

NEW YORK STATE NURSES ASSOCIATION

# LONG-COVID GUIDE

APRIL 2023

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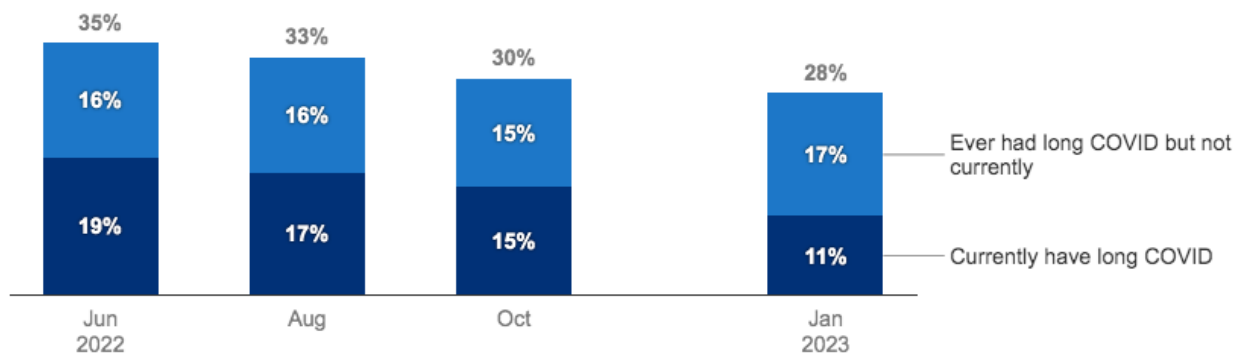
# INTRODUCTION

A U.S. Government Accounting Office report issued in March 2022 estimates that between 7.7 million and 23 million people in the United States have experienced long COVID.<sup>1</sup> Another report in 2022 showed more than 1 million (up to as many as 4 million) out of work because of their long COVID symptoms.<sup>2</sup>

Figure 1

## Among People Who Have Had COVID, the Percentage who Currently Have Long COVID is Declining

Percentage of people reporting that they currently have or ever had long COVID among those who have had COVID as of January 16, 2023



NOTE: The Pulse Survey, an experimental survey conducted by the Census Bureau and National Center for Health Statistics, asked respondents whether they had any symptoms of COVID that had lasted longer than 3 months. This figure reports the findings as of 6/13/2022, 8/8/2022, 10/17/2022, and 1/16/2023.

SOURCE: National Center for Health Statistics. Post-COVID Conditions. Data accessed Jan 26, 2023. Available from: <https://data.cdc.gov/d/gsea-w83j>. • PNG

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Knowledge about the causes, risk factors and treatments for long COVID continues to improve. Data shows that, for many individuals with long COVID, most symptoms do eventually dissipate.<sup>3</sup> In addition, the rate of new long-COVID cases is declining.<sup>4</sup> While these are welcome developments, long COVID remains a devastating long-term result of a short-term acute infection for millions of people.

NYSNA has developed this guide to provide up-to-date information on long COVID and resources for further information and support. Please keep in mind that, as new information about the SARS-CoV-2 virus, treatment for acute and long-term COVID-19 illness, vaccines and virus mutations becomes available, some of the information contained herein may become outdated.

The intention of this guide is not to recommend specific medical care or treatment. Contact your personal medical provider, an occupational health clinic or a long-COVID clinic (see the Long-COVID Resources section) for medical care and advice.

And remember — the best way to avoid long COVID is to prevent COVID-19 infection and reinfection in the first place. If you need assistance regarding health and safety issues in your workplace, please contact your NYSNA facility representative and the NYSNA Occupational Health and Safety Representatives at [healthandsafety@nysna.org](mailto:healthandsafety@nysna.org).

# WHAT IS LONG COVID?

Officially known as Post-Acute Sequelae of COVID-19, the U.S. Centers for Disease Control and Prevention (CDC) defines long COVID as “a wide range of new, returning, or ongoing health problems that people experience after being infected with the virus that causes COVID-19.”<sup>5</sup> Symptoms typically begin four to 12 weeks after the initial COVID-19 infection.<sup>6</sup> Long COVID can develop after asymptomatic, mild or severe acute infection. These post-acute symptoms can be minor or severe. Over 200 long-COVID symptoms have been identified.<sup>7</sup> The most common symptoms of long COVID are:

