

Still Here: Communicating about Long COVID



The Evolving Story of COVID-19

COVID-19 launched a global pandemic, ushering in uncharted territory for public health communications. In the five years since COVID-19 became a household term, messaging has evolved alongside the shifting perspectives on the disease, vaccination, and its community impacts.

The Public Health Communications Collaborative was formed in 2020 to support fact-based, plain language communications about COVID-19. With new research and time-tested communications techniques, public health communicators have become better equipped to reach their communities and help them make informed decisions about their health and well-being.

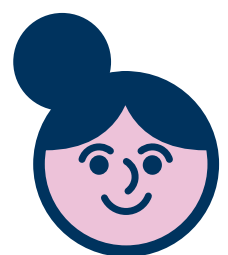
Today, COVID-19 is still circulating worldwide. Cases typically surge during winter months, heavy travel seasons, and periods with an increase of in-person gatherings. Millions of people in the United States get a SARS-CoV-2 infection each year—the infection that leads to COVID-19. COVID-19 symptoms are wide-ranging, from mild to serious, but for many, the longer-term impacts have been more severe than the initial infection. Long-term health issues following COVID-19 are often called Long COVID. Long COVID effects have been [documented](#) across every organ system.

The following guide explores the lasting impact of SARS-CoV-2 infection, Long COVID, and related messaging guidance for public health communicators.



Why We Use the Term Long COVID

The guide uses the patient-coined term Long COVID, which is commonly used by people with Long COVID, researchers, and providers. With expert and patient review, National Academies of Sciences, Engineering, and Medicine (NASEM) [defined Long COVID](#) as both a “disease state” and an “infection-associated chronic condition (IACC)”. While many health organizations like the CDC and WHO describe Long COVID [as a condition](#), as it does not yet have widely accepted biomarkers, [some researchers](#) and people with Long COVID describe it as a disease, since symptoms are triggered after COVID-19. There are other terms that are used to talk about Long COVID, including post-COVID condition, and post-acute sequelae of SARS-CoV-2 infection (PASC). These terms tend to be utilized more in clinical settings and research.



What is Long COVID and Why Does It Matter?

Long COVID refers to chronic health issues that arise after a SARS-CoV-2 infection. It's a broad, umbrella term that includes over 200 potential symptoms across all parts of the body, new diagnoses of other chronic health conditions, and worsened symptoms associated with conditions that were diagnosed pre-COVID.

Why Long COVID Matters

- Researchers estimate that over 400 million people worldwide have experienced Long COVID as of 2024.
- In the U.S., surveys suggest that 15 to 20 million adults are living with Long COVID and over one million children have experienced it.
- Long COVID can be fatal. The Centers for Disease Control and Prevention (CDC) have reported more than 5,000 Long COVID deaths, but outside experts state it is likely a significant undercount.
- Studies have found that Long COVID disproportionately impacts disadvantaged groups, including Black and Latino Americans and transgender people.

Key Features of Long COVID

- Anyone can get Long COVID, including people across all age groups (including young children), races and ethnicities, genders, and sexual orientations.
- Long COVID symptoms occur for at least three months, can last for years, and may be mild to life-altering.
- Someone may experience continuous symptoms starting from the time of their infection, or may appear to recover but then experience new symptoms weeks or months later.
- Common symptoms include dizziness and lightheadedness, neurological issues (sometimes called “brain fog”), heart problems, new allergies and intolerances, altered taste and smell, trouble sleeping, fatigue, and new or worsened symptoms following physical, emotional, or mental activity.
- Even if someone has felt completely fine following prior SARS-CoV-2 infections, a new infection could still lead to Long COVID. Some studies suggest the chances of getting Long COVID may be higher with more infections.
- Many people with Long COVID who have been reinfected with SARS-CoV-2 have reported worsened symptoms and increased disability.
- There is currently no widely accepted test to diagnose Long COVID. Clinicians diagnose it based on symptoms and history. Experts recommend against requiring a positive COVID-19 test for diagnosis due to barriers many people face in accessing testing.



400M+
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How to Communicate about Long COVID

How to Communicate about Long COVID with Your Community

Over the past five years, COVID-19 communications have become more routine. Thanks to your efforts—and the efforts of other public communicators around the country—millions of people better understand how to protect against COVID-19, what to do if they have an infection, and where to find updated information as the science evolves. Communicating about Long COVID requires additional considerations:

- **Use plain language to explain what Long COVID is.** Show that everyone is susceptible to Long COVID, not just people with pre-existing conditions.
- **Engage people living with Long COVID in your community.** Ask them about their experiences and—with permission—share their stories. Many people living with Long COVID experience stigma and discrimination from their workplaces or loved ones. Your messaging should emphasize that Long COVID is real and can happen to anyone.
- **Emphasize the importance of COVID-19 vaccination, masking, and testing to protect those around you.** Reducing the risk of new infection is the best way to reduce the risk of Long COVID. In discussing vaccination and Long COVID, nuance is important—while [studies show](#) vaccination may lower one’s risk of Long COVID, it does not eliminate it.

Long COVID Communications Gaps

One common misunderstanding about Long COVID is that it’s a mysterious, novel illness. While Long COVID is relatively new, it is now one of the most well-studied health issues in medical history. [Tens of thousands of scientific papers](#) have been published about Long COVID since 2020. Long COVID also overlaps with many other chronic diagnoses that have decades of research behind them.

