

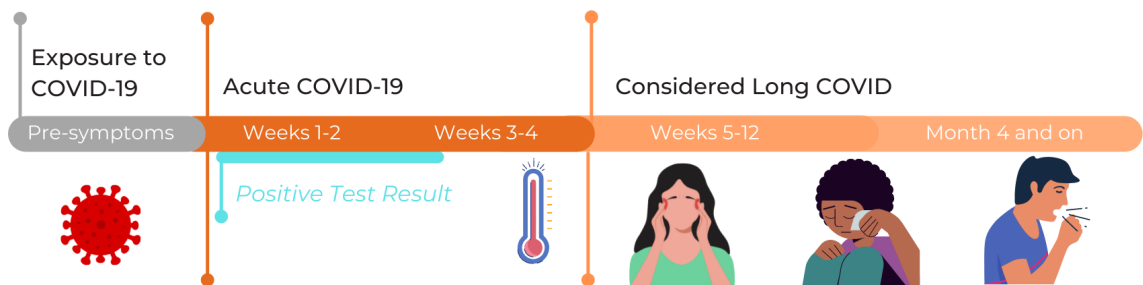


Long COVID:

Navigate Your
COVID-19 Recovery
with AfterCare

What is Long COVID?

Long COVID is a wide range of new, returning, or ongoing health problems people can experience **four or more weeks after first contracting COVID-19**.



- Long COVID can happen to anyone who has had COVID-19, even if it was a mild or asymptomatic infection.
- One out of three of people with COVID-19 might continue to experience symptoms weeks and months after their initial diagnosis.
- Long COVID can also have social and economic impacts, especially for populations already disproportionately burdened by health inequity. Fatigue and pain can affect mobility, concentrating at work is harder with brain fog, and anxiety and depression can alter one's outlook on life.
- Long COVID may also be known as **post-COVID**, **long-haul COVID**, **post-acute COVID-19**, **long-term effects of COVID**, or **chronic COVID**.
- Many patient groups and researchers are working on studies to better understand the root cause of Long COVID and how to treat it. Recovery time varies between people, but rehabilitative and therapeutic approaches can help alleviate symptoms for people with Long COVID.

NYC Health + Hospitals Test & Trace Corps' **AfterCare program** and the City's public health system's dedicated primary care providers are here to support you in your post-COVID recovery.

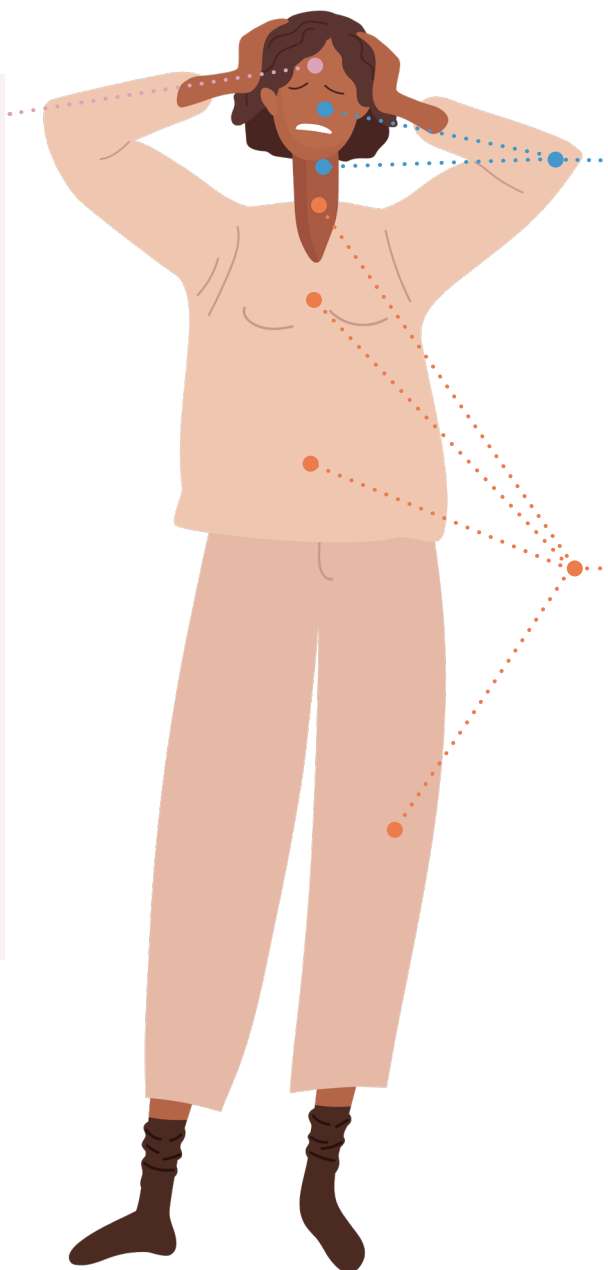
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NYC Test & Trace Corps

What are common symptoms of Long COVID?