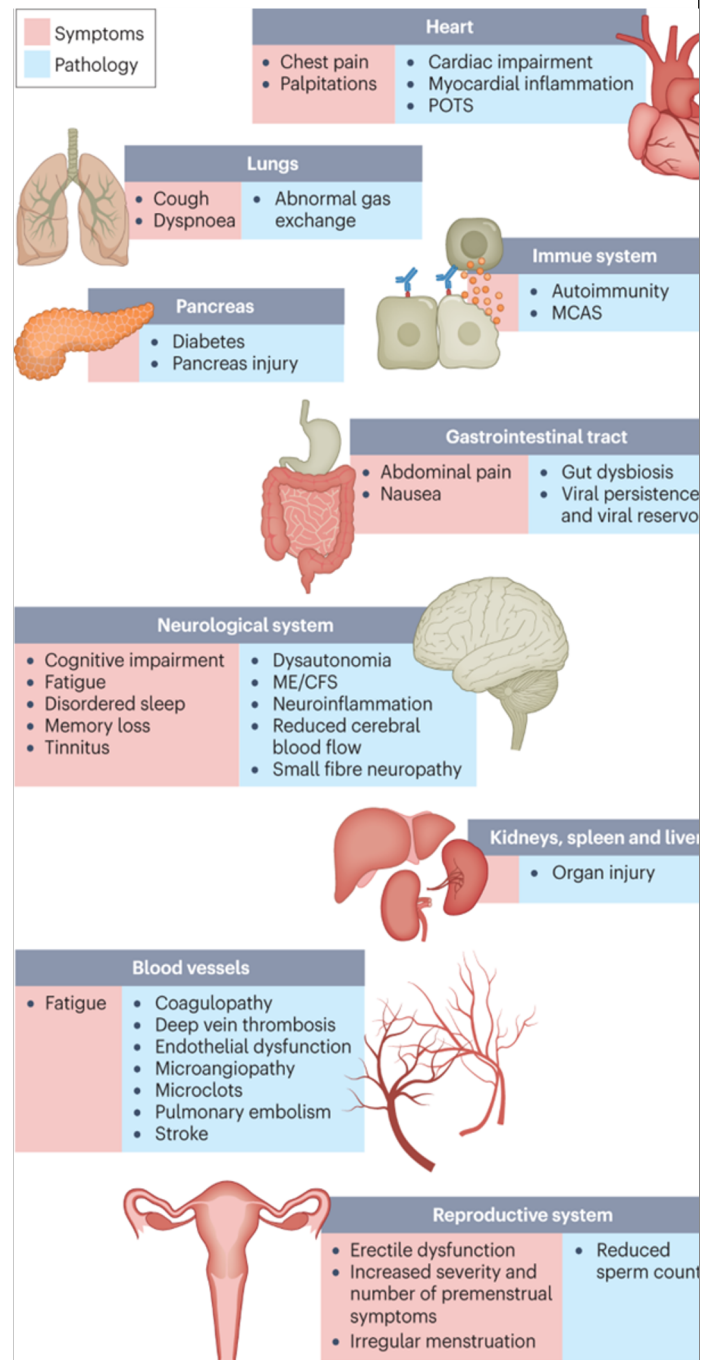
- Fatigue/post exertional malaise
- Shortness of breath
- Cough
- Joint or muscle pain
- Cognitive problems (thinking and memory)
- Depression and/or anxiety
- Loss of smell and/or taste
- Insomnia
- Fever
- Gastrointestinal symptoms
- Rash
- Changes in menstrual cycle

Other frequent, though less common, symptoms include cardiovascular and circulatory issues, postural tachycardia syndrome, blood clots, tinnitus, dizziness, headache, and “pins and needles.”

## Long-term Impacts

In some cases, damage to the heart, kidneys, lungs and other organs has been identified. One study, conducted in the U.K., found that 59% of long-COVID patients had organ impairment one year after acute COVID infection, and 29% had multi-organ impairment.<sup>8</sup> Another study, conducted in China, found that two years after acute infection, 39% of study participants had persistent interstitial lung abnormalities.<sup>9</sup>

## Long COVID symptoms and the impacts on numerous organs with differing pathology



Source: *Nature Reviews Microbiology*, 1/13/2023. ISSN 1740-1534



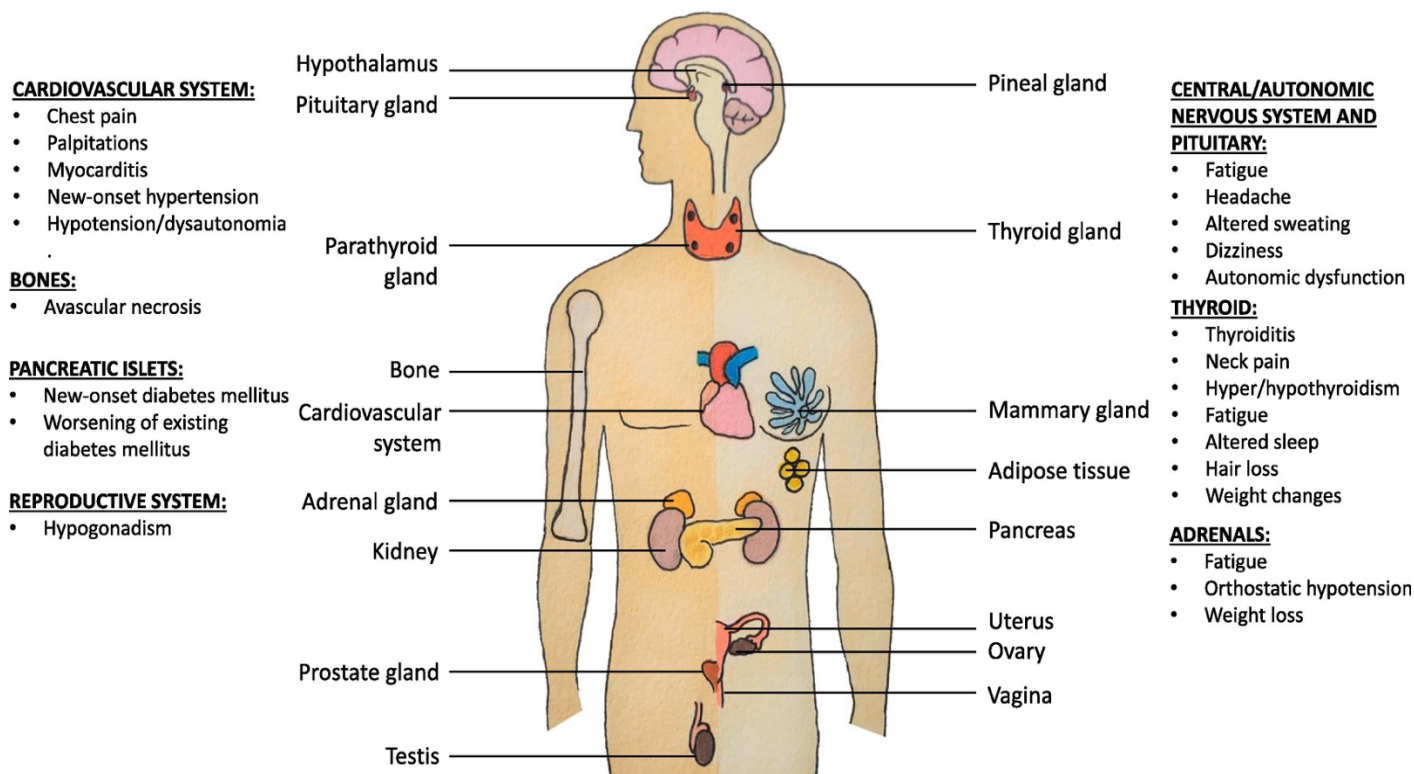
Severe acute COVID-19 infection frequently attacks the kidneys. However, a study that the University of St. Louis conducted determined that even those who did not experience kidney disease during the acute COVID-19 infection period had a higher rate of kidney disease upon follow-up at 30 days and six months post infection. The study found that those who have experienced a mild COVID-19 infection carry a higher risk of long-term kidney disease as well.<sup>10</sup> Because kidney disease often does not cause symptoms until the disease reaches an advanced stage, it is important for medical providers to monitor patients for early markers of kidney dysfunction.

