



For millions, COVID-19 won't quit. Doctors strive for answers on how to ease long-hauler misery.

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Mon, September 13, 2021, 2:39 PM · 18 min read



Nick Guthe's wife Heidi Ferrer died by suicide after getting COVID-19 and experiencing debilitating, long-haul symptoms.

As COVID-19 swept across the country early last year, the primary concern was for the dying. So far, the pandemic has cost at least 656,000 American lives.

But there are others – as many as 12 million and counting – who took months and months to recover, or are still struggling. These “long-haulers” suffer from what’s called Post-Acute Sequelae of SARS-CoV-2 infection, better known simply as long COVID.

Edwin “Avi” Luna was a suit salesman in the Brooklyn borough of New York City when he came down with COVID-19 early in the pandemic. He loved joking around with his children and was passionate about kicking around a soccer ball in his spare time.

Now, Luna, 33, is a double-lung transplant recipient, slowly regaining his strength. His humor is back, but he struggles to climb the steep stairs to the apartment he shares with his parents, wife and two kids.

During nearly 11 months in the hospital, including all of summer 2020 in a coma, he lost more than 40% of his body weight. “I went from an oompa loompa to a stick figure,” he said. Luna makes light of his several near-death experiences but cries, too, when telling his tale.

Ronald Rushing Sr., 46, thought he had a cold when he came down with a sore throat, cough and a headache July 27, 2020. A grocery store manager living in Southern Pines, North Carolina, Rushing’s district manager sent him home to get better.

More than a year later, he’s still not. Pain shoots through his head from the moment he opens his eyes in the morning until he closes them at night.

Working his old job remains out of the question. Though his company extended his employment so he still has health insurance, he was replaced as store manager. The father of six doesn’t blame his bosses, but without that job he questions his identity and self-worth.

“On a daily basis, I feel alone and I feel like no one cares,” said Rushing, who hopes telling his story will help others feel less isolated and restore his sense of purpose. “It’s become the majority of my life, because I’ve lost everything else.”

With the delta variant raging and the U.S. enduring its fourth coronavirus surge, the USA TODAY Network spoke this summer with dozens of experts and patients to understand the consequences of long-haul COVID-19.

Over the next five days, we will share stories of families desperate to regain what they've lost and scientists doing everything they can to help.

Many of the people we talked with help run or participate in long-haul clinics, which have popped up in nearly every state, designed to address the wide range of symptoms that commonly include fatigue and brain fog, breathlessness.

Others are trying to unravel the economic impacts of COVID-19, to figure out how to spend the \$1.15 billion Congress allocated last December to address long COVID.

Dozens of patient support groups have sprung up, including Survivor Corps, with 150,000 members, and the covidCAREgroup, with more than 45,000. The Facebook group BIPOC Women Long COVID-19 Support Group focuses on women of color, another with a self-explanatory name is the Patient-Led Research Collaborative.

And then there are the patients. They struggle with a huge range of problems, compounded by the emotional drain of not getting better. Some can't even prove they had COVID-19 because testing was unavailable or hard to get when they were infected. In other cases, they are told, it's all in their head.

They're all waiting for help and for a better understanding of just what is making them so miserable.

"I do very much understand the feeling where your body is feeling a bit out of control and none of the doctors know why," said Dr. Stuart Katz, principle investigator of NYU Langone's Clinical Science Core,

which has been tasked by the federal government with leading the long COVID-19 research activities of clinical sites around the country.

Katz, a cardiologist, had symptoms for months after his own infection in December. “Obviously it’s very, very disturbing,” he said.

He hopes including patient experiences in the team’s work will bring more clarity more quickly.

Particularly early on, some doctors questioned whether long-haul symptoms were anything more than just anxiety after being ill. But in part because so many caregivers like Katz felt the symptoms themselves, most now are convinced.

“I’m sure that these (symptoms) are real and I’m sure we will someday understand them, but it sure is confusing right now,” said Dr. Julie Gerberding, a former director of the Centers for Disease Control and Prevention, who knows several people suffering from long-haul COVID.

Viral illnesses have long been known to occasionally trigger prolonged symptoms, but the scale of those with long-haul symptoms is unprecedented, she said, as are the range of problems and the devastation of lives.

