

United States: Denial Isn't an Effective Health Care Strategy, Say People With Long COVID

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Gaslighting and disbelief make long COVID worse for people living with long-term effects from the virus.

This article, written for Truthout by Eleanor J. Bader, addresses the issue of long-term COVID in the U.S., but, as she writes, denial has never been an effective healthcare strategy as this issue becomes a major, if hidden, health problem in many countries.

Before Missouri resident Amanda K. Finley had heard of COVID-19 or long COVID, she worked as an archeologist. Although her work schedule was erratic, she was frequently hired by engineering firms to make sure that the development sites they intended to build on conserved the cultural integrity of the land. She did this for 14 years.

Then, in March 2020, 10 months before the COVID vaccine became available, she got the virus for the first time. She has since had it two more times and says that ongoing aftereffects have upended her life.

"Archeology is hard physical work," Finley told *Truthout*. "And since the work was inconsistent, I also did food deliveries to make ends meet." Both occupations are now impossible for her.

"I did not have health insurance the first two times I had COVID," she says. "I finally got coverage after Missouri expanded Medicaid eligibility in late 2021," following a ballot measure that authorized the expansion.

Having health insurance has enabled her to go to a nearby long COVID clinic for her persistent symptoms: breathing difficulties, exhaustion and a spiking heart rate. There are currently approximately [400 such centers](#) located throughout the U.S.

"I used to hop around digging holes and today I can't even climb a flight of stairs," the 46-year-old reports. "I've applied for Social Security Disability Insurance but have been turned down twice."

Finley is now an active member of Body Politic, an all-volunteer mutual aid network of "long-haulers" who provide one another with emotional support as well as information about new research and available resources. Finley calls the network a lifeline and says that it provides solace to those living with a disease that is both misunderstood and, in some cases, denied.

This, she says, is particularly worrisome because the federal government has declared that the

COVID public health crisis is behind us. For her and other long-haulers, as well as folks who have disabling conditions or chronic health problems, the crisis is not only not over, but it seems to be impacting an ever-increasing array of people.

That said, it is impossible to know the exact number of domestic long COVID cases. Nonetheless, what we do know is this: Between March 2020 and early May 2023, [103,434, 569 U.S. residents contracted the virus. More than 1.1 million have died](#), including 1,109 during the week of May 3. As for long COVID, *The Journal of the American Medical Association (JAMA)* estimates that [15 percent of those who test positive will report long COVID symptoms](#). For some, this will mean minor discomfort that lasts about a month and then disappears. For others, however, ongoing symptoms will not only persist, but will be debilitating. The question is why, and *JAMA* concedes that no one knows why some people improve and others do not.

For its part, the Centers for Disease Control and Prevention (CDC) acknowledges that, “Long COVID is a wide range of new, returning or ongoing health problems that people experience after first being infected with the virus that causes COVID-19.” What’s more, it notes that 29 percent of those with long COVID self-report symptoms that have lasted a year or more. In addition, CDC researchers [estimate](#) that one in five adults between the ages of age 18 and 65, and one in four adults over the age of 65, will develop lasting health problems; nearly half, 44 percent, will be unable to work because of them.

Other federal agencies have also chimed in. “We know that Long COVID is real,” the Department of Health and Human Services (HHS) website tells visitors, “with [multi-symptoms that persist and present four weeks or more](#)” after the initial infection.

Moreover, HHS makes clear that “the end of the COVID-19 public health emergency will not signal the end of the effects of the pandemic. These lingering effects may impact the health of the nation for years to come.”

In fact, federal monitors have delineated more than 200 symptoms that result from COVID. Among the most common are fatigue, breathing difficulties, cardiovascular abnormalities, migraines, memory loss, brain fog, balance impairments and depression.

For 43-year-old Scott Rossi, a former fraud analyst, his COVID case was so severe that he went into a coma and subsequently had a stroke. “Since then,” he told *Truthout*. “I’ve had about a four-minute attention span. I still need to go to speech and vision therapy twice a week and spend between four and six hours a day doing therapeutic exercises. One hand is still paralyzed. I lost everything: my home, my job, my car and my independence.”

“I used to hop around digging holes and today I can’t even climb a flight of stairs,” the 46-year-old reports.

Rossi now lives with his parents in Mount Pocono, Pennsylvania. “It’s beautiful,” he says, “but it’s in a red part of the state so it’s been hard to meet people as a progressive gay man. Our politics do not align.”