Despite the [profound impact of Long COVID](#) on nearly every organ system, more research is needed to fully understand Long COVID and how to manage it. Misinformation and dismissive messages often flourish in this information gap, especially as the federal government shuts down important Long COVID programs and data. As a result, people with Long COVID tend to face stigma and challenges when seeking healthcare and support. Communicators can help address this gap by speaking to people with Long COVID with empathy, acknowledging their challenges, and amplifying their experiences.

Raising awareness is also important as some people with long-term health issues following COVID-19 may not realize that they meet the criteria for Long COVID. Some Long COVID researchers and specialist clinics [offer educational programs](#) and resources that may help inform awareness efforts. These include clinics that are part of the federal Agency for Healthcare Research and Quality’s [Long COVID Care Network](#) and the global [Project ECHO](#) initiative.



Common Symptoms of Long COVID

Dizziness

Lightheadedness

Neurological issues

Heart problems

New allergies and intolerances

Altered taste and smell

Trouble sleeping

Fatigue

New or worsened symptoms following physical, emotional, or mental activity



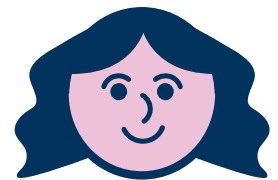
Messages to Build Trust with Long COVID Communities

- **Acknowledge that Long COVID is real and common.** Share that long-term symptoms and new chronic illness diagnoses like [diabetes](#) and [blood clots](#) are common outcomes of SARS-CoV-2 infection.
- **Amplify the voices of people with Long COVID.** Many people with Long COVID have shared their experiences in [essays and op-eds](#), on social media, in podcasts and [videos](#), and more. Amplify these stories to help people understand how Long COVID has changed lives.
- **Talk about and practice prevention.** Many people in the Long COVID community prioritize reducing further SARS-CoV-2 infections, to protect their health and the health of loved ones and community members. They value messaging about preventative measures like vaccination, high-quality masks (N95s, KN95s), testing, and improving air quality. They are more likely to trust communicators who show they understand these are important public health tools and implement them consistently.
- **Incorporate resources into your communications.** Offer resources to help people with Long COVID find healthcare providers, navigate employment issues or applications for disability benefits, find community groups and support networks, and support their mental health.
- **Emphasize options for managing symptoms.** While there are no cures or FDA-approved treatments for Long COVID, there are options for people to manage their symptoms, such as [pacing](#), over-the-counter treatments, and off-label medications. People should consult a medical professional for how to best manage their individual symptoms
- **Uplift existing community groups and mutual aid organizations.** There are many existing groups that offer COVID-19 prevention resources, information, and support, such as [mask blocs](#) (which focus on sharing high-quality masks), [clean air clubs](#) (which make events more accessible), and [Long COVID support groups](#). The [COVID Action Map](#) can help you find groups in your geographic area.
- **Share new research and up-to-date information about COVID-19 and Long COVID.** New scientific papers about Long COVID are published each week! Share new results and updates, such as news about clinical trials that may be recruiting, to help community members stay up-to-date.



**15–20M
Adults**

in the U.S. are living
with Long COVID



**1M+
Children**

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Responding to Common Misconceptions about Long COVID

✘ Long COVID is mysterious and not well understood.	✔ While scientists have not yet identified specific biomarkers or novel treatments, much research has been done to understand the potential mechanisms behind Long COVID.
✘ Long COVID only impacts people with pre-existing conditions	✔ Everyone is susceptible to Long COVID. Long COVID can impact people who have had no prior health issues but can also worsen prior chronic diseases and disabilities.
✘ If you had COVID-19 once, your symptoms will go away.	✔ Anyone who is infected with SARS-CoV-2, which <u>continues to circulate</u> , is susceptible to Long COVID. With every infection, there is a chance that long-term symptoms could develop.
✘ The only Long COVID symptom is fatigue.	✔ Long COVID symptoms include dizziness and lightheadedness, neurological issues (sometimes called “brain fog”), heart problems, new allergies and intolerances, altered taste and smell, trouble sleeping, fatigue, and new or worsened symptoms following physical, emotional, or mental activity.
✘ The COVID-19 vaccine prevents Long COVID.	✔ Studies show vaccination may lower one’s risk of getting Long COVID, but does not fully prevent it.
✘ If I get Long COVID, I can take medication to fully recover.	✔ There are no cures or FDA-approved treatments for Long COVID. Still, different management strategies, <u>over-the-counter treatments</u> , and <u>off-label medications</u> have been shown to help improve symptoms for some.
✘ I can only get Long COVID if I am very sick from COVID-19.	✔ Long COVID can occur after a COVID-19 case of any severity, including asymptomatic cases.

Additional Resources

- [Plain Language for Public Health \(PHCC\)](#)
- [Coronavirus Disease 2019 \(COVID-19\) Resources \(CDC\)](#)
- [Comprehensive Guide to Long COVID \(Longhauler Advocacy Project\)](#)
- [Examining the Working Definition for Long COVID \(NASEM\)](#)
- [2025 Long COVID Fact Sheet \(Patient-Led Research Collaborative\)](#)
- [Long COVID: What We Are Doing to Learn More \(Minnesota Health Department\)](#)
- [Long COVID Justice](#)
- [Long COVID Weekly Newsletter](#)
- [COVID Action Map](#)