

“Digital activism has played an unprecedented role in bringing Long COVID out of the shadows.”

# Long COVID and the Rise of Digital Patient Activism

EMILY MENDENHALL

In May 2020, Italian archaeologist Elisa Perego, living with disabling symptoms in the wake of an acute SARS-CoV-2 infection, first tweeted the hashtag #LongCovid on Twitter (now X). She was residing in the region of Lombardy in northern Italy, an early epicenter of the pandemic, where many people suffered not only from the acute virus but also from a constellation of lingering symptoms. Describing her personal journey with the condition as cyclical, progressive, and multiphasic, Perego attracted thousands of retweets.

At that time, there was limited visibility or understanding in the media, medicine, and society of the idea that this could be a chronic post-viral condition. Even though people were beginning to recognize these symptoms around the globe, there was still no name or collective recognition of the condition's existence. But Perego's "Long COVID" coinage immediately passed into everyday use in support groups, advocacy organizations, and medical discussions.

It was the first time a patient activist had taken control of naming a new health condition through wide-reaching and effective digital activism. This type of activism became a defining feature of the Long COVID experience, providing online portals where members of an emerging movement could organize and share information. Building on the history of previous health movements and drawing on the knowledge of longtime patient activists, the Long COVID movement has cultivated a community and forged a unique solidarity that has

fundamentally shifted how this health condition is perceived among patients and the public alike. Even so, challenges remain with gaining understanding and recognition of the condition, effective treatment, and insurance coverage of non-medical treatments that do work.

## PRECEDENTS FOR A PATIENT MOVEMENT

One formative precedent for the Long COVID movement was the activism of HIV/AIDS patients. In the summer of 1982, television news anchor Tom Brokaw reported that a new study from the US Centers for Disease Control (CDC) found that the "lifestyle" of "some male homosexuals" had "triggered an epidemic of a rare form of cancer." This was less than a year after the CDC had published a report on the first recorded deaths from this mysterious disease. By linking HIV to homosexuality, the news media made this inaccurate and biased association a defining characteristic of that first decade: many people called it a "gay disease" and referred to a "promiscuity paradigm."

By 1983, scientists were already pushing back by identifying a virus and associating it with "immune overload" in medical journals, though this framework was far from the spotlight. Although homophobic stereotyping continued to shape perceptions of the epidemic, it also incentivized activism among gay patients, providers, and scientists. In his 1996 book *Impure Science: AIDS, Activism, and the Politics of Knowledge*, Steven Epstein argued that one factor in the essentializing of gay men as the primary victims of HIV was the advocacy of affluent and relatively privileged gay activists, who were able to make their case in the private offices of physicians, in teaching hospitals, and on the front pages of medical journals. According to Epstein, this type of patient activism was further fostered by the critical writing of gay

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EMILY MENDENHALL is a medical anthropologist and a professor at the Edmund A. Walsh School of Foreign Service at Georgetown University. Her latest book is *Unmasked: COVID, Community, and the Case of Okoboji* (Vanderbilt University Press, 2022).

reporters about the medical and public health community's tendency to blame the AIDS epidemic on promiscuity. Gay physicians were more likely to be sympathetic to the medical community, but were also increasingly vocal about the condition. Their characterization of the emerging virus served to raise the alarm and promote political action around HIV and AIDS among gay men.

In 1987, activists founded the AIDS Coalition to Unleash Power (ACT UP), an international organization committed to demanding a more effective response to HIV and AIDS. Through ACT UP, activists cultivated an "alternative basis of expertise," which allowed them to speak truth to power in both medicine and politics. This embodied health movement involved patients actively mobilizing to demand recognition for HIV and other contested conditions that were unexplained by existing medical knowledge or had environmental explanations that were disputed by medical experts. To push back, AIDS activists challenged government authorities, engaged in deep dialogues with clinicians and medical establishments, grappled for power and relevance, and raised funds for research. In doing so, ACT UP set a precedent for illness activism, becoming a powerhouse for transforming policy and raising public awareness about the epidemic.

