

Understanding Post-COVID Syndrome

Having COVID-19 can cause long-term health effects.

Introduction

One of the biggest challenges from a SARS-CoV-2 (COVID-19) infection are the long-term health effects, called post-COVID syndrome.^{1,2}

Most recover from COVID-19 in a couple of weeks. However, unlike the common cold or flu, many people continue to experience symptoms or develop new ones long after the initial infection.³ These symptoms can be continuous or come and go.⁴ After an initial diagnosis with SARS-CoV-2, if symptoms persist for longer than 4 weeks, the culprit could be post-COVID syndrome.⁵

This document provides a summary of the post-COVID syndrome condition, based on current clinical research findings, including symptoms, testing, and patient resources.

Other Names for Post-COVID Syndrome⁶

- Long COVID
- Long-haul COVID
- Long-term effects of COVID
- Post-acute COVID-19
- Post-acute COVID syndrome
- PASC, or post-acute sequelae of SARS-CoV-2 infection
- Late sequelae
- Chronic COVID

What do scientists know about Post-COVID Syndrome?

Clinicians and researchers are still learning about post-COVID syndrome, including what causes it and how often it occurs. Public health officials around the world are trying to figure out what is causing post-COVID syndrome. Several leading theories about how post-COVID syndrome works include:^{6,7}

- Organ damage arising from the initial infection
- Immune system dysfunction, resulting in increased and unresolved inflammation
- Activation of new or exacerbation of existing autoimmune disease
- Reactivation of dormant, normally harmless viruses contracted years earlier, like Epstein-Barr virus

Researchers are actively studying how often post-COVID syndrome occurs, causes, risk factors, duration, and severity of symptoms after a SARS-CoV-2 infection. Future studies are needed to understand each symptom individually and together with others.

What does Post-COVID Syndrome look like?

● Symptoms

Post-COVID syndrome is a term that describes illness in people who report lasting effects of a SARS-CoV-2 infection. The ongoing nature of this illness can negatively impact the quality of life for the affected individual.⁸

Post-COVID syndrome looks different from person to person, but the most prevalent symptom is chronic fatigue.⁷ Often mistaken for tiredness, fatigue in the context of post-COVID syndrome can be described as utter exhaustion that affects daily living. Post-COVID fatigue can be accompanied by cognitive

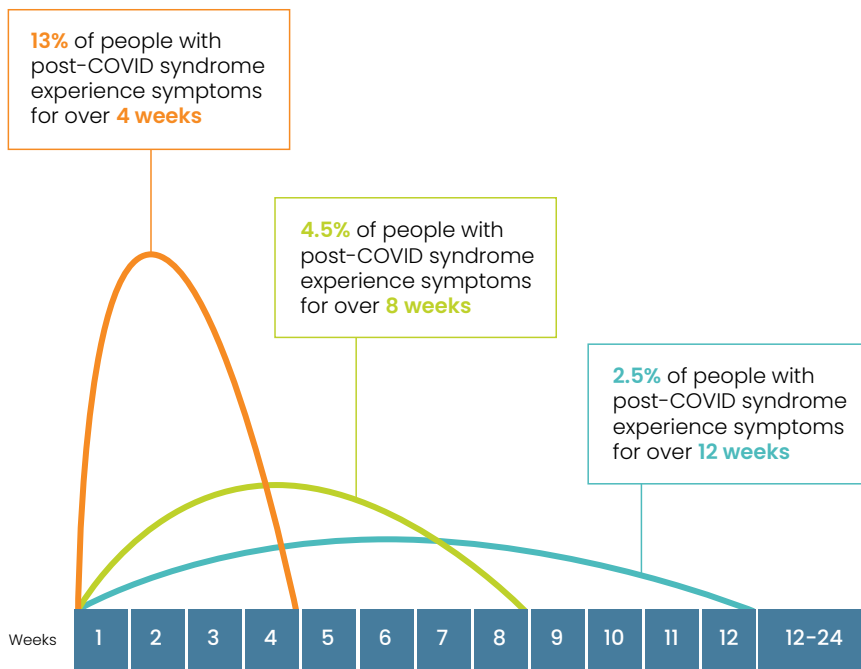


dysfunction symptoms, such as poor memory, difficulty concentrating, anxiety, depression, and/or overall “brain fog.”⁹ In addition, chest pains, breathlessness, and muscle aches/weakness are also common.⁹

● Population

Post-COVID syndrome can affect COVID-19 survivors at all levels of disease severity, including younger adults, children, and those individuals who have not been hospitalized.⁶

Reportedly, 10–30% of individuals who had COVID-19, had at least one persistent symptom present 6 months after their infection was cleared.⁹ Of these individuals, symptoms can last for varying amounts of time, as indicated in the chart below:¹⁰



Patients with post-COVID syndrome are not infectious. However, a person with post-COVID syndrome can have a secondary infection, like RSV or influenza. Therefore, it is important to continue to exercise care in preventive measures like wearing a mask, staying up-to-date on vaccines, and social distancing.

