The HIV Movement Must Come Through

The following opinion piece by HIV activist JD Davids is an edited version of a post from his Substack site, The Cranky Queer. This version is accompanied by a list of additional resources for long COVID.

June 28, 2021 By JD Davids

I've been an HIV-focused activist for most of my life. And although I am not living with HIV, I've spent a lot of that time dealing with illness and chronic pain.

Now, many children, adults and elders who have gone through COVID-19—even with an asymptomatic infection—are experiencing some of the health challenges that have changed my life. For months, over a year or perhaps permanently, they are living with long COVID. People with long COVID, also known as COVID long-haulers, continue to experience symptoms long after the days or weeks that make up a typical course of the disease. They need our understanding and our help.

Moreover, we need to fight together for the comprehensive care and resources we all need. We're already seeing new threats to HIV funding, as health departments struggle to pay for the costs of the COVID pandemic, alongside the ongoing, drastic lack of research and care for complex chronic illnesses that now include long COVID.

As a person living with myalgic encephalomyelitis—known as ME or ME/CFS and often called/minimized as chronic fatigue syndrome—as well as other chronic conditions, I constantly have the three most common symptoms of long COVID: fatigue, cognitive dysfunction (trouble with thinking) and post-exertional malaise (known as PEM, in which symptoms emerge or relapse up to 48 hours after mental or physical effort).

Unlike many, I've been able to get diagnoses and some care for my chronic conditions. But that's largely because I am white, urban and "professional." I have, and have often needed to use, my skills and connections as a research and treatment advocate, and I have private health insurance—although I have to pay out of pocket for my ME specialist and several of my treatments.

My experience can help show why there's a decades-long misunderstanding that ME somehow occurs only in white people. Now, many of the faces appearing in media stories about long COVID

are white, even though it likely has a disproportionate impact among the Black and brown people who were most affected by the COVID pandemic itself. Sound familiar?

Here's another dynamic similar to the early days of HIV: If people don't have a history of a positive COVID test—which many don't have, especially those who already had barriers or faced bias in health care—they aren't eligible for many of the few long COVID care programs or emerging clinical trials, even if they clearly had COVID and are suffering now.

It's like when women living with HIV were locked out of care, benefits and research when the definition of AIDS itself excluded some of the opportunistic infections most common in women, and we said, "Women don't get AIDS; they just die from it."

Long COVID was predicted by disabled people and people with chronic illnesses. But we were talked about, not listened to, as the pandemic approached and began to spiral out of control. That's because while COVID-19 is indeed a new disease, it's been known for over 100 years that people can become chronically ill after a viral infection.

But when we have post-viral conditions, like ME or long COVID, we still struggle to be believed. We scramble to find care providers who can help. We suffer the consequences of systems that split us up by medical specialties rather than our actual needs as humans. And unless there's an expensive treatment for us, we don't see the kind of in-depth consumer health information or support underwritten by drug company advertising.

Today, I'm able to use my experience as an HIV activist as we face these challenges. I hope you'll join me. For example, when I had the honor of collaborating with a group of scientists living with long COVID, I encouraged them to emphasize that they were patient-led as they published their findings.

The Patient-Led Research Collaborative for Long COVID (led by women, by the way) is now a central force in long COVID science and advocacy; its very name emphasizes that the expertise of the collective's members comes from living with long COVID.

Research and care for complex chronic conditions has never been a focus of our public health or medical care systems. It's why we desperately needed, and still need, the Ryan White AIDS Program. It provides funds to coordinate the care of people living with HIV, links and trains medical providers, ensures access to medication and more. And as people living with HIV age, we see that some are very much back in complex care territory, dealing with comorbidities like heart disease and diabetes or conditions like frailty.

But truly, all people need and deserve care and support as we face health challenges, rather than being put in competition for what still amounts to crumbs. May the intensely unjust horrors of the COVID pandemic bring us together to finally achieve what we've had the right to all along—comprehensive universal health care and services for all.

Resources for Long COVID

Research shows that 10% to 30% of people who get COVID-19 will experience some form of long COVID. While people who were hospitalized or in intensive care due to COVID may experience distinct forms of organ damage and ongoing health challenges, many people with long COVID had mild or even asymptomatic illness.

The condition can include a range of symptoms from mild to severe. However, an international patient-led survey of 3,762 participants found that most people with long COVID hadn't returned to previous levels of work in six months.

So what can people with long COVID do? How can their friends and families support them? If you read nothing else in this list, read and share this: #StopRestPace.

Here's why: Many people with long COVID are encouraged to build back stamina and strength through exercise. But we know that some people with myalgic encephalomyelitis (ME), a similar chronic condition, who were able to deeply rest during the first months of illness were more likely to recover. In addition, it is common for people with post-exertion malaise to have setbacks after exercise.

"Pacing is a self-management strategy for activity," explains #MEAction (MEAction.net), a group for people with ME, many symptoms of which mirror those of long COVID. "Patients who pace well are active when able and rest when tired. They may plan extra rest ahead of strenuous activities."

As in the early years of the HIV pandemic, people with long COVID have often been the best source of information for one another. Body Politic, a queer feminist wellness collective in New York City whose founders got long COVID early in the pandemic, hosts dozens of topical discussions in its online support group, which uses the Slack platform. The collective's resource page is updated frequently, and its members have created a list of recommended medical providers.

#MEAction (for which I serve on the board of directors) is tapping the wisdom of the global community of people living with ME to provide information and support to people with long COVID. The COVID-19 Longhauler Advocacy Project maintains a comprehensive guide for both people with long COVID and doctors.

Organizations and individuals can also join the Long COVID Alliance, a growing network of advocates with long COVID, scientists and others who are demanding research on and resources for post-viral illness.

Want to be a good ally to people with long COVID?

- Believe the people in your life who are still sick months after they had COVID—even if they didn't know they had it. Help them find support (such as online support groups like Body Politic) and help them #StopPaceRest.

- Bring long COVID into the conversation about COVID-19, which still is reduced to focusing on acute COVID and viewing vaccines as the solution.
- Fight for equity-based public health and medical care for all people with long COVID, HIV, ME and all other chronic conditions (learn more at bit.ly/chronicinjustice).
- Speak out or stand up for long COVID and ME care for all, regardless of proof of a positive COVID test (bit.ly/covidtestjustice).
- Bridge the gap between HIV advocacy and disability justice to combat the stigma against all of us (start with watching Crip Camp https://cripcamp.com and learn from http://disabilityvisibilityproject.com).

JD Davids (@TheCrankyQueer), is living with ME, fibromyalgia and other chronic conditions and is a board member of #MEAction. Raised by ACT UP Philadelphia, he has organized on many issues, including access to syringes and other HIV prevention methods, health care for people in jails and prison, trans research and health and global access to HIV treatment. He has served as an external adviser to the Centers for Disease Control and Prevention and the National Institutes of Health. He now primarily works with national networks of U.S. people living with HIV and as a strategist and storyteller for The Cranky Queer Guide to Chronic Illness.
