

## Long COVID persists, but doctors are working on treatments



by Jenna Carlesso July 5, 2022



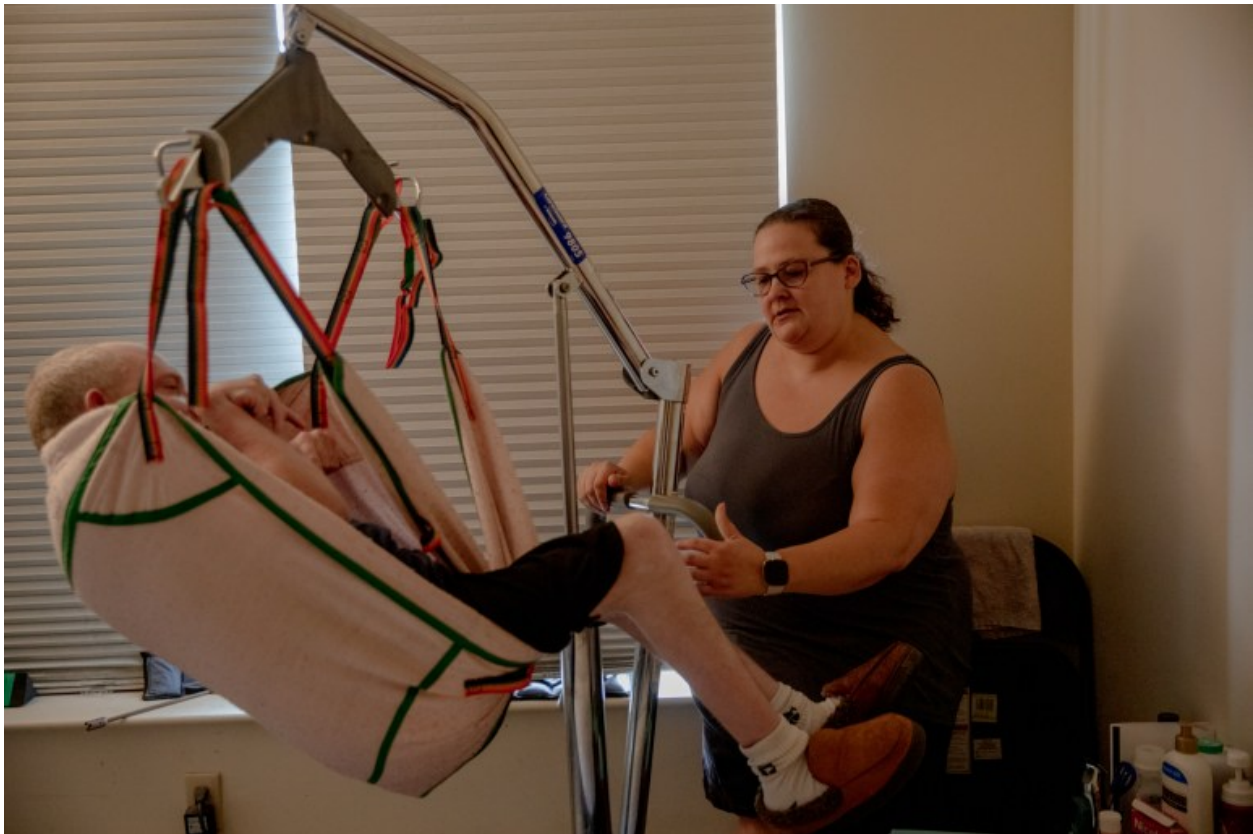
Licensed Acupuncturist Heather Finn demonstrates acupuncture at Trinity Health of New England in Hartford. Acupuncture is one of the methods that the Integrative Medicine & Health department utilizes to treat long covid patients. YEHYUN KIM / CTMIRROR.ORG

Six months after her bout with COVID-19, Jannell Roberts still doesn't feel like herself.

She gets winded walking short distances. She launches into frequent coughing fits and feels her nose running. She can't focus while reading a book, a frustrating ordeal for an avid reader.

