

LONG COVID ESSENTIALS



A SERIES BY The Sick Times × LONG COVID JUSTICE

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LONG COVID ESSENTIALS



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* ABOUT THIS PROJECT

This series of resource sheets provides foundational information about navigating Long COVID. Whether you're newly experiencing confusing symptoms, have had this disease for years, or are helping others in your community, these sheets will direct you to information and resources to support you along the way.

This series is produced by [Long COVID Justice](#) and [The Sick Times](#). It is designed by and for people with Long COVID and associated diseases. All resource sheets have been reviewed by people living with Long COVID and/or caregivers, and by medical experts who provide Long COVID care. **Learn more and access the full series:** tiny.cc/LCE

We are based in the United States, so some of this information is specific to that context. We are currently able to produce them in English and Spanish. We invite you to contact us if you have resources and capacity for translation into other languages.

The resource sheets can be printed and/or shared as digital PDFs. We encourage you to share them with healthcare providers, community leaders and organizations, mutual aid groups, on social media, and more. All resources in this series are available under [CC BY 4.0 Creative Commons](#). You are welcome to republish them free of charge as long as you credit us and link back to this page.

Please note:

- Resources were published in fall 2024; some information may be subject to change.
- Although each sheet has been reviewed by medical professionals, they are informational resources, not medical advice.
- Always talk to your medical providers before trying treatments or symptom management strategies.
- Each offers brief information and is not comprehensive. We know there is much more information on each topic we cover, and that there are additional topics not yet addressed in this series.

PREVENTION: HOW TO AVOID GETTING COVID RIGHT NOW



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Avoiding COVID-19 is important. The more times you get COVID-19, the more likely you are to have bad health outcomes, including Long COVID.

SARS-CoV-2 is the virus that causes COVID-19. **It is airborne, and in the air year-round.** Even during “lows” between surges, there’s still a lot of the virus around. It’s important to keep a consistent prevention routine.

The virus travels in the air like smoke. When you are indoors with poor ventilation, you are at a higher risk of infection: SARS-CoV-2 could be in the air from people who were there before you, even if you are alone or not near anyone else. If no one appears ill, remember that not all cases are symptomatic. Crowded outdoor spaces may also put you in danger of COVID-19.

* CLEAN & FILTERED AIR REDUCES COVID RISKS

To reduce risk of COVID-19 from the air, we can **bring in fresh air (known as *ventilation*)** or **clean the air (known as *filtration*)**:

1. High-quality masks, also called respirators, filter the air. Protect yourself (and others) by **wearing a high-quality mask in indoor public spaces and crowded outdoor spaces** (especially in schools, supermarkets, public transportation, healthcare facilities, pharmacies, and other essential businesses).

- High-quality masks [such as N95s and KN95s](#) are proven to protect people from COVID-19, other airborne viruses, and environmental hazards like pollution and smoke.
- This [video](#) and [document](#) show how to do a “fit test” to find the best respirator for you.
- Surgical masks and cloth masks are significantly less effective than respirators, but are better than no mask.
- Some communities have [groups that distribute free masks](#).

2. Ventilate your home or workplace by **opening windows when possible**, especially if you have roommates or visitors.

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3. You can also filter the air by **using [air purifiers](#)**, including [Corsi-Rosenthal Cubes](#) you can make yourself.

4. When possible, **make plans with friends and family outdoors**, where there is naturally good ventilation.

* **OTHER TOOLS THAT CAN HELP YOU REDUCE RISK:**

- Keep current on [COVID-19 vaccinations](#), which can help reduce the severity of COVID-19. Vaccination may also reduce risk of Long COVID, but does not eliminate it – many vaccinated people have gotten Long COVID.
- Use COVID [tests](#), including rapid antigen tests, [rapid molecular tests](#), or PCR tests, before visiting indoors and unmasking with friends and family.
- In combination with masking, you can use [nasal sprays shown to protect](#) against airborne viruses and gargle with mouthwash that includes [an ingredient called CPC \(Cetylpyridinium Chloride\)](#).

Stay informed about when cases are rising. Knowing when there is a surge can help you strengthen your precautions! We can do so by **tracking [wastewater data](#)**, in which scientists test our sewers to see how much virus is around. Find current information at [The Sick Times](#).

Many of us do not have full control over COVID risk. Join [Long COVID Justice](#) and allied groups to fight for better COVID prevention policies to help us all.

* **RESOURCES**

- Visit [Long COVID Justice's resources page](#) for info on related topics like hosting COVID-safer events, finding local air purifier lending libraries, where to buy masks, etc!

