

Endurance test: Even after coronavirus retreats, the battle continues for long-haulers

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Janelle Janatowski, left, hugs a friend during a welcome home celebration for her son Marcus Hartford who was hospitalized with the coronavirus since April.

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Marcus Hartford can put on his socks.

He can slip on his shirts. He can pull up his pants. He can get off the couch. He can stand. He can walk. He can use the restroom. He can clean himself. He can move a dining chair (not a big one, but big enough) from one room to another.

Last week, gripping onto the railing, he lumbered down the steps to his basement for the first time in nine months. The music studio that greeted him at the bottom, the one that he had built himself, was a throwback to the before-times — to the 24-year-old, award-winning chef at Bar 145 and former lead singer of the death-metal band Hanging Fortress.

Then he tested positive for the coronavirus on April 4. A week later, one of his lungs collapsed. He was intubated, and eventually flown to University Hospitals Cleveland Medical Center for additional treatment.

What followed were seven months of deoxygenated purgatory. After five surgeries and 140 days on a vent, Mr. Hartford finally returned home in November. He was sitting in a wheelchair and plugged with oxygen tubes, but he was alive.

"Just being able to be off oxygen while I walk around the house is huge for me," Mr. Hartford said, just two months later. "Some doctors didn't think that day would come for me, and it's already here."

There are scars — his left foot that's bent not quite right, the semi-permanent hole opened in his chest to clean out his lung, the nerve pain from the extracorporeal membrane oxygenation machine that had been attached to his femoral artery to oxygenate his blood.

Mr. Hartford takes medication for his heart rate, elevated even when he's relaxed; goes to the doctor to measure his liver enzyme levels, high despite a lifetime of abstaining from drugs and drinking; and struggles with occasional short-term memory loss, forgetting names and dates that he shouldn't. Coronavirus has retreated from Mr. Hartford's body, but he's still fighting it.

Dysfunction

According to James Tita, chief medical officer at Mercy Health — St. Vincent Hospital, anywhere between 10 and 30 percent of coronavirus patients develop long-haul syndrome, defined by the Centers for Disease Control and Prevention as symptoms that persist more than four weeks after infection. A recent study of data collected from more than 250,000 patients found that at least 50 percent of coronavirus survivors will experience lingering symptoms for six or more months after their initial recovery.

"This is not a syndrome that's necessarily unique to COVID-19," said Dr. Tita. "These syndromes have been described after many viral illnesses, including influenza and other viruses. The symptoms are similar to what you would see in patients who had Lyme disease, chronic fatigue syndrome, Ehlers-Danlos. What's unique about COVID is the frequency with which we're seeing this."

The most common symptom is chronic fatigue. Others include brain fog, shortness of breath, aching muscles or joints, and cardiovascular issues like an elevated heart rate with minimal exertion. Other symptoms include hair loss, gastrointestinal problems such as diarrhea or abdominal pain, and prolonged loss of smell and taste.

"This doesn't only affect patients who are sickest with COVID, but even those with relatively mild diseases," said Dr. Randall King, medical director of Mercy Health's emergency medical training program. "Many of the patients that I see had relatively mild illness, were not hospitalized, were not severely ill, yet these long-hauler symptoms for most of them are even more acute than the respiratory disease."

When Dr. Blair Grubb, the director of the University of Toledo's Clinical Autonomic Disorders Center, began studying postural orthostatic tachycardia syndrome, or POTS, about 30 years ago, he couldn't have known that it would one day put him in a unique position to pioneer scientific understand long coronavirus.

POTS is a blood circulation disorder characterized by orthostatic intolerance — an inability to stand up without triggering heart palpitations, lightheadedness, and even loss of consciousness. It is the most common form of the autonomic nervous system dysfunction known as dysautonomia. A recent study found that more than half of long-haul coronavirus patients have POTS or similar autonomic problems.

"After the COVID outbreak occurred, we begin to see a number of patients referred to us who develop POTS after a COVID infection rather than after an Epstein-Barr infection," said Dr. Grubb, whose treatment center sees about 2,000 patients a year. "The clinical symptoms and clinical picture was identical to the POTS patients we'd been seeing for years — it's just the virus that triggered it was different."

'Mass disabling'

Since the institutionalized study of POTS is so relatively new — but not the disorder itself — patients suffering from it have historically been dismissed. Dr. Grubb is seeing a similar pattern now with long coronavirus patients.

"In general, post-COVID patients are treated like dirt," said Dr. Grubb. "No one believes them, no one wants to deal with them, and they're dismissed. But oftentimes these were people who were highly productive, gainfully employed, and these illnesses have wrecked their lives. I see so many young people who come to our clinic from New York, New Jersey, Texas, California, in wheelchairs with feeding tubes whose bodies have been stolen from them. ... Overnight they go from being normal to being completely disabled, and then on top of that they have to deal with being dismissed by the medical community."

