

United-States: The Long Covid Revolution

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Millions of American adults are impaired by long Covid. They have a vision for what our society owes to chronically ill and disabled people."

On a muggy late-summer day in September 2022, [dozens of disabled protesters](#) lay on the sidewalk outside the White House. The ground was hot, and sweat clung to their faces under their masks. Many would pay the price with their health in the weeks to come. But the protesters felt they had no choice. The night before, President Biden had announced that "[the pandemic is over](#)." The protesters knew that this wasn't true. Long Covid, they argued, is a national emergency.

#MillionsMissing demonstrations like this one began in 2016 to raise awareness about myalgic encephalomyelitis, an infection-associated complex chronic illness (often abbreviated as ME/CFS). The hashtag alludes to the millions of dollars missing from research into ME/CFS and the millions of patients who are so marginalized from society that they sometimes seem to have disappeared. In the past three years, there has been an explosion of ME/CFS cases. [According to #MEAction](#), the group that organizes #MillionsMissing, nearly half the current cases of long Covid meet the criteria for ME/CFS, and the majority of people with ME/CFS today are Covid-19 long-haulers.

Long Covid [symptoms](#), which commonly include persistent headaches, cognitive-functioning issues, fatigue, neuropathies, dizziness and fainting, significant sleep disturbances, gastrointestinal issues, and post-exertional symptom exacerbation (the worsening of symptoms after physical, mental, or emotional exertion), can affect every system of the body and, like those of ME/CFS, can range from mild to very severe. It's common for Covid-19 long-haulers to receive additional diagnoses for related chronic illnesses. Because scientists also believe [Covid may reactivate dormant viruses](#) such as Epstein-Barr, some people with long Covid have been diagnosed with Lyme disease, shingles, and herpes, among other viruses. Many Covid long-haulers share symptom clusters and illness experiences, but "long Covid" also serves as a political term: It is a way for Covid patients who never fully recovered to advocate for research, public education, and economic support, no matter where they fall on the severity spectrum.

Even before reports of long Covid emerged in the spring of 2020, people with ME/CFS had ample reason to predict a surge in chronic illness; many had been disabled by similar infections. Not all cases of long Covid are ME/CFS, but many cases fit the criteria after six months. Covid long-haulers, like people with ME/CFS, report an [impaired ability to work](#), which often results in substantial financial hardship. As of August 2022, it was estimated that as many as [16 million](#) working-age US adults were living with long Covid, and as many as [2.5 million](#) were living with ME/CFS. Two to four million Americans [may be out of work](#) as a result of long Covid, and people with long Covid and ME/CFS often [struggle to access](#) what are already often [insufficient disability benefits](#). Facing financial hardship as the result of a disability is not an unusual experience, and while the Biden administration recognized long Covid [as a disability in 2021](#) and has released [several reports](#) outlining recommendations for addressing the crisis, it has yet to provide new, direct economic support for Covid long-haulers or respond to [calls](#) to expand Supplemental Security Income and to update Social Security Disability Insurance. The expiration of the federal pandemic emergency in

May will also mean [the end of some enhanced social-safety-net benefits](#).

The #MillionsMissing protesters who put their bodies on the line last fall were hoping to halt the push to “move on” from the Covid pandemic. Their actions build on a long history of disabled and chronically ill people mobilizing on behalf of their communities—from the HIV/AIDS advocates who staged massive street marches campaigning [for better research in the 1980s](#) to the disability rights activists who crawled up the steps of the US Capitol in 1990 to demand [passage of the Americans With Disabilities Act](#) and the disabled activists who protested inside the Capitol in 2017 [to fight cuts to Medicaid](#). People with long Covid, ME/CFS, and related diseases are fighting for patient-centered approaches to research, strengthened social services and financial support, and a societal shift in how disabled and chronically ill people are treated. With millions more now in their ranks, the “missing” are fighting to be seen.

In December 2020, Congress allocated [\\$1.15 billion](#) in funding for National Institutes of Health research into long Covid. But advocates say progress has been slow and argue that it’s long past time the government allowed patients to have “[meaningful involvement](#)” in setting research agendas and designing studies—an idea largely inspired by HIV/AIDS activists, who physically occupied parts of the NIH campus [to demand that researchers expedite clinical trials for HIV drugs](#). Instead, advocates say, NIH researchers seem to be wasting time revisiting treatment approaches that have already been discredited rather than incorporating feedback from patient communities.

