to them," she says.

**Neurologists:** "long COVID can cause a variety of neurological symptoms, and one patient can have multiple types," Dr. McAlpine says. "There can be a constellation of symptoms." She has treated patients for headaches, including new or worsening migraine symptoms. Some have developed neuropathy, a disease of the peripheral nerves that causes numbness or weakness.

But the most common neurological symptoms Dr. McAlpine sees are cognitive difficulties, including issues with attention and memory recall, and language and executive functioning. "Patients will say, "I can't find my words. I lose track of my thoughts in the middle of my sentences. I have to write everything down. I can't multitask anymore,"" she says. "With the alpha and delta variants, the cognitive impairment was quite severe around the acute illness. Then, it would very slowly get better."

Gastroenterologists: Some patients report bloating, constipation, diarrhea, vomiting, and other signs of stomach distress. In March 2023, a [study in \*Nature Communications\*](#) reported that people who had COVID-19 experienced significantly more gastrointestinal symptoms a year after their infection than people who had not had the virus. The study compared almost 150,000 people who were infected in the early days of the pandemic with 5.6 million similar patients who had not had the virus. In the first group, conditions, including [GERD \(gastroesophageal reflux disease\)](#) and peptic ulcer disease, were among the most commonly reported symptoms.

Cardiologists: Cardiovascular symptoms are less common than some in other specialties, accounting for about 5% to 10% of long COVID issues, explains Dr. Spatz. Acute COVID-19 can lead to myocarditis, which causes significant inflammation of the heart muscle, she adds. It also can cause other cardiovascular problems, including thrombosis and acute stress to the heart, resulting in cardiomyopathy or arrhythmia. "We are learning to look for the potential for any of those issues to have occurred and their residual effects," she says.

Heart specialists also care for long COVID patients who develop chest pain, palpitations, or exercise intolerance, or those who may have a cardiovascular syndrome, such as postural orthostatic tachycardia syndrome (POTS), a blood circulation disorder that causes lightheadedness or fainting when standing up from a lying down position.

Another potential concern is heart rate fluctuation, which can be caused by tachycardia (a fast heart rate) and bradycardia (a slow heart rate). Yet another issue is a chest pain syndrome that may be related to [endothelial dysfunction](#), in which the arteries become narrow even though there is no blockage.



## **7. What about long COVID symptoms that aren't easy to categorize?**

Not every [symptom](#) falls into just one category. A challenging one is what's called "post-exertional malaise (PEM)," which Dr. McAlpine describes as a kind of "energy crash" or worsening of other symptoms, such as fatigue, brain fog, and muscle pain after exercise—even if the activity was mild. PEM can range in severity. "Some people will walk up the stairs and then not be able to get out of bed for the rest of the day. Others will go on a 10-minute walk or run errands and then be out of commission for a couple of days," she says.

Physical problems like PEM can lead to anxiety and depression. "It can be a very scary experience," Dr. McAlpine says. "People feel disoriented, and this can cause new mental health issues. It can be a long road." In these cases, mental health treatments, such as cognitive behavioral therapy (CBT) and medications, can help, she adds.

"Another critical issue is sleep," says Dr. McAlpine, who has referred patients to sleep specialists. They often come back with varying diagnoses, including insomnia and sleep apnea, although it can be difficult to say whether long COVID is the cause. "Patients who have had COVID-19 are sensitive to sleep deprivation and disruption, and sleep is so critical to cognitive function, to healing, to headaches—to everything."

## **8. With so many different symptoms, how can I be sure I have long COVID?**

There is no laboratory test to confirm long COVID. And blood tests, chest X-rays, and electrocardiograms may show normal results even if a person has serious symptoms.

To diagnose long COVID, a clinician will ask a patient about their health history, perform a physical examination, and gather information about how their COVID-19 infection was diagnosed. There is an understanding that some long COVID patients can't prove they had the virus, either because they don't have records of proper testing or they didn't even know they had COVID-19.