HIV/AIDS activists organized demonstrations throughout the 1980s, when infection and death were unpredictable and both diagnosis and treatment were in flux. Activists protested in the streets, clinics, and courts with visible lesions on their bodies, withdrawing only when they became too weak and sick to continue.

Though the HIV story is well known, many people with less widely recognized health conditions have also developed innovative methods of activism. Given the nature of their diseases, those with conditions like myalgic encephalomyelitis (ME/CFS), formerly known as chronic fatigue syndrome, could not be as public in their protests.

ME/CFS rose to public awareness in the 1980s, around the same time as HIV/AIDS, affecting mostly women. Sufferers became so sick that they could not engage in street protests, let alone resume a public life. People living with ME/CFS would disappear into their private worlds at home to tend to an illness that is often described as "invisible." The dysregulation of the body takes down multiple internal systems at once, causing disabling fatigue,

dysautonomia, chronic pain, muscle aches, dizziness, headaches, memory inconsistency, and many more simultaneous symptoms. Most people do not die from ME/CFS, but suffer indefinitely, with an estimated one in four cases bedbound for decades.

For years, ME/CFS was considered a contested health condition because there was no biological test to verify it, despite a cluster of common and recognizable symptoms. Some people characterized it as a "wastebasket diagnosis." This made ME/CFS what anthropologist Joseph Dumit has called an illness that "you have to fight to get."

Dumit describes such conditions as having five definitive features. First, they are chronic conditions that do not fit neatly into a distinct disease model. Second, it is not clear what causes them or whether the disease progression is psychological or biological in nature (revealing the fallacy of Cartesian dualism in thinking about these conditions). Third, people may benefit from a variety of therapies, and medical therapies alone are generally not sufficient to assist in healing. Fourth, there are fuzzy boundaries among diagnoses related to these conditions, in part because patients collect overlapping and cross-linked diagnoses. Fifth, such conditions may become legally explosive as people often struggle to access disability status.

A possible sixth factor in contestation over these conditions, argues anthropologist Abigail Dumes in her 2020 book *Divided Bodies: Lyme Disease, Contested Illness, and Evidence-Based Medicine*, is that people within medicine and society fervently disagree about disease etiology, progression, and treatment.

Even so, many people living with ME/CFS and Long COVID steer away from using the terms "contested illness" or "medically unexplained symptoms" because they find them misplaced and harmful, delegitimizing the severity of their symptoms. Many people with ME/CFS present symptoms very similar to some of the worst cases of Long COVID. Although not everyone becomes bedbound or homebound due to these symptoms, many lose their social lives: they are too sick to keep up connections or fearful that they might contract an additional virus in a social setting. Moreover, the lack of funding to find tests or treatments for "contested" conditions has long caused neglect and dismissiveness in science and medicine.

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Other embodied health movements, such as breast cancer activism, have had more success, in part because they had the advantage of better evidence for diagnostics for research and treatment. These movements learned strategies from AIDS activists by using their “alternative basis of expertise” to demand attention, influence legislation, and raise funds. They were also immensely more visible than ME/CFS activists, since they had learned from AIDS activists how to get through to government.

This was exemplified by US breast cancer advocacy groups coming together in 1991 to form the National Breast Cancer Coalition. They elevated knowledge and urgency around the condition by attracting media attention, money for research, and support from politicians. They were so successful that they were able to persuade Congress to increase funding for breast cancer research by nearly 50 percent (around \$43 million) in the mid-1990s. This amount is extraordinary compared with the negligible funding devoted to ME/CFS.

## THE DISABILITY TRANSFORMATION

There are strong alignments between health activism and disability activism. For decades, the disability rights movement was largely focused on access for people with physical disabilities. Its history was tethered to the League of the Physically Handicapped, organized during the Great Depression. Civil rights advances in the United States, such as the 1954 Supreme Court ruling in *Brown v. Board of Education* that ended school segregation, cleared a path toward recognizing the rights of people with disabilities in legislation such as the 1973 Rehabilitation Act. Activism focused primarily on physical mobility led to the Americans with Disabilities Act (ADA) of 1990.

This activism was transformed by the disability justice movement, whose leaders were largely Black, Brown, and queer. They offered a critique of the disability movement’s centering of mobility and whiteness, often excluding minorities. At the turn of the century, AIDS activism began to align with disability activism through the emergence of the disability justice movement.