A large study has found a small but statistically significant decreased brain volume after COVID-19 infection.<sup>11</sup> More specifically, patients experiencing anxiety and depression had shrinkage in the limbic area of the brain as well as changes in the brain's communication systems.<sup>12</sup> Structural changes to the thalamus

and basal ganglia have also been identified in individuals experiencing persistent fatigue after a COVID-19 infection.<sup>13</sup> One possible reason for these changes in brain structure is SARS-CoV-2's ability to damage the blood-brain barrier, which protects the brain from toxins and pathogens that can cause damage.<sup>14</sup>

An analysis of U.S. Department of Veterans Affairs databases shows that, one year after COVID-19 infection, patients had a higher risk for cardiovascular disease, including cardiac arrest, heart failure, pulmonary embolism and stroke.<sup>15</sup> The data also reveals an increased risk of adverse kidney outcomes<sup>16</sup> and type 2 diabetes.<sup>17</sup>

Endocrine system dysfunction is also a likely causal factor for a number of common long-COVID symptoms.<sup>18</sup> For example, studies have identified low cortisol levels in many long-COVID patients who suffer from chronic fatigue.<sup>19</sup>



Source: Bansal, R., Gubbi, S., Koch, C.A. 2012. COVID-19 and chronic fatigue syndrome: An endocrine perspective. *Journal of Clinical & Translational Endocrinology*. Vol 27.

While most people with long COVID experience symptoms that range from mild to debilitating, long COVID may have more severe consequences for some. A recent CDC report found over 3,500 deaths that mentioned long COVID in the death certificate from the period of Jan. 1, 2020, to June 30, 2022.<sup>20</sup> The data analysis found the highest long-COVID fatality rates among men, those 85 or older, and American Indian and Alaska Native people. However, the cause of death listed on death certificates can be affected by an individual's ability to obtain a long-COVID diagnosis as well as the way the main cause of death is identified. Because of these limitations, it is likely that the fatality rate for long COVID is higher than currently estimated.

## Medium COVID

The medical and scientific communities now recognize long-COVID chronic conditions; however, some researchers have identified a

middle period, referred to as “medium COVID,” as a high-risk time for severe medical complications and an increased risk of fatalities. For example, a review of Sweden’s National Health Registry shows a 32 times higher rate of pulmonary embolism one month after acute COVID-19 infection. That risk dropped back to normal after four months.<sup>21</sup> The risk of heart attack and stroke also increases significantly immediately after acute COVID-19 infection. Another study using Swedish data found that the risk of heart attack was three to eight times higher one week after acute COVID-19 infection, and the risk of ischemic stroke was three to six times higher. Over the next few weeks, the risk decreased until returning to normal approximately one month after acute infection.<sup>22</sup> Medical providers should inform patients about this period of higher risk and notify them about what symptoms require immediate medical follow-up.

## WHAT CAUSES LONG COVID?

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There are several causes of the symptoms associated with long COVID. The following are the five most likely causes that researchers have identified:<sup>23</sup>

1. **Autoimmune response**, which causes the immune system to attack one’s own body, often resulting in localized or systemic inflammation and damage to the body.
2. **Viral persistence**, in which remnants of the SARS-CoV-2 virus remain in the body, continuing to cause illness.
3. **Organ damage** caused during the acute phase of the illness, such as permanent damage to the lungs causing long-term shortness of breath.
4. **Microclots** that form in blood vessels, limiting blood flow, which may result in tissue damage.