Four or more weeks after first contracting COVID-19, individuals with Long COVID commonly report experiencing different combinations of the following symptoms:

Psychological Symptoms:

- Feeling disconnected, sad or alone
- Anxiety or depression
- Mood changes
- Difficulty thinking or concentrating (sometimes referred to as “brain fog”)
- Tiredness, low energy or fatigue that does not go away after resting
- Post-exertional malaise (worsening of symptoms following even minor physical or mental exertion)
- Difficulty falling asleep
- Difficulty waking up or staying awake



Cold or Flu-like Symptoms:

- Headaches
- Fever
- Chills
- Congestion or runny nose
- Cough
- Sore throat

Physical Symptoms:

- Changes in taste or smell
- Difficulty breathing or shortness of breath
- Rash
- Chest or stomach pain
- Fast-beating or pounding heart (also known as heart palpitations)
- Dizziness on standing (lightheadedness)
- Changes in period cycles
- Diarrhea
- Nausea or vomiting
- Muscle or joint aches/weakness
- Pins-and-needles feeling
- Pale/gray/blue skin/lips/nail beds

What kind of support can I get?

Right now, the best approach is to get connected with comprehensive care programs that provide physical, mental health, and social support. NYC Health + Hospitals Test & Trace Corps' **AfterCare program** and the City's public health system's dedicated primary care providers are here to support you in your post-COVID recovery.

NYC Health + Hospitals Test & Trace Corps **AfterCare program** provides:

- Long COVID **advice and up-to-date information** on recovery options
- Connects New Yorkers with Long COVID to **health and social needs resources** that support their recovery
- Offers **support to all people**, regardless of income level insurance coverage, and/or immigration status

AfterCare is here to help your journey to recovery. We have resources for:



Physical health: Long COVID can physically affect every part of the body. AfterCare can connect you with primary care and specialized care and provide tips for self-management.



Mental Health: COVID-19 recovery is stressful, and can lead to anxiety, depression, and loneliness. AfterCare's mental health resources can help you feel like yourself again.



Community Support: Navigating your COVID recovery alone can be socially isolating. Connect with support systems of people who are going through similar experiences.



Financial Support: COVID-19 and Long COVID can cause financial strain and unexpected setbacks, especially if your employment or ability to pay rent and access healthcare is affected. Financial support resources can ease you through these obstacles.

Visit nyc.gov/AfterCare or call 212-268-4319 and press 4

How can I get connected to resources?

NYC Health + Hospitals has two Community Health Centers in the Bronx and Queens, dedicated to those recovering from COVID-19 and offering a wide range of services to keep you and your family healthy. There are many other post-COVID care centers that are also available throughout New York City, available on the nyc.gov/aftercare website.

Call our centers for more info at **844-NYC-4NYC (844- 692-4692)** or visit online at www.nychealthandhospitals.org/covid-19-center-of-excellence/.



**NYC Health + Hospitals
Gotham Health, Roosevelt
COVID-19 Center of Excellence**
37-50 72nd St.
Jackson Heights, NY 11372

**NYC Health + Hospitals
Gotham Health, Tremont
COVID-19 Center of Excellence**
1920 Webster Ave.
Bronx, NY 10457



To get connected with **AfterCare** resources, call 212-268-4319 and press 4 to speak with a member from our **AfterCare** Navigation team.

To find out more information about Long COVID and AfterCare, visit nyc.gov/AfterCare.



Stay strong! Stay healthy!
NYC Test & Trace Corps



Navigating your COVID Recovery

NYC Health + Hospitals' Test and Trace Corps' AfterCare program created this guide to help you work with your healthcare provider to manage Long COVID symptoms. The following **patient self-advocacy tools** can help you speak about your experience with Long COVID. (All fields are optional.)

If you think you have long COVID symptoms:

- 1 Check off any symptoms you may have on **"My Symptom List"** (pg. 7).
- 2 Reach out to your primary care provider. If you don't have a primary care provider or if you're worried about the costs, our **AfterCare Navigators** can help connect you with NYC Care.
 - **NYC Care** is a health care access program that guarantees low-cost and no-cost services to New Yorkers who do not qualify for or cannot afford other health insurance, regardless of immigration status. Call **646-692-2273** or visit <https://www.nyccare.nyc>.
- 3 Prepare for meeting with your provider, using **"Tips for Your Medical Appointment"** (pg. 8) and completing **"My Health History"** (pgs. 11-12).
- 4 Fill out your **"My COVID Story"** (pg. 13) to share your experience.
- 5 Keep an eye on your symptoms with the **"Daily Symptom Log"** (pgs. 14-15).