Not surprisingly, others experience long COVID differently.

Bilal Qizilbash told *Truthout* that he contracted COVID in a Jackson, Mississippi, hospital following

surgery to remove benign stomach tumors. “It was 2020. I was 33 and was basically young and healthy,” he said. “After I got COVID, breathing felt like inhaling fire. They gave me three experimental treatments, including Remdesivir infusions; it was like being injected with glass shards. The pain was excruciating, but I am now somewhat improved. The fluid in my lungs is gone but I still get phantom smells, like burning rubber or cigarette smoke, that are a warning sign that I will soon be in terrible pain. The pain is like being stung by wasps. It lasts for hours and occurs all over my body, my ears, my skull, my back... If I had a regular job, I would have been fired long ago.”

Instead, Qizilbash runs his small company — EasyKale, which sells powdered kale that can be sprinkled on food — from his bed. “Most days I feel like I’m being torn apart,” he said. “I work curled up in the fetal position.”

But as bad as the physical manifestations have been, Qizilbash says that being treated with contempt by doctors and medical workers has been worse. “Being gaslit and having my pain ignored has been awful,” he said. “One Caucasian doctor looked at my brown skin and treated me like I was a drug abuser even though I had not asked for pain meds.”

Similarly, New York resident Kathryn Destin feared that medical racism would negatively impact her care when she was diagnosed with COVID in March 2021. Later, when the symptoms recurred, she worried that doctors would not take her seriously when she described her pain. “As a Black woman, I feared that no one would believe me when I said I was sick,” she told *Truthout*. “I was fearful that when I said I couldn’t take a full breath, they’d think I was making it up.” Although Destin was eventually given medication after nine hours in the ER, she resents having to contend with medical neglect and racial profiling on top of illness.

She is also appalled by the decision to declare the health emergency over. “The government should be doing more to acknowledge that COVID is still here, that it can have damaging long-term effects. We should do a 180-degree turn — not another lockdown, but the resumption of limited indoor seating capacity, resumption of masking when indoors, and resumption of government payment for testing and treatment. Vaccine effectiveness should be stressed and new vaccines developed. It makes no sense to ‘go back to normal.’ Nothing is normal. Everyone is scarred by COVID.”

Like Destin, Finley, Qizilbash and Rossi, writer-educator Jesse Hagopian, author of [Black Lives Matter at School](#) and a longtime anti-racist activist and teacher, has had his life turned upside down by long COVID. Diagnosed in August 2022, he is constantly dizzy.

“My bed is now my desk,” he told *Truthout*. He is currently completing another book — *Teach Truth: The Attack on CRT and the Struggle for Antiracist Education* — due out in 2024 from [Haymarket Books](#).

“When I’m writing, I’m in bed. I also facilitate online trainings and study groups with the [Zinn Education Project](#),” he said. “As soon as I’m finished, I lie down. Movement intensifies the dizziness.”

Things he used to do, including ferrying his two kids to activities, are now impossible since he can no longer drive. He also used to play music with Daniel Rapport and released an album, [The Blue Tide: Plague Blues](#), in 2022 but a scheduled release tour had to be canceled because of his illness.

“I no longer think about when long COVID will end for me,” Hagopian said. “At first, doctors told me that symptoms are usually gone in a month. Then, after a month, they said they’re unlikely to last more than three months. At six months, they said some people’s symptoms last longer. It’s shocking that Biden has said the pandemic is over. It’s certainly not over for me.”

Countless people share Hagopian's sentiment. Some have parosmia — a distorted sense of smell or the kind of phantom odors Qizilbash described — that are common in people with long COVID. Others have anosmia, the complete loss of smell and taste.

Line cooks, chefs and food/wine critics have been particularly impacted. The disorder is theorized to occur because the nose is a major infection site for COVID-19. A staffer for the Long COVID Alliance tells [Epicurious](#) that the virus is thought to bind to "cells that house hairs in the noses' mucous membrane." When these cells are damaged, people lose their sense of smell, which impacts the ability to taste; this can force cooks from their jobs even if they are otherwise healthy. Three Facebook groups (two closed, one public) exist for people with anosmia and parosmia; together, they have more than 25,000 members.

In addition to personal support groups, people are pushing back in numerous other ways. [The People's CDC](#), for example, is a coalition of public health professionals, scientists, health care workers, educators, activists and concerned community members who are working to promote strategies to mitigate the harm caused by the pandemic. Members say that equipping people with information, even as it evolves, is the best way to counter the government's downplaying of the threat.

