Long COVID Patient Fact Sheet

Coronavirus disease, also referred to as COVID-19, occurs when you are infected with the novel coronavirus (SARS-CoV-2). Some people with COVID-19 do not have any symptoms, while others experience a variety of symptoms, ranging from mild to severe. We are still learning about the long-term impact of COVID-19 on the body. Most people will recover completely from COVID-19 within a few weeks. However, some people may continue to experience symptoms even after the first part of the illness is over, regardless of the severity of the initial illness.

‘Long COVID’ is the term that is often used to describe these persistent symptoms. You are considered to have ‘Long COVID’ when you are still having symptoms at least 4 weeks after the initial infection. Long COVID may also be referred to by other names such as post-COVID conditions, PASC (post-acute sequelae of COVID-19) or long-haul COVID.

Who Could Develop Long COVID?

Researchers around the world are trying to understand why some people develop Long COVID. People of all ages have been diagnosed with long COVID, including people with no underlying health conditions. Young and otherwise healthy people, and even those with mild infections, can be affected. More research is needed on the wide range of symptoms and why some people have more severe symptoms than others.

How do you know if you have Long COVID? (Signs and Symptoms)

COVID-19 may affect many organs including the lungs, heart, brain, liver, kidney and gastrointestinal (GI) tract. Since COVID-19 can affect so many organs, it causes a wide range of symptoms. People with Long COVID may have symptoms that persist for several weeks or months. The most common symptoms are:

- Fatigue
- Shortness of breath or difficulty breathing
- Difficulty thinking or concentrating (also referred to as ‘brain fog’)
- Headache

Other symptoms include:

- Feeling tired or unwell after tasks or activities that require minimal effort
- Chest pain
- Fast-beating or pounding heart (heart palpitations)
- Sleep disturbances
- Mood changes, depression, or anxiety
- Joint or muscle pain
- Changes in ability to taste or smell
- Sore throat or cough
- Fever
- Nausea or diarrhea
- Feeling dizzy or lightheaded
- Changes in menstrual cycle
- Rashes
- Hair loss

People who were in the intensive care unit (ICU) for COVID-19 may experience other specific symptoms. These include weakness, and post-traumatic stress disorder (PTSD). Post-intensive care syndrome or PICS refers to symptoms experienced by people recovering from critical illness (i.e. being hospitalized in the ICU). If a patient was hospitalized with COVID in the ICU, they may have overlapping symptoms between PICS and long COVID. For more information about PICS—see the ATS fact sheet at www.thoracic.org/patients.

How is Long COVID diagnosed?

There is still no definite single diagnostic test for Long COVID. For now, the diagnosis is based on reported symptoms with a history of known COVID infection. Many Long COVID symptoms are also common in other health conditions. If these symptoms have been worse since you fell ill, or you are experiencing them for the first time, then the cause of these symptoms may be Long COVID. Your doctor may order tests to see if there are any impacts to your lungs, heart or kidneys, as such changes may be found in Long COVID, although they are not required to make the diagnosis.

How is Long COVID treated?

We still have a lot to learn about Long COVID and how to care for patients with this condition. There is no known treatment specifically for Long COVID. Management of Long COVID focuses on decreasing the severity of symptoms. Your doctor may prescribe treatments that are used to
manage similar symptoms that happen with other health conditions. You may be referred to a specialist who has experience treating patients with similar symptoms. If you experience ongoing breathing problems and difficulty in performing your daily activities, your doctor may order a chest x-ray, CT scan, or breathing tests to check for signs of lung injury. You may be advised to take part in an exercise and education program called pulmonary rehabilitation. A pulmonary rehab or exercise program may help to reduce the severity of symptoms and improve your quality of life. For more information on pulmonary rehab see the ATS fact sheet at www.thoracic.org/patients.

There have been some reports that vaccination may help alleviate symptoms of Long COVID, however studies looking into this are still ongoing. What is clear, however, is that people who are vaccinated are less likely to develop Long COVID, even if they do get COVID-19. Vaccines are recommended for people who have tested positive for COVID-19 in the past as the protection from vaccines is longer-lasting than natural immunity.

Self-care guidance

Some people with Long COVID experience worsening of symptoms after extreme exertion. You should carefully pace yourself when doing activities. Try to limit your stress and prioritize taking care of both your mental and physical health. If you are experiencing symptoms that are limiting your ability to return to your usual activities, it is important to reach out to your healthcare provider for more guidance.

Action Steps:

✓ Call your healthcare provider if you had COVID-19 and are still experiencing symptoms more than 4 weeks after the initial infection. Your healthcare provider can help you manage your symptoms and refer you for additional care if needed.

✓ Do not assume that any new symptoms are related to Long COVID as they could be unrelated and part of a different illness or disease process and require immediate attention.

✓ You should seek immediate care if you have any of the following:
  - Sudden and severe shortness of breath
  - Chest pain
  - Suicidal thoughts
  - Coughing up blood
  - Severe headache
  - Weakness on one side of the body and slurred speech

Healthcare Provider’s Contact Number:

Resources:

American Thoracic Society
- www.thoracic.org/patients
- COVID 19
- COVID 19 vaccines
- Post-ICU Syndrome (PICS)
- Pulmonary rehabilitation

Centers for Disease Control and Prevention

American Lung Association (ALA)

World Health Organization
- https://www.who.int/docs/default-source/coronaviruse/risk-comms-updates/update54_clinical_long_term_effects.pdf?sfvrsn=3e63ee5_8

WHO—Support for Rehabilitation Self-Management after COVID-19 Related Illness

This information is a public service of the American Thoracic Society. The content is for educational purposes only. It should not be used as a substitute for the medical advice of one’s healthcare provider.

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