* **FULL SERIES OF FACTSHEETS WITH LINKED RESOURCES + MORE:**

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* **QUESTIONS?** connect@s4hi.org

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WHAT TO DO IF YOU OR SOMEONE ELSE IN YOUR HOUSEHOLD HAS COVID-19



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With changing and conflicting guidance from national and local public health agencies, it can be confusing to know what to do if you get sick with COVID-19. But by planning, isolating, seeking care, and monitoring your symptoms, you can prevent the spread of COVID-19 and help decrease the risk of adverse health outcomes like Long COVID.

* ISOLATION

1. First, **if you tested positive, you should immediately isolate in your room.** If possible, open all windows and turn on [air purifiers](#) to clean the air, if you have them.
2. All members of the household, including the person who tested positive, should **put on high-quality respirators** or masks.
3. The person who tested positive **should remain in isolation until they have two negative rapid COVID-19 tests 48 hours apart.** Some public health agencies recommend isolating for 5 to 7 days and masking for at least 10 days from the first positive test or onset of symptoms, as people are most contagious during these days. However, [some people can test positive and be infectious](#) for 20 days or more. Negative rapid tests give the best guarantee of safety for leaving isolation.

* NOTIFY YOUR COMMUNITY

1. **Notify everyone in your household and others you could have exposed** in the past 3 to 5 days before you tested positive. This way they can test, isolate, and make their own plans.
2. Since you'll be isolated for at least 5 days, **notify work, school, and other commitments that you've tested positive.**

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* **SEEK MEDICAL CARE, RADICALLY REST, MONITOR SYMPTOMS**

1. **Set up a virtual doctor's appointment** as soon as possible so you can potentially access medications for COVID-19. These drugs are most effective when started early. If you do not have a provider, [Dr. B](#) is one online service that can help you get a prescription.
2. During your appointment, ask the provider about the **antiviral drug Paxlovid** which can lower your chances of severe symptoms. Also ask about **Metformin, a common and inexpensive drug** used to treat diabetes that has been [found to reduce risk of Long Covid](#).
3. Make sure there is a **record that you have COVID-19**. This could be [a record of a positive test](#) or notes from your doctor's appointment. If you develop Long COVID, doctors may ask for this record.
4. **Order a pulse oximeter**, which helps keep track of oxygen levels. If your levels fall below 90% and remain there for several minutes, go to the emergency room immediately. Note that these monitors [can be inaccurate](#) for people with darker skin.
5. If you develop any symptoms that feel life-threatening, **go to the ER or call an ambulance**.
6. Start **tracking your rapid tests, symptoms, and oxygen levels** using [this helpful table made by the Clean Air Club](#).

* **REST AND DO FOLLOW-UP MEDICAL TESTING**

Continue to rest after your initial infection clears up, and **get medical testing and support if needed for lingering symptoms or new or worsening health issues**.

* **RESOURCES**

- [Why you should rest—a lot—if you have COVID-19 \(Time\)](#)
- [What To Do if You Have COVID](#) (Peoples CDC)
- Paxlovid access: [Find locally](#) | [Cost-saving options](#)
- Record your test results: [Make My Test Count](#)

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STILL FEEL UNWELL AFTER COVID-19? HERE'S WHAT YOU NEED TO KNOW ABOUT LONG COVID.



LONG COVID ESSENTIALS: A SERIES BY The Sick Times × **LONG COVID JUSTICE**

If you still feel sick or unwell weeks or months after getting COVID-19, you are not alone. COVID-19 [can lead to a disease called Long COVID](#) that has over 200 symptoms. It can affect every part of the body. People in all age groups, from children to older adults, can get Long COVID.

For some people, their symptoms never resolve after getting infected. Others develop the disease weeks or months later. These symptoms can happen even if you never felt very sick during your initial COVID-19 case or if you never tested positive. That can make them hard to recognize. Here's what you need to know:

* COMMON SYMPTOMS OF LONG COVID

- Fatigue (tiredness, weakness, or heaviness)
- Headaches
- Problems concentrating, thinking, or remembering (sometimes called “brain fog”)
- Dizziness when standing or sitting up
- Post exertional malaise (PEM) (profound exhaustion and worse symptoms after even mild physical, emotional, or mental activity)
- Chest pain (*If you have symptoms of a [heart attack](#), which include chest pain and pressure spreading to the arms, back, neck, or jaw, go to the emergency room immediately.*)
- Problems with digestion
- Behavior changes in children (difficulty with school, sports, and social activities)

See other resources in this series for more common symptoms.