The new movement transformed disability activism through an intersectional framework focused on disability, human rights, and racial justice. This led to several amendments to the original ADA, broadening the scope of how disability is defined and who is protected under the law. The disability justice movement emphasized creative

and online forms of resistance to back its broad definition of disability. This more inclusive framing created a space for people who were chronically ill from conditions like ME/CFS, chronic Lyme disease, and now Long COVID. Without it, many people living with Long COVID today would not have access to disability support from the government.

At the same time, digital activism was generating attention for lesser-known health conditions. An early viral form of digital activism was the 2014 “Ice Bucket Challenge” for amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease. ALS is a rare and progressive neurodegenerative disease affecting the nerve cells that control muscles. Inviting people to post a video of themselves pouring a bucket of ice water over their head and giving a donation to support ALS research elevated awareness about the condition in a way few could imagine before the challenge spun digitally around the world.

This is one of hundreds of examples of “hashtag activism.” Focusing on themes of illness or disability, activists use hashtags on social media to share their experiences of political struggle, bringing their largely private lives into the public sphere and speaking truth to power in spaces they might not have previously occupied. The ME/CFS movement has used hashtag activism to promote awareness of the condition through campaigns such as the #MillionsMissing protests.

These protests were organized by #MEAction, an activist organization led by patients who have raised awareness not only digitally, but also in science and policy. Founded in 2017, the group urged members to “SHOW UP FROM HOME” and amplify the experiences and needs of ME/CFS patients by posting online together with shared hashtags. ME/CFS activists have argued that the private is political, whether in the length of showers people take, the number of likes they give to a social media post, or the GoFundMe pages they initiate to pay their escalating medical bills. Patient activism has required such creativity because so many patients have been too sick to be visible in the street. Elevating political movements through digital spaces opens points of access for disabled activists around the world.

## SUFFERING AND CAMPAIGNING IN A PANDEMIC

Long COVID emerged during a health activism renaissance. When Elisa Perego first tweeted about

#LongCOVID in May 2020, Fiona Lowenstein was already using digital activism to bring together other people exhibiting chronically severe and disabling symptoms following an acute bout of the coronavirus. As Lowenstein explained in the *New York Times*, “I felt alone in my healing process. I wanted information, and to connect with others who shared my experience.”

She was not alone. Millions of people around the world would be afflicted with Long COVID over the course of 2020, and some of them have never recovered. In certain ways, the post-viral form of COVID-19 resembles the experiences of many people who were irrecoverably disabled during the Great Flu epidemic of 1918 or from viruses embodied in what we call ME/CFS. But in a departure from previous pandemics, digital activism and online communities played an outsize role in cultivating global recognition of Long COVID and legitimizing the condition very early on.

At the beginning of the COVID-19 pandemic, Lowenstein was the president of a queer-feminist wellness collective called Body Politic. Rooted in the disability justice movement, it cultivated a space for inclusivity, accessibility, and crucial discussions about health, well-being, and justice. Lowenstein and Body Politic board member Sabrina Bleich initiated an online support group via WhatsApp for people suffering from Long COVID. It grew to more than 14,000 members residing in over 30 countries.

Many people sought such communities in 2020 because they, like Lowenstein, felt completely alone—dismissed and disbelieved by family, friends, and clinicians. This experience, unfortunately, is common among people living with complex chronic illnesses like ME/CFS, Lyme disease, and other conditions that lack a verifiable test, destabilize the body through multiple systems, and have few effective treatments.

Supported early on by #MEAction and other existing disability rights groups, Body Politic activists connected Long COVID patients with resources, information, and communities. They quickly mobilized a movement that became a source of comfort, information, and companionship in the struggle for formal recognition. For many people living with Long COVID, this was the only space where they felt comfortable sharing

their experiences and where others believed that their symptoms were real.

Body Politic eventually transferred the WhatsApp group to another messaging platform, Slack. Several channels formed, fostering distinct patient communities. Two channels of note developed into independent research and advocacy groups. One is known as Long COVID SOS, a UK-based charity that focuses on elevating knowledge and awareness of the condition, promoting recognition, research, and rehabilitation for those living with it. Another Slack channel called “data nerds” became an independent organization, Patient-Led Research Collaboration (PLRC).