HIV/AIDS activists fought for and won an [Office of AIDS Research](#), coordinating information across the whole of the nation’s biomedical research establishment. Similarly, [Covid long-haulers are pushing for a new NIH institute](#) dedicated to studying diseases like long Covid, ME/CFS, and similar post-infectious illnesses—a [National Institute of Complex Chronic Conditions](#). Three years into the pandemic, the economic case for such an institute is clear. In October, the Center for Economic Policy Research released an analysis of the latest Census Bureau data about long Covid’s new epidemic of disability. The [study](#) found that of the more than 119 million Americans who had tested positive for Covid by late September 2022, about 15 percent reported symptoms lasting longer than three months, which is consistent with US government findings that estimate between 10 and 30 percent of Covid-19 survivors develop prolonged post-viral symptoms. In all, there are 9.9 million long-haulers who said their daily activities are slightly reduced and 4.4 million who reported “a lot” of day-to-day impairment. Because it’s common for long-haulers to experience temporarily or permanently worsened health after periods of exertion, pushing past symptoms in order to work can be dangerous. Some long-haulers are not able to work [at all](#). Those who can but lack the workplace accommodations necessary to perform their jobs safely are likely to get sicker.

And as long Covid destroys livelihoods and contributes to the [labor shortage](#), it also overwhelms the patchwork array of clinics set up around the country that provide multidisciplinary care for the complex constellation of symptoms that long-haulers face. These clinics are riddled with issues. There is [no uniform standard of care](#) (no specific license is required for a clinic to call itself a “long Covid” clinic), and the clinics that do exist can be [costly](#) and are hampered by [long waiting lists](#) and limited capacity. For providers, hour-long appointments are frequently needed to evaluate patients with a dozen distinct symptoms, but billing codes only accommodate 15-minute visits.

“Many centers—like my own—do not have those [necessary] resources and may even close or stop taking patients,” says Dr. Monica Verduzco-Gutierrez, the medical director of the Post Covid Recovery Clinic at the University of Texas Health Science Center at San Antonio. “To put it plainly, the need for these clinics far outstrips the resources available in many areas of the country.”

Some larger medical centers have the funds to cover the extensive costs of maintaining an adequate level of services, but many community health centers do not. To make matters worse, a lack of

clinical education on ME/CFS and related diseases means that the few providers who were well-versed in them before the pandemic are now [in short supply](#). Some are leaving ME/CFS patients for the growing ranks of Covid long-haulers, exacerbating tensions between two patient communities that have shared interests. Solving this problem will require centers of excellence that can treat long-haulers and those with related illnesses. It also requires that medical schools [update their curriculums](#) to help develop a new generation of providers who are better educated on post-infectious illnesses.

In order for long-haulers to get the multidisciplinary health care they need, the federal government must act urgently, says Dr. Steven Flanagan, the president of the American Academy of Physical Medicine and Rehabilitation. During the pandemic, the AAPM&R has helped 41 long Covid clinics around the country publish consensus [guidance statements](#) for health care providers. It has also championed several bills in Congress, including the [TREAT Long Covid Act](#), proposed by Representative Ayanna Pressley, which would provide up to \$2 million in grants for community health clinics dedicated to long Covid.

Flanagan notes that the Biden administration has made progress recently by publishing its national action plan on long Covid, but, he says, “there’s more work to be done.” Last fall, as part of the administration’s initiative, the Department of Health and Human Services sent Congress a [\\$750 million budget request](#) for the long Covid agenda that included research, treatment, and support for community-based organizations providing case management for patients. But despite lobbying by Senator Tim Kaine, himself a long-hauler, Congress allocated just [\\$10 million](#) for it when it passed its end-of-year omnibus bill in December.

Another important measure would be a national fund to process claims from the millions disabled by long Covid and provide compensation based on standardized diagnostic criteria. Such a program might take inspiration from the [September 11 Victim Compensation Fund](#), established in 2001. Like those made ill by 9/11, many Covid long-haulers feel that the government is responsible for their acquired disability because of its failures to adequately mitigate Covid infections, provide safe workplaces, or publicly warn of the harms of long Covid after the disease was identified in the spring of 2020.