5. **Disruption of the immune system**, allowing dormant viruses, such as Epstein-Barr and other herpesviruses, to reactivate.

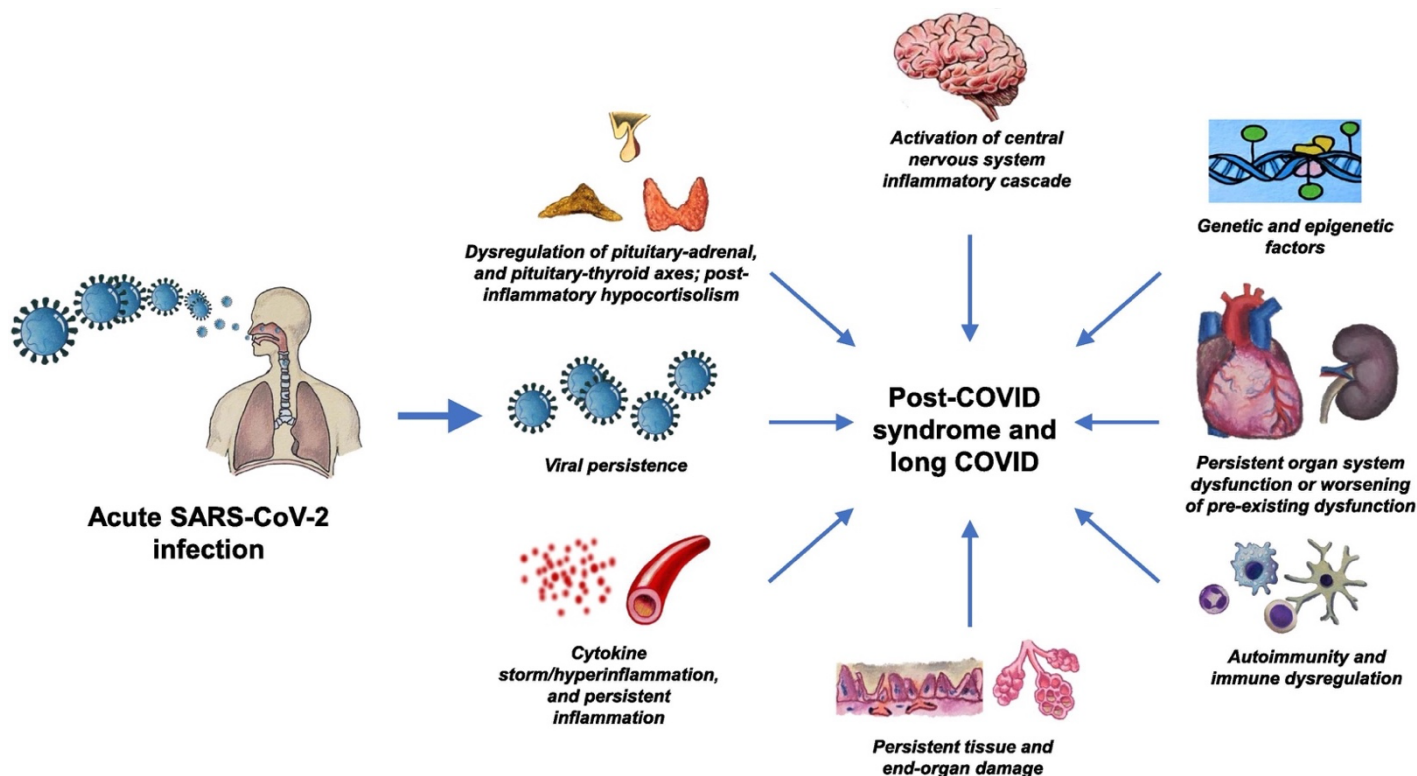
New research has also found other interesting possible causes of long-COVID symptoms and organ damage. Researchers at Columbia University, for example, examined autopsied heart tissue from patients who had died of COVID-19. Their study found that the infection caused damage to cells that regulate calcium levels. The same damage was identified in other parts of the body of mice infected with COVID-19. Calcium ions help regulate heart and other organ function.<sup>24</sup>

# Immune Response and COVID

Medical providers and researchers recognized very early on in the COVID-19 pandemic that immune response played a significant role in causing COVID-19 and long-COVID symptoms. However, recent studies are teasing out some of the specific causes of immune dysregulation. One study, which compares phenotypic characterizations of SARS-CoV-2 T cells in long-COVID and non-long-COVID individuals, was able to identify unique features in the T cells of individuals experiencing long COVID.<sup>25</sup> The study also found variations in the T cell characteristics and locations in women and men. This may provide some insight into one of the reasons men and women experience long-COVID symptoms at different rates. Also identified in the study was a dysregulation between T cells and B cells, both of which are important parts of the body's immune response.

T cells and B cells must communicate with each other in an organized way to effectuate a proper immune response. Without this communication, the immune system can under- or overreact to an infectious pathogen. Fully recovered individuals not suffering from long COVID were found to have a coordinated T cell and B cell response.

There is no one test to determine whether someone is suffering from long COVID, and it is not always possible to determine what the cause of specific symptoms is. Personal health history, history of prior COVID-19 infection, symptomology and risk factors must all be taken into consideration. Long-COVID clinics, which specialize in diagnosis and treatment, are now available throughout the country (see the Long-COVID Resources section for more information). Studies on treatment protocols are ongoing with a goal of determining the most effective treatments for different symptoms and disorders.