Part of that dismissal, Dr. Grubb thinks, stems from standard-issue misogyny — the majority of POTS and long coronavirus patients are women, who are more prone to autoimmune problems.

Another is the sheer variety and apparent randomness of the symptoms, rendering diagnosis difficult. Indeed, documented long-hauler symptoms are so voluminous — more than 200, by some counts — and so generic "that tying them back to the COVID problem in the first place can be difficult," said Dr. King. It can be done, however, with the help of immunization and infection records.

There's no doubt in Dr. King's mind that long coronavirus is not some purely psychological phenomenon. It's real, and devastating. If anything, the dizzying number of coronavirus infections even before the omicron surge, coupled with the significant percentage of patients that have developed persistent post-viral symptoms, has led some in the health care

community to call the pandemic “the largest mass disabling event in history,” said Lauren Stiles, president and co-founder of the nonprofit organization Dysautonomia International, Inc.

“If you’re leaving millions and millions of people with chronic illness,” she asked, “is our health care system set up to handle that?”

Hydra

The short answer is no. The long answer is that scientists across the country are scrambling to keep pace with the 200-headed hydra of long coronavirus. Its causes are unclear, and therefore so are its solutions.

“There are no specific therapies for this condition,” said Dr. Tita.

Vaccination is highly encouraged, because even in the event of a breakthrough infection, “the risk of you developing the long-hauler symptoms after your breakthrough infection is less than if you had developed the infection and were not vaccinated,” said Dr. King. It’s the closest thing we have to a universal treatment for long coronavirus.

That doesn’t mean other, narrower treatments can’t provide significant relief. Dr. Tita has worked with Healthy State Alliance, a collaboration between Mercy Health and the Ohio State University Wexner Medical Center, to develop best practice guidelines for managing coronavirus long-haulers.

“Much of it revolves around gentle exercise, teaching people how to breathe,” Dr. Tita said. “Patients who have shortness of breath frequently change their breathing pattern, so they use the muscles of their upper chest to breathe rather than their diaphragm. That’s a very inefficient breathing pattern, and it causes them to actually expend more energy.”

Ohio is home to one of the few long coronavirus health clinics in the country. In early August, while Marcus Hartford was fighting for his life at University Hospitals Cleveland Medical Center, the nearby UH Ahuja Medical Center launched the UH coronavirus Recovery Clinic. Its personalized approach accounts for the many organ systems in which long-haul coronavirus can manifest: pulmonary, hematologic, cardiovascular, neuropsychiatric, renal, endocrine, gastrointestinal and dermatologic. The clinic also offers integrative health interventions such as acupuncture, stress management and relaxation techniques.

“The demand is much greater than we thought it’d be,” said clinic director David Rosenberg, with more than 120 patients treated in less than six months.

Dysautonomia International, meanwhile, has begun funding studies into the relationship between POTS and long coronavirus. One of the first beneficiaries of its Long coronavirus Research Fund? The University of Toledo.

The UT study, which is examining immune system and blood platelet dysfunction, is being led by Dr. Grubb and hematologist William Gunning. It began a few months ago with the aim of measuring antibodies in the blood of four groups of people: those who are healthy, those who have POTS, those who have long-haul coronavirus with POTS-like symptoms, and those who have recovered from long coronavirus. The expectation is that long coronavirus and POTS patients will have identical antibodies.

“If we can show that post-COVID and POTS patients have these distinct antibodies, then we’d have the basis of a diagnostic blood test to help confirm the illness, which will open up a whole new range of therapies that we can use to treat the affected people,” said Dr. Grubb.

Fortress

Long coronavirus patients, Dr. Rosenberg observed, tend to be denied the “psychological relief” that comes with proper “coordination of care and communication.” We have to “let people know that they’re not alone.”

Dr. Grubb hopes that his research can do that for his patients. Too many of them, when they finally find him, are “angry, frustrated, and financially depleted” by a never-ending chain of misdiagnoses and referrals.

“Oftentimes people in Toledo don’t think highly of themselves or the city,” reflected Dr. Grubb. “[But] Toledo does some really advanced scientific research that’s very important and can change the world. We contribute to the greater welfare of the country and the world, in our own way, and I think the people here need to take pride in that.”

Mr. Hartford, too, is working to change the world — his world. Bland, boring normalcy is the dream that keeps him going. He knows he won’t be able to work 13-hour days as a chef again, but he also knows he hasn’t lost his knife-to-board skills or his talent for burger-making.

So he exercises daily, practices cooking short-order meals, and maintains a diet low in fat, high in protein, and higher in appreciation — for being able to walk up the stairs, take showers, and do the laundry.

“It could be worse,” he said. “I’m glad that I came out of it at least this well.”