“The consequences of such an exposure...should not be the burden of the individual who did not give their consent to be exposed,” says Netia McCray, the director of education for the Covid-19 Longhauler Advocacy Project. “If Covid exposure and subsequently long Covid is a necessary risk, for the sake of society, it should be compensated. That’s the cost of doing business.” Howard Bauchner, a former editor in chief of the *Journal of the American Medical Association*, suggested in an article in [Health Affairs](#) that a long Covid compensation program could be funded by pharmaceutical companies or a tax on vaccines.

Dangerous burnout: A common effect of long Covid is post-exertional symptom exacerbation, the worsening of symptoms after physical, mental, or emotional exertion. (Martin Pope / SOPA Images / LightRocket via Getty Images)

In the absence of robust federal funding to secure care, the advice of grassroots activists and online peer-support groups has often been the most effective prescription for patients in need. When Dr. Raven Baxter began to develop long Covid, her doctors didn’t have answers. So Baxter turned to a robust online community of long Covid patients for advice. When she tweeted about feeling worse after physical activity, patients explained post-exertional symptom exacerbation. When Baxter’s heart rate spiked upon standing, patients with orthostatic intolerance recommended increased sodium. When Baxter’s mobility decreased, patients and wheelchair users offered tips on the best mobility aids and how to access them. “I felt so grateful to have that type of support,” Baxter says.

When the first wave of Covid long-haulers got sick in the winter and spring of 2020, there was little public information available about the disease, and patients were forced to rely on one another for guidance and support. Today the information landscape looks different. People who have developed long Covid in the past two years face an intimidating slew of online information and misinformation on the disease, some of which is put out by the anti-vax movement, people who desire to move on from the pandemic, or businesses [attempting to profit off of patients](#). Some articles on long Covid argue that its symptoms and prevalence have been [exaggerated](#), or that the disease may have no connection to Covid-19 and is instead driven by “[psychosocial distress](#),” patient-support groups, or [media coverage of the disease](#).

This sort of skepticism is not new. People with ME/CFS have fought, arguably for centuries, to [be accurately diagnosed](#) and treated by providers who were eager to assign symptoms to psychological causes. The [disproportionate impact](#) of these diseases on people assigned female at birth and the fact that these disabilities are sometimes “[invisible](#)” have likely played a part in these hasty diagnoses. The results have been harmful for patients. Interventions designed for mental illness—such as exercise and [cognitive behavioral therapy](#)—are often detrimental for people with energy-limiting illnesses that cannot be cured by modifying behavior. Skeptics eager to frame long Covid as psychosomatic also often disingenuously omit [the evidence of biomedical abnormalities found in long-haulers](#), or the fact that many patients have already tried ill-advised interventions such as graded-exercise therapy in desperate attempts to find a cure.

The lack of investment in ME/CFS research and awareness has directly contributed to the proliferation of articles in the media casting doubt on long Covid’s origins and to research trials that attempt to reinvent the wheel. It has also meant that providers and policy-makers are ill-prepared to support long Covid patients. Public health messaging still fails to adequately identify long Covid as a primary pandemic harm. According to a May 2022 [study](#), state health departments posted 49,310 times on Facebook about Covid between July 2020 and February 2022, but only 137 of those posts mentioned long Covid.

The emergence of grassroots support groups and advocacy networks has been a lifeline for long-haulers who are struggling, but three years into the pandemic, community leaders are burning out. “We have done this work in the absence of the kind of philanthropic or government support that a mass disabling event such as this should warrant,” says Angela Meriquez Vázquez, a disabled long Covid patient advocate and children’s activist who runs the [Body Politic Covid-19 Support Group](#). JD Davids, a longtime AIDS and chronic illness activist who is a co-founder of [Long COVID Justice](#), recounts attending a New York City Council hearing on long Covid at which Ted Long, the executive director of the NYC Test & Treat Corps, mentioned the Body Politic support group as a primary resource but failed to explain that “the city doesn’t give a penny to Body Politic, which basically has no funding.”

Long Covid advocates are not the first people who have filled gaps in information through community efforts, and they’re not the first advocates who have struggled to maintain this work in the absence of significant support from the government. From the mid-1980s through the early 2000s, HIV/AIDS groups emerged to disseminate crucial information about prevention, care, and eventually access to testing and treatment. But after antiretroviral therapies became available in the United States in the mid-1990s, funding and media attention [were redirected](#) toward fighting the disease abroad, while HIV rates continued to climb in Black communities here.

