

Fatigue, loss of smell, organ damage: A range of symptoms plague many long after COVID-19 infection

31 December 2020, by Meredith Cohn, The Baltimore Sun

Just as much of the nation was shutting down because of the coronavirus pandemic in March, Michaelene Carlton's 17-year-old son tested positive for COVID-19 and quickly passed it to his parents.

Carlton had the worst of the symptoms but never went to a hospital and mostly recovered in a couple of weeks.

"Then, six weeks later I got ridiculously sick, like so sick I lost about 10% of my body weight and could barely get out of bed," said the usually healthy 46-year-old Delaware woman who eventually landed at a Johns Hopkins Hospital clinic for post-COVID-19 patients.

She was profoundly fatigued, her head pounded and her heart raced so fast when she stood that she thought she'd pass out, symptoms that suggested an incurable blood circulation disorder. It's called POTS, for postural orthostatic tachycardia syndrome.

Increasingly, doctors are seeing the disorder among patients well after their COVID-19 infection, but it's far from the only lingering condition. Some patients can't shake the shortness of breath or loss of smell. Others are developing new symptoms such as heart palpitations or a "brain fog" well after their initial infection.

Together, the National Institutes of Health is referring to the maladies collectively as post-acute COVID-19 syndrome, or simply long COVID. The sufferers are known as long haulers.

No one knows how many long haulers there are among the approximately 18 million Americans infected with COVID so far during the pandemic, with estimates ranging from 3% to as many as

40%.

Discussions and investigations have begun, and there are some historical clues to the medical mystery. But doctors still don't know who is most likely to become a long hauler or how long they will live with symptoms ranging from mildly annoying to completely debilitating.

For now, doctors are treating long COVID symptoms piecemeal—and warning that the virus doesn't always end in death or recovery.

"It will take time to figure out what we're dealing with," said Dr. Andrea Levine, a pulmonary and critical care specialist at the University of Maryland Medical Center who runs a post-COVID-19 clinic.

She said a major issue is the variety of symptoms in long-haul patients, who range in age, race and level of health. They had varying levels of sickness from their initial COVID-19 infection. Because of the growing number of long COVID patients, more hospitals are creating outpatient clinics with multiple specialists or expanding centers that initially focused only on patients leaving intensive care units.

The medical community also has begun sharing information on the long COVID phenomenon in virtual seminars and journal articles, and patients have taken to social media to form support groups.

A U.S. Centers for Disease Control and Prevention website lists the most common long COVID symptoms: fatigue; shortness of breath; headache; cough; joint, chest and muscle pain; intermittent fevers; heart palpitations; inflammation of heart muscles; depression; and difficulty thinking and concentrating.

Melissa Hunt, a technician who helps treat heart patients at the University of Maryland hospital, is among the long haulers. She was infected in April, returned to work in June but was sidelined again weeks later with worsening symptoms.

Like Carlton, Hunt was never hospitalized for COVID-19. The 33-year-old Odenton woman tested positive in early April and called her symptoms "moderate," with shortness of breath that left her winded after walking two or three blocks.

She never fully recovered but, when her improvement plateaued, she got impatient and returned to work. Hunt's job involves 10-hour shifts on her feet and nights on call, and each time the physical demands wrecked her for the entire next day. Before getting COVID, she'd take in a spin class or go for a three or four-mile walk.

A couple of weeks after returning to work, as she was being fitted for a new N95 mask, a co-worker said her breathing sounded awful. Hunt went home and now spends much of her time on her sofa slowly improving but still feeling like she has "the flu without the fever." Often, she said she can't recall common words and has to describe her meaning to her husband, the brain fog described by other long haulers.

"My doctor tells me to keep walking on my own, just don't push myself too hard," Hunt said. "I would love to go back to work. I feel guilty leaving my co-workers short handed."

She said it's been helpful knowing there are other long haulers.

"Mentally, it's better knowing I'm not the only one," she said. "I did feel kind of crazy in the beginning. Now I want an explanation."

NIH dedicated a two-day workshop in early December to long haulers, led by experts including Dr. Michael Saag, an infectious disease expert from the University of Alabama at Birmingham.

A first step is defining the term long hauler and getting a handle on how many are affected, said Saag, an associate dean for global health and

director of the university's Center for AIDS Research. He estimated 3% to 5% of American COVID-19 patients have debilitating symptoms more than a month after their infection. That doesn't count people, like him, with lingering loss of hearing and taste, and fatigue that doesn't prevent him from working.

Then researchers need to dig into causes.

"This syndrome is so new and so varied that we don't really know what's driving the symptoms," Saag said. "So we're left guessing how to treat it."

