

# Understanding Long COVID: Implications for Family Physicians

## Introduction

Long COVID refers to health issues some individuals experience within a few months of being diagnosed with COVID-19. Other interchangeable terms include long-haul COVID, post-COVID-19 conditions, chronic COVID and post-acute sequelae of SARS-CoV-2.<sup>1</sup> The National Academies of Sciences, Engineering, and Medicine defines long COVID as “an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least three months as a continuous, relapsing and remitting or progressive disease state that affects one or more organ system(s).”<sup>2</sup> Long COVID is not one specific condition, but rather overlapping conditions with various biological causes, risk factors and outcomes.

## Key Takeaways

- The definition of long COVID is evolving, as is the diagnosis, management and treatment.
- Established symptom management approaches, such as individualized, structured and titrated activity programs, pacing strategies and avoiding post-exertional malaise are all essential.
- Models of care for long COVID require creativity and flexibility.
- Continuous patient education and health care provider and caregiver training are critical for diagnosing, managing and treating long COVID.

## Epidemiology and Economic Burden

Estimates of long COVID vary depending on the study methodology and definition, but here are some statistics about the prevalence of the condition and cost to society:

- Studies and surveys vary from almost 7% to as high as nearly 18% of U.S. adults reporting ever having long COVID.<sup>3,4</sup>
- Among individuals reporting ever having long COVID, the prevalence was highest among Hispanic/Latino individuals (21%) compared to other ethnic groups

and higher for individuals with disabilities (26%) compared to individuals without disabilities.<sup>4</sup>

- A Harvard study estimates the total economic cost of long COVID to be \$3.7 trillion, which is equivalent to \$11,000 per capita or 17% of the 2019 gross domestic product.<sup>5</sup>

The U.S. Department of Health and Human Services issued guidance that long COVID can be considered a disability under the Americans with Disabilities Act.<sup>6</sup>

## Symptoms

Long COVID can manifest in various ways, often presenting with multiple symptoms or conditions affecting a wide range of body systems following either mild or severe SARS-CoV-2 infection(s).<sup>2</sup> Symptoms can be similar to or different from those of COVID-19, and may overlap with symptoms of myalgic encephalomyelitis/chronic fatigue syndrome. Long COVID affects people differently, with individuals experiencing various health issues from different combinations of symptoms. These symptoms can appear, persist, disappear and recur over varying periods. Common symptoms in one study included post-exertional malaise, fatigue, brain fog, dizziness, gastrointestinal complications and heart palpitations.<sup>7</sup>

Some individuals with long COVID may develop or continue to have symptoms that are difficult to explain and manage. Those who had severe COVID-19 may experience effects on multiple organs or auto-immune conditions, with symptoms lasting weeks, months or even years after their illness. Individuals who have had any severe illness, hospitalization or treatment may develop issues like post-intensive care syndrome.<sup>2</sup> The Centers for Disease Control and Prevention maintains a further list of possible symptoms on its Signs and Symptoms of Long COVID webpage ([www.cdc.gov/covid/long-term-effects/long-covid-signs-symptoms.html](https://www.cdc.gov/covid/long-term-effects/long-covid-signs-symptoms.html)).

“Long COVID can affect children and adults, regardless of health, disability or socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity or geographic location.”<sup>2</sup>

## Diagnosis

Identifying and managing patients with long COVID in primary care settings requires a multifaceted approach due to the varied and complex nature of the condition. The diagnostic process benefits from a comprehensive patient history, physical examination, symptom assessment and documentation of symptoms or conditions that have lasted for three months or longer. Patients with long COVID particularly benefit from longitudinal, continuous care delivered by a family physician and their clinical care team.