As a result, some smaller community organizations were forced to shut down, which left many patients without access to information and treatment. According to Kenyon Farrow, the former managing director of advocacy and organizing at PrEP4All, far too many people still aren’t aware of current HIV treatment and prevention options. “Information is not received by everyone equally,” he

explains. “You do need messengers in communities...to reaffirm or translate that information in ways that specific communities understand.”

Long Covid advocates face similar issues. Vázquez is “incredibly concerned” about low-income people of color who have not received proper information about the symptoms of long Covid or how to manage them and may risk undermining their health further with ill-advised exertion.

Vázquez and Davids say the government must do more to provide existing groups of community health workers (CHWs) with resources and information on long Covid. Most CHWs are funded by Medicaid and serve as nonclinical liaisons between medical and social services and their local communities, with whom they share identities and experiences. “There will not be adequate care [until] we have an integrated, strategic, and well-funded system bridging research and care from the neighborhood level—where people you know and trust speak your language to accompany you through the systems of care you may need,” Davids says.

The time is ripe for this, says Vázquez, who points out that the Department of Health and Human Services recently [invested millions of dollars](#) in strengthening the CHW workforce. “We need to significantly increase investments and [build the] capacity of community health workers to disseminate information and facilitate access to health care for these marginalized groups,” Vázquez says. She adds that any future legislation on long Covid must “actively incorporate state Medicaid agencies” to advise them on releasing state guidance on long Covid and provide incentives for states to invest in local public health campaigns.

Taking inspiration: In 1990, disability activists staged direct actions in Washington, D.C., to demand the passage of the Americans with Disabilities Act. (Jeff Markowitz / AP Photo)

It’s been clear ever since the first cases of long Covid were documented that the disease would take an economic toll. It’s expensive to be sick, and disabled people in the US are twice as likely to live in poverty as nondisabled people. A recent [CDC study](#) found that four out of five people with long Covid report trouble performing day-to-day activities.

While a compensation fund could provide long-haulers with immediate support, it’s unclear how eligibility for such a fund would be determined and who might get left out. The diagnostic criteria for long Covid are still developing, and some patients have already been shut out of care and benefits because they lacked [medical documentation](#). Some advocates have pushed for a [guaranteed income](#) to support chronically ill and disabled people regardless of their diagnoses. The debate raises a question that long Covid advocates have grappled with from the start of the pandemic: Can the long Covid crisis be a turning point in the fight for better safety nets for all disabled and chronically ill people?

Most of the legislation that’s been proposed so far has failed to address the systemic causes of poverty among disabled populations, focusing instead on research, education, and clinical care that is specific to long Covid. Lisa McCorkell, a founding member of the Patient-Led Research Collaborative, says these bills are important in order to sustain current clinics and make sure that people with long Covid are aware of the benefits and services that do exist. But, she adds, “the point of these bills is not to improve overall disability policy.” They don’t shorten application-processing times for Social Security disability benefits, nor do they recommend updates on [asset limits](#) or increases in benefits. “We need big policy solutions that will address larger systemic issues,” she says, “and we need those solutions to be created with a disability-justice lens in order to...ameliorate the cycle of poverty that is disabled poverty.”

Ultimately, the long Covid advocacy movement’s ability to address these systemic issues will

determine its success. Sixty-one million US adults—about one in four eligible voters—have a disability, and disabled people represent a historically overlooked voting bloc. More than 30 years after the passage of the Americans With Disabilities Act, disabled Americans still face food insecurity at three times the rate of nondisabled people, and they make up roughly half of those who turn to homeless shelters every night. The 2020 election cycle was a breakthrough, with nearly every major Democratic candidate releasing a full disability policy platform. Still, though, just [three in 10 disabled](#) voters believe that leaders in Washington care about people with disabilities, according to a recent poll by the Century Foundation and Data for Progress. “The economic crisis facing the US disability community long predates Covid-19,” says Rebecca Vallas, a senior fellow at the Century Foundation and codirector of the Disability Economic Justice Collaborative. But “one takeaway at this moment in our nation’s history must be that we can no longer afford to ignore disabled people in our policy-making.”

Fiona Lowenstein is an independent journalist, the founder of Body Politic, and the editor of *The Long Covid Survival Guide*.

Ryan Prior is a journalist-in-residence at the Century Foundation and the author of *The Long Haul*.

P.S.

- The Nation. APRIL 11, 2023:
<https://www.thenation.com/article/society/long-covid-disability-policy/>
- *Fiona Lowenstein’s article in The Nation:*
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