

Symptom & Activity Journal



www.LongCovidFamilies.org

The Centers for Disease Control & Prevention cites the latest research published in May 2022, reporting that **1 / 5 individuals develop a post-covid condition.** Symptoms can be difficult to describe, range from mild - severe, and vary from day-to-day.

This document is intended to help patients and doctors identify lingering or new symptoms, trends, and discuss patient health, after an infection with Covid.

It was created by Long Covid Families, a patient-led, nonprofit organization in the United States.

About Long Covid Families

Long Covid Families is a 501c3 nonprofit organization that supports caregivers, children, and anyone whose life has been disrupted by post-infectious and / or triggered illness.

We understand that illness can disrupt every aspect of someone's life. Simply put, we help the Long Covid community discover practical ways to enjoy life while impacted by chronic illness.

Patients Name:

Date of Birth:

Goals for today's visit:

1.

2.

Top 3 most difficult symptoms:

How do symptoms limit daily functioning?

Today's Date:

Today's Activities:

Today's Symptoms:

(rate each on a severity scale 1-10, 10 being most severe)

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Summary of CDC Guidance on Evaluation of Post-Covid Conditions

<https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html>

- Post-acute sequelae SARS-CoV-2 infection (PASC) or “Long Covid” is used to describe Post-Covid medical conditions. Diagnosis can be made using the code U09.9 Post COVID-19 condition, unspecified
- A positive COVID test is not needed for diagnosis due to home testing, PCR and antigen availability and sensitivity limitations.
- There is no one test to identify Long Covid. A lack of laboratory or imaging abnormalities does not invalidate the existence, severity, or importance of a patient’s symptoms or conditions. Post-COVID conditions involve multiple organ systems, doctors should perform thorough physical examination:
 - **Standard vital signs:** Blood pressure, heart rate, respiratory rate, pulse-oximetry, body temperature and BMI
 - **Orthostatic vital signs for those reporting postural symptoms:** dizziness, fatigue, cognitive impairment, or malaise. (IE: 10 minute NASA lean test)
 - **Laboratory testing** should be guided by the patient history, physical examination, and clinical findings. It is important to rule out any life threatening conditions and diseases.

Patients with post-COVID conditions may share some of the symptoms that occur in patients who experience:

- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
Fibromyalgia
- Post-treatment Lyme disease syndrome
- Dysautonomia (POTS, Orthostatic Intolerance)
Mast cell activation syndrome (MCAS)

Common symptoms:

Dyspnea, fatigue, post-exertional malaise and/or poor endurance*, “brain fog,” cognitive impairment, cough, chest pain, headache, palpitations and/or tachycardia, arthralgia, myalgia, paresthesia, abdominal pain, diarrhea, insomnia and other sleep difficulties, fever, lightheadedness, impaired daily function and mobility, pain, rash (e.g., urticaria), mood change, anosmia or dysgeusia, menstrual cycle irregularities.

* Post-exertional malaise (PEM) is abnormal physiological response to exertion, not due to deconditioning that causes a worsening of symptoms following even minor physical or mental exertion. This response can be delayed hours to days after the activity and lasting for days, or even months.

Patients with PEM are encouraged to practice pacing activities to prevent deterioration of their condition. Graded exercise therapy may be harmful for this patient group and should be avoided.

- **Use of patient-centered approaches** to optimize the quality of life and function in affected patients. Focus on treating specific symptoms (e.g., headache) or conditions (e.g., dysautonomia) is recommended.
- **Outcomes from post-COVID conditions vary.** Some patients may experience symptom improvement within the first three months, others may continue to experience prolonged symptoms.



COVID-19

Patient History and Physical Exam

Evaluating and Caring for Patients with Post-COVID Conditions: Interim Guidance

Updated June 14, 2021 [Print](#)

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A Suggested Workup for Post-COVID Conditions

Patient history

The history of present illness should include the patient's COVID-19 disease course, severity of illness, and treatments received. When possible, healthcare professionals should establish a timeline of when symptoms emerged during acute illness and afterwards. Commonly reported symptoms are included in **Table 1**.^(1-4, 6-9, 12, 20, 39-46)



Table 1. Symptoms commonly reported among people with post-COVID conditions

- Dyspnea or increased respiratory effort
- Fatigue
- Post-exertional malaise and/or poor endurance
- "Brain fog," cognitive impairment
- Cough
- Chest pain
- Headache
- Palpitations and/or tachycardia
- Arthralgia
- Myalgia
- Paresthesia
- Abdominal pain
- Diarrhea
- Insomnia and other sleep difficulties
- Fever
- Lightheadedness
- Impaired daily function and mobility
- Pain
- Rash (e.g., urticaria)
- Mood changes
- Anosmia or dysgeusia
- Menstrual cycle irregularities

* **Post-exertional malaise (PEM)** is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.