Long COVID may look and present differently in each person. Symptoms can appear to resolve before returning. Long COVID is usually noticeable 1 to 3 months after infection. But if you have health issues at any point after COVID-19, you should see a doctor.

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* TALK TO YOUR DOCTOR OR FIND A LONG COVID CLINIC

Talk to a doctor about your symptoms, your recent COVID-19 case, and your concerns about Long COVID. You can also ask them [to order these tests](#) (page 9-10) or to refer you to a [Long COVID clinic](#). Some Long COVID clinics don't need referrals.

Long COVID can include many health issues. Ask doctors about:

- [Dysautonomia](#) (including postural orthostatic tachycardia syndrome, POTS)
- [Myalgic encephalomyelitis](#), also called chronic fatigue syndrome (ME/CFS)
- [Hypermobility](#)
- [Mast cell activation syndrome \(MCAS\)](#)
- Diabetes
- High cholesterol
- Heart disease

* RESOURCES FOR YOU

Many people may not be able to see a doctor familiar with Long COVID. But as you wait and look for care, there are a few things you can do:

1. Track your symptoms in a journal or on a free app like [Visible](#).
2. Rest as much as possible and keep your heart rate low.
3. Use a technique called "pacing" where you self-manage your energy. Here's a [helpful guide for adults](#) and [one for children](#).
4. Join a [support group](#) on social media or from a [research center](#).
5. Consider joining a [clinical trial](#) to participate in research on Long COVID.
6. Do all you can to avoid getting COVID-19 again, as it may make symptoms worse or delay recovery.

* RESOURCES FOR YOUR DOCTORS

Long COVID Justice has a great list of [resources that were created especially for doctors](#), which includes information and research related to diagnosing and treating Long COVID and associated diseases.

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WHAT IS LONG COVID?



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Long COVID is a set of health issues after someone has COVID-19. These could be: new health issues, ongoing issues, or worsening of previous symptoms or conditions. Long COVID is a biological disease that affects hundreds of millions of people around the world. It can cause significant disability and can be fatal. It is a continuing health crisis.

Long COVID is [an “umbrella” term](#). This means it can include many symptoms as well as other diseases or medical diagnoses. It can affect all parts of the body. It affects people in all age groups, races and ethnicities, genders, and sexual orientations. People with or without prior health issues can develop the disease. It can happen after asymptomatic or mild infection.

For more information about the wide range of Long COVID symptoms, see other resources in this series. [A 2024 report by the National Academies of Sciences, Engineering, and Medicine](#) also has more information.

Scientists are studying how Long COVID occurs. **They think these factors play a role:**

1. **Autoimmunity** – COVID-19 could cause the immune system to become overactive and attack your body.
2. **Viral persistence** – SARS-CoV-2 is the virus that causes COVID-19. Pieces of the virus may remain in the body long after acute infection. These pieces aren't contagious, but can cause symptoms.
3. **Viral reactivation** – Sometimes a virus can cause other viruses that are dormant (not causing harm) in the body to “wake up,” including Epstein Barr virus, which causes mono.

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* SYMPTOM MANAGEMENT

There are no cures for Long COVID, but some treatments might help improve certain symptoms, or bring relief or ease. Learning about other chronic diseases that overlap with Long COVID may help you, as there are recognized therapies for many of these diseases.

These overlapping diseases can include:

- [Dysautonomia](#) (including postural orthostatic tachycardia syndrome, POTS)
- [Myalgic encephalomyelitis](#), also called chronic fatigue syndrome (ME/CFS)
- [Hypermobility](#)
- [Mast cell activation syndrome \(MCAS\)](#)
- Diabetes
- High cholesterol
- Heart disease

Long COVID can [change over time](#). Symptoms can come and go. To help manage and reduce symptoms, some people [use a technique called pacing](#).

* RESOURCES

There are [many COVID-19 and Long COVID support and advocacy groups](#) (online & more).

Other resources include:

- [The Long Covid Survival Guide](#): stories and advice from people with Long COVID
- [Long COVID Physio](#): videos and guides in many languages
- [Employers guide](#): for managers supporting employees with Long COVID
- [How others can help](#): tips for supportive loved ones and community members
- [Long COVID definition](#): detailed report and one-page summaries in different languages for medical providers
- [Long-term health effects](#): detailed report and summaries about potentially-disabling symptoms

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DIZZINESS, LIGHTHEADEDNESS, AND RACING HEART AFTER COVID-19? IT COULD BE DYSAUTONOMIA

LONG COVID ESSENTIALS: A SERIES BY The Sick Times × LONG COVID JUSTICE

Many people with Long COVID develop a condition called **dysautonomia**, in which your [autonomic functions](#) (or things your body does by itself, like heart beating) are disturbed. There are many kinds of dysautonomia; one form seen commonly in Long COVID is called [POTS](#), or “postural orthostatic tachycardia syndrome.”