"Saying that the pandemic is over is a public health failure," a People's CDC spokesperson told *Truthout*. "We should be telling people about the risks of long COVID, showing them how to be careful, arming them with knowledge about the risks, and teaching them prevention strategies."

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Health care workers are also pushing for this. [Tara Rynders](#), a Colorado-based RN and an interdisciplinary dance and video artist who runs workshops for medical workers, stresses that there is an urgent need "to take care of people who take care of others."

But instead of doing this, she reports that negative judgments from health care administrators and professionals have become pervasive. "We treat people as if they're using COVID as an excuse. This is devastating for medical workers and patients alike. People who aren't believed about long COVID second-guess themselves," Rynders said. "It's a disservice to say that the crisis is over. Perhaps if nurses and health professionals were at the table when decisions about health care delivery were being made, we could have stopped this from happening. I think the fallout from COVID is just beginning. People are still getting sick, still dying, and we are not prepared."

At the same time, there are protocols for promoting and protecting public health.

Tehea Robie, a hospital-trained acupuncturist and doctor of Chinese herbal medicine, told *Truthout* that while symptoms of long COVID "are all over the map," there's been a messaging failure. "From the very beginning of the pandemic, politicians could have stressed that each person's health and well-being is tied to their neighbor's health and well-being. It's about all of us, in community, together. Then, the fact that the U.S. is a gatekeeper of Western medicine meant that federal health agencies presented non-Western ideas about care and treatment like they were snake oil."

Antipathy toward China has played an obvious deleterious role, Robie says. SARS, Severe Acute Respiratory Syndrome, shares approximately 70 percent of its genetic makeup with COVID. "China

had experience with SARS and could have helped the U.S. jumpstart integrative health care,” she said. “During the first weeks of COVID, some hospitals in China developed ways to merge traditional herbal and antiviral treatments. They were doing research and developing formulas for some of the most common problems, including the production of phlegm so that it would not go deep and cause fibrosis. But we didn’t coordinate.”

This, of course, has left patients with long COVID in the lurch, especially if they are attempting to work despite their impairments. And, while employers are bound by the [Americans with Disabilities Act](#), the fact that there is no test to detect long COVID has given them wiggle room. Workers, however, can [demand](#) accommodations such as ergonomic workstations, flexible or remote hours, less physically demanding tasks, additional breaks, time to attend medical appointments or to use a nebulizer or inhaler, and utilizing a service animal.

But, sadly, accommodations do nothing to address the fact that [41 states still do not provide paid family and medical leave](#) to workers needing to care for themselves or someone in their family and [37 still do not require employers to provide paid sick time](#).

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Lastly, according to the [National Employment Law Project](#) (NELP), the federal agency charged with ensuring that workers are protected from serious workplace hazards, the [Occupational Safety and Health Administration \(OSHA\)](#) has been deficient in its role. “The agency,” a [NELP memo](#) explains, “has failed to issue any COVID-19 related safety provisions that employers must implement. Further, though over 8000 workers have filed complaints with OSHA asking for an inspection of their workplace due to COVID-19, OSHA has done only a handful of on-site inspections.”

People with long COVID are paying the price for this inaction. They also know what is needed. “People, whether they have long COVID or not, need a basic income and health coverage that extends to gig workers as well as those with 9-5 jobs,” Finley said. “We need to change the system so people can take time off when they’re sick and not worry that it will cause them to lose their homes. That’s essential.”

How care is delivered also has to change.

“People working in health care are not factory workers on an assembly line,” Robie concludes. “Budgets should not be determined by the needs of capitalism, but by the needs of individuals needing care. This was true before COVID, but the pandemic made this even clearer. People in the U.S. tend to think that if they do not have the answer to a problem — in this case, how to treat and avoid long COVID — it’s okay to brush it aside. But denial has never been an effective health care strategy.”

Eleanor J. Bader, TRUTHOUT

P.S.

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Note: This article has been updated to clarify that Amanda Finley is now working with Body Politic rather than Survivor Corps.

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- Eleanor J. Bader is an award-winning journalist who writes about domestic social issues, movements for social change, books and art. In addition to Truthout, she writes for The Progressive, Lilith Magazine and blog, the LA Review of Books, Fiction Writers Review and other online and print publications.

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