“I’m tired all the time. I have trouble concentrating,” said Roberts, who lives in West Haven. “I try to keep myself awake, but there are a lot of times in the afternoon or early evening where I’ll just start nodding off. I can’t really focus or I won’t be able to sit still.

“I could be just walking down the hall and all of a sudden, I’ll be out of breath and think, where the heck did that come from? I shouldn’t be out of breath.”



Jannell Roberts, a personal care aide, moves Michael Whelan to a wheelchair. Roberts got COVID at the beginning of 2022 and has persistent symptoms, including short of breath, brain fog and fatigue. YEHYUN KIM / CTMIRROR.ORG

Nicole Bongiovanni caught the coronavirus early in 2021. More than a year later, the Madison resident is still without her sense of taste and smell. She has a cough that comes and goes, and gone are the nights when she can stay up until midnight watching television. Her new bedtime is 8 p.m.

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Bongiovanni, an aide who cares for people in their homes, went from three clients to two as her exhaustion set in.

“My energy went down. I get tired really easily,” she said. “I begin to cough. I feel like I’m sick when I’m not really sick.” When she finishes work for the day, “all I want is to do is go to sleep.”

Both women have a condition known as long COVID, or post-COVID syndrome, a growing problem in Connecticut and elsewhere. The Centers for Disease Control and Prevention estimate that one in five people under 65 who have had the coronavirus experienced at least one health issue that could be deemed long COVID. For people 65 and older, that figure is higher — one in four.

Other studies have estimated that anywhere from 10% to 30% of coronavirus cases result in long COVID, while a few — including one from the Penn State College of Medicine — say more than half of people who had the disease develop the condition.

## **MORE STORIES IN HEALTH**

In Connecticut, providers say 5% to 30% of cases here lead to long COVID. A CDC analysis of Census data show 29.3% — nearly a third — of adult COVID survivors in Connecticut have experienced lingering symptoms.

Even on the lower end of estimates nationally, the numbers are staggering. CDC data through February 2022 show that nearly 60% of Americans have been infected with the virus, including three in four children and adolescents. That means millions of people in the U.S. could be suffering with symptoms of long COVID.

For some, it is debilitating. Patients can experience shortness of breath, fatigue, brain fog, headaches, cardiac and central nervous system problems, cognitive dysfunction and musculoskeletal issues, among other symptoms, for weeks or months. Some have chronic pain.

Although there is currently no cure, treatment programs have emerged with the aim of managing symptoms and helping people to recover as much as possible. And research is underway to better understand the condition and what interventions might prove effective.

At the same time, medical providers and advocates are trying to raise awareness about long COVID as public health mandates are rolled back and people resume pre-pandemic activities.

“We all have to think about long COVID,” said Dr. Kathleen Mueller, head of the COVID Care Recovery Center at Trinity Health of New England. “I see people who were in excellent health with no complicating conditions before they had COVID, and a number are in a wheelchair. Some people are not able to focus at work and are on disability because of long COVID. It’s unsettling. I do not want this.

“We’re all tired of masks and we’re all tired of social isolation. We’re tired of all of this. And yet, COVID is not gone.”

### A growing problem

Long COVID occurs in people with a confirmed or probable case of the virus who develop lingering symptoms and for whom no other diagnosis can explain the symptoms. Those symptoms can last a minimum of four weeks but often go on longer.

Health officials say the condition can grow out of severe or mild cases of the virus. It can even affect some who initially had no COVID symptoms.

For some people, the symptoms come and go without explanation. Others have suffered consistently since their diagnosis. And still others have seen symptoms stop abruptly, either because of a vaccination, a booster shot or another reason.

The symptoms are wide ranging. The CDC lists 19 conditions most commonly reported, including fatigue that interferes with daily life, fever, cough, chest pain, anxiety, depression, headache, dizziness, change in taste or smell, stomach pain, diarrhea, joint pain and changes in menstrual cycles — but providers say there are far more. They can be respiratory, neurological, digestive, musculoskeletal and beyond.

