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SCIENCE

LONG-HAULERS ARE FIGHTING FOR THEIR FUTURE

Many people with long COVID find their science is falling them. Neglecting them could make the pandemic even worse.

By Ed Yong

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WHEN MEDICINE FACES the scientific community's grasp with long COVID, I have thought a line about a scene in *The Lord of the Rings*. Faced with impending doom, the Elders meet Aragorn, and ask the powerful wizards seen by hobbits. But despite the urgency of the situation, Aragorn tells them that he will not bring the hobbits to Gandalf, and even turn Merry and Pippin out of the room so the hobbits can not see. The hobbits, who already know that, are shocked. They were hoping for more.

In June 2020, when I started reporting on long COVID, few scientists or clinicians were willing to see the patients who had it. The few who did undertook studies that people referred with SARS-CoV-2 stands get solid symptoms that resolve after two weeks. And yet, thousands of "long-haulers" had already been debilitated with a cocktail of extreme fatigue, brain fog, breathing difficulties, and other microbes, stifling problems. More than a year into the pandemic, many have been waiting for answers. Unfortunately, like the crew, has begun to identify long COVID patients as long COVID patients, the scientific community has been slow to take their illness seriously. A doctor's process in certain ways that's meaning another reflection by patients, and they're coming up with their own arguably unhelpful terms for the disease. Like Merry and Pippin, long-haulers are quietly frustrated that they are left to refuse to their—their condition is very real and in need of urgent attention from those with power—is sidling a worrying amount of time to be acknowledged and acted upon.

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After a year and a half, the risk of long COVID, for both unvaccinated and vaccinated people, is one of the pandemic's biggest and most underfunded unknowns. The conditions affect many young, healthy, and athletic people, and even some "mild" or at-risk people who never had to be hospitalized for symptoms. I calculate Sandman, the medical director of a long COVID clinic in Boston, Massachusetts, Dr. Jessica Hellmann, the environmental scientist who has been long-haulers for breakthrough infections, although she has known long-haulers for two common much cases, because they aren't being included. Myocarditis, abnormal, neurological, stiffness of lungs, and other long-term effects.

Long-haulers were the ones who described, debunked, and drew attention to their conditions. They've formed the "patient-led long Covid" nexus Facebook, the geographer Felicity Gabriel and the archaeologist Elisa Perego, were in a financial system. Were worth if that their experiences were being ignored. And even knowledge is being excluded from investigations into their own illness. The emerging science. *Thank for everything, everything, and the fear from loss.*

Gandalf is slowing down long COVID research and denying its loss. Both long-haulers and researchers who work with them have told me about flawed studies that gave an inaccurate picture of the conditions, or claims that are recommending potentially harmful treatments. Many researchers, they argue, are missing the full picture because they are approaching COVID complexity now and, ignoring sifting similarities to other complex illnesses, or to multiple complicated/interlinkers fatigue syndrome (ME/CFS).

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"The interest of the biomedical community is welcome—we wanted their attention!" says Melissa Mantero, a neuroscientist at Columbia College Cohort who's part of the Patient-Led Research Collaboration, a group of long-haulers who have been working with researchers to design and conduct studies. "But we want to, also, are concerning, concerning, concerning,

Others aren't connecting the dots, or doing the reading. "When talking to a lot of researchers, we don't get the impression that they have knowledge of this field," McCorkell told me. About 90% of PCS researchers, with little funding, have found evidence of both persistent infections and self-directed antibodies—two of the leading hypotheses for long COVID. They've studied diagnostic biomarkers, the role of reactivated viruses, and problems of the spine and connective tissues—topics that long-COVID researchers are now stumbling upon. "We're regenerating an evidence base that already exists," Body Politic's Angela Meriquez Vázquez told me.

Without knowing that base, some doctors are treating long-haulers in unhelpful and frustrating ways. A few months ago, Athena Akrami's husband, who is also a long-hauler, developed vertigo, dizziness, and other signs of POTS—a disorder of the autonomic nervous system that is common in long-haulers. POTS can be diagnosed by monitoring a patient's heart rate and blood pressure as they stand up, but because most doctors know to do that, Akrami's husband received a series of incorrect diagnoses—including earwax buildup. He was diagnosed correctly only after he saw a cardiologist who specializes in POTS. Akrami wants agencies like the CDC and the WHO to develop guidelines that tell doctors how to recognize and test for POTS, ME/CFS, and other conditions that many long-haulers develop.

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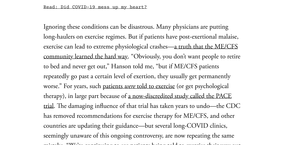

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Ignoring these conditions can be disastrous. Many physicians are putting long-haulers on exercise regimes. But if patients have post-exertional malaise, exercise can lead to extreme physiological crashes—a truth that the ME/CFS community learned the hard way. "Obviously you don't want people to retire to bed and never get out," Hanson told me, "but if ME/CFS patients repeatedly go past a certain level of exertion, they usually get permanently worse." For years, such patients were told to exercise (or get psychological therapy), in large part because of a now-discredited study called the PACE trial. The damaging influence of that trial has taken years to undo—the CDC has removed recommendations for exercise therapy for ME/CFS, and other countries are updating their guidance—but several long-COVID clinics, seemingly unaware of this ongoing controversy, are now repeating the same mistake. "We're continuing to see patients being told to exercise their way out of it," McCorkell told me.