POTS symptoms often include:

- Racing heart
- Dizziness, or feeling like you might faint
- Headache
- “Brain fog” or trouble thinking clearly
- Chest pain

POTS can happen when your body doesn’t respond well to changing positions. The automatic bodily functions that are supposed to keep your circulation working properly aren’t quite doing their job, and your heart beats extra hard to try to make up for it.

Cardiologists or neurologists usually diagnose POTS using an [active standing](#) or [NASA Lean test](#). These tests monitor what happens when you change position, to see if your heart beats too fast. This is best done by a professional to rule out other issues and ensure you don’t faint. If you don’t have a provider, find a friend (for safety) to help you [do an at-home test](#).

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There are some things you can do at home to help manage POTS:

- *Move slowly, lie down where possible.* [Transition](#) from sitting to standing slowly and gradually.
- *Get lots of water and salts.* This will help your body maintain a reasonable blood volume.
- *Compression garments gently squeeze your blood vessels, to help with circulation.*
- *Try sleeping with your head slightly elevated.*
- *Eat smaller meals throughout the day.*
- *Avoid the heat.* Hot weather can make symptoms like [heat intolerance worse](#).

Some will find they need additional relief. If so, doctors have used medication to help POTS patients, even though there are no medications officially approved for it in the US. You may want to ask your doctor about:

- Beta blockers, which slow the heart rate
- Fludrocortisone, which helps your body hang on to fluids
- Midodrine, clonidine and pyridostigmine, which can help rebalance your autonomic nervous system in different ways

* RESOURCES

- The patient-led organization Dysautonomia International [offers educational resources and more](#)
- Long COVID Physio has a helpful [video and resources on dysautonomia and POTS](#)
- POTS UK has an [informative booklet on managing symptoms](#)
- The Canadian Cardiovascular Society has published a [proposed treatment algorithm](#)
- Hot weather can worsen POTS and Long COVID symptoms. Learn more in [this feature from *The Sick Times*](#)

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“BRAIN FOG,” MEMORY PROBLEMS, AND OTHER NEUROLOGICAL ISSUES AFTER COVID-19

LONG COVID ESSENTIALS: A SERIES BY The Sick Times × LONG COVID JUSTICE

Neurological symptoms like memory loss or other cognitive dysfunction (sometimes called “brain fog,”) are very common after COVID-19.

These symptoms can happen to anyone of any age group. Brain fog and other neurological symptoms can make daily life, school and work difficult. There are no approved treatments for these symptoms, but there are some ways you can help manage them.

* SIGNS OF “BRAIN FOG” OR COGNITIVE DYSFUNCTION

- **Forgetfulness:** Having more trouble than usual remembering where you put your keys, what you just said in a conversation, or the name of an old friend.
- **Problems with executive function:** More difficulty than usual making plans, completing complex tasks, managing finances, or managing your time.
- **Difficulty concentrating or paying attention:** Trouble concentrating on tasks at work, sitting through movies, or remembering what someone said a moment ago in conversation.

* OTHER NEUROLOGICAL SYMPTOMS

People with Long COVID can develop other symptoms that affect the brain and nervous system such as pain, internal tremors, tingling, and numbness throughout the body. Other neurological symptoms include headaches, problems with balance, and sensitivity to light and sound.

Some people may also lose their sense of [taste and smell](#). Unlike other symptoms that often don't resolve on their own, people [may recover taste and smell over time](#).

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* SYMPTOM MANAGEMENT

There are some strategies and providers you can use to help manage these symptoms/conditions.

- [Pacing](#): Planning and spacing out physical and mental exertion throughout the day can help you manage some of these symptoms, as they may be a result of post-exertional malaise (PEM), or worsened symptoms after physical, emotional or mental activity. This can include even very mild activity.
- Medical conditions like [dysautonomia](#), [mast cell activation syndrome \(MCAS\)](#), [myalgic encephalomyelitis \(ME/CFS\)](#), and others that overlap with Long COVID could make neurological symptoms even worse. It is often very hard to find a specialist to diagnose these conditions. However, if you are able to get a diagnosis, it could help with accessing treatments and resources.
- Occupational therapists and/or speech/language pathologists, especially at Long COVID clinics, can help implement strategies to adjust to or work around cognitive symptoms.
- Although there are currently no approved treatments, medical providers might suggest supplements or drugs off-label, like [guanfacine](#) or [low-dose naltrexone](#).