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Keep track of your symptoms

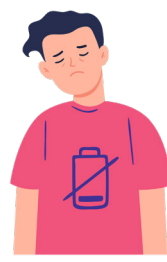


MY SYMPTOM LIST

I have symptoms that **have come back/never went away** (circle one).

My symptoms are **mild/moderate/severe** (circle one).

(For those vaccinated after they got COVID) My symptoms got **better/worse/stayed the same** (circle one) after I was vaccinated.



My ongoing symptoms are (check all that apply):

- | | |
|--|---|
| <input type="checkbox"/> Fever | <input type="checkbox"/> Dizziness on standing
(lightheadedness) |
| <input type="checkbox"/> Chills | <input type="checkbox"/> Sore throat |
| <input type="checkbox"/> Cough | <input type="checkbox"/> Congestion or runny nose |
| <input type="checkbox"/> Shortness of breath or
difficulty breathing | <input type="checkbox"/> Nausea or vomiting |
| <input type="checkbox"/> Tiredness or fatigue | <input type="checkbox"/> Changes in menstruation
(period cycles) |
| <input type="checkbox"/> Post-exertional malaise
(worsening of symptoms
following even minor physical or
mental exertion) | <input type="checkbox"/> Diarrhea |
| <input type="checkbox"/> Muscle or joint aches/weakness | <input type="checkbox"/> Rash |
| <input type="checkbox"/> Headache | <input type="checkbox"/> New confusion or brain fog |
| <input type="checkbox"/> Chest or stomach pain | <input type="checkbox"/> Mood changes |
| <input type="checkbox"/> Fast-beating or pounding heart
(also known as heart palpitations) | <input type="checkbox"/> Anxiety or depression |
| <input type="checkbox"/> Change in taste or smell | <input type="checkbox"/> Difficulty falling asleep |
| <input type="checkbox"/> Pins-and-needles feeling | <input type="checkbox"/> Difficulty waking up/staying awake |
| | <input type="checkbox"/> Pale/gray/blue skin/lips/nail beds |
| | <input type="checkbox"/> Other: |

Tips for your medical appointment



Preparing for your appointment

- **Keep a log of your symptoms with your “Daily Symptoms Tracker”** to bring with you to your appointment.
- **Write down your questions** ahead of time.
- **Bring someone with you.** It might be helpful to have another person listen and ask any questions you may have forgotten.
- **Create your “COVID story”** (pg. 13). Your COVID story can help your provider see symptom patterns, so you can figure out what treatment works and what doesn’t.
- **Bring the results of any tests that you may have already had done.** For example, chest scan (X-ray), EKG, etc. Test results can help providers understand the full picture in your recovery.
- **Prepare a list of information** you might need from your provider, especially for disability benefits or workplace accommodations. Please note that you do NOT need to provide any documents regarding your immigration status.

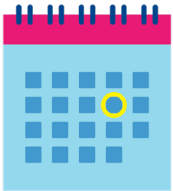
During your appointment

- **Take note of the provider’s responses.** Write down or ask your physician to write down important information. Ask for an explanation or repeat your question if you don’t understand the answer. If you would like something to be noted in your chart, let your healthcare provider know.
- **Create an action plan** with your provider. Communicate your personal health goals to your provider.

During your appointment (cont.)

- **If you feel uncertain or uncomfortable** about recommendations from your provider you can ask for another recommendation or ask for a copy of your medical record. This is your health and you have a right to know.
- **Tell your provider** what documents you may need for disability benefits or workplace accommodations, and ask them to complete any necessary fields. Ask for contact information where you can follow up if required.
- **Ask for copies or a list of any referrals.** It can be helpful to bring your own copy to the next appointment. The list of referrals is often included in the “After Visit Summary”.

After your appointment



- **Schedule your next appointments.** This includes your follow-up appointments with your primary care provider, and specialist appointments.
- **Pick up any prescriptions.**
- **Continue to track your symptoms.** Keep a daily record of your symptoms to help you and your provider understand if you are feeling better or if you need additional support.
- **It's ok to get a second opinion.** You can speak with another primary care provider or ask the clinician at your next referral appointment.
- **Submit any paperwork** you need for disability benefits or workplace accommodations. Follow up with the agency or department that provided these forms if you need more information.



