

'Post-COVID Syndrome' Is Causing Lingering Symptoms in Some Coronavirus Survivors—Here's What to Know

These people survived the coronavirus, only to struggle with lingering symptoms months after recovery. Here's what doctors say about this mysterious syndrome.

By **Barbara Brody**

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One day in March, Diana Berrent woke up with a fever and "felt like an elephant was sitting on my chest." An international photographer and mom of two who lives in a New York City suburb, Berrent found out she had a moderate case of COVID-19. "I was sick for a couple of weeks but recovered at home with Tylenol and Gatorade," she says. That's hardly the end of her story.

Soon after, Berrent founded [Survivor Corps](#), a social media-based group of patients determined to improve their own health, educate the public, and aid the scientific community in efforts to better understand the novel coronavirus. The group's Facebook page recently hit 100,000 members, many of whom come to the group to discuss the symptoms they've been having long after they "recovered" from COVID-19.



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"Survivor Corps members are recording experiences in real time, so we're hearing about things before they hit the media," Berrent tells *Health*. "We saw [COVID toes](#) a month before it hit the media. Same with hair loss." Other complaints have

included a prolonged loss of taste and smell, as well as more serious issues such as [mini strokes](#) and new-onset diabetes.

This summer, the group joined forces with a professor at Indiana University School of Medicine to survey survivors and learn more about what some of the "long haulers" are going through. More than 1,500 people responded to their [July survey](#). Some reported lingering respiratory and cardiovascular trouble, but they concluded that joint pain, rashes, muscle aches, dizziness, confusion, vision changes, depression, and anxiety were also relatively common.

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Long-lasting fatigue, muscle and body aches, and difficulty concentrating or focusing seem to be especially widespread among COVID-19 survivors. This constellation of symptoms, which some have dubbed "post-COVID syndrome," has been likened to chronic fatigue syndrome (CFS), though most people who develop it following COVID-19 do not meet the diagnostic criteria for CFS.

Surviving COVID—but struggling with lingering health issues

"Why people experience fatigue is not well understood, but it likely has to do with immune system dysregulation, ongoing inflammation in the body, and direct damage to the brain or spinal cord that can interrupt communication between neurons," Esther Melamed, MD, PhD, assistant professor of neurology at Dell Medical School at The University of Texas at Austin, tells *Health*.

Whether or not any of these post-COVID symptoms are truly unique to COVID-19, however, is not clear. Ann Parker, MD, PhD, an assistant professor in the Division of Pulmonary and Critical Care Medicine at Johns Hopkins University in Maryland, who studies post-critical care recovery, says it's not unusual for people who battle any kind of serious infection to feel weak and fatigued for months afterward. Cognitive issues and mental health issues akin to [PTSD \(post-traumatic stress disorder\)](#) are also common, especially among people who were so sick that they spent time in the ICU.

"I think folks are looking for the novel aspect of this disease, and there may be one," Dr. Parker tells *Health*. "But at six months [into the pandemic in the U.S.] we're just at the point of learning whether people infected in February even have long-lasting symptoms."

Rebecca Keith, MD, co-director of the [Respiratory Recovery Clinic at National Jewish Health](#) in Denver, agrees that it's too soon to determine whether the problems that are cropping up are specific to COVID-19, but she and her colleagues—including those at their sister institution, Mount Sinai in New York—are hoping to find out. She has been intrigued by the wide variety of people who come to their clinic seeking answers.

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"Some patients were never admitted to the ICU or even hospitalized," Dr. Keith tells *Health*, noting that it's not only those who were initially severely ill who are having problems months later. In certain cases, patients say their early symptoms never fully resolved. Yet in many others, patients thought they recovered only to later experience a resurgence of symptoms—or develop brand-new symptoms that they believe are linked to COVID-19.

Real women, real symptoms

Berrent, the Survivor Corps founder, is among those who felt fine for a while yet are now dealing with mysterious ailments. She says she has recently developed middle ear pain, headaches, nausea, and blurry vision. "As a photographer for the past 12 years, I'm keenly aware of my eyesight," she says. "I went to my son's lacrosse game and could not figure out which player he was."