Source: Bansal, R., Gubbi, S., Koch, C.A. 2012. Covid-19 and chronic fatigue syndrome: an endocrine perspective. *Journal of clinical & translational endocrinology*. Vol 27.

# LONG COVID'S ECONOMIC IMPACT

## Total economic cost of long Covid

Long Covid is estimated to cost about \$3.7 trillion. Here's the breakdown.

Reduced quality of life

\$2.2T

Reduced earnings

\$997B

Increased medical expenses

\$528B

Note: Costs based on 80.5 million confirmed U.S. Covid cases at time of analysis.  
Figures do not account for future caseloads.

Chart: Mike Winters and Morgan Smith

Source: David M. Cutler, Harvard University



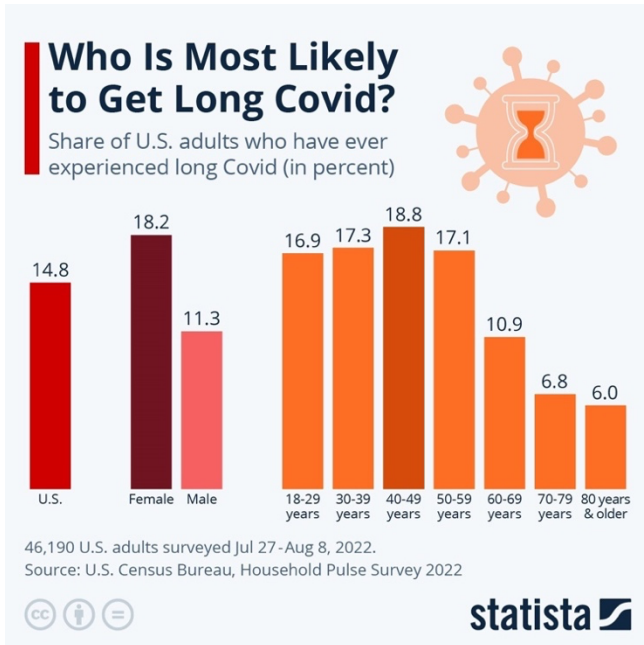
The public health and economic implications of the millions of people suffering from long COVID cannot be overestimated. Both a Bookings Institution report,<sup>26</sup> based on the U.S. Census Bureau's Household Pulse Survey, and a separate estimate run by Harvard economist David Cutler<sup>27</sup> estimate that lost wages due to long COVID equal approximately \$200 billion per year.

A study recently released by the New York State Insurance Fund, New York's largest insurance carrier, found that during the first two years of the pandemic, over 70% of people the Fund identified as experiencing long COVID required continuing medical treatment or were unable to work for six months or more. Almost 20% were still unable to work after a year. Nearly one-third of New York State workers' compensation cases for COVID-19 were for long COVID. These long-COVID claims were responsible for over 80% of the funds paid out in workers' compensation for COVID-19 cases.<sup>28</sup>

In a November 2022 speech to the Hutchins Center for Fiscal and Monetary Policy at the Brookings Institution, Federal Reserve Chair Jerome Powell acknowledged the significant effect long COVID has had on the workforce, stating that "Some of the participation gap reflects workers who are still out of the labor force because they are sick with COVID-19 or continue to suffer lingering symptoms from previous COVID infections ('long COVID')." <sup>29</sup>



# RISK FACTORS FOR DEVELOPING LONG COVID



A number of risk factors put certain people at higher risk of continued symptoms long past the acute COVID-19 infection period. Here are some of the most common factors that increase the risk of developing long COVID:

## Age

The Pulse Study, a large study that the U.S. Census Bureau conducted in 2022, finds that rates of long COVID are highest among people in their working years — from 18-59 years old. Within this age range, the highest rate falls into the 40-49 age group. It is possible that the rate of long COVID falls off precipitously after age 59 because a greater percentage of people 60 and older die from their acute infection than younger people.<sup>30</sup>

## Gender

Numerous studies have determined that women are more likely to experience long COVID than men.<sup>31</sup> While it is not known exactly why this is the case, one theory is that, in general, women have stronger immune systems than men. An overactive immune response is believed to cause some long-COVID symptoms.

## Race

Racial breakdown of long-COVID sufferers shows that Hispanics/Latinx people experience the highest rate of long COVID (20%), followed by white (14%), Black (13%) and Asian (10%) people.<sup>32</sup> Many factors may play into these differences, including access to healthcare, comorbidities, job risk (high COVID-exposure jobs), vaccination status and home living conditions (multigenerational households). Those groups that experienced higher rates of COVID-19 infection also experience higher rates of long COVID.

## Severity of acute infection

A systemic review and meta-analysis that the European Centre for Disease Prevention and Control conducted looked at whether those who experienced severe enough COVID-19 symptoms to require hospitalization had higher rates of long COVID.<sup>33</sup> The review determined that, for five long-COVID symptoms — fatigue, shortness of breath, depression, headache and dizziness — long-COVID rates were higher for those who had been hospitalized due to their acute infection than for those who did not require hospitalization.

## Comorbidities

Many studies have been conducted on comorbidities that increase the risk of developing long COVID. A few studies are listed below.