The broad spectrum of signs and symptoms reported thus far in persons with post-COVID conditions warrants a broad approach to the review of systems. Since information on post-COVID conditions in children and adolescents is limited, it is possible that other signs and symptoms than those listed in **Table 1** may be present or more common in younger age groups. Both for children and adults, healthcare providers should elicit the frequency, severity, and evolution of symptoms and their impact on quality of life and functional ability, including the degree to which symptoms interfere with their ability to return to school or work.

Past medical history should include assessment for prior conditions that could impact the severity of COVID-19 disease, including but not limited to asthma, allergies, chronic obstructive pulmonary disease, interstitial lung disease, chronic kidney disease, diabetes mellitus, obesity, sleep disorders, prior autoimmune disease, mood disorders (e.g., anxiety or depression), trauma and stressor-related disorders (e.g., adjustment disorder or PTSD), hypertension, migraines, fibromyalgia, or chronic fatigue.

Social history should include assessment of the level of material and social supports and resources available to the patient (e.g., finances, employment, housing, access to food) and their potential impact on the capacity of patients to access health and recuperation services. Healthcare professionals should establish the patient's current and pre-infection level of activity (e.g., nature of work or school activities, activities of daily living) as well as screen for potential or known substance use disorder. The Centers for Medicare and Medicaid Services provide a [useful tool](#)   for assessing these and other social needs and determinants of health.

For patients with clinical features warranting further evaluation, healthcare professionals might consider the broad range of possible post-COVID conditions. These could have been present prior to and unmasked by SARS-CoV-2 infection or they may have been caused more directly by SARS-CoV-2 infection. Additional system-based conditions that have been reported following SARS-CoV-2 infection can be found in **Table 2.** ^(1-3, 6, 39, 40, 46, 47)

Table 2. System-based conditions reported following SARS-CoV2 infection

Body System	Conditions (subject to change and not mutually exclusive)
Cardiovascular	Myocarditis, heart failure, pericarditis, orthostatic intolerance (e.g., postural orthostatic tachycardia syndrome (POTS))
Pulmonary	Interstitial lung disease, reactive airway disease
Renal	Chronic kidney disease
Dermatologic	Alopecia
Rheumatologic	Reactive arthritis, fibromyalgia, connective tissue disease
Endocrine	Diabetes mellitus, hypothyroidism
Neurologic	Transient ischemic attack/stroke, olfactory and gustatory dysfunction, sleep dysregulation, altered cognition, memory impairment, headache, weakness, and neuropathy
Psychiatric	Depression, anxiety, and post-traumatic stress disorder (PTSD), psychosis
Hematologic	Pulmonary embolism, arterial thrombosis, venous thromboembolism, or other hypercoagulability
Urologic	Incontinence, sexual dysfunction
Other	Weight loss, dysautonomia, vitamin D deficiency, allergies and mast cell activation syndrome, reactivation of other viruses, pain syndromes, and progression of comorbid conditions

As more is learned about the natural history of SARS-CoV-2 infection, this list of symptoms and conditions will likely change over time.

Physical examination and vital signs

Summary of The American Academy of Pediatrics Post-Covid-19 Conditions in Children & Adolescence

<https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/post-covid-19-conditions-in-children-and-adolescents/>

All patients who test positive for a SARS-CoV-2 infection should have at least one follow-up conversation or visit with their primary care medical home. Acute COVID-19 severity does not necessarily predict subsequent or ongoing symptoms. **People who test positive for SARS-CoV-2 should not exercise until they are cleared by a physician.**

Follow-up assessment should include the American Heart Association 14-element screening evaluation with special emphasis on cardiac symptoms including **chest pain, shortness of breath out of proportion for upper respiratory tract infection, new-onset palpitations, or syncope** (fainting) and perform a complete physical examination and an EKG.

Any child or adolescent who reports these signs/symptoms should have an in-office visit that includes a complete physical examination, and consideration for an EKG should be given prior to clearance to return to physical activity.

- **In-person visit is recommended for**
 - Pediatric patients with moderate & severe disease (more than 4 days of fever, chills, body pain, lethargy) due to greater risk for subsequent cardiovascular disease.
 - Pediatric patients who report signs & symptoms regardless of acute infection severity.
- **Follow-up visit by phone or a video visit may be sufficient** for patients who were asymptomatic or mild disease severity (less than 4 days of fever, chills, body pain, lethargy), ***if all residual symptoms are resolved.***

If cardiac sign/symptom screening is positive or EKG is abnormal, referral to a cardiologist is recommended. The cardiologist may consider ordering a troponin test and an echocardiogram at the time of acute infection. Depending on the patient's symptoms and their duration, additional testing including a Holter monitor, exercise stress testing, or cardiac magnetic resonance imaging (MRI) may be considered.

