

For some COVID-19 survivors, serious problems continue long after the infection is gone

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Josh Wiese, 45, of St. Louis, was training for ultramarathons before what was likely COVID-19 forced him to quarantine at home in March. Now, he must use an inhaler twice a day and can barely jog two miles. He struggles with his memory and finding the right words.



Stacy Case, 51, of Rochester, Illinois, tested positive for COVID-19 on May 20 and has tested positive nearly every week since then. She needs two negative tests in a row to return to work. Except for fever, Case said her symptoms have never gone away. Normally healthy and active, she continues to suffer with fatigue, congestion and headaches. Just going on a walk causes shortness of breath and chest pain.

John Lincoln, 62, of St. Louis, had just retired as a union carpenter and said he was "in perfect health" when he contracted COVID-19 in April. Lincoln spent over a month in <u>intensive care</u> on a ventilator. He spent another month in a long-term acute care hospital and rehabilitation facility before coming home June 25. Lincoln still needs supplemental oxygen to breathe. His feet and hands are swollen. He doesn't have the strength to drive his car. His heart rate climbs dangerously if he walks too fast.

For every person who died of COVID-19 complications in the United States, there are more than 10 survivors.

A majority of those who have recovered may have experienced worse hangovers. Countless others, however, are nowhere near their old selves months after being near death in intensive care. And some are still dealing with debilitating problems weeks after getting over the illness at home.

Experts are still learning about how the new coronavirus affects the body differently from other viruses; and it's become increasingly clear that some "long-haulers," as doctors call them, have mental and physical problems long after fighting off the acute infection.

Doctors at a clinic set up in Rome to care for former hospitalized COVID-19 patients recently studied nearly 150 patients two months after their symptoms began. They found 55% still had three or more



symptoms and 32% had one to two. The patients' average age was 56.

Even some adults with mild cases can't seem to shake symptoms, according to a multistate phone survey by the Centers for Disease Control and Prevention released July 31. The study found 35% reported lingering problems two to three weeks after testing positive, which is not typical for a virus.

Even 19% of previously healthy adults under the age of the 35 said they continued to experience conditions like shortness of breath, cough, fatigue and headaches, the survey found.

"We have this idea that people get it, and they get through it, and they're back to normal—and that's probably true for the majority of cases. But a significant minority may have some persistent symptoms," said Dr. David Carr, a professor of geriatrics and neurology at Washington University School of Medicine.

Washington University is planning to open a post-COVID clinic within the next month to care and study such patients.

"It can be very devastating for folks that do survive it," Carr said. "So, I think we've got to keep that in mind as we continue to deal with the disease and its aftermath."

Wiese said he's used to pushing his body beyond the limit. It's what he finds exciting about racing more than 30 miles through mountains and trails.

"But this I can't push through," he said. "It doesn't seem like there is any end in sight. I hope there is, but it sure doesn't seem like it."

Rodrick Cunningham, 56, of St. Louis was admitted to the hospital on



March 30 and spent three weeks on a ventilator. After he was released May 2, he needed kidney dialysis three days a week for a month and continues to take kidney medication.

Before getting COVID-19, Cunningham worked in manufacturing and would frequently run through Forest Park. Now, four months after getting out of the hospital, he struggles to breathe. The vision in his right eye is blurry.

"I have nowhere near the strength I used to have. My feet are always cold. I take medication for that also," Cunningham said. "My memory is not what it used to be, I know that."

Dr. Prateek Grover, the medical director for the Rehabilitation Institute of St. Louis, is used to caring for patients who have spent weeks in intensive care. But patients recovering from COVID-19 are unique, he said, in how multiple <u>organ systems</u> can be severely impacted.

"They are just requiring a lot of rest, and they are requiring a lot of care and a lot of monitoring, so certainly something we have not seen before," Grover said.

Researchers are starting to hypothesize that COVID-19—rather than a respiratory infection—may actually be a blood vessel infection that can start in the lungs and then lead to the heart, kidneys, intestinal tract and brain.

Patients with COVID-19 become malnourished. They need dialysis. They have blood clots, which are leading to strokes and amputations.

"So when you think of <u>long-term complications</u>, then we have to think of the long-term complications for each of these," Grover said.



They often spend two weeks or more in intensive care, which also causes them to lose lots of muscle and strength.

Dr. Sean Muldoon is the chief medical officer of Kindred Healthcare's 71 long-term acute care hospitals—including two in the St. Louis area—which care for patients still too sick for a rehabilitation facility.

He sees the same multi-organ failures in COVID-19 patients. Part of the problem, he says, is that there are no effective treatments.

"Whatever organ got affected by the virus is only marginally helped by medication. To some degree, it is what we call supportive care—where we keep you alive and keep your organs going long enough to where the body either finally wins or finally loses," Muldoon said.

The immune system also spirals out of control, creating dangerous inflammatory response known as "cytokine storm" where it's not only fighting the infection, but healthy tissue as well.

"That is why symptoms persist so long after the infection is basically gone," Muldoon said.

The storm nearly took the life of Dr. Nadeem Qureshi, 55, of Chesterfield. The father of three spent a month in intensive care before he was released April 27 from the hospital. In addition to a ventilator, Qureshi spent 10 days on an ECMO machine, which pumps and oxygenates blood for the body, considered a last-ditch, lifesaving effort.

Qureshi, accustomed to working long strenuous hours as pediatric emergency room doctor, had to regain strength to comb his hair, brush his teeth and get dressed.

He spends every afternoon in physical therapy fighting to become strong



enough to return to work at Cardinal Glennon Children's Medical Center. He's made tremendous strides, but his heart and lungs are still weak.

