

Is long COVID ‘psychogenic’? Challenging claims that the disease is ‘all in the head’

In the early months of 2020 as Covid swept the world, I was a science writer with a mandate to tell the human stories of the pandemic.

I started reaching out to patients living through the aftermath of Covid, people who got sick and stayed sick. As leaders were telling the public that those infected with the virus would recover within a couple of weeks, I met dozens of survivors whose bodies gave a much different accounting of the facts. Each individual’s story seemed to echo the others, fitting a pattern and timeline apart from the mainstream narrative. Nationwide, millions were suddenly experiencing the same seemingly new disease, long Covid.

But for those following the science of chronic illness—and those who’d lived it themselves—the appearance of long Covid was as predictable as the rise of the morning sun. For several decades, scientists had been finding disruptions in the bodies of those with post-infectious conditions. The specific pathways are too numerous to comprehensively list here, but studies show they include weakened immune response due to low levels of virus-fighting [natural killer cells](#) and [heightened inflammation](#) driven by elevated levels of signaling chemicals called [cytokines](#). The list of abnormalities also includes the reactivation of viruses previously dormant in the body and the [dysregulation of cortisol](#), a hormone needed in order to properly respond to stress.

A host of infectious triggers, from [SARS](#) and [Epstein–Barr virus](#) to [Lyme disease](#) and [strep](#), can set off the same constellation of disabling symptoms, including brain fog, [unrelenting fatigue](#), and pain. Such infections can also make an [imprint](#) through [sleep disorders](#), [nerve damage](#), and air hunger, where you feel as if you can’t get enough air and struggle to breathe. In the worst cases, such patients experience [disability on par](#) with late-stage AIDS or [congestive heart failure](#). Despite continued reports, patients with this presentation are routinely dismissed. If only their symptoms could be traced to a physiological cause, a whole class of illnesses currently labeled “medically unexplained” or “contested” would be routinely understood by mainstream medicine. And despite the utter tragedy of long Covid, our newest pandemic illness offers the opportunity for just that.

But instead of accepting evidence emerging from university labs and teaching hospital clinics devoted to the study of long Covid, a new movement has evolved to lump together these endlessly sick patients with others who don’t get well—including individuals with fibromyalgia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and persistent symptoms of Lyme disease. Rather than accepting the reality of our latest agonizing illness, a string of news articles, backed by a contingent of scientists, has begun to call long Covid “psychogenic”—all in the head. We are at a pivotal moment. With the Centers for Disease Control and Prevention (CDC) estimating that nearly one in five people develops long-term symptoms after a Covid infection, it is time to rise up and stop the gaslighting—the rejection of the latest research and the experience of patients. We must stop this dismissal before long Covid joins ME/CFS and persistent Lyme as just one more contested disease.

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A number of recent magazine articles have bought into this dangerous perspective. They warrant an informed response that recalibrates the debate with human empathy, scientific accuracy, and historical scope. [One story](#), published in *The New Republic*, manages to miss much of the scientific literature, erroneously arguing that these conditions are not biological diseases but rather “functional neurological disorders,” or conversion disorders, in which a psychological condition is “converted” into bodily symptoms with no biological cause.

Similarly, a [recent article](#) in *New York* magazine titled “Has Long COVID Always Existed?” highlights a group of psychiatrists pushing an outdated, often harmful form of treatment called graded exercise therapy even as the [tide of science](#) turns against them. In this therapy, patients are instructed to engage in physical activity, such as walking, and gradually increase their exertions each day as they regain strength. A telltale marker for ME/CFS, however, shows up in a cardiopulmonary test in which patients are observed as they ride an exercise cycle on two successive days. It shows that patients’ performance [plummets](#) on the second day, a stark difference from the results for healthy control subjects or those with clinical depression. This phenomenon, called “post-exertional malaise,” occurs when the body fails to recover properly from even minor physical or cognitive exertions. It therefore follows that pushing or exercising your way through the illness is one of the surest ways to make it worse, not better. And, like those with ME/CFS, the majority of those with long Covid experience post-exertional malaise.

For doctors to continue advising exercise for these patients ignores not just patient experience but also the avalanche of true physical evidence now emerging from clinicians and research labs around the world. To see a small group of researchers drive national media with the claim that long Covid, too, is psychogenic, dismisses real illness for a larger group of patients than ever before.

The human penchant to blame the sufferer for the illness permeates history. In ancient times, disease and misery were often attributed to the wrath of an angry deity taking retribution for sins or crimes. As science developed, many diseases could be explained through germ theory or modern genetics and immunology. But even as doctors embraced modern science and rejected the wrath of God as a cause of illness, the idea that patients caused their own misery often stuck. Women, especially, were accused of imagining or inventing their ills. In the 19th century, the rest cure was a popular prescription for “nervous” women deemed unable to perform the duties assigned to their gender. It was the father of psychoanalysis, Sigmund Freud, who extended such notions to a diagnosis of “hysteria,” said to be caused by traumas, real or imagined, of the past. The idea took off: In 1949, physicians writing for *The Journal of Clinical Investigation* even suggested that the [pain of childbirth](#) could sometimes be psychogenic. The diagnosis of “all in your head” swept men up as well. The popular label “conversion disorder” held that patients whipped up disabilities from paralysis to seizures out of their troubled minds from whole cloth.