If cardiac workup is negative, gradual return to physical activity may be initiated after 10 days have passed from the date of the positive test result, and a minimum of 1 day of symptom resolution (excluding loss of taste/smell) has occurred off fever-reducing medicine.

Identify all necessary supports to facilitate return to activities of daily living (including return to learning, play, and employment.) This may include::

- Gradual return to school and cognitive activities based on tolerance
- Cognitive "rest periods" throughout the school day
- Interval academic accommodations
- Close monitoring and communication by the family, school, and pediatrician to assess progress
- Other academic adjustments or accommodations as needed.

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Although children and adolescents may have less severe acute illness than adult populations, **COVID-19 can lead to many secondary conditions, which can range from subacute to severe.** Long-term effects from SARS-CoV-2 infection may be significant, regardless of the initial disease severity.

Youth Prevalence

The United Kingdom Office for National Statistics estimates:

12.9% of children 2 to 11 years of age

14.5% of children 12 to 16 years of age

still experienced symptoms 5 weeks after infection.

The reported frequency of post-COVID-19 conditions varies widely in the medical literature, several studies show that long-term symptoms can occur in children and adolescents.

- Respiratory
- Cardiac
- Anosmia and/or Ageusia
- Neurodevelopmental
- Cognitive Fogginess or Fatigue
- Physical Fatigue/Poor Endurance
- Headache
- Mental Health/Behavioral Health Sequelae

* Post-exertional malaise (PEM) is abnormal physiological response to exertion, not due to deconditioning that causes a worsening of symptoms following even minor physical or mental exertion. This response can be delayed hours to days after the activity and lasting for days, or even months.

Patients with PEM are encouraged to practice pacing activities to prevent deterioration of their condition. Graded exercise therapy may be harmful for this patient group and should be avoided.

Although a conservative approach (ie, minimal diagnostic evaluation, optimizing function and working toward achievable healthy goals) can be considered for the 4 to 12 weeks following illness because potential harm may arise from excessive testing, pediatricians should also consider other differential diagnoses and pursue additional investigation as clinically appropriate. If concerns persist past 12 weeks (3 months), then additional diagnostic testing (see CDC Interim Guidance on Post-COVID Conditions) and/or referral to a multidisciplinary post-COVID-19 clinic for consultation may be appropriate.