"I was hoping to be back by September or October, but my pulmonologist feels it's not safe to go back," Qureshi said. "Right now I'm thinking, I'll be back to work January 2021. That is an estimate."

As researchers try to understand how and why the heart is injured by the coronavirus, early findings are increasing the concern about long-term damage.

A study released in May showed 20% of hospitalized patients had cardiac injury. German researchers in a study published July 27 revealed that even middle-aged adults with mild cases have concerning imaging test results.

The researchers looked at 100 patients ages 45 to 53, two-thirds of whom recovered from COVID-19 at home. Half were more than two months past their diagnosis.

Magnetic resonance imaging, or MRI, tests showed that a majority—78—had abnormal findings. Signs of heart muscle damage were found in 71 subjects, and inflammation of heart tissue was seen in 60.

While 36 subjects reported ongoing shortness of breath and fatigue, others felt fine.

Inflammation can lead to serious, long-term problems such as heart failure or chronic abnormalities in heart rhythms, said Dr. Kory Lavine, a Washington University School of Medicine cardiologist.



"Some patients can recover from myocarditis (inflammation of the heart) and be fine, while others don't," Lavine said. While the findings sound scary, he said, an MRI test is very sensitive and can reveal abnormalities that may never cause problems.

Lavine said he and his colleagues have seen myocarditis in hospitalized COVID-19 patients of all ages and illness severity, but he was surprised by the large number of patients who showed abnormalities in the study.

"I think that is the big take-home point, that COVID-19 disease is injuring the heart. It can injure the heart of patients who are critically ill and it can injure the heart of patients who recovered at home," he said.

Lavine said he expects to see more cases like that of Boston Red Sox pitcher Eduardo Rodriguez, 27, who developed myocarditis after testing positive for COVID-19 before the start of the team's summer camp. Rodriguez was cleared to play July 18 before an MRI revealed the heart damage. The team announced Aug. 1 that the pitcher would be out for the rest of the season.

Doctors don't know whether the heart damage is caused by the <u>coronavirus</u> infecting the heart muscle cells, or by an overly active immune system attacking healthy tissue, Lavine said.

Knowing would determine how best to treat it, he said. Providers are unsure if they should use anti-viral agents or things like steroids and antibodies that target the immune system.

"That is going to vary from one physician to another, because as a field, we just don't know what to do, honestly," Lavine said. "That's what makes this kind of scary."

Kids, brain health



These early findings are prompting concerns for long-term implications when it comes to other areas such as the brain and children's health.

Since mid-May, the CDC has been tracking a new multisystem inflammatory syndrome that appears in children two to four weeks after testing positive for COVID-19 or having close contact with someone infected. Different body parts become inflamed, including the heart, lungs, kidneys, brain, skin, eye or gastrointestinal organs.

As of July 15, the CDC has reported 342 cases and six deaths. The average age is 8 years old, and 70% are Hispanic or Black.

Scientists don't understand why some children develop the syndrome and others do not.

Dr. Alexis Elward, pediatric infectious disease specialist and chief medical officer at St. Louis Children's Hospital, said physicians are mindful of the inflammatory syndrome and long-term problems seen in adults as they care for pediatric patients.

While kids are much less likely to be severely ill, Elward said two to four children are in the hospital's intensive care unit with COVID-19 on any given day.

Doctors are starting to see older children with an increased risk of blood clots after a severe COVID-19 infection, she said.

"How long does that period of risk last? We still don't really know," Elward said. "I think the bottom line message is that we still need to work really hard to try to prevent infections, period, in kids."

When it comes to long-term problems for the brain, Keith Fargo, director of scientific programs for the Alzheimer's Association points to



several reasons to be concerned.

Studies show as many as a third of hospitalized COVID-19 patients experience delirium—a sudden and severe state of confusion that arises from illness or surgery—which can increase the risk of later developing dementia.

Impaired blood flow to the brain can increase the risk of dementia, and some viral infections like herpes have also been found to increase the risk.

"It's almost like we're seeing a massive natural experiment happening right now in front of our eyes and none of us really know what that outcome ultimately will be," Fargo said. "But there are lots of reasons to be worried."

Post-COVID clinic

The National Heart, Lung and Blood Institute launched an effort in June to identify 3,000 adult patients hospitalized with COVID-19 and measure their recovery six months later. The hope is to find what risk factors lead to poor outcomes.

Research will also be an important component of a post-COVID clinic that Washington University plans to open in the next month. Dr. Maureen Lyons, general internist and medical educator for the university, will likely serve as the clinic's primary care doctor and connect patients to specialists.

"It's important we reach these patients and offer them appropriate medical care and support and plug them into medical systems that can help," Lyons said.



Lyons has been meeting with specialists in cardiology, nephrology, pulmonology, neurology and mental health and familiarizing herself with the persistent symptoms each are seeing among patients.

The providers are working together to create a template for measuring symptoms in patients and how to best help them recover.

Another long-term health concern is that stark racial disparities discovered in COVID-19 infections and hospitalizations will continue as patients struggle post-infection.

"It's pretty clear that COVID has illustrated injustices that exist in our society, and that is likely to continue after the acute phase of illness," Lyons said. "We all have biases, and the more we can standardize, the more just and equitable this care can be."

Wiese, the ultramarathoner, said he got an X-ray last month that showed what appeared to be scar tissue in the area of his heart. This week, he is getting a pulmonary test.

"I think I will need to go in for an MRI," Wiese said. "I might go just to be safe."

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