PLRC members were motivated to “study ourselves” because they felt dismissed in medical settings. This transnational group was formed when Hanna Davis, Lisa McCorkell, Gina Assaf, Hannah Wei, and Athena Akrami organized a survey—despite being very sick from Long COVID—to systematically document their symptoms. Building the first patient-led database of Long COVID symptoms, they initially shared their survey and research

report on people with Long COVID (another first) in an open Google Doc file. It was eventually published in *eClinicalMedicine*, an open-access medical journal run by *The Lancet*.

PLRC conducted a follow-up survey with more than 200 symptoms, including write-in symptoms from the first survey (like post-exertional malaise, tremors, tinnitus, brain fog, and heart palpitations), as well as social issues like the inability to work. The group also developed other programs prioritizing patient concerns, needs, and perspectives. Patients served on a review panel to determine which research projects should be funded. In addition, PLRC founded the *Patient-Generated Hypotheses Journal* to promote the ideas and projects of scientists and funders living with Long COVID, a path-breaking approach for medical science.

Although the Body Politic Slack groups shut down such operations due to lack of funding, their ongoing digital presence promotes other ground-up, patient-led groups devoted to elevating the health and well-being of Long COVID patients. For instance, they work closely with Karyn Bishof, a single mother in Florida who launched the COVID-19 Long Hauler Advocacy Project in June 2020. After Bishof became sick, she lost her job

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as an emergency responder and was too disabled to go back to work. Instead, she dove into conducting surveys and polls of the Long COVID community to use for advocacy. Her group founded a chapter in every state, and a few others focused on special populations like caretakers, partners, and support circles. It uses ground-up research to lobby the federal government to require better medical coverage and disability insurance for COVID long haulers.

Other organizations that have supported Long COVID patients include The Mighty (a platform for peer support), #MEAction, Bateman Horne Center (for Zoom support meetings), and several private Facebook groups, such as Dysautonomia International, the Black COVID-19 Survivors Alliance, Long COVID Support, and Long COVID Families.

The Body Politic groups involved people exhibiting Long COVID symptoms around the world, even though the original organizers were in the United States and the United Kingdom. Notably, the global digital presence of these groups has had an impact on patient-organizing in other contexts. One example is the work of Wachuka Gichohi, a Kenyan patient activist who engaged with Body Politics' WhatsApp group to get through the first part of the pandemic, eventually moderating one of the sub-groups focused on integrative healing.

Gichohi noticed that few other Kenyans were talking about Long COVID, so she brought her story to the Kenyan media. She realized that local stigmas associated with complex chronic conditions like HIV affected how people in Kenya perceive and conceptualize Long COVID. Gichohi found that many Kenyans were much more private than people on global messaging forums about their experiences of illness, and she assumed that this was why few Kenyans were engaged in global digital communities. In response, Gichohi built a private social network exclusively for Kenyans suffering from Long COVID to connect, learn from each other, and share treatment experiences.

## SCIENTIFIC ACTION

Although patient activism has largely been patient-focused, the urgency it fosters has bolstered rapid scientific discovery for Long COVID. Building on decades of previous research about ME/CFS and other complex chronic conditions, from lupus to Lyme disease, scientists have identified several pathways through which COVID-19 dysregulates the body over the long term via the blood, brain, gut, and other tissues. Much of this

research was ongoing long before SARS-CoV-2 emerged, though it was somewhat marginalized, considered obscure, and underfunded.

Harvard neuroscience researcher Michael VanElzakker and microbiologist Amy Proal founded the nonprofit PolyBio Research Foundation in 2020, focused on probing how post-viral conditions make people sick and why. Since Long COVID came to prominence, PolyBio has gained recognition and research funding. Its work, informed by a decade of theoretical thinking, has been influential for the understanding of Long COVID biology: where the virus hides long after the initial infection and what it does to dysregulate multiple bodily systems.