A large-scale study conducted in the U.K. of nonhospitalized patients with long COVID found a number of comorbidities that increased the risk of developing long COVID.<sup>34</sup> Comorbidities found to increase the risk of long COVID include:

- Smoking
- High BMI
- COPD
- Depression
- Anxiety
- Asthma.
- Eczema



A study of over 200 patients (71% hospitalized, 29% outpatient) at the Swedish Medical Center in Washington involved taking nasal swabs and blood samples from patients at the time of their acute infection, conducting a series of tests and then following up with patients two to three months later to determine who was experiencing long COVID.<sup>35</sup> The study identified the following four risk factors for long COVID:

- High levels of SARS-CoV-2 virus RNA in the blood early in the infection (indicative of high viral load).
- Presence of certain autoantibodies that mistakenly attack tissue.
- Reactivation of previously dormant Epstein-Barr virus.
- Type II diabetes.

Data obtained from the U.S. Veterans Affairs Corporate Data Warehouse was used to analyze almost 200,000 patients with COVID-19 in 2020 and 2021.<sup>36</sup> This data revealed that the comorbidities most likely to cause long COVID include:

- COPD
- Asthma
- Congestive heart failure
- Prior myocardial infarction
- Cerebrovascular disease
- Chronic kidney disease
- Diabetes

In addition, this study found that those receiving opioids or calcium channel blockers were also at higher risk of developing long COVID.

Research continues into both the risk factors for long COVID in general and for specific symptoms of long COVID.

### **Vaccination status**

Several studies have found a correlation between COVID-19 vaccination and decreased risk of developing long COVID.<sup>37</sup> However, the mechanism by which vaccination decreases risk is not fully understood and requires further study. One theory is that, if the vaccine clears the virus from the body faster, it decreases the risk of damage due to the virus itself and

damage from immune response. Another is that, because one risk factor for developing long COVID is severity of disease and vaccination can be protective of developing severe disease, those who are vaccinated have a decreased risk of developing long COVID. Further studies are needed to determine whether the type of vaccine, the time since vaccination and the role of booster shots affect the likelihood of developing long COVID.

### **Anti-viral treatment**

A large study (not yet peer reviewed) conducted of Veterans Affairs patients has found that treatment with nirmatrelvir (Paxlovid) within five days of symptom onset or positive COVID-19 test result decreased the risk of developing many common symptoms of long COVID by 26%.<sup>38</sup> These long-COVID symptoms include:

- Fatigue
- Shortness of breath
- Muscle pain
- Blood clotting problems
- Cardiovascular problems
- Liver disease
- Acute kidney disease
- Neurocognitive impairments like brain fog

Treatment with Paxlovid did not decrease the risk of developing new-onset diabetes and cough. This study is limited in that the cohort used for this analysis was predominantly male, white and older — therefore not fully representative of the general public. Also, only those infected persons who have at least one risk factor for severe disease can be prescribed Paxlovid. It is unclear from the study whether the reduction in risk of developing long COVID would carry over to a population that has no risk factors for developing severe disease.

# LONG-COVID DIAGNOSIS & TREATMENT

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*(Please note: This guide is not meant to provide treatment recommendations or advice. Please contact your personal healthcare provider, an occupational health clinic, or reach out to a long-COVID clinic for medical guidance.)*

When long COVID was first recognized, few diagnostic or treatment options were understood or available. That has changed significantly in a relatively short time. There is no “silver bullet” treatment, but effective interventions are now available for many long-COVID symptoms, and new protocols are constantly being studied to improve overall treatment.

## What to Expect: Diagnosis

At this time, there is no single diagnostic test for long COVID. However, work is underway on tests using biomarkers that will be able to identify long COVID in general, not just specific symptoms. Until that is achieved, diagnosis will involve the healthcare provider obtaining a detailed clinical history from the patient. Based on this information, the provider can make a determination on long-COVID status. According to the World Health Organization, long COVID is defined as “the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.”<sup>39</sup>

To obtain a detailed clinical history, the provider will have to take a significant amount of time to talk and listen to patients regarding the onset, continuation and nature of each patient’s COVID-19 illness and symptoms. The provider may or may not order imaging and other diagnostic tests. However, even if this testing occurs, it should not be the sole determinant of whether or not a patient has long COVID. These are the practice guidelines at this time, meaning that the employer, insurance provider and workers’ compensation system, if applicable, will have to accept the provider’s determination.<sup>40</sup> Long-COVID sufferers are well advised to keep a symptoms journal that they can then refer to when seeing medical providers. If a journal is not

possible, the patient may create a list from memory of their symptom histories. This documentation will help provide an accurate record for the treating healthcare professional.

## What to Expect: Treatment

There are currently no broadly effective treatments that address all long-COVID conditions. Instead, there are a host of different strategies that focus on each of the different, individual sequelae of long COVID. Those being treated should review with their provider the different strategies that are available for each of their symptoms. A primary provider may have to refer long-COVID patients to different medical specialists to determine possible treatments for different symptoms or organ systems.

A recent review article in *Nature Reviews Microbiology*,<sup>41</sup> lists 20 different measures for many of the common conditions associated with long COVID, along with reference to supporting evidence for each (see the table on page 12).

Another treatment resource is the *Long COVID Handbook*, published in 2022.<sup>42</sup> This comprehensive resource reviews a host of potential treatment options and evaluates the relative strength or weakness of supporting evidence. The book emphasizes the importance of randomized controlled trials (RCTs) in determining the efficacy of treatments. At this point in time, there is only one published account of an RCT on long COVID. With time, many more RCTs are likely to become available.