* RESOURCES

- [Helpful video on cognitive dysfunction](#) – Long COVID Physio
- [Cognitive dysfunction info page](#), includes some potential treatment options – MEpedia
- [Cognitive dysfunction resource page](#) – World Health Organization

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WHY YOU SHOULD BE CAREFUL ABOUT ACTIVITY & EXERCISE AFTER COVID-19



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After having COVID-19, it's important to get as much rest as possible. Slowly restart activity at the pace your body can tolerate.

For some people, routine activities that were okay before Long COVID could cause [energy depletion](#), make symptoms worse, or cause [muscle damage](#). This is not the case for every person after COVID-19, but affects an estimated 80% of people with Long COVID.

* WHAT COUNTS AS EXERCISE OR EXERTION?

- Everyday activities like caring for children, working, reading a book, or taking a shower may lead to severe fatigue and worsening symptoms. This is called [post-exertional malaise \(PEM\)](#) or post-exertional symptom exacerbation (PESE). **Physical, cognitive, orthostatic stress and emotional exertion can all contribute to PEM.**
- Although some doctors may recommend exercise for these symptoms, **often activity can do more harm than good.** Make sure your doctor understands the difference between PEM and exercise intolerance. With exercise intolerance, someone has less capacity for physical exercise than expected. People with PEM may *also* have exercise intolerance, but not everyone with exercise intolerance has PEM.
- **[Avoid high-intensity activities](#)** as much as possible. Figuring out what your body can handle may take time.

* HOW SOON TO RETURN TO HIGHER ACTIVITY LEVELS?

- Take it easy for at least 6 weeks after COVID-19, if your life circumstances allow.
- Gradually introduce lighter forms of exercise like yoga or walking - not too much at once.
- [Breathwork, stretching, and bodywork](#) can be helpful before restarting exercise. Stretching while lying down may be easier than upright activities.
- [Pacing](#), or finding the balance between activity and rest, can help you to manage and preserve your energy.
- Monitor your body's response to activity. Remember: there may be a delay of 24 to 72 hours in the start of PEM symptoms after the activity itself.

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* IF YOU'RE EXPERIENCING CONCERNING SYMPTOMS

- Track your symptoms for several days after specific activities in a journal or on a free app like [Visible](#). This can help you figure out what's too much for your body and help with recording information to bring to medical visits.
- Use a pulse oximeter or wearable device to track your heart rate. Take note of your heart rate while doing activities and standing. Talk to a doctor if you notice increases of more than 30 beats per minute (bpm) with activity, or a resting heart rate over 100 bpm.
- Treating [orthostatic intolerance](#) can help reduce your symptoms with activity.

* RESOURCES FOR MANAGING ACTIVITY-TRIGGERED SYMPTOMS, INCLUDING PHYSICAL THERAPY AND REHAB

- There are now many clinics for [Long COVID and post-COVID treatment](#).
- **Not all healthcare workers are trained to recognize PEM.** Listen carefully to how they talk about exercise. If they minimize your experiences or urge you to ignore or push past your symptoms, they are likely not the best provider for this issue.
- Talk to others with Long COVID or ME/CFS to help find trustworthy medical providers. See [lists of recommended providers and advocacy groups](#).
- Some cases of Long COVID and post-COVID symptoms [can be treated with pulmonary rehabilitation](#) or [autonomic conditioning](#).
- [Long COVID Physio](#) and [Workwell Foundation](#) provide many resources on rehabilitation, fatigue, PEM exacerbation, pacing, and more.

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RACING HEART OR CHEST PAIN? HEART PROBLEMS AFTER COVID-19

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COVID-19 can trigger a host of problems affecting the heart. It can also increase your risk of future cardiovascular trouble. Even more than a year after COVID-19, a [major study](#) found people were more likely to experience a heart attack, heart disease, and abnormal heart rhythms — issues that can be life-threatening.

If you have symptoms of a [heart attack](#), which include chest pain and pressure spreading to the arms, back, neck, or jaw, go to the emergency room immediately.