A Checklist of Post-COVID Syndrome Symptoms^{5,8,10,11}

- Fatigue
- Headaches
- Attention difficulties
- Depression
- Anxiety
- Brain fog
- Cognitive issues
- Memory loss
- Sleep apnea
- Hair loss
- Difficulty breathing
- Loss of smell
- Loss of taste
- Cough
- Rapid breathing/panting
- Chest pain/discomfort
- Nausea
- Hearing loss or tinnitus
- Joint pain
- Fever
- Dizziness
- Resting heart rate increase
- Chills
- Musculoskeletal pain
- Weight loss
- Hypertension
- Digestive disorders
- Limb swelling
- Numbness/tingling
- Post-exertional fatigue
- Muscle weakness

Who gets post-COVID syndrome?

Although post-COVID syndrome is poorly understood, clinical research suggests that having more than 5 symptoms in the first week of COVID-19 is a strong risk factor for developing post-COVID syndrome.¹⁰







Post-COVID syndrome can affect:

- Asymptomatic or mildly symptomatic people
- People with preexisting conditions
- Healthy people without previously known health conditions
- Communities where access to quality healthcare is limited¹²
- Although rare, post-COVID syndrome has been documented in children¹³
- People who experience higher instances of post-COVID syndrome include:
 - Vulnerable groups characterized by racial/ethnic disparities¹⁴
 - Healthcare workers

The potentially long-lasting problems from COVID-19 make it even more important to reduce the spread of COVID-19. Anecdotal evidence suggests that the COVID-19 vaccine may help lessen lingering COVID symptoms. Be sure to follow precautions, such as wearing masks, social distancing, avoiding crowds, getting a vaccine when available, and washing your hands.

Testing for post-COVID syndrome

There is currently no diagnostic test for post-COVID syndrome. However, COVID-19 tests can determine an active or past infection. A positive COVID-19 test is not required to diagnosis post-COVID syndrome. Testing for a reinfection of COVID-19 should be considered for a person with new or worsening symptoms.¹⁵

	 MOLECULAR TEST	 ANTIBODY TEST
Purpose of test	 To determine active infection	 To determine an immune response to COVID-19
Additional names	<ul style="list-style-type: none"> • Nucleic acid amplification test (NAAT) • Polymerase chain reaction (PCR) test • Transcription Mediated Amplification (TMA) Test 	<ul style="list-style-type: none"> • Serology test
Specimen type	 Nasopharyngeal swab	 Blood test
What do results mean?	<ul style="list-style-type: none"> • Majority of people with post-COVID syndrome test negative with a molecular test, indicating microbiological recovery (there is no active infection taking place) • A positive test may indicate the need to quarantine in order to prevent infecting others 	<ul style="list-style-type: none"> • Should be collected at least 14-21 days after the onset of symptoms or known exposure • Two types of antibody tests: <ul style="list-style-type: none"> • Spike Protein Antibody Test: If positive, may indicate prior infection, or an immune response to COVID-19 vaccination. There are no FDA authorized tests for individuals who have received a COVID-19 vaccination, and performance characteristics or clinical significance of authorized antibody tests have not been established. • Nucleocapsid Protein Antibody Test: If positive, indicates a prior or recent infection.

What tests can be done to help evaluate post-COVID syndrome?

The CDC has provided interim guidance on caring for patients with post-COVID conditions, including patient-centered care to improve the quality of life in affected individuals. For example, healthcare professionals and patients are encouraged to set achievable goals through shared decision-making and by focusing on specific symptoms and conditions. Guidance for healthcare professionals will likely evolve over time as clinical research continues to make advances in our understanding of COVID-19. These guidelines are to evaluate patients for any non-COVID conditions that are treatable and manageable.

Basic diagnostic lab testing:

- CBC, electrolytes, renal function
- Liver function
- Inflammatory markers
- Thyroids
- Vitamin deficiencies

Specialized diagnostic lab testing:

- Rheumatological conditions
- Coagulation disorder
- Myocardial injury
- Differentiate symptoms – cardiac or pulmonary
- Vitamin deficiencies

Advanced testing:

- Pulmonary imaging
- Echocardiogram & electrocardiogram

Conclusion

This document presents the current understanding of post-COVID syndrome, a new and puzzling condition that affects COVID-19 survivors, regardless of initial disease severity or age. While symptoms vary from person to person, the hallmark of post-COVID syndrome are the lingering symptoms that last more than 4 weeks after a COVID-19 infection.

● Additional resources & support

It can be scary navigating a disease that even the medical community is still researching. If you or your loved ones are experiencing the long-term health effects of COVID-19, the resources below may be helpful in understanding and navigating the condition.

