

People with long COVID continue to experience medical gaslighting more than three years into the pandemic

April 24 2023, by Simran Purewal, Kaylee Byers, Kayli Jamieson and Neda Zolfaghari



Credit: AI-generated image ([disclaimer](#))

It's increasingly clear that the [SARS-CoV-2 virus is not going away](#) any time soon. And for some patients, their symptoms haven't gone away either.

In January 2023, our team of researchers at the [Pacific Institute on Pathogens, Pandemics and Society](#) published a [research brief](#) about how people seek out [information](#) about long COVID. The brief was based on a scoping review, a type of study that assesses and summarizes available research. Our interdisciplinary team aims to understand the experiences of people with long COVID in order to identify opportunities to support health care and access to information.

Lingering long COVID

Long COVID (also called [Post COVID-19 condition](#)) is an illness that occurs after infection with COVID-19, lasting weeks to months, and even years. First coined by a [patient on Twitter](#), the term also represents a collective movement of people experiencing the long-term effects of COVID-19 and advocating for care. [Around 15 percent](#) of adults who have had COVID still have [symptoms](#) after three months or more.

Long COVID affects systems [throughout the body](#). However, [symptom](#) fluctuations and limited [diagnostic tools](#) make it challenging for health-care providers to diagnose, especially with [over 200 symptoms](#) that may present in patients. Perhaps because long COVID presents itself in many different ways, the illness has [been contested](#) across the [medical field](#).

To identify opportunities to reduce barriers to long COVID care, our team has explored how patients and their caregivers access [information about long COVID](#). We have found that one of the most significant barriers faced by patients is [medical gaslighting](#) by the people they have turned to for help.

Lack of validation leads to stigma

[Medical gaslighting](#) occurs when health-care practitioners dismiss or

falsely blame patients for their symptoms. While new information about long COVID has become more readily available, some patients continue to face gaslighting and feel that their symptoms are [treated less seriously](#) by some health-care professionals.

This dismissal can [erode trust](#) in the health-care system and can also lead to [stigma and shame](#).

Preliminary findings from our ongoing study with long COVID patients indicate that, when [medical practitioners](#) do not validate a patient's condition, this extends into community networks of family and friends who may also dismiss their symptoms, contributing to further stigmatization at home.

Medical gaslighting can present additional barriers to treatment, such as not being referred to specialists or long COVID clinics. This can, in turn, compound other symptoms such as fatigue, and [exacerbate the psychological symptoms of long COVID](#), such as depression and anxiety.

Medical gaslighting isn't new. It has been documented by patients with other chronic conditions, such as [myalgic encephalomyelitis or chronic fatigue syndrome](#). And while this is common for patients with [non-visible illnesses](#), medical gaslighting is more commonly experienced by [women and racialized people](#).

Long COVID patients also note gender biases, as women with prolonged symptoms feel they are not believed. This is particularly worrisome, as studies have found that [women are disproportionately more likely to experience long COVID](#).

Where do we go from here?

While long COVID information is constantly shifting, it's clear that

patients face many barriers, the first of which is having their illness minimized or disregarded by others. To ensure that patients have access to compassionate care, we suggest:

1. Educating physicians on long COVID

Because definitions of long COVID, and its presentation, vary widely, [primary care physicians](#) need support to recognize and acknowledge the condition. General practitioners (GPs) must also provide patients with information to help manage their symptoms. This requires actively listening to patients, documenting symptoms and [paying close attention to symptoms that need further attention](#).

Training physicians on the full range of symptoms and referring patients to available supports would reduce stigma and assist physicians by reducing their need to gather information themselves.

2. Raise awareness about long COVID

To increase awareness of long COVID and reduce stigma, [public health](#) and community-based organizations must work collaboratively. This may include a public awareness and information campaign about long COVID symptoms, and making support available. Doing so has the potential to foster community support for patients and improve the mental health of patients and their caregivers.

3. Ensure information is accessible

In many health systems, GPs are [gatekeepers to specialists](#) and are considered trusted information sources. However, without established diagnostic guidelines, patients are left to [self-advocate](#) and prove their condition exists.

Because of negative encounters with [health-care](#) professionals, patients turn to [social media platforms](#), including long COVID [online communities](#) on Facebook. While these platforms allow patients to validate experiences and discuss management strategies, patients should not rely only on [social media](#) given the [potential for misinformation](#). As a result, it is crucial to ensure information about long COVID is multi-lingual and available in a wide range of formats such as videos, online media and physical printouts.

The [recent recommendations of the chief science advisor of Canada](#) to establish diagnostic criteria, care pathways and a research framework for long COVID are a positive development, but we know patients need support now. Improving long COVID education and awareness won't resolve all of the issues faced by [patients](#), but they're foundational to compassionate and evidence-based care.

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