Find a Pediatric Post-Covid Clinic

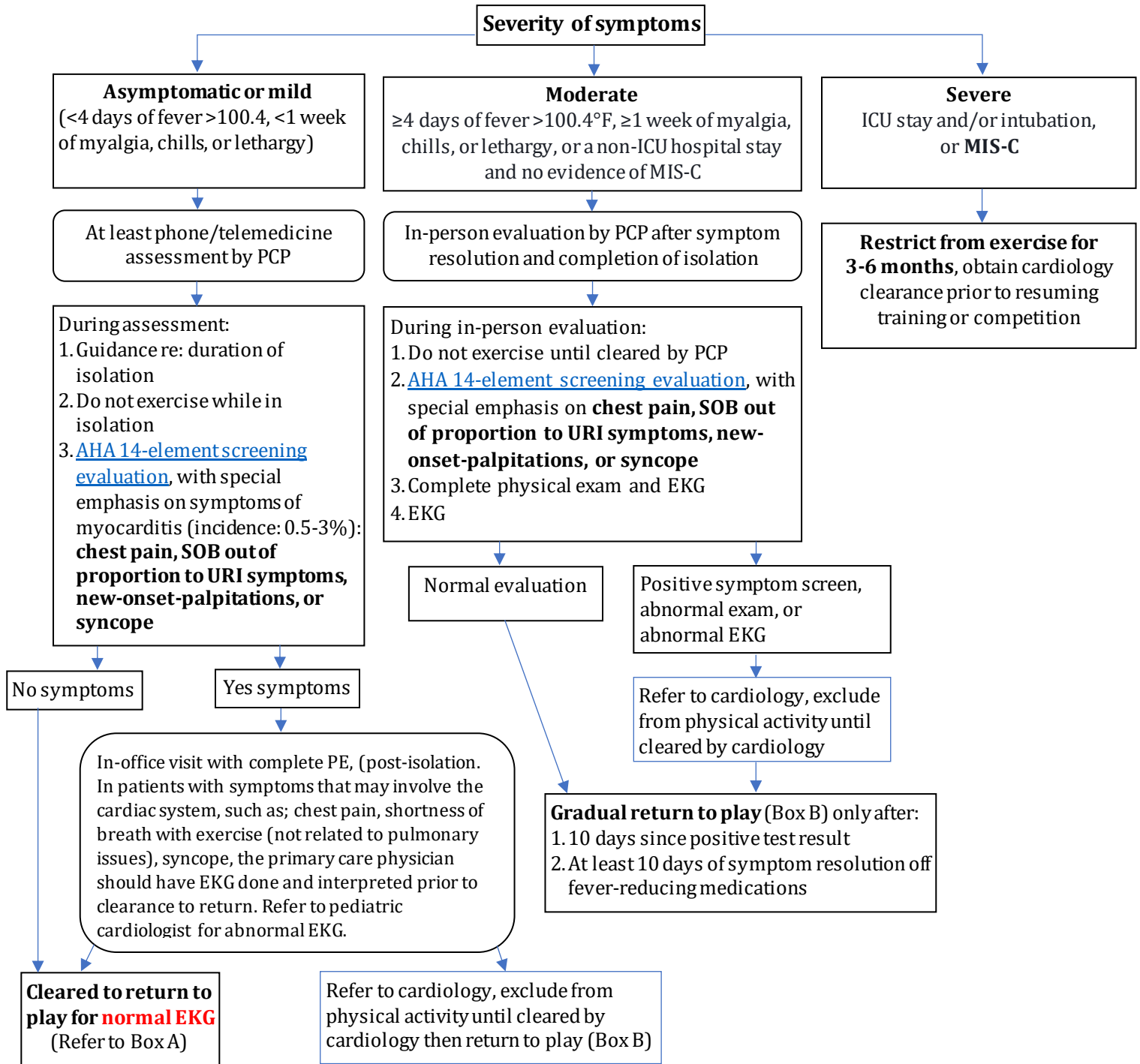
<https://LongCovidFamilies.org/Healthcare>

Return to play after COVID-19 infection

Adapted from the *AAP COVID-19 Interim Guidance: Return to Sports and Physical Activity* by Anna Zuckerman, MD, FAAP and Jonathan Flyer, MD, FAAP, FACC.

Healthcare professionals are likely to encounter many questions about the safety of participation in school sports during the pandemic, as well as the need to clear athletes to return to play after COVID-19 infection. For detailed guidance, please refer to the [AAP COVID-19 Interim Guidance: Return to Sports and Physical Activity](#).

Additionally, please find a chart below that summarizes the guidance regarding clearing athletes to return to play:



Additional note: if the patient has already advanced back to physical activity on their own and is without abnormal cardiovascular signs/symptoms, then no further evaluation is necessary. COVID19 disease history should be documented.

Abbreviations: PCP: primary care physician; SOB: shortness of breath; URI: upper respiratory infection; PE: physical exam; EKG: electrocardiogram; MIS-C: multisystem inflammatory syndrome in children.

Return to play after COVID-19 infection (continued)

BOX A: Additional Guidance on Returning to Play

When should children and adolescents return to play?

- 1) Completed isolation and minimum amount of symptom free time has passed
- 2) Can perform all activities of daily living
- 3) No concerning signs/symptoms

At what pace should children and adolescents return to play?

- 4) <12yo: progress according to own tolerance
- 5) 12+: gradual return to physical activity (Box B); should be done over a 7-day minimum and may extend duration for children with moderate symptoms

When should children and adolescents pause return to play?

- If patient develops any chest pain, SOB out of proportion to URI infection, new-onset palpitations, or syncope when returning to exercise, immediately stop and go to PCP for in-person exam

BOX B: Gradual Return to Play

(Adapted from Elliott N, et al, infographic, British Journal of Sports Medicine, 2020; copied from AAP Policy statement)

Stage 1: Day 1 and Day 2 – (2 Days Minimum) – 15 minutes or less: Light activity (walking, jogging, stationary bike), intensity no greater than 70% of maximum heart rate. NO resistance training.

Stage 2: Day 3 – (1 Day Minimum) – 30 minutes or less: Add simple movement activities (eg. running drills) – intensity no greater than 80% of maximum heart rate.

Stage 3: Day 4 – (1 Day Minimum) – 45 minutes or less: Progress to more complex training – intensity no greater than 80% maximum heart rate. May add light resistance training.

Stage 4: Day 5 and Day 6 – 2 Days Minimum) – 60 minutes: Normal training activity – intensity no greater than 80% maximum heart rate.

Stage 5: Day 7 – Return to full activity/participation (ie, contests/competitions).