Some conditions linked to COVID-19 include:

- **Myocarditis and Pericarditis:** Myocarditis is inflammation of the heart muscle. Pericarditis is inflammation of the tissue surrounding the heart. Both can happen when the immune system causes inflammation in response to an infection. Symptoms can include chest pain and shortness of breath.
- **Coronary artery disease:** COVID-19 can infect the [arteries of the heart](#) and cause plaque inside the arteries to become inflamed. This disease may happen without symptoms but sometimes causes chest pain and shortness of breath.
- **Arrhythmias:** Inflammation can lead to an irregular heart rhythm. Atrial fibrillation is one type of [abnormal heart rhythm](#). This can feel like fluttering, pounding, or a racing heartbeat.
- **Heart attacks:** Heart attack deaths have [spiked during](#) the pandemic — especially among young people — and tracked with surges in COVID-19 cases.

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* GETTING HELP

A cardiologist can diagnose and treat heart problems. They may order tests like an [EKG](#), an [echocardiogram](#), or a [heart MRI](#), which can help check for abnormal heartbeats, inflammation, and more. Depending on the diagnosis, there may be some available treatments.

If you can't see a doctor right away, you can monitor your heart rate with [a pulse oximeter](#). If you're having heart symptoms, try to rest and avoid strenuous exercise until a medical professional has cleared you. **Important note: Sometimes, these meters may give incorrect results in people with darker skin. Please talk to a medical provider if you have questions or concerns about the oximeter readings.**

* DYSAUTONOMIA

A fast heart rate, dizziness, and/or feeling like you're going to faint are common symptoms of Long COVID. This might indicate problems with the nervous system which affects your heart, called dysautonomia.

One of the most common forms of this in people with Long COVID is called postural orthostatic tachycardia syndrome, or POTS. Read more about it in [our dysautonomia and POTS resource](#).

* RESOURCES

- [Heart Problems After Covid](#) – Cleveland Clinic
- [Long-term cardiovascular outcomes of Covid-19](#)– Nature Medicine
- [Covid-19 Surges Linked to Spike in Heart Attacks](#)– Cedars Sinai
- [Postural Orthostatic Tachycardia Syndrome](#)– Dysautonomia International
- [The Problem with Pulse Oximeters: A Long History of Racial Bias](#)– John Hopkins

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NEW ALLERGIES OR FOOD INTOLERANCE AFTER COVID-19? MAST CELL AND HISTAMINE ISSUES



LONG COVID ESSENTIALS: A SERIES BY The Sick Times × LONG COVID JUSTICE

People with Long COVID often experience new or worse reactions to foods or other things they could previously eat or encounter without issues. These symptoms can be related to cells called “mast cells.” When activated, mast cells release chemicals that cause inflammation, such as histamine.

People experiencing these reactions may have **Mast Cell Activation Syndrome (MCAS)**. MCAS can include sensitivities to foods, fragrances, medications, and other chemicals. Reactions to these can cause a wide variety of debilitating symptoms.

* COMMON MCAS SYMPTOMS

- **Allergic:** Congestion, runny nose, coughing, sneezing, itching, hives, and sometimes anaphylaxis (severe allergic reaction)
- **Dermatological:** Rashes, flushing, burning sensations
- **Gastrointestinal:** Diarrhea, constipation, stomach pain after meals
- **Neurological:** brain fog, fatigue, anxiety, depression

High histamine foods that can cause symptoms:

- Alcohol
- Fermented foods (like yogurt, miso, sauerkraut)
- Sugary drinks
- Tomatoes
- Aged cheeses
- Some nuts
- Citrus
- Chocolate
- Caffeine
- Spinach
- Preserved foods like deli meat

Over time leftovers can develop higher histamine content, causing symptoms. To avoid this, some people cook large batches of food that can be immediately frozen in individual portions, then reheated one at a time to eat later.

MCAS and histamine issues can also make people sensitive to fragrances and chemicals, like cleaning products. Many MCAS patients react poorly to medications (or the other ingredients in them), or can only tolerate small doses of them.

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Possible causes of MCAS after COVID-19 include:

- COVID-19 can cause widespread [inflammation](#) and mess up the immune system, which includes mast cells. Mast cells regulate the production of inflammation-related chemicals, so [when they are overactive](#), they cause reactions. .
- There may be a [genetic component](#) making some people more likely to develop MCAS. People with pre-existing allergies [may be at higher risk](#).
- [Exposure to toxic mold, chemicals, and airborne allergens](#) may also increase the risk.

People who have MCAS also often have: [POTS](#), [interstitial cystitis](#), gluten and milk intolerance, [irritable bowel syndrome](#).

* DIAGNOSIS

MCAS is difficult to officially diagnose. Your doctor may test [histamine and tryptase levels in the blood and/or through a 24-hour urine sample](#). But these tests are imperfect.