Questions to ask your healthcare provider

NOTE: If your provider does not seem to know about Long COVID or believe that you have it, you can always seek another provider to answer your questions. Your own feelings are the best judgment.

Symptoms

- What could be causing my symptoms? (Be specific about the symptoms you may have. Refer to your symptom log.)
- I've been hearing/reading about Long COVID. Are you aware of Long COVID? Is it possible that I have Long COVID?
- Are there any other symptoms I should be aware of?

Recommendations for recovery

- What do you recommend for patients who have Long COVID?
- What tests should/can I get?
- Are there alternative or complementary therapies that could help me? (i.e.: acupuncture, massage therapy, physical therapy).
- What changes do you suggest to improve my symptoms, recovery, and/or health? (i.e.: changes in diet, tobacco use, alcohol consumption, pacing, stress management).

Following up

- Are you aware of any support groups for Long COVID?
- Are there specialists (other doctors/experts) that I may need to see?
- What is the best way to get a medication refill?
- What is the best way to get in touch with your office if I need something? What is the best way to contact you?
- How often should I follow up with you?
- Do you have a patient portal (an online system for communicating with the care team, requesting refills, making appointments, viewing notes) that I can sign up for?

Visit nyc.gov/AfterCare or call 212-268-4319 and press 4



MY HEALTH HISTORY *(fill in applicable information)*

Primary care provider: Insert full name, speciality (if any), and phone number

Specialists: Insert full name, specialty, and phone number

Recent test results: List your most recent labs results (i.e. blood tests, MRI, CT scan(s), or EKG results) here. Remember to bring copies when visiting your health care provider.

COVID-19 treatment: List any medication you took or any treatment you received if you were hospitalized, or received during your first two weeks of symptoms if not hospitalized.



Past medical history: Such as heart disease, high blood pressure, high sugar/diabetes, cancer, etc.

Past surgical history: Please list history of procedures by date - not including dental work.

Procedure(s)

Date of procedure(s)

MY HEALTH HISTORY (fill in applicable information)



Social history:

- ____ hour(s) of exercise/fitness activities a day, ____ day(s) a week
- Smoke ____ pack(s) of cigarettes or e-cigarettes per day **rarely/sometimes/a lot** (circle one)
- ____ drink(s) that contain alcohol per week
- ____ cup(s) of coffee per day, ____ cup(s) of caffeinated tea per day
- Diet or dietary restriction(s):
- Other substances, such as cocaine, heroin, methamphetamine, or pills that were not prescribed to me:



Home medications: (taken by mouth/nose, or injected, etc.)

Prescription(s)

Over-the-Counter (herbs, supplements, etc.)

Allergies to medications:



MY COVID STORY

MY EXPERIENCE

(Fill in the blanks below to help your provider understand your covid history)

On/around _____ (date), I started having COVID-like symptoms. I **tested/did not test** (circle one) positive for COVID-19.

My symptoms lasted _____ **days/weeks/months** or **are still happening** (circle one). I was **hospitalized/not hospitalized** (circle one) at _____ (if so, name of hospital), for _____ days.

I **required/did not require** (circle one) treatment in the intensive care unit (ICU). I **did/did not** (circle one) go to therapy/rehab afterwards. I am **not/partially/fully** (circle one) vaccinated. I **received/did not receive** (circle one) a vaccine (if vaccinated). I received the **Moderna/Pfizer/J&J** vaccine. My first dose was on (insert date) ____ / ____ / _____. My second dose was on ____ / ____ / ____ (leave blank if you only received first dose).

Sources:

Patient-Led Research Collaborative: <https://patientresearchcovid19.com>. The Centers for Disease Control: Post-COVID Conditions (Updated September 2021) <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects> #ME Action: Pacing and Management Guide for ME/CFS: <https://www.meaction.net/stoprestspace> Incidence, co-occurrence, and evolution of long-COVID features: A 6-month retrospective cohort study of 273,618 survivors of COVID-19. Taquet M, Dercon Q, Luciano S, Geddes JR, Husain M, et al. (2021) PLOS Medicine 18(9): e1003773. <https://doi.org/10.1371/journal.pmed.1003773>

Daily Symptoms Tracker

This symptom log can help your provider understand your “COVID Story” and assist in deciding what recommendations to make about your health, and it can also help you to keep a record of your Long COVID symptoms.

[illegible]

Date	Symptom	How many mins/ hours does it last?	How many times per day?	Severity of symptom (mild/moderate/severe)	The symptom starts before or after I ... (activity or action)	I feel better when I ... (activity or action)	I feel worse when I ... (activity or action)

