TuSalud

Where Are the Treatments for Long COVID?

We don’t know why the virus can lead to persistent symptoms. We urgently need more research on therapies anyway.

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Shaney Wright, a safety and risk management professional who has been suffering from long COVID for three years, doesn’t hide his frustration about the fact that there are no proven therapies for his condition.

“Long COVID is a vile disease that affects every bodily system. It affects your ability to live, eat, sleep, and work,” he said. “Many people have been struggling for two to three years, with no end in sight. Finding treatments makes humanitarian and economic sense. The lack of urgency is profoundly unethical and irrational.”

Like many people with debilitating long-term symptoms, Wright, now 32, was young and healthy when he got COVID-19 in April 2020. Since then, he’s experienced issues ranging from a racing heart and low blood pressure to constant tinnitus, dizziness, and shortness of breath.

A growing body of evidence shows that SARS-CoV-2 can lead to more than 200 post-acute symptoms, leaving some patients so disabled they can barely leave their beds. The prevalence of long COVID remains unclear, with the World Health Organization definition encompassing anyone who has symptoms like fatigue or shortness of breath after three months. But even if the fraction of people with persistent illness is small, that still could add up to millions of Americans—more than the 1.2 million people living with HIV.

Scientists don’t know why some patients with COVID fail to get better, though a number of avenues are being explored. The clues they have suggest that patients would likely benefit from pharmaceutical therapies, but without a known mechanism or definitive diagnostics, government agencies and pharmaceutical companies seem reluctant to develop and test treatments. That leaves patients like Wright in a terrible lurch.

“We’ve been knocking on the doors of every company. They say, ‘Interesting idea—come back to us when you know how to measure long COVID,’ ” said Steven Deeks, a professor of medicine at the University of California, San Francisco, and one of the world’s leading HIV-cure researchers. “We desperately need tests to provide a way to diagnose and manage the syndrome.”

A major government effort to bridge the gap seems to have stalled out. In February 2021, the National Institutes of Health launched RECOVER, a $1.15 billion effort to better understand long COVID and test treatments. But two years later, with the funding mostly used up, the initiative has yet to enroll a single patient in treatment trials, according to a recent STAT and MuckRock investigation.

The delay, patient advocates charge, has wasted time, resources, and patient goodwill. Although advocates demanded—and have gotten—seats at the table, many feel RECOVER decision-makers aren't really listening. Some are especially incensed about a plan to rehash studies of exercise, which patients with myalgic encephalomyelitis/chronic fatigue syndrome, also known as ME/CFS—a related condition also thought to arise from viral infection—say can make their condition worse.

"For people who have been profoundly ill for years, it's devastating to learn that RECOVER hasn't launched any treatment trials yet. We have no time to lose by wasting money on debunked and even dangerous interventions," said JD Davids, a longtime AIDS activist and co-founder of Long COVID Justice. Long COVID can be disabling, he added, and according to the Centers for Disease Control and Prevention, it's already played a part in more than 3,000 deaths.

It's not yet clear what causes long COVID. Hypotheses include persistent SARS-CoV-2 infection, reactivation of existing latent viruses (such as Epstein-Barr virus), immune responses that never reset after acute infection, a leaky gut, and autoimmunity, according to Michael Peluso, an assistant professor at UCSF who runs one of the country's largest long COVID observational studies. These are not mutually exclusive, and each suggests a different line of attack.

The common thread tying these together is ongoing immune activation and inflammation, which can wreak havoc throughout the body. This can lead to abnormal blood clotting (which deprives tissues of oxygen), mitochondrial dysfunction, hormonal imbalances, and impaired neurological signaling. These, in turn, can trigger relentless fatigue, brain fog, postural orthostatic tachycardia syndrome, and other autonomic nervous system problems, and post-exertional malaise, or the inability to recover after physical or mental activity. Standard diagnostic tests may fail to find anything wrong, but more-sophisticated assays show changes in biomarkers that point to an immune system gone awry.

With the government effort lagging, citizen-scientists, academic researchers, small companies, nonprofits such as PolyBio, and patients themselves have stepped into the breach. Sharing their experiences on Facebook and Twitter, people with long COVID are using countless therapies on a trial-and-error basis. Among the most popular are low-dose naltrexone, anticoagulants, antivirals, beta blockers, statins, antihistamines to calm overactive mast cells, and probiotics to improve gut health. Several of these have reportedly helped people with ME/CFS, and some have shown promise in small studies.

"It's really about not reinventing the wheel," said Hannah Davis, a machine learning researcher who co-founded the Patient-Led Research Collaborative after developing long COVID in early 2020.