Saag said some doctors still may be skeptical that their patients' symptoms are even COVID-19 related. That's what happened for years to Lyme disease sufferers, who reported new symptoms well after their initial infection. Same for people infected with HIV, who later came down with AIDS.

In contrast, long COVID is starting to get recognition during the ongoing pandemic because so many people have it, he said.

He said the cause may be similar to a prevailing theory about Lyme disease: that a new autoimmune disease is triggered by the bacteria that causes Lyme weeks after a course of antibiotics clears the acute symptoms.

"But who knows," Saag said. "COVID is less than a year old."

One doctor who suspected he may see lingering symptoms from COVID-19 is Dr. Tae Chung, director of the Hopkins POTS Clinic and Carlton's doctor. He said a small number appear to have developed POTS after other coronavirus infections, including SARS in 2003 and even the common cold.

He's now treating a dozen long haulers that he believes have POTS, though the condition is not normally diagnosed until people have symptoms for six months.

POTS, affecting an estimated 1 million Americans, wasn't well understood even before the coronavirus pandemic. Cases often affect people with

underlying health conditions or a genetic mutation. Treatment can vary but often involves hydration and exercise and wearing compression socks to help return blood to the heart from the legs.

COVID-19 is providing an opportunity for study, a "positive thing out of a scary pandemic," Chung said.

"The question is whether there is something specific to COVID-19 that makes people prone to develop POTS," he said. "We really are learning as we go."

Long haulers are eager for more research, including Carlton, who misses her work assisting in a classroom and her home life as soccer mom and family cook.

"I've not made dinner for my family for months," she said.

Rick Dressler is a 52-year-old Air Force reservist, aviator and medic who also worked as a federal criminal investigator. He wants to apply his skills to the mystery for himself and other "outliers" with long COVID.

Dressler tried to recover from his COVID-19 infection at home but eventually went to an emergency room in St. Mary's County near his Leonardtown home in March after having trouble breathing. He went home but returned after coughing up blood. He ended up on a ventilator twice, the second time prepping himself and his wife via text message for the prospect he might never come off.

He eventually recovered enough to be discharged but remains far from his military-level of mental and physical fitness. He remains chronically short of breath, fatigued and with a constant low-grade headache and joint pain. His senses of smell and taste have not returned, he often forgets things and he finds himself lacking patience. He needs hours-long naps.

Even the joy of brewing good coffee has vanished. He can't stand the metallic taste.

Tests reveal little other than that he no longer has COVID-19 but is still making extra red blood cells like someone who lives at a high altitude and needs more oxygen carried around his body.

"No one can explain that," he said. "It's like I live in Denver, but I don't live in Denver. We're at sea level."

There also is no explanation for why Dressler got so sick and remains symptomatic when his wife and one of his 12-year-old twin boys didn't get that sick and have recovered. His other son never showed symptoms.

"It's absolutely frustrating," he said. "When I wake up, the first thing I think is when can I go back to bed, which is utterly ridiculous."

He now spends part of his day reading and trying to suss out any information that may be helpful to researchers. Exactly what are his symptoms, how have they changed and what helps? What other tests may uncover the genesis of long COVID? What studies can he volunteer for? He discusses them with Dr. Levine in the post-COVID clinic at the University of Maryland where he's been treated.

"I would love to help find funding for a study," Dressler said. "But that comes after awareness."

Dr. Ashraf Fawzy, a pulmonary disease and critical care doctor at Johns Hopkins who tends to patients in the hospital's post-COVID clinic, said doctors already are looking into some areas of similarities among some long COVID patients. They include lung problems due to acute respiratory distress syndrome, a severe inflammatory response to the viral infection that is known to cause long-term lung damage and scarring.

Another area being investigated involves psychiatric conditions, which Fawzy said have long been seen in patients after lengthy stretches in an ICU. Some have depression, anxiety or even PTSD after a critical illness.

Sometimes doctors discover patients had underlying health conditions or genetic predispositions they did not know about, which may

help explain why some people get so sick and who stays sick.

But doctors still are seeing unexpected symptoms, such as hair loss. A dermatologist is now on the Hopkins team with other specialists. Together they are currently treating about 300 long haulers.

Fawzy said the nation will need more post-COVID clinics at hospitals with specialists as the pandemic continues, though many medical staffs still need to focus on acute cases.

"People have been focused on mortality rates," Fawzy said. "But it's important to keep in mind that there are a lot of people who survive the infection, whether or not they needed hospitalization, but end up with debilitating and life-altering residual after effects."

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APA citation: Fatigue, loss of smell, organ damage: A range of symptoms plague many long after COVID-19 infection (2020, December 31) retrieved 23 September 2021 from <https://medicalxpress.com/news/2020-12-fatigue-loss-range-symptoms-plague.html>

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