A key part of the diagnosis is ruling out other conditions, Dr. Lutchmansingh adds. "That's one of the most important things about having an internist who coordinates the care of long COVID patients," she says.

## **9. Can Paxlovid help long COVID patients?**

There is not enough evidence to show that Paxlovid, the primary treatment for COVID-19, is an effective treatment for long COVID. But, Iwasaki and cardiologist and scientist Harlan Krumholz, MD, SM, are co-leading a randomized clinical trial to investigate whether it could help some patients.

"Studying Paxlovid is important because people with long COVID have no therapies available to them," Iwasaki says. "Even though we don't understand fully what the underlying mechanisms of the disease are, it's important that we start the trial and learn who benefits from specific medications."

Iwasaki and Dr. Krumholz believe that long COVID may have different pathologies in different patients, which suggests that not everyone would benefit from the same treatments. "We're collecting blood samples before, during, and after Paxlovid delivery, so we will be able to classify people who respond positively to it versus those who respond negatively—or not at all," Iwasaki says.

Participants can give samples at specified locations and otherwise participate in the study from home. (The trial is currently available to people who live in Connecticut, New York, and Florida, and it may expand to other states.)

Once such classifications are made, the researchers will be able to recruit people for a larger trial to learn more about those who have a positive response to Paxlovid. "We're looking for the kind of signal that will help us administer the proper therapies to people," Iwasaki says. "Even if it benefits 10% of people, that's still a lot."

## **10. Can vaccines prevent or help treat long COVID?**

It's unclear whether vaccines can prevent long COVID. Researchers are still looking for answers. "There have been so many studies on this topic," Iwasaki says. "Now, the consensus is that there is about a 30% reduction of risk of long COVID in those who were vaccinated prior to infection."

While the 30% figure is based on prevention, vaccination may also impact the severity of a person's long COVID symptoms, Iwasaki says, adding that more research is needed.

## **11. Can I recover from long COVID?**

There is research showing that many people do get better. A [study from Israel published in the \*British Medical Journal \(BMJ\)\*](#) in January 2023 found most cases of long COVID in almost 300,000 children and adults who had mild COVID-19 infections resolved within a year of diagnosis. The research covered a period between March 2020 and October 2021, before the omicron variant emerged, and it included vaccinated and unvaccinated participants.

Anecdotally, Dr. Lutchmansingh says she has two sets of patients who remain in her pulmonary practice. One includes people whose condition has improved, even if they are not back to their pre-COVID-19 baseline. "The other includes those who continue to have difficulty. These are patients who still have multiple symptoms, including pulmonary issues, fatigue, and neurological problems," she says.

In both groups, there aren't many patients who feel they've gotten better to the point where they forgot they had COVID, Dr. Lutchmansingh adds. "Their body knows something happened to them, but they're not as debilitated as they were in 2020 or 2021," she says.

## **12. COVID-19 is no longer considered a public health emergency. Does that mean long COVID will go away?**

It's impossible to know what long COVID will look like in a year or five years, Iwasaki explains.

With omicron, long COVID is seemingly less common, and the severity may be lower. "But we'll have to see," she says, noting that while the public health emergency may have ended, the SARS-CoV-2 virus is unpredictable. "If a new variant comes along that significantly evades immune responses, then we don't know what the outcome would be," she says.

## **13. What about those who think long COVID shouldn't be taken seriously?**

Yale Medicine doctors say it's important to know that long COVID is a real condition, and people with it can benefit from medical attention. "There's a proportion of people who have difficulty accepting long

COVID because the science hasn't caught up with it," says Dr. Lutchmansingh, adding that it can be frustrating when a patient is reporting symptoms, but clinical testing doesn't show any abnormality.

"I don't think that's a reason not to believe the patient," she says. "We want to affirm that this is a real condition and let people know we are working on strategies and treatments to help them."

Provided by Yale University

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