

Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Informational Tool for Primary Care Providers

Introduction

According to National Academies of Sciences, Engineering, and Medicine (NASEM), “Long COVID is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems”.¹

In some cases, COVID-19 may result in a new chronic disease. Multi-system diseases in which onset is often associated with infection are known as infection-associated chronic illnesses, or infection-associated chronic conditions (IACC). Examples of IACCs that we have known for a long time include myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia, postural orthostatic tachycardia syndrome (POTS), and mast cell disorders.² ME/CFS is a neurological disease that presents with immune dysregulation, mitochondrial dysfunction, and other pathology impairing or disabling the body.³ Here we focus on information to help clinicians diagnose and manage patients with long COVID who present with ME/CFS.

Ultimately, the most important aspect to diagnosis and management of patients with long COVID is going to be their specific symptom experience. This guide, while specific to managing patients with long COVID who present with ME/CFS, may also provide considerations for patients who have similar symptoms but don’t meet the criteria for ME/CFS.

Coding

Long COVID is the umbrella diagnosis. It is important to use long COVID (also called post COVID-19 condition) to indicate that the symptoms occurred due to COVID-19. In addition, providers should code for specific conditions that occur as a result of long COVID, such as ME/CFS, when applicable.

The ICD-10 code G93.32, myalgic encephalomyelitis/chronic fatigue syndrome, is the most specific code for ME/CFS. The long COVID (Post COVID-19 condition) ICD-10 code is U09.9. The full list of ME/CFS codes is available at: [Diagnosing ME/CFS | ME/CFS | CDC \(https://www.cdc.gov/me-cfs/hcp/diagnosis/index.html\)](https://www.cdc.gov/me-cfs/hcp/diagnosis/index.html). For more coding resources, see [For Health Care Providers: Post-COVID Conditions - MN Dept. of Health \(https://www.health.state.mn.us/diseases/longcovid/providers.html\)](https://www.health.state.mn.us/diseases/longcovid/providers.html).

Audience

While this resource is primarily intended for primary care clinicians, it is designed to be accessible to all healthcare professionals.

¹ National Academies of Sciences, Engineering, and Medicine. 2024. *A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences*. Washington, DC: The National Academies Press. doi.org/10.17226/27768.

² Ibid

³ Institute of Medicine. 2015 *diagnostic criteria*. (2024, May 10). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. <https://www.cdc.gov/me-cfs/hcp/diagnosis/iom-2015-diagnostic-criteria-1.html>

Primary care providers may provide an accurate diagnosis, symptom management, and coordinated, whole-person care for people with long COVID, particularly in patients who may lack access to specialty centers.^{4,5} They can also rule out other potential causes of symptoms. Provider documentation of diagnostic codes and symptom impacts on disability and quality of life can be crucial for patients seeking access to workplace accommodations, support at school, disability benefits, and other social services and programs.^{6,7}

When should I be thinking of ME/CFS?

We recommend looking for ME/CFS in any patient suspected to have long COVID. Studies suggest **50%** of people with long COVID at six months may meet diagnostic criteria for ME/CFS.^{8,9} Based on the Institute of Medicine criteria, diagnosis of ME/CFS is based on having these five symptoms:¹⁰

- Post-exertional malaise (PEM) (see more in Table 1 below)
- Significant reduction in function
- Extreme fatigue
- Unrefreshing sleep
- Cognitive changes AND/OR orthostatic intolerance

The above symptoms should be present about 50% of the time or more and rated at least moderate in severity. Other symptoms of ME/CFS can include but are not limited to muscle weakness, lymph node tenderness/swelling, flu-like feelings, pain, headaches, gastrointestinal or genitourinary symptoms, and new or worsened sensory sensitivities or allergies.^{11,12}

Of note, even if a patient doesn't meet the criteria threshold, there are still benefits from therapies discussed below.

Characteristics of Post-Exertional Malaise (PEM)¹³

PEM is an increase in the severity of symptoms and/or appearance of new symptoms after physical and cognitive exertion, often manifesting after a characteristic 24-hour delay. However, 12 to 48 hours is common. Some symptoms that may be part of PEM presentation are outlined below, with common language descriptions.

⁴ Berger, Z., Altiery DE Jesus, V., Assoumou, S. A., & Greenhalgh, T. (2021). Long COVID and Health Inequities: The Role of Primary Care. *The Milbank quarterly*, 99(2), 519–541. doi.org/10.1111/1468-0009.12505.