Beyond tests, diagnosis is largely based on symptoms and response to treatment. If a low-histamine diet helps you, you may have MCAS.

* SYMPTOM MANAGEMENT

Though there is no cure for MCAS or histamine problems, some [medications](#) can help. Be careful to start at low doses to avoid symptom flares and see what works for you.

Following a [low histamine](#) diet can help manage symptoms. As symptoms improve, try slowly reintroducing certain foods.

Medications that can also help control symptoms include:

- [H1 and H2 antihistamines](#)
 - Over-the-counter H1 antihistamines such as cetirizine (Zyrtec), fexofenadine (Allegra), loratadine (Claritin)
 - Antihistamine nasal sprays
 - Prescription H1 antihistamines like hydroxyzine (Atarax or Vistaril)
 - H2 antihistamines such as famotidine (Pepcid)

CONTINUED →

- Asthma [inhalers](#)
- [Mast cell stabilizers](#) like cromolyn sodium (oral, nebulized or nasal spray form), ketotifen (both antihistamine and mast cell stabilizer)
- Leukotriene inhibitors like Montelukast (Singulair)
- Supplements like Quercetin
- Biologics targeting Mast Cells (Monoclonal Antibodies)
 - Omalizumab (Xolair)
- Short or longer-term corticosteroid treatment
- [Epi-pen](#), for anaphylaxis
- [DAO supplementation](#) before meals (and other supplements)
- [Low-Dose Naltrexone](#)

* **RESOURCES**

- [Article about MCAS](#) – Rupa Health
- [Approach for patients](#) – PatientPop
- [MCAS resource page](#) – RTHM
- [Histamine Intolerance facts](#)– Dr. Tina Peers

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* **QUESTIONS?** connect@s4hi.org

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WHAT TO DO WHEN YOUR SENSES OF TASTE AND SMELL ARE CHANGED BY COVID-19



LONG COVID ESSENTIALS: A SERIES BY The Sick Times × LONG COVID JUSTICE

Loss of or distorted taste and smell are common symptoms of COVID-19. In some people, these symptoms continue after COVID-19 and become symptoms of Long COVID. [One study](#) estimated that 60 percent of people infected with SARS-CoV-2 in 2021 lost some ability to taste and smell, and more than a quarter of those didn't fully regain that ability.

* RELATIONSHIP BETWEEN TASTE AND SMELL

The senses of taste and smell are closely related. Even when the sense of taste is not itself damaged, you may experience a diminished or distorted sense of taste if your sense of smell is damaged.

[Some research suggests coronavirus could linger](#) in the nose, tongue, and taste buds after infection, contributing to smell and taste issues.

Total loss of smell is sometimes called anosmia, while a distorted sense of smell is called parosmia. Ageusia refers to the loss of taste, and dysgeusia is a distorted sense of taste.

Loss of taste and smell carries several risks. People who can't taste properly may not eat or drink enough, leading to risks of malnutrition, dehydration, or unhealthy weight loss. They may be at risk of food poisoning because it's hard to tell when food has gone bad, or unable to perceive threats like fires and gas leaks.

CONTINUED →

* GETTING HELP

Taste and smell are usually treated by an ear, nose, and throat doctor, or otorhinolaryngologist. A doctor may give you a smell test, where you sniff and identify different scents. They may also do a taste test, where you taste substances applied directly to your tongue or different liquids you sample and then spit out.

One promising treatment option is called a [stellate ganglion block](#). It is an injection of local anesthetic into nerves in the side of the neck. Traditionally used to treat pain, the treatment has [had some success in restoring taste and smell](#). Not everyone responds, but for those who do, the results can be dramatic.

Some experts also recommend self-management options like adding additional spices and seasonings to meals and eating foods with varying textures.

* RESOURCES

- [Loss of Taste and Smell](#) – Cleveland Clinic
- [Smell and Taste Association of North America](#)
- [New Treatment Restores Sense of Smell in Patients with Long COVID](#) – Radiological Society of North America
- [Swirl of Hope](#)

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HAVING TROUBLE SLEEPING AFTER COVID-19?



LONG COVID ESSENTIALS: A SERIES BY The Sick Times × LONG COVID JUSTICE

Having trouble falling or staying asleep after COVID-19? Do you still feel tired when you wake up? You're not alone. As many as four in five people with Long COVID experience sleep disturbances.

