Long COVID: What to know about post-COVID conditions

What is “long COVID”?
“Long COVID” is one term for post-COVID conditions, which are new, returning, or ongoing symptoms experienced for weeks or months after having COVID-19. Most people who have COVID-19 feel better within a few days or weeks. But for some people, symptoms can last months or longer. Long COVID can affect multiple body systems, and symptoms may get better or worse at different times. Most patients’ symptoms slowly improve with time.

People who have had COVID-19 may also be more likely to develop new health conditions such as diabetes, heart conditions, blood clots, or neurological conditions compared with people who have not had COVID-19. In July 2021, “long COVID” was added as a recognized condition that could result in a disability under the Americans with Disabilities Act (ADA).

There is no single test to find out if someone has long COVID. While long COVID is more common in persons who experienced severe COVID-19, some people develop long COVID after an infection with mild or no symptoms. You can be diagnosed with long COVID even if you don’t have proof of a positive test.

Is it possible to prevent long COVID?
The best way to prevent long COVID is to take steps to protect yourself from becoming infected with COVID-19 by wearing a mask, keeping events and gatherings small and outdoors or improving ventilation, and staying away from others who have COVID-19. Staying up to date with COVID-19 vaccines strongly protects against severe illness and reduces your risk of becoming infected. Research suggests that people who are vaccinated and get COVID-19 are less likely to report long COVID, compared to people who are unvaccinated.

New research also suggests that getting treated for COVID-19 infection with Paxlovid reduces the risk of developing long Covid.

How common is long COVID?
Research studies are in progress to better understand long COVID and how many people experience this condition. Different studies have come to different conclusions based on the type of research study, when it took place, and the population who took part in the study.

Who is at greatest risk for developing long COVID?
- People who have severe COVID-19 illness, especially those who are hospitalized or need intensive care
- People who are not vaccinated against COVID-19
- People who have underlying health conditions prior to COVID-19 infection

Although long COVID does appear to be more common in adults, children and adolescents can develop long COVID. The CDC and other researchers are working to understand more about who experiences long COVID and why, including whether groups most impacted by COVID-19 are at higher risk for long COVID.
What are the symptoms of long COVID?

General symptoms
- Tiredness or fatigue that interferes with daily life
- Symptoms that get worse after physical or mental effort
- Fever

Respiratory and heart symptoms
- Difficulty breathing or shortness of breath
- Cough
- Chest pain
- Fast-beating or pounding heart (also known as “heart palpitations”)

Neurological symptoms
- Difficulty thinking or concentrating (sometimes referred to as “brain fog”)
- Headache
- Hearing loss or ringing in the ears
- Sleep problems
- Dizziness when you stand up (lightheadedness)
- Pins-and-needles feeling
- Change in smell or taste
- Depression or anxiety

Digestive symptoms
- Diarrhea
- Stomach pain

Other symptoms
- Joint or muscle pain
- Rash
- Changes in menstrual cycles
- Erectile dysfunction

Symptoms can vary after a COVID-19 infection. Some people have mild symptoms, but for other people, symptoms make it hard to carry out regular daily activities. Some studies suggest that having COVID-19 more than once can worsen long COVID symptoms or cause symptoms to return.

What do I do if I think I have long COVID?
Make an appointment with your healthcare provider if you have one. If you have health insurance but do not have a primary care provider, you can call the customer service number on the back of your insurance card OR other providers in your health plan to see if there are available appointments. If you don’t have health insurance, visit our Health Insurance webpage today for information about signing up.

You can track your symptoms using this log. Please also see the CDC’s Patient Tips: Healthcare Provider Appointments for Post-COVID Conditions.

How will my healthcare provider help me?
Your provider will ask about your symptoms and the impact they’re having on your life. They will want to make sure that your symptoms are not related to a different health problem.
Your provider may ask about the care and support you might need. You may be given advice about how to manage and monitor your symptoms at home.

If the symptoms are having a big impact on your life, you may be referred to a clinic that specializes in the specific symptoms you have.
Are there research studies I can participate in?

There are several research studies happening in the Bay Area. One large study, called RECOVER (Researching COVID to Enhance Recovery) was launched by the National Institutes of Health (NIH) to better understand post-COVID conditions. You can learn more about the trial and how to join at the RECOVER webpage or the UCSF clinical trial page.

The California Department of Public Health (CDPH) is also studying post-COVID conditions through partnerships with academic institutions, such as UCSF. One study, INSPIRE (Innovative Support for Patients with SARS CoV-2 Infection Registry) uses an online platform to enroll people 18 years or older after they test positive for COVID-19 and sends surveys over time to learn about the long-term effects of COVID-19. You can learn more about how to participate on the UCSF study page.

There is also a study at Stanford called Paxlovid for Treatment of Long Covid. (Paxlovid is already used to treat COVID infection). Enrollment information can be found on the study page.

The UCSF CARE BEAR-LC study is focused on cardiac rehabilitation for persons with long COVID who have difficulty tolerating exercise. More information can be found on the study page.

Are there support groups or other resources for people with post-COVID conditions?

Yes, there are support and patient advocacy groups for people with post-COVID conditions including: Survivor Corps, Body Politic, Long COVID Alliance, and Long COVID Kids.

Some additional resources can be found below:

- Long COVID or Post-COVID Conditions (CDC)
- Caring for People with Post-COVID Conditions (CDC)
- Post-COVID Conditions (Long COVID) Questions & Answers (CDPH)
- NHS Post-Covid Information Pack
- Royal College of Occupational Therapists: How to Conserve Your Energy
- JHU: Bouncing Back from Long COVID
- How Right Now (CDC)