

## Resources for Primary Care Providers (PCPs)

The following information is designed to be shared with your PCP or other medical providers who may not be familiar with Long COVID. Please consider it a resource and feel free to bring it to your appointments.

### Fast Facts About Long COVID

**Prevalence:** Around 10–20% of people infected with SARS-CoV-2 may experience lingering symptoms lasting beyond 12 weeks.

**Symptoms Are Multisystemic:** Long COVID can affect the brain, heart, lungs, gut, immune system and autonomic nervous system, often with fluctuating or relapsing patterns. Symptoms can range between mild, moderate, and severe.

**Not Just Severe Cases:** Long COVID affects people regardless of whether their initial COVID infection was mild, moderate or severe and impacts people even if they were never hospitalized.

**Post-Exertional Malaise (PEM):** Many patients experience symptoms worsening after physical, cognitive or emotional exertion. Pacing and energy conservation are critical. Physical and/or Occupational Therapy which do not take PEM into account, programs such as Graded Exercise Therapy (GET), or programs that focus solely on mental health without addressing underlying physical symptoms can be harmful.

**Dysautonomia & POTS:** A significant portion of people with Long COVID develop autonomic dysfunction, including postural orthostatic tachycardia syndrome, which requires tailored management.

**Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder:** Patients with an underlying connective tissue disorders such as EDS or HSD—which may have been dormant or asymptomatic prior to a COVID infection—may be at higher risk to develop Long COVID

**Overlap with ME/CFS & Other Post-Viral Syndromes:** Many symptoms parallel those seen in ME/CFS, mast cell activation, chronic Lyme and small fiber neuropathy, offering valuable cross-condition management strategies.

**Recovery Varies:** While many improve over time, others experience persistent symptoms for months or years, needing long-term support and adaptive care strategies. Some patients become temporarily or permanently disabled.

**Multidisciplinary Care Matters:** Because symptoms span so many systems, coordinated care across specialties leads to better patient outcomes.

## What Your Patient with Long COVID Wants You to Know

- “Please listen and believe me.”  
Patients often struggle to feel validated. They need you to believe their symptoms are real and impactful, even if lab tests and imaging are normal.
- “This is not just anxiety or deconditioning.”  
While mental health support can help, the underlying drivers of Long COVID are biological and multisystemic. Deconditioning is usually a result of symptoms, not their cause. Many patients have worsening with exertion, not improvement.
- “I need you to understand post-exertional ‘crashes’.”  
Scientific evidence from conditions such as ME/CFS shows that pushing through activity can make symptoms worse and lead to poorer long-term prognosis. Help patients learn pacing strategies to minimize and avoid crashes. Do not recommend graded exercise therapy unless guided by a provider who is knowledgeable about PEM.
- “Please support me on this challenging journey.”  
Patients may need help accessing disability supports, accommodations at work or school and referrals to specialized care. Patients may need help accessing referrals to specialized care; documenting the need for disability accommodation at work or school; documentation and medical support for medical leaves, short- and/or long-term disability, and social security benefits
- “Stay with me and advocate for me.”  
Long COVID can be unpredictable and exhausting. Having a PCP who offers continuity, compassion and regular check-ins makes a meaningful difference in coping and recovery.
- “Please take the time to educate yourself on this complex condition.”  
We know you have your hands full with your existing patients, and it can be overwhelming to find time in your busy schedule to access learning resources. However, patients need you to rise to the challenge of their significant need, to the best of your ability. Many resources for providers exist to learn more about Long COVID and associated conditions.

## Information and Links for Providers

### **Administration for Community Living (ACL): Resources for People with Long COVID**

Information on requesting and providing workplace accommodations for individuals living with Long COVID.

<https://acl.gov/covid19/resources-people-experiencing-long-covid>

### **The American Academy of Physical Medicine and Rehabilitation (AAPM&R)**

A multi-disciplinary collaborative of experts to address Long COVID, its diagnosis, treatment, and long-term follow up. The collaborative developed a compendium to help clinicians evaluate and manage adults experiencing Long COVID symptoms and provides symptom-specific guidance.

<https://onlinelibrary.wiley.com/doi/epdf/10.1002/pmrj.13397>

### **Bateman Horne Center: Provider Medical Education**

Evidence-based webinars, training materials, resources, and expert guidance for clinicians working with ME/CFS, Long COVID, MCAS, EDS, and other related conditions. A leader in clinical education in the space.

<https://batemanhornecenter.org/providers/medical-education/>

### **CDC: Clinical Care Guidance for Post-COVID Conditions**

Detailed recommendations for clinicians on managing and treating patients with post-COVID conditions.

<https://www.cdc.gov/covid/hcp/clinical-care/management-and-treatment.html>

### **CDC: Clinical Overview of Long COVID**

A concise summary of Long COVID symptoms and management strategies tailored for primary care settings.

<https://www.cdc.gov/covid/hcp/clinical-overview/index.html>

### **CDC: Living with Long COVID**

Guidance for individuals experiencing Long COVID, including symptoms, management strategies and support resources.