A major concern associated with treatment options at this time is related to how healthcare is deployed and the possible impact of bias in the treatment of long-COVID symptoms. Several factors come into play here, including:

- The majority of long-COVID patients are women. Medicine has historically failed to take into account health and treatment variables for women.<sup>43</sup> There is a very specific and long-standing problem with how the medical establishment has viewed and managed certain conditions prevalent in women — such as chronic fatigue, postural orthostatic tachycardia syndrome (POTS) and immune dysfunction, for example. Some of the differences between women and men regarding certain conditions and treatments are still vastly understudied.<sup>44</sup>
- Racial and economic disparities in health and healthcare are a fact in the U.S.<sup>45</sup> Disparities already play a big role in a range of serious health conditions, such as diabetes, high blood pressure and asthma. Some of these same disparities also play a role in access to treatment for long COVID. Certain racial groups suffer higher rates of long COVID than other groups (see the Risk Factors for Developing Long COVID section for more information) and often have a harder time accessing healthcare in general. Although the U.S. government made certain tests and treatments for acute COVID-19 infection free while a federal health emergency was in effect, treatment for long COVID has not been included in these government-funded programs. Ending federal funding will likely increase healthcare disparities.
- The multiplicity of symptoms and conditions can make it more difficult to obtain good care from just one general practitioner. Multiple specialists may be needed, which may or may not complicate and/or delay care delivery and may make it harder for some individuals to access care than others.
- Long-COVID specialist access may be difficult. While large urban centers such

as New York City may have many specialized clinics for the care of long-COVID sufferers, this may not be the case in many other parts of the country.<sup>46</sup>

Current treatment protocols and trials focus on the causes of specific symptoms and already-known treatments for diseases that cause similar sequelae. For example, symptoms that an overactive or dysregulated immune response likely cause may be treated with steroids, which have been used for some time to treat autoimmune diseases. Symptoms that viral persistence may cause are being treated with antiviral medications such as Paxlovid, which is used to stop viral replication during acute COVID-19 illness. Naltrexone, a drug found to be somewhat effective for treatment of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is being used to treat neurological symptoms experienced by some long-COVID sufferers. Some cognitive symptoms are being treated with the same protocols used for post-concussive conditions.

Some very interesting work has been done around the use of pacing, breathing exercises and physical therapy methods, including autonomic rehabilitation. (See the Long COVID Physio website in the Long-COVID Resources section for more information on these modalities.)

It is extremely important for individuals with long COVID to know that effective treatment options are available for many components of the disease, and their healthcare providers need to be aware of the latest proven interventions that are safe for each patient. There are several long-COVID clinics to choose from (see the Long-COVID Resources section for more information) if patients are concerned that they are not getting adequate assessment and treatment with other providers. In the future, many more trials and studies will take place that may shed further light on viable diagnostic and treatment options.

## Summary of candidate treatments and supporting evidence<sup>47</sup>

Symptoms and/or biological mechanism	Treatments	Supporting evidence	Comments
Postexertional malaise	Pacing	ME/CFS literature	Exercise, cognitive behavioural therapy and graded exercise therapy are contraindicated
POTS	Pharmacological: $\beta$ -blockers, pyridostigmine, fludrocortisone, midodrine	POTS and ME/CFS literature	Options can be prioritized on the basis of a specific constellation of symptoms
	Non-pharmacological: increase salt and fluid intake, intravenously administered salt, compression stockings	POTS and ME/CFS literature	–
Immune dysfunction	Intravenous immunoglobulin	ME/CFS literature	Consider consulting an immunologist on implementation
Cognitive dysfunction	Cognitive pacing	ME/CFS literature	Consider implementation alongside pacing physical exertion
Cognitive dysfunction	Postconcussion syndrome protocols	ME/CFS and postconcussion syndrome literature	–
Fatigue	Coenzyme Q10, d-ribose	ME/CFS literature	–
Pain, fatigue, neurological symptoms	Low-dose naltrexone	ME/CFS and other literature	Substantial anecdotal reports of success within the patient community
Fatigue, unrefreshing sleep, brain fog	Low-dose aripiprazole	ME/CFS literature	–
Autoimmunity	BC007	Long COVID case report	Neutralizes G protein-coupled receptor autoantibodies
Abnormal clotting	Anticoagulants	Long COVID pilot study	Additional trials in progress
Abnormal clotting	Apheresis	ME/CFS literature, long COVID pilot study	–
Viral persistence and antivirals (COVID-19)	Paxlovid	Long COVID case reports	No active trials, despite strong evidence for viral persistence
Viral persistence and antivirals (reactivations such as of EBV, HCMV and VZV)	Valaciclovir, famciclovir, valganciclovir and other antivirals	ME/CFS literature	–
Endothelial dysfunction	Sulodexide	Long COVID pilot study	–
Gastrointestinal symptoms	Probiotics	Long COVID pilot study	Resolved gastrointestinal and other symptoms
Dysautonomia	Stellate ganglion block	Long COVID case report	Effects may wane over time and require repeated procedures
Endothelial function, microcirculation, inflammatory markers and oxidative stress	Pycnogenol	COVID-19 pilot study	–
MCAS	H1 and H2 antihistamines, particularly famotidine	Long COVID case reports, MCAS literature	Expected to treat symptoms, not underlying mechanism
Autonomic dysfunction	Transcutaneous vagal stimulation	Long COVID pilot study	–



# LONG-COVID BENEFITS & RIGHTS

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## Workers' Compensation

If the COVID-19 infection that resulted in long COVID was likely caused by a work-related exposure, then you may be entitled to workers' compensation benefits. These benefits may include lifetime coverage of medical expenses related to your long-COVID condition, a portion of your salary due to lost work time and other benefits due to certain permanent disabilities.