To identify a patient with long COVID, start by taking a comprehensive patient history, focusing on new or worsening symptoms post-COVID infection, tolerance to physical and cognitive activities and any recurrent infections or hospitalizations.<sup>2</sup> A thorough physical examination should follow, emphasizing symptom-specific assessments and screenings for conditions such as orthostatic intolerance, using tests like the NASA 10-minute Lean Test<sup>8</sup> ([https://batemanhornecenter.org/wp-content/uploads/filebase/providers/mecfs/10-Minute-NASA-Lean-Test-Clinician-Instructions-06\\_12\\_2022.pdf](https://batemanhornecenter.org/wp-content/uploads/filebase/providers/mecfs/10-Minute-NASA-Lean-Test-Clinician-Instructions-06_12_2022.pdf)) or an active standing test.<sup>9</sup>

## Testing

Diagnosing long COVID is complex, and no serologic test is available at this time.<sup>10</sup> A patient with symptoms of long COVID may not test positive for SARS-CoV-2 and have normal or nondiagnostic laboratory and imaging studies. While no definitive laboratory test(s) can distinguish long COVID conditions from other conditions with different etiologies, laboratory evaluations might include general testing levels of vitamins B1, B6 and B12, as well as testing for the protein ferritin,<sup>11,12</sup> with additional tests tailored to specific symptoms (e.g., thyroid-stimulating hormone for fatigue<sup>13</sup> and vitamin deficiencies for cognitive impairment<sup>14-16</sup>).

Imaging and other procedures, such as chest X-rays or cardiovascular stress tests, may be indicated for patients with severe cardiopulmonary symptoms,<sup>17-19</sup> while specialized tests, including auto-antibody panels, may be indicated in suspected auto-immune cases.<sup>20-22</sup> The CDC offer further information for health care providers about post-COVID conditions ([https://archive.cdc.gov/www\\_cdc\\_gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html](https://archive.cdc.gov/www_cdc_gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-conditions.html)).

## Management Strategies

Most patients with long COVID can be longitudinally managed within family medicine practices. However, management of long COVID by family physicians is often complicated due to widely variable patient symptoms.<sup>23</sup> Effective management strategies should focus on

optimizing a patient's function and quality of life through a multidisciplinary approach involving primary care providers and other specialists.<sup>10</sup>

## MULTIDISCIPLINARY CARE MODELS

There are various models of care for long COVID. Family physicians play an integral role in the initial evaluation and ongoing management of care by coordinating and consulting with other specialists when indicated.<sup>23,24</sup> The ideal model of care will depend on local factors, including available expertise and resources, populations served and geographical considerations.<sup>23</sup> Every model should streamline pathways to specialties and professions knowledgeable about long COVID and dysautonomia, such as physical therapy, psychiatry, pulmonology, cardiology, neurology, neuropsychology, occupational therapy, speech and language pathology and other specialties, as appropriate.

## PHYSICAL SYMPTOM MANAGEMENT

Many long COVID symptoms can be improved through established symptom-management approaches. A comprehensive rehabilitation plan may be helpful for some patients, while personalized, physical rehabilitation plans might be indicated for other patients, such as those focusing on post-exertional malaise.<sup>10</sup> The American Academy of Physical Medicine and Rehabilitation has useful guidance ([www.ncbi.nlm.nih.gov/pmc/articles/PMC8441628/pdf/PMRJ-13-1027.pdf](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC8441628/pdf/PMRJ-13-1027.pdf)) to assess and treat fatigue for patients with long COVID. Physical symptom management plans should emphasize education and self-management strategies, including lifestyle components for patients and their families or caregivers. As tolerated, the plan should focus on an individualized, structured and titrated return-to-activity program, along with the 4 P's of Energy Conservation (Planning, Pacing, Prioritizing, Positioning) ([www.advancedptsm.com/blog/2019/10/2/the-4-ps-of-energy-conservation](http://www.advancedptsm.com/blog/2019/10/2/the-4-ps-of-energy-conservation)). Regular multidisciplinary follow ups coordinated by family physicians are important to monitor progress, adjust treatment plans and provide ongoing support. Encouraging patients to document changes in health condition(s) and symptom severity in diaries and calendars can help track the timing and effects of treatment.

## MENTAL HEALTH MANAGEMENT

Addressing mental health is critical, given the high prevalence of anxiety, depression and cognitive impairment for patients with long COVID. However, physicians will want to take caution with attributing the complex symptoms associated with long COVID to behavioral health conditions, while being mindful and sensitive to patients who believe physicians have been attributing their long COVID symptoms to anxiety.

