

What You Need to Know About **LONG COVID**

As many as 23 million Americans may have symptoms of Long COVID. Many are unaware that their symptoms were brought on by a COVID-19 infection.

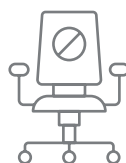
Long COVID is real. Community-based organizations like yours have a unique opportunity to share information about it with community health professionals and others in the community. You can also help us learn more about Long COVID by encouraging people to take part in research studies.

What is Long COVID?

Long COVID is defined as signs, symptoms, and conditions that continue or develop after initial infection with SARS-CoV-2 (the virus that causes COVID-19).

Long COVID may also be called:

- Long-haul COVID-19
- Post-COVID-19 conditions
- Chronic COVID-19
- PASC, or Post-acute sequelae of SARS-CoV-2



Roughly 1 million people are out of the workforce at any given time due to Long COVID.

It affects people for weeks, months, or even longer after getting COVID-19. People may have difficulty carrying out daily activities because of their symptoms. Roughly 1 million people are out of the workforce at any given time due to Long COVID.

What are common symptoms?

Symptoms may:

- Start soon after infection or after recovery from COVID-19
- Come and go
- Be different than the symptoms of COVID-19
- Go away with time

Some people who didn't feel sick when they first got infected may still go on to develop Long COVID.

Long COVID does not affect everyone the same way. We are only beginning to understand the nature of the symptoms. Long COVID may include some illnesses already linked to COVID-19 such as heart inflammation, lung damage, or diabetes. Health care providers can follow known medical approaches to treat these illnesses.



Long COVID may also include non-specific symptoms that can be more difficult to recognize and manage. These symptoms include tiredness or fatigue, "brain fog," and anxiety, among others. It is also possible to experience a combination of illnesses and symptoms. So far, there is no known test or treatment for Long COVID.

Common Long COVID Symptoms

Worrying too much or feeling very sad

Feeling weak and tired

Fever

Headache

Trouble breathing

Trouble thinking

Fast-beating or pounding heart

Trouble sleeping

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Who is more likely to get Long COVID?

Scientists are working to understand this question. They think people are more at risk if they:



Had severe COVID-19, for example, if they were sick enough to be hospitalized



Had other health conditions such as diabetes or a lung condition before getting COVID-19



Did not get a COVID-19 vaccine

Is Long COVID considered a disability?

Yes, Long COVID can be a disability under federal civil rights laws. Someone with Long COVID has a disability if their symptoms substantially limit one or more major life activities, some of which include walking, standing, concentrating, thinking, communicating, or working. Federal laws protect people with disabilities from discrimination by employers, schools, and health care providers. Long COVID disability guidance is available from the Department of Health and Human Services.

How can Long COVID be prevented?

The best prevention is to avoid getting COVID-19 in the first place. Vaccination lowers the chances of getting COVID-19 and then getting Long COVID. People should also take other steps to avoid COVID-19, like wearing a mask indoors in areas with high CDC COVID-19 Community Levels.



Health providers can make a difference by talking to people about Long COVID.

If someone thinks they may have long COVID, it is important to:

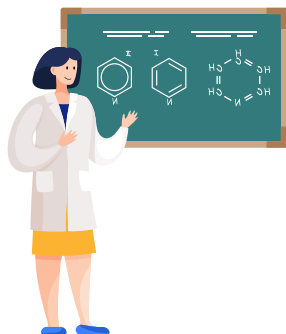
- **Acknowledge** the significance of their symptoms and validate their experiences. The symptoms of Long COVID can be frustrating and confusing, for patients and experienced clinicians alike. Some people with Long COVID are worried that health care workers won't believe them.
- **Encourage** them to talk to a health care provider about their symptoms. While there is no specific test or treatment for Long COVID, other tests may help providers understand specific symptoms. Treatment plans can focus on how to manage symptoms.
- **Help** people get ready to discuss Long COVID by reminding them to include details such as:
 - A brief history of their experience with COVID-19 and Long COVID
 - Any medications they take
 - Questions they may have

Find more information on services and support for Long COVID at [covid.gov/longcovid](https://www.covid.gov/longcovid)

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Long COVID Research

Volunteers can help scientists understand Long COVID



The Researching COVID to Enhance Recovery (RECOVER) Initiative is a study to understand, prevent, and identify treatments for Long COVID. RECOVER wants to learn how many people have Long COVID, who is at risk, and why some people recover while others do not.


Anyone can help us learn more about Long COVID by volunteering to participate in RECOVER research studies. This includes people with Long COVID, as well as people who currently have COVID-19, people who had COVID-19 in the past, and people who have never had COVID-19. [Recovercovid.org](https://www.recovercovid.org) has more about how to join studies.


Diversity in Long COVID Research


It is important that people from all walks of life participate in research. To better understand how Long COVID affects different people, studies need to include volunteers of all:




Since communities of color have been hard-hit by COVID-19, they may also be at more risk for Long COVID. That's why it's especially important that people of color participate in this research.

 American Indian or Alaska Native: **3.1x** more likely

 Black or African American: **2.4x** more likely

 Hispanic or Latino: **2.3x** more likely

 Asian: **0.8x** more likely

Other people may be more at risk for Long COVID due to the same circumstances or health inequities that put them at high risk for COVID-19. These groups include:



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Bring community voices to Long COVID research

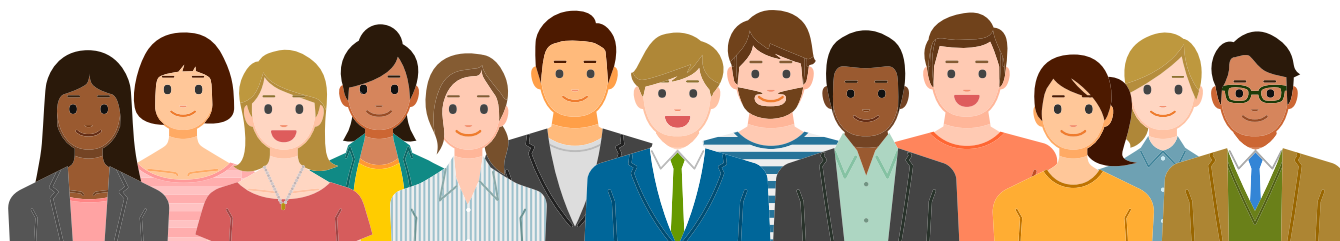
The RECOVER Initiative values the perspectives of patients, caregivers, and community members. Feedback from people across the country has shaped RECOVER research from the beginning and continues to shape the Initiative's activities and communications. RECOVER wants to hear from more people about their experiences, even if they don't participate directly in the studies. Contact RECOVER to share and encourage others to do the same. More information is available at recovercovid.org.

Share how research volunteers are more protected than ever before

Mistrust and other barriers to participation have kept many people, including those in the communities hardest hit by the pandemic, from volunteering for research studies. Although the mistrust has been earned — through historical injustices and exclusions from research in the past — including people from every community is very important. It gives us better information about how drugs or vaccines work for different people. **Today, volunteers' rights and well-being are protected when they volunteer for a research study.**

Researchers are required to protect personal information but cannot reduce risks to zero. All studies funded by the U.S. government, including RECOVER, have several groups that watch over the research. Every study goes through careful review at each phase: before, during, and afterwards. These reviews include independent reviewers, some of them patients, who are separate from the people conducting the studies and who make the safety and well-being of participants the top priority.

Read more about some of the people working to protect research participants and make research studies as safe as possible at every step along the [Scientific Pathway to COVID-19 Research](#) (from CEAL).



Learn more about Long COVID at covid19community.nih.gov/long-covid