To qualify for workers' compensation benefits, you must notify your employer of your acute COVID-19 infection that resulted in long-COVID symptoms within 30 days. You must file for workers' compensation with the New York State Workers' Compensation Board within two years of your acute COVID-19 infection that resulted in long-COVID symptoms.

Find long COVID information on the New York State Workers' Compensation Board website at <http://www.wcb.ny.gov/covid-19/information-workers.jsp#long-haul>.

For assistance or more information, please contact NYSNA Occupational Health & Safety representatives at [healthandsafety@nysna.org](mailto:healthandsafety@nysna.org).

## Social Security Disability

If a person with long COVID has one or more disabilities that have lasted, or will last, for 12 months or longer and that prevent the employee from doing their job, they may qualify for Social Security Disability (SSD). Please note that no benefits are paid for the first six months of disability. However, you can file for SSD at any time. Find information on applying for SSD benefits at [www.ssa.gov/benefits/disability/](https://www.ssa.gov/benefits/disability/)

## Disability Accommodations in the Workplace

If one or more long-COVID symptoms substantially limit one or more major life activities, an employee may be entitled to workplace accommodation under the Americans with Disabilities Act (ADA). The ADA requires the employer to make reasonable accommodations for workers with disabilities who, with these accommodations, can perform the essential job functions.

Find more information on long COVID and the ADA at

<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html> and <https://blog.dol.gov/2021/07/06/workers-with-long-covid-19-may-be-entitled-to-accommodations>.

## Protection from Workplace Discrimination

The U.S. government considers long COVID to be a disability if any of its symptoms, either physical or mental, substantially limit one or more major life activities. People whose long COVID qualifies as a disability are entitled to the same protections from discrimination as any other person with a disability. Laws that protect disabled workers include the ADA, the Rehabilitation Act of 1973 and the Affordable Care Act.

Find more information on workplace protection against discrimination due to long-COVID disability at <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>.

# LONG-COVID RESOURCES

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## **Survivor Corps**

[www.survivorcorps.com](http://www.survivorcorps.com)

Survivor Corps is one of the largest grassroots movements providing education and resources for COVID-19 patients, connecting them with medical and scientific research efforts and helping with the national response. The Survivor Corps website can identify long-COVID treatment centers in your geographic area.

## **New York State Workers' Compensation Board**

<http://www.wcb.ny.gov/covid-19/information-workers.jsp#long-haul>

If you have ongoing medical issues due to work-related COVID-19 or your long COVID symptoms cause you to miss work, you may be eligible for free medical care and/or lost wage replacement through workers' compensation insurance.

## **U.S. Department of Health and Human Services**

<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>

This guidance explains that long COVID can be a disability under Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Patient Protection and Affordable Care Act (Section 1557). Each of these federal laws protects people with disabilities from discrimination.

## **U.S. Department of Labor Office of Disability Employment Policy**

<https://www.dol.gov/agencies/odep/topics/coronavirus-covid-19-long-covid/workers>

This site provides information on job accommodations, return to work, benefits, workers' compensation, unemployment insurance and more for those suffering from long COVID.

## **U.S. Government Accountability Office**

<https://www.gao.gov/products/gao-22-105666>

This report looks at the estimated number of long-COVID cases in the U.S, the economic and health impacts, the science behind long COVID, and knowledge gaps and steps the government is taking to fund research and support long-COVID patients.

## **Long Haul COVID Fighters**

<https://www.c19recoveryawareness.com/>

The Long Haul COVID Fighters' mission is to provide support for those whose health has been affected by COVID-19; promote public awareness and education regarding lengthy COVID-19 recovery; and advocate for the medical, mental health and social interests of long-COVID survivors.

## **Body Politic**

<https://www.wearebodypolitic.com/covid-19>

Through a global network of COVID-19 patients, chronic illness allies, and health and disability advocates, Body Politic breaks down barriers to patient-driven, whole-person care and well-being, particularly for historically marginalized communities, by facilitating peer-support, cultivating patient-led research and public education, and leading community-based advocacy.

## **Preparing to Discuss Post-COVID Conditions with a Healthcare Provider**

<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/post-covid-appointment/before-appointment.pdf>

This site offers suggested steps to prepare for a discussion with a healthcare provider regarding long COVID.

## National Research Action Plan on Long COVID

<https://www.covid.gov/assets/files/National-Research-Action-Plan-on-Long-COVID-08012022.pdf>

This Department of Health and Human Services report outlines research, federal services and mechanisms of support available to the American public in addressing the longer-term effects of COVID-19.

## Long COVID Physio

<https://longcovid.physio>

Long COVID Physio is an international peer support, education and advocacy, patient-led association of physiotherapists (physical therapists) living with long COVID and their allies. They work internationally across advocacy, policy, guideline development and research. Their educational materials are for anybody living with long COVID and people wanting to learn more.

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