Access to mental health services should be integrated into care plans, including referral(s) to psychiatry and psychology when indicated, using the following strategies:

- Patient-centered care: Mental health management plans should be tailored to individual patient needs, considering specific symptoms, underlying conditions and personal circumstances. Shared decision making is crucial to ensure that treatment goals align with patient preferences and expectations.<sup>23</sup>
- Continuous monitoring and adjustment: Follow ups are essential for mental health management to monitor progress and adjust treatment plans with tools like patient diaries and calendars to track symptom changes and treatment responses.<sup>10</sup> Ongoing evaluation can refine management strategies to meet patient needs better.
- Education and training: Given the evolving nature of long COVID, continuous education and training for patients, health care providers and caregivers is essential.<sup>25</sup>

### Treatment Considerations

Treating long COVID can be challenging, as patients can have varying symptoms in multiple body systems that can linger for weeks, months or years. Additionally, treatment options can be insufficient, as researchers are still learning about the disease and the virus that causes it. As you treat patients diagnosed with long COVID, consider the following effective communication and treatment practices:

- Validate the patient's description of their symptoms and condition (see the box to the right for sample conversation examples).<sup>26</sup>
- Implement a pacing strategy for patients by encouraging them to balance activity with rest to prevent the exacerbation of symptoms, especially fatigue and post-exertional malaise.<sup>27</sup>
- Incorporate respiratory training and an individualized, structured and titrated return-to-activity program.<sup>28</sup>
- Make accommodations for patients with a disability.
- Screen for and encourage patients to implement a healthy lifestyle, including diet, exercise and avoiding risky alcohol and substance use.<sup>29,30</sup>
- Screen for obstructive sleep apnea<sup>31</sup> and encourage sleep optimization through sleep hygiene (i.e., behavior and diet that impacts sleep), behavioral interventions (i.e., stimulus control therapy, relaxation, sleep restriction) and pharmacological treatments.<sup>32</sup>
- Encourage patients to manage stress and utilize social support resources, positive social connections and peer support groups.<sup>33</sup>

- Continue to treat patients' coexisting conditions.
- Start low and go slow for all medications. Be mindful of symptom exacerbation versus medication side effects.
- Reduce or discourage the use of polypharmacy.
- Utilize specialty consultation if the diagnosis is unclear and symptoms are severe, persistent and/or worsening.
- Follow up with care and continue to manage symptoms, treatment response and medication changes.
- Encourage patients to stay current on COVID vaccines to combat new variants.

### Sample Conversations

- "Long COVID is a real condition and consistent with your symptoms. Many people experience it, so know that you are not alone."
- "Every person is different, and treatment can be different for different people. Many patients, but not all, will improve or fully recover over several months or sometimes years."
- "Although we don't have a cure right now, many patients can manage their symptoms and improve their quality of life with the treatment strategies we do have."
- "Researchers are learning more about long COVID daily, and we can work together to ensure you can access any new treatments that are right for you."

### Coding, Billing and Reimbursement

Effectively coding and billing for long COVID services can maximize reimbursement and ensure comprehensive patient care. The American Medical Association has introduced new CPT codes for COVID-19 and long COVID services, including various diagnostic tests and treatments.<sup>34</sup> The ICD-10 code U09.9 is designated for "post-COVID-19 condition, unspecified,"<sup>35</sup> with proper coding essential for accurate billing and reimbursement. For example, if a specific COVID-related condition is known, then that condition should be coded as the primary diagnosis, followed by U09.9 as a secondary code. If the specific COVID-related condition is unknown, U09.9 can be used as the primary diagnosis.

The 2024 Medicare Physician Fee Schedule includes updates, such as the new add-on code G2211, for visit complexity and changes to time thresholds for

prolonged services.<sup>36</sup> Medicare has also extended telehealth coverage through 2024, including audio-only consultations, benefiting all patients, but especially those in rural or underserved areas.<sup>37</sup> Thorough documentation of patient history, symptoms and treatments is crucial to support proper coding and reduce the risk of claim denials.

## Conclusion

Family physicians play a pivotal role in managing long COVID, from initial diagnosis to ongoing care, support, treatment and coordination with other specialists. In order to manage long COVID, it is imperative to stay informed about the latest developments and best practices. Adopting a holistic and patient-centered approach can help alleviate the burden of long COVID for patients and their communities, improve patient outcomes and enhance the quality of life for those affected.

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