Although skepticism remains strong among clinicians in some contexts, it has dissipated in others. Many physicians have contracted Long COVID themselves and become powerful patient activists. Some clinicians caring for Long COVID patients, like David Putrino, the director of Rehabilitation Innovation at Mount Sinai Health System in New York, have had a measurable impact in transforming how clinical care is designed and delivered for people living with Long COVID. In Ryan Prior's 2022 book *The Long Haul*, Putrino is quoted as saying that he has been motivated by "a core guiding principle of community co-design," a "nothing about us without us' mentality."

That framing harkens back to the earliest AIDS activists, the disability justice movement, and mental health advocates. Practitioners like Putrino are translating knowledge of Long COVID patients for a broader medical audience. This is encouraging medical settings that tend to focus on a specific organ, function, or area of the body for diagnosis and treatment to rethink how to care for patients living with complex chronic conditions.

Hashtag activism has become another important conduit of science education, in some cases connecting a curious public directly with cutting-edge scientists, as well as shifting the narrative about whose stories matter. Akiko Iwasaki, an immunobiologist at Yale, educated followers on Twitter regarding what was known and unknown about Long COVID symptoms. This work had an extraordinary impact on Iwasaki's own understanding of the virus, contributing to medical innovations such as a nasally administered COVID-19 vaccine.

Hashtag activism has also affected how society perceives conditions like ME/CFS and Long COVID. Patient activists have fought for recognition of the

complex faces of Long COVID, bringing intersectional differences among patients out of the shadows. Imani Barbarin's advocacy through the hashtag #MyDisabledLifeIsWorthy inspired thousands of disabled people to engage in public debates on Long COVID. Similarly, Chimère Sweeney has drawn attention to the experiences of Black Long COVID patients, promoting the production of a documentary called *Black and (un)Believed*.

These efforts continue to receive attention in part because so many people are living with Long COVID and still lack diagnosis, treatment, and disability accommodations. The latter factor remains an urgent matter for many Long COVID patients who can no longer work; some have lost their homes and parts of their social networks. Many who developed Long COVID at the beginning of the COVID-19 pandemic continue to experience persistent symptoms. For some, the need for disability accommodations has become a matter of life and death, and legal counsel has become one of the most essential health interventions.

## OUT OF THE SHADOWS

Digital activism has played an unprecedented role in bringing Long COVID out of the shadows. As many patients continue to fight for legitimacy, diagnoses, and care, technology has radically increased their visibility at a pace that was never possible before. At least in part, patient activists have revolutionized how we think about health and health care, forcing medicine to take a deep look at itself and recognize that specializations have failed to capture the complexity of some conditions.

Digital activism has also cultivated safe spaces for people with diverse views to interact and share with, learn from, and legitimate each other. This is particularly important for patients who may not feel safe or listened to in clinical spaces, such as trans people, children, and those with low incomes. Others have

described online spaces as offering access to a diversity of views and experiences that may not be available in their immediate communities.

Like many embodied health movements that have raised awareness about diseases from breast cancer to AIDS, Long COVID activists reveal their power by building community locally, nationally, and globally. Long COVID is unique: an extraordinary pandemic swept across the world and left lingering effects on people in different cultures, political contexts, and health care systems. But together, patient activists have been able to share information to challenge governments, engage in deep dialogues with clinicians and medical establishments, raise funds for research, and increase public awareness.

This has resulted in extraordinary political progress. The World Health Organization recognized the Long COVID movement as early as 2020. In the United States, the Biden administration committed to providing funding and prioritizing scientific research into Long COVID. Both the United Kingdom and Italy issued Long COVID care guidelines. These achievements are unprecedented, and they show how elevating the voices of many people—even if they are speaking digitally, from their beds—can inspire real social change.

We know from the AIDS movement, however, that attention to a health condition will ebb and flow over time. The social life of an illness is often transformed, particularly when alarms around the emergency diminish. With millions of people around the world still experiencing Long COVID symptoms that affect their work, domestic labor, family life, and social relations, a great deal remains to be done. Understanding how health activists formed a movement to revolutionize approaches to this debilitating condition creates opportunities to further transform health care for the benefit of those suffering in the shadows of medicine, politics, and society. ■