“This clearly is different and exaggerated and more pronounced and more frequent than anything I’ve ever seen before,” said Gerberding, now executive vice president and chief patient officer at Merck & Co. “We will be able to understand this. It’s just not happening fast enough to be helpful to the people who are currently afflicted.”

The good news is most people *will* recover eventually, said Dr. Ravindra Ganesh, medical director of the post-COVID clinic at the Mayo Clinic in Rochester, Minnesota.

Medical treatment may be able to shorten symptoms, he and others said. But it’s also possible the interventions don’t matter and everyone who gets better would have anyway. It’s too soon to be sure.

In the meantime, said Dr. Steven Flanagan, a specialist in rehabilitation medicine at NYU Langone Health in New York, “anybody who’s had COVID, regardless of your race, whatever your socioeconomic status is, you need help.”

Not even the same person

The medical system didn’t do much for middle school English teacher Chimère Smith, 39, of Baltimore, as she fought COVID-19 and then sought help for the unrelenting brain fog and pain that followed.

People of color, whose communities were hardest hit by COVID-19, often face additional challenges as they try to recover. Smith, who is black, said she was turned away repeatedly when she tried to get help for her initial infection, which began March 22, 2020.

Short of breath, feverish, unable to pass waste and losing her vision, she says she watched white people across the emergency room hallway treated as if they were positive for COVID-19, while her symptoms were dismissed as merely acid reflux and dry eye.

“This is all in your head,” she said she was told. “It made me sicker. I was humiliated. I was ashamed.”

It took until this summer, 15 months after her infection, for a doctor to finally note in Smith’s medical record that she was presumed to have had COVID-19.

Like Smith, many people of color had a harder time getting diagnosed with the virus than whites, particularly early in the pandemic. It can be harder for them to access care for long-haul symptoms, said Dr. Amy Kontorovich, a genetic cardiologist at the Icahn School of Medicine at Mount Sinai.

“I don’t think there are any groups that are genetically predisposed,” she said. “But I wouldn’t dismiss the possibility that we’re not seeing even representation of people who are effected in more marginalized communities because of issues like access.”

Latino communities were devastated by COVID-19 infections, so they are likely to represent a high number of long-haulers as well. “It is the Latino community that is projected to carry the biggest burden,” said Noreen Sugrue, director of research for the nonprofit Latino Policy Forum.

“We’re losing, I hate to say a generation, but certainly a significant number,” added Sylvia Puente, the forum’s president and CEO. More than 1 in 11 Latinos in her home state of Illinois has had COVID-19, and the death rate has been higher in her community than any other.

Many are now unable to return to the two or three jobs they used to hold, either because of their own symptoms or because the virus unraveled their safety net – a grandmother who can no longer care for her grandchildren, for instance.

The Latino Policy Forum is leading an investigation into the long-term social and economic consequences of COVID-19 in the Latino community, Sugrue said. “A lot of people have started picking up on this.”

It’s important to create dedicated studies, because people of color may have distinct issues, said Marina Del Rios, an emergency room doctor and associate professor at the University of Illinois Chicago.

The signs of heart attack were missed for years in women because most heart attack studies were in men. Del Rios worries the same thing will happen to minority populations if research into long-haulers focuses mainly on those who seek care.

“Just like we’re all in to prevent COVID, we should be all in to understand what the consequences are for all of us,” Del Rios said.

Abigail Echo-Hawk, executive vice president at the Seattle Indian Health Board, said she’s “deeply concerned” by the lack of data on long-haul COVID-19 in the Native American and Alaska Native

populations, who are three-and-a-half times more likely to be diagnosed with COVID-19 than non-Hispanic whites.

“Anecdotally, I am hearing story after story after story that is related to long-haul COVID, yet I am seeing no meaningful efforts to include American Indians and Alaska Natives in research studies,” said Echo-Hawk, also director of the Urban Indian Health Institute. “Since western research began, we’ve been under-represented within clinical trial research studies and we’re seeing that happen again.”

It’s also hard to track these populations in electronic medical records, because many fail to collect appropriate racial information, she said, which means there will be fewer resources for her community going forward. “What we’re going to see is disparities grow as a result,” she said. “I’m terrified of what could happen.”

Back in Baltimore, Smith, who used to dream of becoming a school principal, is coping with her new reality. After COVID-19 she was diagnosed with a painful inflammatory condition in her brain stem, the area that regulates involuntary activities, such as heartbeat and breathing. It’s left her with brain fog, spinal pain, vertigo and migraines.