Ruby Engel, a Westchester, New York resident who has spent the last few months in Colorado visiting Keith's clinic, had an extremely mild case of COVID-19 in March. "Ninety-nine percent of my colds are worse," she tells *Health*. Since then, however, she's had bouts of breathlessness, palpitations, and chest pain. She was recently diagnosed with [cardiomyopathy](#) (weakening of the heart muscle).

Engel has also experienced flare-ups of asthma and reflux, ailments she had pre-COVID but were well under control. "It's almost like this virus reactivated previous health problems," she says.

That's completely possible, believes Dr. Keith: "Say you had a chronic cough for years related to nasal drainage or reflux and it was controlled. If COVID exacerbated your upper airway sensitivity, we may need to go back and treat those underlying problems again. We have to step back and look at the whole patient."

From a research perspective, "the trick will be to tease out which [symptoms] are ongoing health issues that could have been exacerbated by any viral illness from those that are related to COVID itself," she explains. Either way, patients need help.

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Dr. Parker agrees that people who have had COVID-19 and are now sick should not be ignored. "Any symptoms that patients are experiencing are real symptoms that need to be addressed," she says. Unfortunately, that's not always happening, Berrent laments. "It's a huge problem, especially for women. Some are being [gaslit by their doctors](#); they're being diagnosed with anxiety when they actually have tachycardia," she says.

What doctors know about post-COVID right now

At this point, no one knows how many people who get COVID-19 will end up with persistent health problems. Reynold Panettieri, MD, professor of medicine at the Rutgers Robert Wood Johnson Medical School in New Jersey, estimates that about 10% of COVID-19 patients will develop a chronic issue. "It's a minority of patients, but we're still talking about hundreds of thousands of people," he tells *Health*.

Some were extremely sick or had an [underlying condition like diabetes or obesity](#) before getting COVID-19, but not everyone. "I've seen trained athletes who are experiencing profound fatigue and exhaustion with exercise," he says. "We don't fully understand why. They've been devastated." Persistent physical challenges

often go hand-in-hand with emotional stress, Dr. Panettieri adds. "Post-illness, people can become depressed, and the isolation and social distancing doesn't help that," he says.

The good news is that many long-haulers will not have COVID-related problems for the rest of their lives. "Every patient is a snowflake, but in aggregate most people who have this [post-COVID] syndrome appear to be improving," says Panettieri, who adds that many of his patients who were very ill have been able to return to their normal level of functioning within three or four months.

Dr. Keith is also relatively optimistic: "We've seen chronic cough, breathlessness, cardiovascular complications, and lung disease, and we have seen these kind of abnormalities even three to six months out [from the initial infection]. But most of these patients are slowly getting better."

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Only time—coupled with ample scientific research—will reveal what ultimately happens to the COVID-19 long-haulers. In addition to the Survivor Corps/Indiana University surveys, a variety of studies on COVID-19 survivors are underway around the country. In June, the National Heart, Lung, and Blood Institute (NHLBI) launched the [COVID-19 Observational Study](#), which will focus on the long-term implications of the virus. The Centers for Disease Control and Prevention (CDC) also has a response team charged, in part, with keeping tabs on post-COVID outcomes. Similar research efforts are taking place internationally. In the UK, for instance, the [National Institute for Health Research](#) is spearheading the "Post-Hospitalisation COVID-19 Study."

It will take many months, if not years, for science to provide definitive answers. The current uncertainty can be stressful for long-haulers who don't know what their future will look like. At the same time, many are concerned that those who haven't shared their experience aren't taking the potential aftermath seriously enough—which means they might be more cavalier about protective measures, such as wearing masks and practicing social distancing.

"A lot of people think if you weren't on a respirator and hospitalized, you're fine," says Engel. "Surviving doesn't always equal recovery."

The information in this story is accurate as of press time. However, as the situation surrounding COVID-19 continues to evolve, it's possible that some data have changed since publication. While Health is trying to keep our stories as up-to-date as possible, we also encourage readers to stay informed on news and recommendations for their own communities by using the [CDC](#), [WHO](#), and their local public health department as resources.

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