“If you could find one symptom that is not under the banner of long COVID, you’re doing a good job, because the list is enormous,” Mueller said. “The breadth and the depth is just humbling.”

Women who survive COVID are more likely than men to have lingering symptoms, according to a CDC analysis of Census data. Hispanic and Black adults were more likely to experience the condition (39.6% and 37.8%, respectively) than white adults (33.8%) and Asian adults (25.4%) who have had the coronavirus, the data show.

Bisexual and transgender adults were more likely to have experienced long COVID symptoms than people of other sexual orientations and gender identities. And 58% of adults with disabilities have suffered from ongoing symptoms, the study found.

The CDC analyzed Census Household Pulse Survey data from June 1 to 13.

Long COVID can exacerbate existing health problems. A person with asthma who already has breathing difficulty may find breathing to be even more challenging, and someone who already has heart issues can see those problems worsen.

But it can also trigger new issues. A person who has never experienced brain fog or breathing problems can suddenly have those challenges, providers say.

Anyone can develop long COVID, but in a study published in the journal Cell, researchers found four conditions that appear to be correlated with an increased risk of lingering symptoms: the amount of coronavirus RNA in a person's blood early in the infection (an indicator of viral load), the presence of certain autoantibodies (antibodies that mistakenly attack tissues in the body), the reactivation of Epstein-Barr virus, and having Type 2 Diabetes, the New York Times reported.

With a growing number of people getting long COVID, treatment programs have launched in Connecticut and elsewhere to help patients manage the symptoms. Health systems such as Trinity Health of New England, Hartford HealthCare, Yale New Haven Health and Bristol Health now have treatment initiatives.

In many programs, a patient will be assessed and then paired with doctors in a range of specialties. The programs include cardiologists, pulmonologists, neurologists and physical and speech therapists, among others. They also involve practitioners outside of traditional medicine. For example, acupuncturists have been enlisted to help patients with fatigue.



have to get your story first,” said Dr. Kathleen Mueller, who consults long COVID patients at Saint Francis Hospital. “And then I have to take all these tools that we have all lined up and pull in the ones that I think are going to work for you.” She said acupuncture has been effective to treat fatigue, which is common among long COVID patients. YEHYUN KIM / CTMIRROR.ORG

“The best thing we found for fatigue is acupuncture,” Mueller said. “Within three to six visits, some people start to get their energy back. Then we touch base again and see how they’re doing, and we gradually increase movement.”

Medication may be prescribed if appropriate. Sometimes physical therapy plays a role.

A big part of the initial appointment for long COVID patients is validating the person’s condition. Because evidence of lingering symptoms doesn’t always show up on medical testing and not all physicians are familiar with long COVID, patients have reported being told by doctors that the symptoms are all in their head.

“In our conversations with patients, we find there’s a cathartic release of someone recognizing and validating that their symptoms aren’t just anxiety, or that it’s not just going to go away on its own,” said Dr. Andaleeb Shariff, primary care clinical lead for Hartford HealthCare’s COVID Recovery Center. “That can be half of their healing process.”

“Just having somebody listen to your story and understand that you’re not making it up, that you’re not just looking to avoid going back to work, is important,” Mueller added. “You can’t go back to work because you’re so debilitated from this illness. That’s been one of the great gifts we’ve been able to do in the recovery center is help people understand these are long-term effects of an infection, and it’s not all in their heads.”

As more people seek treatment for the condition, advocates say it’s important for doctors not to be dismissive of patients’ symptoms and to understand how long COVID works.

“Studies have found long COVID is more prevalent in women, and research shows that women are often less believed about health issues that aren’t really obvious,” said Lisa Freeman, executive director of the Connecticut Center for Patient Safety. “I’m concerned that they’re not being taken as seriously when they present with long COVID symptoms. It has to do with a lot of societal and preconceived notions. But I think we need to make sure that all patients are given the respect and the regard for what they’re saying.”