⁵ Landhuis EW. How Primary Care Physicians Can Recognize and Treat Long COVID. *JAMA*. 2023;329(20):1727–1729. doi:10.1001/jama.2023.6604.

⁶ SSA.gov. (n.d.). Long COVID: A guide for health professionals on providing medical evidence for social security disability claims. In *Long COVID: A Guide for Health Professionals on Providing Medical Evidence for Social Security Disability Claims*. <https://www.ssa.gov/disability/professionals/documents/EN-64-128.pdf>.

⁷ National Academies of Sciences, Engineering, and Medicine. 2024. *Long-Term Health Effects of COVID-19: Disability and Function Following SARS-CoV-2 Infection*. Washington, DC: The National Academies Press. doi.org/10.17226/27756.

⁸ Vernon, S. D., Hartle, M., Sullivan, K., Bell, J., Abbaszadeh, S., Unutmaz, D., & Bateman, L. (2023). Post-exertional malaise among people with long COVID compared to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Work (Reading, Mass.)*, 74(4), 1179–1186. doi.org/10.3233/WOR-220581.

⁹ Jason, L. A., & Dorri, J. A. (2022). ME/CFS and Post-Exertional Malaise among Patients with Long COVID. *Neurology international*, 15(1), 1–11. doi.org/10.3390/neurolint15010001.

¹⁰ Institute of Medicine 2015 diagnostic criteria. (2024, May 10). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. <https://www.cdc.gov/me-cfs/hcp/diagnosis/iom-2015-diagnostic-criteria-1.html>

¹¹ Ibid

¹² Institute of Medicine. 2015. *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. Washington, DC: The National Academies Press. doi.org/10.17226/19012.

¹³ Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Mayo Clinic proceedings*, 98(10), 1544–1551. doi.org/10.1016/j.mayocp.2023.07.032

Table 1. Post-Exertional Malaise (PEM) Symptom Descriptions

Symptom Type	Symptom Description
Sensory	New or increased sensitivity to light, sound, smell or temperature
Autonomic	Nausea, Vertigo, dizziness, increased sighing and yawning, drop in core temperature, “The shakes”, heart pounding
Cognitive	Can’t process words, Trouble retrieving words, Thinking is effortful “brain fog”, Trouble starting and changing tasks
Pain	Headache, aches and pains, pain where the skull meets the spine
Immune	Flu-like symptoms, fever, sore throat, swollen lymph nodes
Neuromuscular	Muscles less responsive/non-responsive, Feels “heavy”, “leadens”, like “wet concrete”, Muscles painful, burning, tingling or “buzzing”
Energy level	A falling, pooling or “pulled plug” sinking sensation; in “shutdown”, “locked in my body”, “my battery is low”, “wired but tired”
Metabolism	“feeling poisoned”, “like a hangover”

Table adapted from: *Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*, Grach, Stephanie L. et al. *Mayo Clinic Proceedings*, Volume 98, Issue 10, 1544 - 1551

PEM is not:

- Being more tired than usual after an activity
- Second-day muscle soreness
- Necessarily relieved by sleep
- Deconditioning*
 - ME/CFS symptoms often get misattributed as deconditioning. Studies have shown that the manifestation of symptoms that occur with ME/CFS have a different pathophysiological process compared to people who are simply deconditioned.¹⁴ This is a reason why pacing is the recommended therapy rather than graded exercise.

Post-exertional malaise (PEM) is a pathological state in which many symptoms worsen and/or new symptoms appear after physical or cognitive activity, often but not always 24 hours after the exertion. PEM is a hallmark symptom of ME/CFS but some people with long COVID can have signs of PEM without meeting the full ME/ CFS criteria.

According to Grach et al,¹⁵ and NICE Guidelines¹⁶, ME/CFS severity is often divided into mild (25%), moderate (50%), and severe/very severe (25%). **Even mild ME/CFS can result in a 50% reduction in function compared to baseline.** A person with mild ME/CFS may be able to maintain a 40-hour work week, but often at the sacrifice of any personal activities and/or activities of daily living. People with moderate ME/CFS may be able to do limited part-time work or schooling and/or other minimal additional activities outside the home. People with severe or very severe ME/CFS are generally housebound and bedbound, respectively.