ORGANIZATION	LOCATION
Survivor Corps	Global
Long COVID Alliance	Global
RECOVER, an initiative from the National Institutes of Health (NIH)	National
George Washington University: Covid-19 Recovery Center	DC
Emory Executive Park Post-COVID Clinic and Grady Memorial Hospital Post-COVID Clinic	GA
Johns Hopkins Post-Acute COVID-19 Team (PACT)	Maryland
Kennedy Krieger Institute – Pediatric Post COVID-19 Rehabilitation Clinic	Maryland
Beth Israel Deaconess Medical Center Critical Illness and COVID-19 Survivorship Program	Massachusetts
Boston Children’s Hospital – Post-COVID clinic	Massachusetts
Brigham and Women’s Hospital COVID Recovery Center	Massachusetts
CS Mott Children’s Hospital – University of Michigan Health – Pediatric Post-COVID Syndrome Clinic	Michigan
University of Michigan Health – Multidisciplinary Post COVID-19 Clinic (COVID-19 Long Haul Clinic)	Michigan
Virtua Health Care After COVID Program	New Jersey & National via telehealth
Mount Sinai – Center for Post-COVID Care	New York

References

1. Raveendran AV, Misra A. Post COVID-19 Syndrome (“Long COVID”) and Diabetes: Challenges in Diagnosis and Management [published online ahead of print, 2021 Jul 28]. *Diabetes Metab Syndr.* 2021;15(5):102235. doi:10.1016/j.dsx.2021.102235
2. Phillips S, Williams MA. Confronting Our Next National Health Disaster – Long-Haul Covid. *N Engl J Med.* 2021;385(7):577–579. doi:10.1056/NEJMp2109285
3. Centers for Disease Control and Prevention (CDC). Post-COVID Conditions. Updated September 16th, 2021. Accessed September 23, 2021. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>
4. Nabavi N. Long covid: How to define it and how to manage it. *BMJ.* 2020;370:m3489. Published 2020 Sep 7. doi:10.1136/bmj.m3489
5. Nalbandian A, Sehgal K, Gupta A, et al. Post-acute COVID-19 syndrome. *Nat Med.* 2021;27(4):601–615. doi:10.1038/s41591-021-01283-z
6. Yong SJ. Long COVID or post-COVID-19 syndrome: putative pathophysiology, risk factors, and treatments. *Infect Dis (Lond).* 2021;53(10):737–754. doi:10.1080/23744235.2021.1924397
7. Reddy S. Are Latent Viruses Causing Long Covid-19 Symptoms? Patient Groups Push for Testing. *Wall Street Journal.* Published July 13, 2021. Accessed September 23, 2021. <https://www.wsj.com/articles/are-latent-viruses-causing-long-covid-19-symptoms-patient-groups-push-for-testing-11626181200>
8. Davis HE, Assaf GS, McCorkell L, et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine.* 2021;38:101019. doi:10.1016/j.eclinm.2021.101019
9. Huang C, Huang L, Wang Y, et al. 6-month consequences of COVID-19 in patients discharged from hospital: a cohort study. *Lancet.* 2021;397(10270):220–232. doi:10.1016/S0140-6736(20)32656-8
10. Sudre CH, Murray B, Varsavsky T, et al. Attributes and predictors of long COVID [published correction appears in *Nat Med.* 2021 Jun;27(6):1116]. *Nat Med.* 2021;27(4):626–631. doi:10.1038/s41591-021-01292-y
11. Carvalho-Schneider C, Laurent E, Lemaignan A, et al. Follow-up of adults with noncritical COVID-19 two months after symptom onset. *Clin Microbiol Infect.* 2021;27(2):258–263. doi:10.1016/j.cmi.2020.09.052
12. Cooney E. Researchers fear people of color may be disproportionately affected by long Covid. *Stat News.* Published May 10, 2021. Accessed September 23, 2021. <https://www.statnews.com/2021/05/10/with-long-covid-history-may-be-repeating-itself-among-people-of-color/>
13. Lewis D. Long COVID and kids: scientists race to find answers. *Nature.* vol. 595(7868), pages 482–483, Published July 22, 2021. Accessed September 23, 2021. https://ideas.repec.org/a/nat/nature/v595y2021i7868d10.1038_d41586-021-01935-7.html
14. Berger Z, Altiery DE, Jesus V, Assoumou SA, Greenhalgh T. Long COVID and Health Inequities: The Role of Primary Care. *Milbank Q.* 2021;99(2):519–541. doi:10.1111/1468-0009.12505
15. Centers for Disease Control and Prevention (CDC). Assessment and testing: Evaluating and Caring for Patients with Post-COVID Conditions: Interim Guidance. Updated June 4, 2021. Accessed September 23, 2021. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-assessment-testing.html>