Advocates also called for a more robust public education campaign around long COVID, something state officials said could happen in the fall before an expected winter surge.

“This is one of the risks of what is happening as our society is opening. For some people, because they’ve heard anecdotes of COVID being relatively mild or not as severe, it is safe in many people’s minds to take calculated risks and go on with life,” said Dr. Manisha Juthani, Connecticut’s public health commissioner. “But for some people, I do think they feel they were unaware of what the potential consequences could be. COVID is not new. In fact, we heard about long COVID within the first several months of the pandemic, and people have known about it. But I do think many people are not aware that it may still be a possibility at this point.”

Long COVID doesn’t have a precise definition, and research into the condition is still underway. Juthani said she would continue to watch for new information and could envision broader messaging on the topic in the fall.

“There is information out there that the CDC and others have provided, but I’m looking for a little bit more to really try to help people understand what that risk is. The more I can understand that and qualify that, the better we can explain it to people,” she said. “The risks of long COVID are something I would want to really make people aware of as we go into another wave, when risks will be higher again.”

### **An issue for children, too**

Adults aren’t the only ones experiencing long COVID. In Connecticut, pediatricians and health care systems are devoting more resources to kids with lingering coronavirus symptoms.

Connecticut Children’s Medical Center had a “soft” launch of its long COVID program six months ago. Since then, physicians have seen about 50 kids believed to have the condition, although not all turned out to have it, said Dr. Juan Salazar, physician-in-chief at Connecticut Children’s.

Symptoms in children include fatigue, poor physical endurance, difficulty concentrating, trouble breathing, muscle pain, chronic headaches, heart palpitations, gastrointestinal issues, sleep disorders, changes in smell or taste, and lightheadedness upon standing.

Estimates on how many children are developing long COVID vary widely. One study released in March says that one in four children and teens who contract the coronavirus and have symptoms develop lingering problems. In 2021, the New York



Times quoted an official from the National Institutes of Health who said 11% to 15% of infected youths could end up with the condition.

Pediatricians say long COVID appears to be less common in children than adults.

“For kids, it’s been a smaller number,” said Dr. Jody Terranova, a pediatrician with UConn Health and president-elect of the Connecticut chapter of the American Academy of Pediatrics. “But kids aren’t necessarily going to verbalize some of their symptoms. The adults and the doctors have to be paying attention and recognize that when a kid is having trouble in school, maybe it’s not ADHD, maybe it’s not something else. Maybe it is related to their COVID. So making that connection, I think, is going to be the hardest part.

“Where adults may be more able to advocate for themselves or recognize that they had COVID and now they aren’t thinking as clearly and have that brain fog, kids might not know what’s happening. It’s going to be a little bit of a challenge, and we have to be proactive in asking about that.”

If children aren’t able to play as long as they typically would, have shortness of breath or are having difficulty focusing in school, those could be signs of long COVID, Terranova said.

“Some kids are having prolonged headaches, some are having trouble concentrating in school,” she said. For others, “while playing outside with their friends, you could see they weren’t keeping up with their peers.”

Long COVID programs for children are similar to those for adults. At Connecticut Children’s, for example, specialists are brought in to treat a constellation of symptoms in kids.

“Specialists who treat these patients could include a psychologist, developmental pediatricians, a cardiologist, a physical therapist or a rheumatologist,” Salazar said. “This is where we put our entire children’s hospital to work to try to solve a situation that could be attributed to COVID.”

Connecticut Children’s will soon be part of a large study, funded by the National Institutes of Health and run through New York University, that tracks trends and identifies treatment for people with long COVID. The hospital plans to enroll as many as 200 children over the next two years who are willing to participate in the study and also receive treatment for their lingering symptoms.

“We’re gearing up to do a far more robust launch of the program,” Salazar said. “We’ll be enrolling kids who have COVID-19 and their parents and doing long-term follow-up to see who develops complications, what are the complications, and how do we best treat them. ... That will give us a much better chance of identifying patterns.”

The broader program is expected to launch at Connecticut Children’s in the next month or two.