¹⁴ van Campen, C., & Visser, F. (2022). Comparison of the Degree of Deconditioning in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Patients with and without Orthostatic Intolerance. *Medical Research Archives*, 10(6). doi:10.18103/mra.v10i6.2858

¹⁵ Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Mayo Clinic proceedings*, 98(10), 1544–1551. doi.org/10.1016/j.mayocp.2023.07.032

¹⁶ National Institute for Health and Care Excellence. (2021, October 29). *Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: Diagnosis and management (NICE Guideline NG206)*. <https://www.nice.org.uk/guidance/ng206>

What can a clinician do for symptoms of ME/CFS?

Pacing is one of the most important strategies that someone with an energy-limiting condition can practice. Pacing means having your patient engage in activities based on their individual capacity and avoiding pushing their body too much, as this can lead to PEM “crashes.” and a worsening of symptoms. People who show signs of PEM generally do better when they pace. As not all patients know when PEM is about to be triggered, smart watches that record health metrics, heart rate monitors or pacing phone apps can help, before they push too far.^{17,18,19,20}

Pacing can feel difficult at first, especially since many people with PEM want to be active. Depending on the body’s energy capacity — and knowing that there can be “good days” and “bad days” — they may be able to modify activities in a way that makes them easier to do. Below are some examples of things a person with PEM might do depending on their capacity^{21,22}

Table 2: Examples of pacing activity modifications that can help PEM

Reduce sensory input	Avoid aggravating exertion	Improve blood flow
Apply screen filters	Remote school or work	Keep hydrated
Wear tinted glasses	Sit and elevate feet, take frequent breaks	Use salt or electrolytes (ask your doctor)
Use headphones or earplugs	Recumbent, anaerobic > upright, aerobic exercise*	Use abdominal, thigh, and/or leg compression
Avoid busy shopping times	Utilize mobility devices	Lay down as needed

*as based on the individual’s capacity

Table created by author; informed by [Long Covid at Work: A Manager’s Guide \(hbr.org\)](#).

Activity management strategies that incorporate scheduled, regular increases in activity (such as graded exercise therapy) are not recommended.

¹⁷ Vernon, S. D., Hartle, M., Sullivan, K., Bell, J., Abbaszadeh, S., Unutmaz, D., & Bateman, L. (2023). Post-exertional malaise among people with long COVID compared to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Work (Reading, Mass.)*, 74(4), 1179–1186. doi.org/10.3233/WOR-220581.

¹⁸ Ghali, A., Lacombe, V., Ravaiau, C. *et al.* The relevance of pacing strategies in managing symptoms of post-COVID-19 syndrome. *J Transl Med* 21, 375 (2023). doi.org/10.1186/s12967-023-04229-w.

¹⁹ Myalgic Encephalomyelitis Action (MEAction) Network. (2025). *Pacing and management guides*. <https://www.meaction.net/resource/pacing-and-management-guide/>

²⁰ Bateman Horne Center. (2022, February 3). *ME/CFS Crash Survival Guidebook: The art of living with ME/CFS*. <https://batemanhornecenter.org/education/mecfs-guidebook/>

²¹ Bach, K., Praslova, L. N., & Pollack, B. (2024, May 7). *Long Covid at work: A manager’s guide*. Harvard Business Review. <https://hbr.org/2024/05/long-covid-at-work-a-managers-guide>

²² Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Mayo Clinic proceedings*, 98(10), 1544–1551. doi.org/10.1016/j.mayocp.2023.07.032

Some people with ME/CFS find supplements helpful. A few supplements such as CoQ10 with NADH and oxaloacetate have been formally studied and showed potential benefit.^{23,24,25} You can support your patients by helping them avoid supplements that are contraindicated with existing medications or conditions or known to cause harm.

There are also prescription medications that can help patients feel better. Low-dose forms of naltrexone, aripiprazole, and pyridostigmine have been studied in ME/CFS and may help with energy, cognitive function, and dysautonomia.^{26,27,28}

Low dose naltrexone is currently being studied for treatment of long COVID (See accompanying Evidence Summary). It is not currently approved by the Food and Drug Administration (FDA) for the treatment of long COVID since the studies are ongoing.

When trying medications, it is crucial to “**start low and go slow**,” as patients may have sensitivities even to low doses that require them to introduce and titrate medications slowly. In highly reactive cases, patients may even react to the extra ingredients in pills. If you suspect this in your patient, consider trying a different formulation or dye-free or liquid options. from a compounding pharmacy if available or accessible to patient.