“Some days it feels like there are five rubber bands tightly wrapped around my skull,” she said. “I was a wordsmith. Now I can’t even think of words to say.”

She fills her empty hours lobbying on behalf of black long-haul COVID-19 patients. She says she’ll never be able to inspire young people with Shakespeare again.

“I can’t even be who I really was,” she said. “I’m not even the same woman or person.”

What long-haul COVID looks like

COVID-19 is known to affect every organ system in the body, from circulation to the skin.

In a detailed, though not yet peer reviewed study of 107 long-haul patients, about 20% to 25% showed lung damage, blood clots, heart failure or similar symptoms caused by their initial infection, said Mayo's Ganesh.

Current treatments are usually directed first at problems like these that show up on medical tests, and then at the most bothersome symptoms – but there's no standard therapy for tiredness, and lung, brain and cardiac scans often come up clean.

“Doctors are completely lost,” said Rushing, who has had a slew of tests including two MRIs and been put on “medicine after medicine,” all to no avail. “It doesn't make any of us feel any better to know that they're lost.”

Long-haul patients seem to skew female and younger – in their 30s and 40s rather than the older people who had more severe COVID-19 infections, said Dr. Zijian Chen, an endocrinologist and medical director of the Center for Post-COVID Care at the Icahn School of Medicine at Mount Sinai in New York.

Of the first 7,500 people who responded to an online survey about long-haul COVID symptoms, 83% were women and 90% were white, said Shruti Mehta, who is helping run the study at the Johns Hopkins Bloomberg School of Public Health.

“As far as I know there is no data to support a biological reason for this, white women being at higher risk for long COVID,” said Mehta, an infectious disease epidemiologist. “Are we seeing this trend because this disproportionately affects white women or is it because they are more vocal, more likely to engage in research efforts? We don't know the answer yet.”

There are no good numbers for how many people have lingering symptoms after a COVID-19 infection but scientists say as many as 30% of those infected are long-haulers. A recent study out of China found that half of those who had COVID-19 early on report at

least one continuing symptom a year later and their overall health isn't as good as those who escaped infection.

In one survey of nearly 4,000 people, more than 90% said they still had symptoms eight months after their bout with COVID-19. Over 45% said they had reduced their work hours since their infection and an additional 22% said they were unable to work at all.

The survey recorded 203 symptoms ranging from the most common – exhaustion, breathlessness, brain fog, pain, headaches, gastrointestinal problems, racing heart – to the bizarre, including hallucinations, painfully swollen toes, and full-body convulsions.

Roughly 70% of COVID-19 patients lose their sense of smell during the infection, and for as many as 30% it can take months to get back. When smell does return it can be disordered and disorienting, with everyday foods now repulsive and familiar places and people suddenly seeming foreign.

It's also a scary prospect. The nerve cells that sense smell go directly to the brain. If they are affected, other parts of the brain likely are, too, said Dr. Megan Ranney, an emergency room physician and researcher at the Brown University School of Public Health.

“That’s a direct attack on the brain,” she said. “It is inconceivable to me that this virus will not have long-term effects for a portion of people ... but I also fully expect that we’ll find treatments.”

It's too early to say whether the delta variant, which causes very high viral loads, will increase the risk of long-haul COVID-19. Not enough time has passed since delta began taking over at the end of May.

The causes of long-haul COVID-19 remain unclear.

“This virus does something strange to the immune system and the autonomic system that we just don’t fully understand yet,” Ranney said.

In some people, bits of the virus that causes COVID-19 may linger in the body triggering symptoms. In others, the immune system may not be able to quiet back down after revving up to fight COVID-19. There also is a possibility the virus may reactivate an old pathogen that's been dormant in the body for years.

For about 20% of long-haulers, a COVID-19 vaccine [seems to improve symptoms](#), Mayo Clinic's Ganesh said, suggesting the shot may be "rebooting" the immune system in some patients. Or maybe, Ranney said, the vaccine triggers an immune response that somehow straightens out whatever went awry during COVID-19.

[Some, unfortunately, feel worse after their shots.](#) Rushing and many like him are afraid getting vaccinated will exacerbate their symptoms. "If I feel any worse than I do now, I would not want to be on this earth," he said. "I couldn't."