“These are Band-Aids—they’re not anywhere near cures—but when you’re living 1 percent of the life you used to, even a 5- or 10-percent improvement is such a meaningful difference.”

Therapies proposed by patients and researchers include everything from the abortion pill mifepristone and Viagra to repurposed HIV and hepatitis C drugs to psilocybin and natural blood thinners made from worms. But navigating these waters requires skepticism: For every patient who reports improvement, others say they saw no change or got worse. Long COVID symptoms can wax and wane, and without randomized controlled trials, it’s hard to know who would have improved without any intervention at all, by simply waiting. Many drugs and supplements are cheap and generally safe, but some patients are trying more costly and risky therapies, such as blood washing, setting themselves up for exploitation by grifters and profiteers.

“The truth is, patients and clinicians are mostly flying blind,” said Chris Maddison, an assistant professor of machine learning at the University of Toronto who has been living with long COVID since February 2022. “People are very desperate, and this makes us vulnerable to dangerous treatment fads. Patients are falling through the cracks and into the hands of unscrupulous providers.”

This is not the first time patients have struck out on their own. “I don’t blame anyone for reaching out in desperation to try things. I tried a bunch of stuff that didn’t work,” veteran AIDS activist Peter Staley said of his early days with HIV. Combining hands-on caregiving, street protest, and insider negotiations, AIDS activists set up buyers clubs for unapproved therapies, demanded research funding, and pressured the Food and Drug Administration to speed up the drug approval process.

At an April 25 hearing, the FDA heard testimony from dozens of patients who described how long COVID has changed their lives, how much they needed effective treatments, and the risks they’re willing to take to get them. Some think the agency should allow expedited access to experimental therapies, providing a much-needed layer of oversight and formal data collection. But existing FDA mechanisms have limitations. The emergency use authorization invoked for COVID vaccines applies only during a public health emergency.

Under expanded access (also known as compassionate use), the FDA allows people with life-threatening conditions who have no other options to try experimental therapies that have been deemed safe in Phase 1 trials. The Right to Try Act, passed in 2018, lets patients obtain experimental therapies from drug companies without the FDA’s permission. Accelerated approval is for therapies that have shown promise in midstage trials. For medications that are already approved, doctors may prescribe them off-label for other conditions.

The FDA process can be slow and tedious, but right now it’s not the main roadblock for long COVID treatments, according to Staley. “AIDS activists won concessions [from the FDA] very early on and quickly pivoted to the core problem, which was that we really didn’t have much in the pipeline that could save us,” he said. “When AIDS treatment activists offer advice today, it’s ‘Please, please don’t abandon the need for basic science and good clinical research.’ ”

This suggests that what's really needed at this stage is more studies about the mechanisms underlying long COVID so scientists can test therapies that address specific problems. But suffering patients don't have time to wait patiently for more basic research—and some experts think we already know enough to move forward more quickly. In fact, testing treatments now could help illuminate why long COVID occurs in the first place.

"I'm strongly of the opinion that we don't need to know the mechanisms in play to figure out what works, and if something works for a lot of patients, that might help us understand the mechanisms," Davis said. "You need a doctor who's on your team and who you feel like a partner with on this journey—not someone who thinks they know everything already."

Akiko Iwasaki, a professor of immunobiology at Yale University School of Medicine, agrees. "I'm a basic scientist. I'd like to figure out the disease before treating anything. But at this point, I don't think we have that kind of time or luxury. I think we have to start doing clinical trials and learning who benefits and how to improve these therapies," she said. "The best kind of trial will not just look for symptom improvement but also look for biomarkers of responsiveness. Once we identify those, we could then go out and look for people who might benefit."

For example, several studies have found persistent virus, or viral fragments, in the blood and organs of people with long COVID. If patients improve after trying antivirals such as Paxlovid, that could confirm the viral-reservoir hypothesis. Some people with long COVID report improvement after vaccination, and studying them could point the way to immunotherapies that mimic this effect. There are even lessons to be learned from the rare individuals who develop symptoms resembling those of long COVID after receiving COVID vaccines.

If there's any silver lining to COVID, it could be a better understanding of the long-term consequences of viral infections, immune dysfunction, and other chronic conditions. In the meantime, as they watch their lives pass them by, desperate long COVID patients are not waiting for business as usual and are willing to roll the dice with unproven therapies.

"You feel as though you have no other choice but to buy medications on the internet and try things. The gaslighting, minimization of the disease, and the lack of urgency changes your risk calculus," said Wright. "Many of the trials we see are enormously under-ambitious. Patients do not have decades. We don't even have five years. Without effective biomedical treatments, there is a high chance we will not get our lives back. We are literally pleading for help."

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