Even today, doctors puzzled by patients presenting with sudden, or idiopathic, pain or fatigue arising from seemingly nowhere often refer them to psychiatry instead of doing the deep testing required to get to the root cause. And when such patients defy laboratory diagnosis—coming up normal on routine blood tests despite disabling symptoms—there is pressure to lump those symptoms into the category of “medically

unexplained.” Whole areas of psychiatric research have laid claim to studying these patients and their supposed “false illness beliefs.” These patients, many influential psychiatrists have said, suffer psychological depression and physical deconditioning caused by lack of activity, or outright hypochondria or conversion disorder.

Such was the premise a dozen years ago when researchers in the United Kingdom enrolled 641 participants in a large, £5 million study (a little over \$6 million in today’s dollars) called the PACE trial, which seemingly showed that ME/CFS could be treated with exercise. The researchers’ findings, published in [The Lancet](#) in 2011, have influenced treatment recommendations by major academic bodies and national governments—until recent years, that is. Since publication of the PACE trial, ongoing research in the ME/CFS field has [systematically discredited](#) the study, and experts have exposed glaring inadequacies in how it was designed and executed.

For instance, midway through the study, researchers lowered the bar for their statistical definition of what it meant to “improve” or “recover,” making their results seem more significant than they really were. They relied on subjective participant ratings about whether they felt better or not. On objective outcomes, such as returning to work or getting off [government assistance](#), patients in the exercise cohort didn’t improve at all. Generally speaking, it was shoddy science.

Ultimately, the National Academy of Medicine, perhaps the most authoritative medical body in the United States, appointed an expert panel to examine the [nearly 9,000](#) peer-reviewed papers about ME/CFS. It issued a [seminal report in 2015](#) summarizing the state of knowledge in the field. The sum total of peer-reviewed literature up to that time clearly showed a cascade of damage in a multitude of anatomical systems: [nervous](#), [immune](#), [endocrine](#), and [vascular](#). Noting that trend in science, and patient experience, the panel proposed renaming ME/CFS “systemic exertion intolerance disease,” highlighting the cardinal feature of post-exertional malaise.

The CDC removed its recommendation of graded exercise therapy from its website. Later, so did the United Kingdom’s National Institute for Health and Care Excellence. The PACE trial and the psychogenic outlook were losing out to the biological model for what was likely a post-viral disease. The psychologists’ false beliefs about the illness were slipping away into the dustbin of history. In short, one could say that the true, physical nature of post-infectious ills was settled in 2015.

Then a pandemic hit.

The global experience of long Covid thrust the condition onto the front pages of newspapers and inaugurated what was in essence the largest-ever natural inquiry into post-infectious diseases. There were more patients than ever to study. The debate was no longer cloistered in patient forums or in academic review committees, and it was unfolding at scale in real time. Just as with evolution and genetics, long Covid shows how some of the most innovative science emerges from outside the scientific establishment.

The heart of the long Covid story is a story of citizen science, a 21st-century version of what Aristotle

would call *phronesis*, or practical wisdom. True expertise flourishes when theory meets practice, as it did when a group called the Patient-Led Research Collaborative (PLRC) launched a long-Covid study whose findings originally surfaced as an influential [preprint](#) in April 2021 before being published in [eClinicalMedicine](#), a journal run by *The Lancet*. The study, which Francis Collins, director of the National Institutes of Health at the time, [called](#) “the first-draft description of Long COVID syndrome,” validated the experiences of millions of long-haulers and influenced decisions in [national capitals](#) around the world. It is in the top [0.1 percent](#) of all scientific papers cited during the pandemic, according to Altmetric. In tracking the lived experiences of 3,762 Covid long-haulers through the first seven months of the pandemic, the study recorded some 203 symptoms across 10 organ systems. Notably, it showed that 89 percent of the patients experienced post-exertional malaise, reporting symptom relapses following exertions.

This important research, self-generated by patients themselves, set the bar for where the field could go next. As Susannah Fox, former chief technology officer at the Department of Health and Human Services, [wrote in her blog in early 2021](#), “We are watching patients, caregivers, clinicians, researchers, and policymakers move through the stages of peer-to-peer health innovation at a fast clip. Faster than I’ve ever seen in my 20 years of tracking this phenomenon.”

The PLRC has collaborated with universities and government agencies and is now doling out [millions of dollars](#) in grants to cutting-edge researchers. From [viral reactivations](#) to persistent brain inflammation to [immune abnormalities](#), [dozens of findings](#) on ME/CFS and its sister conditions are being repeated in long Covid.

And promising new paths are being forged. One of the most [provocative pilot studies](#) traces small “microclots” that distort the flow of blood throughout the body and could be one explanation for the multisystem symptoms. Harvard neuroscientist Mike VanElzakker told me that one reason why the scientific establishment hasn’t coalesced around an underlying biological mechanism is that it is either not looking the right way or not looking in the right place. He compares the situation to someone who’s dropped his keys in a dark alleyway but looks for them only [under a lamppost](#) “because that’s where the light is.”

The trick, as with any worthy scientific endeavor, is finding a way to see into the dark, pioneering new diagnostic tools and creating new ways to leverage collaboration between patients and scientists. Success does not come by reviving debunked concepts and invalidating patients as head cases, nor by creating yet another contested disease, but by getting to the bottom of what ails them so they can return to health.

We are living through a mass disabling event not unlike what occurred in the aftermath of polio or HIV. In the 1980s, AIDS patients shook up the health care system, demanding a place on government committees and scientific review panels. They set an example for a generation of civil rights activists. Covid long-haulers show a similar promise in transforming how we see patients’ involvement in the future of health care.

This is the moment to bring a whole group of patients, those long left out of mainstream medicine, into the fold.

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