A CONDITION AS COMPLEX and wide-ranging as long COVID is unlikely to be cured by any one medication. But some clinics are successfully helping long-haulers manage their more debilitating symptoms. "Almost every single person I've seen is getting better, including the most severe situations where it seemed hopeless," Lekshmi Santhosh of UCSF told me. The mere promise of help is itself helpful, as is the simple acknowledgment that their symptoms are real. "They want someone to try for them," Denyse Lutchmansingh said.

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But there aren't enough long-COVID clinics. Many have lengthy wait lists, or accept only patients with positive tests, or are connected to large universities and too distant from long-haulers in rural areas. And medical help of any kind is hard to secure when people can't work. In the Patient-Led Research Collaborative's first survey, conducted last fall, 45 percent of long-haulers were working reduced hours and 22 percent couldn't work at all. "People are losing their jobs because their employers aren't letting them take root breaks, or requiring in-person work," Vázquez told me. "If you have a fatiguing chronic illness, the commute alone is going to zap your day."

"A lot of us can't afford our medications or groceries, and quite a few of us are going homeless," Amanda Finley, the founder of the COVID-19 Long-Haulers discussion group on Facebook, told me. She lost her home last July and is now living with a fellow long-hauler. She and others have resorted to mutual aid, sending groceries or small sums of money to whoever needs it most. It is hard for her to see $1.2 billion go to biomedical research that might not pay off for years while so many long-haulers need social support yesterday.

Some long-COVID clinics have social workers embedded within them. In October, long-COVID will go in your code in the International Classification of Diseases—a global diagnostic system run by the WHO. In July, the Biden administration announced that American long-COVID patients are entitled to disability rights under the Americans With Disabilities Act. But despite these welcome changes, long COVID will still have a huge effect on the workforce. "I don't think anyone truly understands the magnitude of this," Lutchmansingh said. "The majority of my patients are between 40 and 60 years of age. They're in the prime of their work lives, and they're debilitated." And with every COVID-19 surge, their numbers grow.

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The Delta variant is so transmissible that it will be impossible to fully eradicate. Instead, the pandemic will end when the virus goes endemic—that is, when most everyone has some immunity, preferably through vaccination or, alternatively, through infection. The virus will still circulate, but the shield of immunity will blunt its sting for both individuals and societies. Although breakthrough cases will undoubtedly occur, they should be milder. But just ask a long-hauler what a "mild" infection can do.

To be clear, even in the Delta era, vaccination reduces the risk of infection, which should consequently reduce the risk of long COVID. "If no one was vaccinated, there'd be much more long COVID," Akiko Iwasaki, the immunologist, told me. But no one knows the odds of developing long COVID after a breakthrough infection. The only formal data come from an Israeli study that tested about 1,500 fully vaccinated health-care workers and found 39 breakthrough cases, of whom seven still had symptoms after six weeks. In the U.S., support groups have begun seeing small numbers of long-haulers who were fully vaccinated, as have a few long-COVID clinics. In those still-rare cases, the condition is playing out much as it did in the pre-vaccine era. "I've only seen three or four, but they look like long COVID," Purtiso told me. "We need to understand what the rate is."

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Some scientists have argued that the rate theoretically should be low: Mild infections in vaccinated and unvaccinated people aren't equivalent because in the former, the immune system should be stamping out the virus. But that might not make a difference if, for example, long COVID is an autoimmune disease. With so much uncertainty around the condition's nature and roots, confident predictions are unwarranted.

"My hope is that what we're seeing with long COVID is an immune system's overreaction to a novel virus," Purtiso told me. As immune systems become familiar with that virus, through vaccinations, boosters, or natural encounters, the likelihood of developing long COVID should hopefully fall, he added. But even in that scenario, long COVID will still exist, just as ME/CFS and other related illnesses still do. Long COVID has a special name, attention, and funding because a lot of people happened to get sick with the same brand-new pathogen in a matter of months. By contrast, people who develop related chronic illnesses rarely know what the infectious trigger was (or if there even was one). What proportion of ME/CFS is long flu, or long Epstein-Barr, or long cold? No one knows, because few people have cared to look or been funded to do so.

The risk is that long COVID becomes yet another neglected disease wherein some uncounted number of people become debilitatingly sick every year and fruitlessly hang for help on the door of an unconvinced medical establishment. But a better future is also possible, in which long-haulers—vocal, united, and numerous—finally galvanize research into the long-term consequences of viral infections; in which such research proceeds quickly as patient experts become partners; in which the world gets ways of preventing and treating long COVID, ME/CFS, and other marginalized conditions; and in which the ents' interminable meeting ends in action and victory.

Ed Yong is a staff writer at *The Atlantic*, where he covers science.

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