The most desperate option

[Heidi Ferrer, of Santa Monica,](#) California, felt like she had tried everything to treat her long-haul symptoms. But nothing helped combat the exhaustion, body aches, foot pain, racing heart, sleeplessness and frequent diarrhea that made it impossible for her to leave the house.

Her March 2020 bout with COVID-19 was relatively mild and she checked none of the boxes of those presumed at highest risk. Just 50, Ferrer was trim and healthy. The successful screenwriter and blogger ate organic food, walked 90 minutes a day and hadn't had a drink in three-and-a-half years.

By mid-July, though, her feet hurt so much, it was like walking on shards of glass.

She was still learning to cope with the unrelenting pain the following March when she got vaccinated against COVID-19.

Then, the full-body tremors began. She'd shake so much, she couldn't carry a glass of water up the stairs, her husband said. Internal tremors lasted for hours and kept her from sleeping at night.

Her husband Nick Guthe used to kid Ferrer about the size of her Kindle bill, but she no longer had the attention span to read a single book.

"I can't walk. I can't travel. I can't even read a book. What's left?"
Guthe remembers her saying. **"It was hard to argue with her."**

On May 2, she finished writing her memoir – including the story of her recovery from alcoholism and the couple's struggle for proper care of their now 14-year-old son's spinal problems. **She died by suicide**
May 22, after scrubbing her computer's history, so no one would see
what she'd been searching in those final days.



Nick Guthe's wife Heidi Ferrer died by suicide after getting COVID-19 and experiencing debilitating, long-haul symptoms.

Her organs were transplanted on what would have been her 51st birthday.

As painful as it is to recall the suffering of his wife of 28 years, Guthe said he's committed to sharing her story to hopefully protect others.

"The one thing Heidi said to me was, 'Let the world know what happened to me,'" said Guthe, who is seeking a publisher for her memoir. "It's been very therapeutic to direct my grief to help save other people."

Fulfilling a promise

Some of those who continue to struggle the most are those who were the sickest with their initial infection.

Dr. Wes Ely, an expert in critical care at Vanderbilt University School of Medicine in Nashville, Tennessee, said most patients who go through intensive care will have long-term physical and mental health problems and over half will leave with what he calls "acquired dementia."

"They're going to have years and years of cognitive rehabilitation, physical rehabilitation, therapy to get over the PTSD of it all," Ely said.

And it's not just the patients who suffer. Their loved ones are often traumatized, too. "No one should see a person they love the way that I saw him," said Luna's wife, Mayra, describing the two as going together like mac and cheese. "He's the pasta; I'm the cheese."

When Luna was first admitted to Maimonides Medical Center in late April 2020, his blood oxygen level, which in healthy people registers in the mid- to upper-90s, measured just 76. He could barely walk a few steps without stopping to catch his breath.

In early May, out of other options, doctors insisted they needed to try him on a ventilator, even though at the time about a quarter of ventilated patients died.

When Luna woke up again, a nurse asked him what day he thought it was. Late April? May? he wondered aloud. “It’s September,” she told him.

His lungs were badly scarred. By early December, it was clear they weren’t going to get any better.

That’s when a transplant surgeon from NYU Langone came to visit. Luna made a promise: If he could get a new set of lungs, he would prove he deserved them. He wanted to be there for Mayra and the kids.

“Give me a second chance at life and I’ll try my hardest to get back on my two feet again,” Luna told the surgeon. “You get me those lungs and I promise you, I’ll work hard.”

Again, it wasn’t easy. He barely survived a repeat bacterial infection shortly after his transfer to NYU Langone. The transplant left Luna with crushing chest pain and blood clots that required surgery to avoid amputating his leg.

The March day he left the hospital, almost exactly 11 months after his admission, Luna, at 5 foot, 3 inches, weighed less than 100 pounds.

By late summer he was back up to 135 pounds and was regaining his strength, though his conversations were still sometimes punctuated by a deep, hacking cough.

“It’s just amazing what a body can do – a body, mind and soul, you could say,” he said. “I’m very fortunate.”

At one point, doctors gave Mayra X-rays of Luna's old lungs showing how ravaged they were from COVID-19. One day, Luna expects he'll be able to look at those pictures.

But not yet.

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