### Searching for answers

Researchers at Yale are seeking to put a more formal definition to long COVID, study the way it affects people and learn what interventions might be most effective.

Akiko Iwasaki, professor of immunobiology and molecular, cellular and developmental biology at the Yale School of Medicine, and Dr. Harlan Krumholz, a cardiologist at Yale, recently began a wide ranging study of the condition with the hope of enrolling people across the country.

“The ignorance about long COVID is profound still, and there’s a need for us to rapidly try to develop some evidence so we can begin to understand what this is,” Krumholz said.

“What we’re trying to do is accumulate a large number of people who believe they have long COVID and also people who are just interested in research to serve as controls so we have a comparison group, and characterize them by their symptoms, their medical histories and, essentially, their experience.”

The study will involve participants filling out surveys, sharing medical history and, in some cases, giving samples of blood and saliva.

“Part of what we’re trying to learn is how many different clusters or groupings of people are out there with common symptoms,” Krumholz said. “There’s a whole group of people who describe feeling internal vibrations or tremors; it’s kind of an unusual thing, but it turns out there are a lot of people who describe having that. And so we’re trying to understand what might be different from that group and a group that mostly has fatigue, or another group that mostly has brain fog.”

Krumholz said he and others are in discussions to also explore treatments and interventions. Some key questions they are hoping to answer with the study: Who is most susceptible? What put them at risk? What’s the underlying cause or causes? Who

gets better, and who gets worse? What things are people trying that seem to make a difference?

“We want to collect information about the challenges people are facing, but we also want to be able to help people feel less alone,” Krumholz said. “People are going to doctors and doctors have never seen this pattern before, or they’ve never heard of that series of symptoms, and some people feel very alone and isolated.

“We can show that if you look at the big picture, there are various groupings of people with very similar circumstances. Let’s try to understand what those people have tried, what they’re doing. Let’s try to understand the biology so we can begin to get to diagnostics and therapeutics.”

Physicians say there is hope for patients with long COVID. In Trinity Health’s program, Mueller said many of her patients have achieved some recovery.

“We certainly have people who we see in this clinic who are still struggling from 2020. Those patients have gotten better, but some of them are not back to their baseline,” she said. “The majority, though, end up doing fine. They get some help, they do a variety of different techniques that we use and they get better. But the jury is still out when we have someone who’s only been diagnosed six months ago. What’s the one-year data? I don’t know yet.”

One study, published in The Lancet, found that the omicron variant is less likely than the delta variant to cause long COVID. But almost 5% of people who get omicron still report having difficulty concentrating, heart conditions, headaches and other health problems at least a month after their infection, the study found.

Mueller said she has seen fewer people in the last few months than during the first two years of the pandemic, though she is unsure if that’s due to the variants or uptake of the COVID vaccine. Physicians have reported anecdotally seeing fewer cases of lingering symptoms in people who are vaccinated.

For now, doctors and researchers familiar with long COVID are urging people to continue taking precautions, even as many seek to reclaim a sense of normalcy.

“Because we don’t have any concrete evidence to confirm there is a reduced risk with the current variant, the same concern you have for getting COVID should be your concern for getting long COVID,” said Shariff, the Hartford HealthCare physician. “There are still very much things you can do to reduce your risk, and I would continue to encourage people to do those cardinal safety protocols.”

“It’s so frustrating to me to hear people say, ‘I’m just not going to wear my mask anymore. Because why bother? I already had COVID.’ It makes me heartsick,” added Mueller. “We see people who are suffering from those decisions. I don’t know what else we can do except to put the science out there. I really would like to emphasize that this is serious business. We’re still losing people to COVID-19.”

Krumholz hopes the Yale study will illuminate some of the risks and long-term consequences of COVID.

“I think part of our research needs to show how big of a deal this is — what are the consequences, how much does it linger and who’s at risk — maybe for people to take it seriously,” he said. “Right now, it’s just not something people want to hear.”

*CT Mirror reporter Katy Golvala contributed to this story.*

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