

Redefining Covid-19: Months after infection, patients report breathing difficulty, excessive fatigue



By [Ryan Prior](#), CNN

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(CNN) It's been five months since Lucy Gahan contracted Covid-19, and her life still hasn't returned to normal.

Gahan, a clinical psychologist in Shrewsbury, United Kingdom, hasn't been able to return to work.

The disease causes what she calls "storms," disabling periods when she feels shortness of breath, numbness in her hands and feet and her heart rate shoots up from simple tasks. Even taking a shower is possible only during an occasional respite in symptoms.

"In May and June, I could barely talk because I was so ill," she said.

Before contracting the disease in early April, the mother of two ran three times a week and had a regular yoga routine.

"I can only walk as far as the corner," she said. "In terms of running, I can't imagine when that will happen, if ever."

Many hospitalized for Covid-19 at risk to become 'long haulers'

About three-quarters of those hospitalized for Covid-19 could become long haulers, according to a paper [uploaded](#) to the pre-print server medRxiv on August 14 without having yet been vetted by outside experts or accepted for publication.

Researchers from the Academic Respiratory Unit of the North Bristol NHS Trust in the UK looked at 110 Covid-19 patients, whose illnesses required hospital stays for a median of five days between March 30 and June 3.



Twelve weeks after patients were released from the hospital, 74% of them reported symptoms, including breathlessness and excessive fatigue.

Despite these symptoms, however, 104 of the 110 patients in the study had normal basic blood test results, with just 12% showing an abnormal chest X-ray and 10% showing restrictive lung function through spirometry tests.

The British Medical Journal released new guidance for health providers in August on how to treat long-haul Covid-19 patients, estimating that up to 10% of all people who have tested positive could develop a prolonged illness. The guidance includes specific blood tests to perform, possibly referring patients to pulmonary rehabilitation and having them use pulse oximetry at home to measure oxygen saturation in the blood.

Results like these fly in the face of a narrative that took hold early in the pandemic, in which many medical professionals believed that the average Covid-19 patient would be sick for a couple weeks, clear the virus and be fine afterward.

That turns out not to be the case for everyone. The BMJ guidance cited "weak or absent antibody response, relapse or reinfection, inflammatory and other immune reactions, deconditioning, and mental factors such as post-traumatic stress" as contributing to longer-term symptoms. It acknowledged that similar parallels had occurred in patients with SARS and MERS.

"The classic case we all have in our hands is not always what really happens," said Dr. MeiLan King Han, a pulmonologist and professor of medicine at the University of Michigan. "For the patients I have followed, many continue to complain of cough, breathing issues and severe fatigue long after their first infection."

Long haulers and dysautonomia

One of the key issues in caring for each long-haul Covid-19 patient is to figure out how many of their symptoms can be chalked up to the heart and lungs and how much of the illness is actually the result of a deeper form of neurological dysfunction the coronavirus has unspooled, according to Noah Greenspan, a New York-based physical therapist and founder of the Pulmonary Wellness Foundation.

Before engaging in physical or respiratory therapy, he asks that all his patients get a full workup from their doctor to rule out a cardiac condition, stroke or pulmonary embolism before starting physical therapy.

Some patients' symptoms are mild and can start a more traditional rehab plan, he said, "but there are others, which are turning into the biggest group of people, which are these long haulers."

The primary trend across the Covid-19 long haulers that Greenspan is working with is a condition called dysautonomia, a condition marked by a miscommunication between the autonomic nervous system and the rest of the body.

The autonomic nervous system regulates automatic body functions such as breathing, sleep and digestion. When it's not working, symptoms can present in myriad different ways, depending on the person.

"Reach into a bag of symptoms and pull out a bag of symptoms, and that's what they have for the day," Greenspan said. "It's a twisted ball of yarn and takes a week to unravel one string."

While shortness of breath and cardiovascular problems do present in his patients, Greenspan said, these are not usually the most common underlying cause of their misery.

Gahan and others with long-haul Covid-19 symptoms face a condition called postural orthostatic tachycardia syndrome, which refers to a sharp rise in heart rate that occurs when moving from a reclining to standing position. The pull of gravity causes blood to pool in the legs. This condition can cause dizziness, lightheadedness and fainting.

"Their heart rate goes up 50 to 75 points if they get up to get water," Greenspan said. "They have fast heart rates that don't have anything to do with what they're actually doing, that are not commensurate with their workload."

Many patients are exhibiting neurological symptoms consistent with myalgic encephalomyelitis/chronic fatigue syndrome, according to the BMJ and National Institute of Allergy and Infectious Diseases Director Dr. Anthony Fauci. That diagnosis requires at least six months of symptoms, a benchmark most long haulers haven't yet reached.

For many, lung damage not the biggest issue

Many Covid-19 patients feel that the medical system is gaslighting them, telling them there's nothing wrong even though their whole lives have been upended by Covid-19's aftermath.

Corey Coopersmith, a 36-year-old fitness consultant in Las Vegas, hasn't been able to work since first getting sick in late February. He suffers a constant ebb and flow of symptoms, and yet visit after visit to medical specialists has turned out a series of "normal" lab tests.

"A month ago, I had a pulmonary exam, and I got 120% on the gas exchange test," Coopersmith said, noting the doctor told him, "Your lung function is amazing."

But a breakthrough came when he finally visited an immunologist who performed tests that indicated abnormally low function of immune cells, including T cells and B cells.

"Have you been tested for HIV?" the immunologist asked Coopersmith, he recalled. "Your blood work looks like someone about to get AIDS."

An immunologist finally found disturbances in Coopersmith's immune system that appeared to be on par with HIV/AIDS even though he doesn't have HIV.

A mixed martial arts fighter in his 20s, Coopersmith was in great shape when he contracted Covid-19 in February, boasting of a resting heart rate of 58 beats per minute.

Now though, when he wakes up in the middle of the night to go to the bathroom, POTS can drive his heart rate to 200.

To make it possible to sleep under his new constraints, he bought a continuous positive airway pressure machine, a device with a face mask that pushes oxygen into his lungs.

"I lie there gasping for air, fighting for life," he said.

For many, lung damage not the biggest issue

Coopersmith is one of many Covid survivors trying to grasp why he feels so breathless even though his lung function is excellent.

"I feel like my lungs have recovered quite well," Gahan, the clinical psychologist in the UK, said.

Her main issue has been pinpointing what has been causing the storms of illness, which are primarily neurological symptoms, including migraines and numbness in her feet and hands. She feels they can be explained by dysautonomia.

"I can't do anything except to just go to bed," she said, noting how lights and sounds and emotional stressors exacerbate her ongoing sickness. "I can't stand any interaction."

Patients hope their stories of halted recoveries might dissuade others from taking risks with infection by traveling, partying or gathering in large groups prior to development and distribution of a vaccine.

"It's not about fatigue. It's about really nasty symptoms that take over your whole life for who knows how long," Gahan said. "Think about people like me when you're thinking about what decisions you should make."

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