These issues most often include:

- Trouble falling asleep (insomnia)
- Restless, unrefreshing, or non-restorative sleep
- Excessive daytime sleepiness
- The feeling of “restless legs”
- Involuntary muscle contractions or jolts when falling asleep, called “hypnic jerks”
- A condition called obstructive [sleep apnea](#) - in which your throat muscles relax and partly block your airway during sleep

Several practices known as *sleep hygiene* help your body establish a routine that supports your natural circadian rhythm. [Popular tips](#) you might have run across include: setting a consistent sleep time, wake time, and wind-down practice; getting bright light in the morning and avoiding it at night; reducing screen-time before bed; and keeping your bedroom as cool, dark, and quiet as possible.

Some supplements to consider (but watch for such side effects as increased brain fog):

- Regular melatonin use can help, especially with insomnia.
- Magnesium supplements can help with restless legs and muscle contractions.
- If cannabis-based products are available, some small studies suggest they may help with insomnia.

CONTINUED →

If sleep hygiene practices and natural supplements do not help your sleep issues, it's time to see a medical provider.

Be sure to ask whether any other conditions associated with Long COVID might be affecting your sleep. Managing other issues like pain, mast cell activation syndrome (MCAS), dysautonomia, and others can often improve sleep. Your provider may recommend a sleep study to identify other treatable problems.

If more active management is needed, there are medications you can discuss with your provider.

* RESOURCES

- Two clinicians at the Royal Holloway University of London (Jan 2023) wrote a [concise summary of the challenges of sleep in Long COVID and the ways in which they can be addressed](#)
- The ME Association has a free [sleep management e-book on Long Covid and ME/CFS](#)
- A private clinic, Mamedica, gives an [overview of cannabis-based treatments for Long COVID symptoms](#)
- Guezguez et al. (Feb 2023) published a [detailed clinical overview of current management practices](#)

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HOW DOES COVID-19 AFFECT REPRODUCTIVE HEALTH?



LONG COVID ESSENTIALS: A SERIES BY The Sick Times × LONG COVID JUSTICE

COVID-19 can cause reproductive health issues for many people. This can happen even for people who didn't have any issues prior to COVID-19. COVID-19 can affect reproductive health systems for all genders and can seriously impact people's lives.

* SYMPTOMS

For people born with a **uterus and ovaries**, possible complications include:

- Complications with ovarian tissue function
- Complications maintaining a pregnancy, such as miscarriage or stillbirth
- Complications during pregnancy, such as changes in breathing patterns or blood flow
- Complications after giving birth, such as fatigue and joint stiffness
- Complications with bleeding patterns and menstrual cycles
- Complications with memory, fatigue, and perimenopausal symptoms

For people born with a **penis and testes**, possible complications include:

- Complications maintaining an erection
- Complications to sperm quality
- Changes to testosterone levels

These issues can affect sexual health, reproductive health, ability to engage in and enjoy sexual activity, fertility, and overall health status.

Although we don't fully understand how or why COVID-19 affects the reproductive health systems, scientists have these theories:

- For pregnant people, COVID-19 can trigger autoimmune responses, in which the immune system mistakenly attacks healthy cells.
- Endocrine and blood vessel issues can occur from COVID-19.
- Viral reactivation – a virus can sometimes cause another virus that is dormant in the body to be re-activated.

Further research is needed to better understand how COVID-19 impacts reproductive health. Scientists are still learning about potential symptoms and complications.

CONTINUED →

* SYMPTOM MANAGEMENT

Some tips and guidelines:

- Track your health concerns [with an app, diary, or journal](#).
- Schedule an appointment with your primary care provider, obstetrician, gynecologist, urologist, or endocrinologist.
- Ask your healthcare provider for any bloodwork or examinations that can be done to assess your baseline health, such as a complete metabolic panel (CMP), Vitamin D and B12 levels, a thyroid panel, or a complete blood count (CBC).

Talking about reproductive health issues can be quite hard and even traumatizing at times. While these topics might be scary, it is important for you to be honest with your healthcare provider about your concerns.

If you feel your healthcare provider does not take your concerns seriously, it's important to find a provider who believes you. [Other resources in this series](#) discuss how to find doctors and navigate care.

* RESOURCES

There are [many COVID-19 and Long COVID support and advocacy groups](#) you can connect with virtually and/or locally. Support groups specific to reproductive health concerns can be hard to find. Looking at social media or COVID-conscious websites might be helpful.

Other resources include:

- [A literature review](#): detailed discussions about impacts of Long COVID for people with a uterus and ovaries
- [A review article](#): to learn about COVID-19 and erectile dysfunction
- [Postpartum health realities](#): how COVID-19 can affect pregnancy and postpartum health

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