<https://www.cdc.gov/covid/long-term-effects/living-with-long-covid.html>

### **CDC ME/CFS Healthcare Provider Toolkit**

Educational resources, diagnostic tools and management strategies to help providers understand and support patients with ME/CFS, with lessons relevant to Long COVID.

<https://www.cdc.gov/me-cfs/hcp/toolkit/healthcare-provider-resources.html>

### **Centers for Medicare & Medicaid Services (CMS): Long COVID Education, Engagement, and Care Management**

A program improving education and engagement in the care of people with Long COVID, involving primary care and specialty societies.

<https://cmss.org/programs-and-resources/long-covid-education-engagement-and-care-management/>

### **Clinician's Pacing and Management Guide for ME/CFS and Long COVID**

Developed by the Patient-Led Research Collaborative to support assessment and treatment of Long COVID and ME/CFS

<https://patientresearchcovid19.com/clinicians-pacing-and-management-guide-for-me-cfs-and-long-covid/>

### **Covid for Doctors**

Developed by Dr Nancy Malek, an anesthesiologist from in Sydney, Australia. She is actively involved in improving education around COVID and advocates for evidence-based airborne precautions in hospitals to safeguard both staff and patients.

<https://covidfordoctors.org/>

### **The Ehlers-Danlos Society: Resources for Clinicians**

A leading non-profit on Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder, with many clinician resources.

<https://www.ehlers-danlos.com/healthcare-professionals/>

### **Harvard Medical School: Long COVID CME Course**

A Continuing Medical Education course designed to equip PCPs with the latest knowledge on diagnosing and managing Long COVID.

<https://info.primarycare.hms.harvard.edu/long-covid-cme-course-for-primary-care>

### **International Consensus Primer for ME/CFS**

A detailed clinical guide outlining diagnostic and treatment approaches for ME/CFS, including symptom management and clinical pearls.

<https://growthzonesitesprod.azureedge.net/wp-content/uploads/sites/1869/2020/10/Primer Post 2014 conference.pdf>

### **Long COVID: emerging pathophysiological mechanisms**

Mueller MR, Ganesh R, Beckman TJ, Hurt RT. Long COVID: emerging pathophysiological mechanisms. *Minerva Med.* 2025 Apr;116(2):156-165. doi: 10.23736/S0026-4806.25.09539-4. Epub 2025 Mar 19. PMID: 40105889.

<https://pubmed.ncbi.nlm.nih.gov/40105889/>

### **The Long COVID Repository**

An organized set of trusted resources aimed at helping clinicians understand and care for people with Long COVID. Includes tools across major symptom areas.

<https://cmss.org/programs-and-resources/long-covid-resource-repository/>

### **Massachusetts Department of Public Health: Long COVID Resources**

Information on symptoms, prevention and resources for individuals experiencing Long COVID.

<https://www.mass.gov/info-details/long-covid-or-post-covid-conditions>

### **ME/CFS Clinician Coalition: Clinical Management**

Practical recommendations for managing post-exertional malaise, orthostatic intolerance, cognitive issues and more in ME/CFS, highly applicable to Long COVID care.

<https://mecfscliniciancoalition.org/clinical-management/>

### **ME/CFS Clinician Coalition: Treatment Recommendations**

Targeted treatment recommendations for ME/CFS, including energy management, pharmacologic strategies and comorbidity care.

<https://mecfscliniciancoalition.org/wp-content/uploads/2021/05/MECFS-Clinician-Coalition-Treatment-Recs-V1.pdf>

### **Minnesota Department of Health: Post-COVID Conditions for Providers**

Baseline assessment tool, guidelines for managing long-term effects of COVID-19, advice for coordinating services and more.

<https://www.health.state.mn.us/diseases/longcovid/providers.html>

### **National Institutes of Health (NIH): RECOVER Initiative**

A major research initiative to understand, prevent and treat Long COVID, with resources and updates for healthcare providers.

<https://recovercovid.org/>

### **Solve ME/CFS Initiative: Long COVID Resources**

A collection of resources to help individuals find care for Long COVID, including lists of healthcare providers and care centers.

<https://solvecfs.org/solve-long-covid/long-covid-resources/>

### **Updated Clinical Practice Guidelines for Long COVID (PMC)**

An evidence-based guideline to assist clinicians in diagnosing and treating Long COVID, with integration of recent research findings.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC10990882/>

### **U.S. Department of Veterans Affairs (VA): Whole Health System Approach to Long COVID**

A comprehensive guide integrating whole health principles into Long COVID care, including mind-body strategies, nutrition and rehab.

[https://www.publichealth.va.gov/n-coronavirus/docs/Whole-Health-System-Approach-to-Long-COVID\\_080122\\_FINAL.pdf](https://www.publichealth.va.gov/n-coronavirus/docs/Whole-Health-System-Approach-to-Long-COVID_080122_FINAL.pdf)

### **World Health Organization (WHO): Post-COVID-19 Condition Fact Sheet**

Global insights into Long COVID symptoms and the importance of rehabilitation and self-management.

<https://www.who.int/news-room/fact-sheets/detail/post-covid-19-condition-%28long-covid%29>