²³ Cash A, Kaufman DL. Oxaloacetate Treatment For Mental And Physical Fatigue In Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Long-COVID fatigue patients: a non-randomized controlled clinical trial. *J Transl Med*. 2022 Jun 28;20(1):295. doi: [10.1186/s12967-022-03488-3](https://doi.org/10.1186/s12967-022-03488-3). PMID: 35764955; PMCID: PMC9238249.

²⁴ Castro-Marrero, J., Segundo, M. J., Lacasa, M., Martinez-Martinez, A., Sentañes, R. S., & Alegre-Martin, J. (2021). Effect of Dietary Coenzyme Q10 Plus NADH Supplementation on Fatigue Perception and Health-Related Quality of Life in Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Prospective, Randomized, Double-Blind, Placebo-Controlled Trial. *Nutrients*, 13(8), 2658. doi: [10.3390/nu13082658](https://doi.org/10.3390/nu13082658)

²⁵ Cash A, Vernon SD, Rond C, Bateman L, Abbaszadeh S, Bell J, Yellman B and Kaufman DL (2024) RESTORE ME: a RCT of oxaloacetate for improving fatigue in patients with myalgic encephalomyelitis/chronic fatigue syndrome. *Front. Neurol.* 15:1483876. doi: [10.3389/fneur.2024.1483876](https://doi.org/10.3389/fneur.2024.1483876)

²⁶ Crosby, L.D., Kalanidhi, S., Bonilla, A. et al. Off label use of Aripiprazole shows promise as a treatment for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): a retrospective study of 101 patients treated with a low dose of Aripiprazole. *J Transl Med* 19, 50 (2021). doi: [10.1186/s12967-021-02721-9](https://doi.org/10.1186/s12967-021-02721-9).

²⁷ Joseph P, Pari R, Miller S, Warren A, Stovall MC, Squires J, Chang CJ, Xiao W, Waxman AB, Systrom DM. Neurovascular Dysregulation and Acute Exercise Intolerance in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Randomized, Placebo-Controlled Trial of Pyridostigmine. *Chest*. 2022 Nov;162(5):1116-1126. doi: 10.1016/j.chest.2022.04.146. Epub 2022 May 6. PMID: 35526605.

²⁸ Hurt RT, Yadav S, Schroeder DR, et al. Longitudinal Progression of Patients with Long COVID Treated in a Post-COVID Clinic: A Cross-Sectional Survey. *Journal of Primary Care & Community Health*. 2024;15. doi: [10.1177/21501319241258671](https://doi.org/10.1177/21501319241258671).

Want to learn more about ME/CFS?

Provider resources:

- [ME/CFS Basics | ME/CFS | CDC \(https://www.cdc.gov/me-cfs/about/index.html\)](https://www.cdc.gov/me-cfs/about/index.html)
- [Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - Mayo Clinic Proceedings \(https://www.mayoclinicproceedings.org/article/S0025-6196\(23\)00402-0/fulltext\)](https://www.mayoclinicproceedings.org/article/S0025-6196(23)00402-0/fulltext)
- [Clinical Management - U.S. ME/CFS Clinician Coalition \(https://mecfscliniciancoalition.org/clinical-management\)](https://mecfscliniciancoalition.org/clinical-management)
- [Top Resources - Bateman Horne Center \(https://batemanhornecenter.org/education/top-resources\)](https://batemanhornecenter.org/education/top-resources)

Patient Resources:

- [MEAction: Pacing and Management Guides - #MEAction Network \(https://www.meaction.net/resource/pacing-and-management-guide/\)](https://www.meaction.net/resource/pacing-and-management-guide/)
- [ME/CFS Guidebook - Bateman Horne Center \(https://batemanhornecenter.org/education/mecfs-guidebook/\)](https://batemanhornecenter.org/education/mecfs-guidebook/)

Want to learn more about Long COVID?

- [MDH Long COVID Program \(https://www.health.state.mn.us/diseases/longcovid/about.html\)](https://www.health.state.mn.us/diseases/longcovid/about.html)
- [Long COVID ECHO Series for Primary Care Providers \(https://www.youtube.com/playlist?list=PLrX6m5cvp8hCbPkungsFtgh_7y-ywIBC7\)](https://www.youtube.com/playlist?list=PLrX6m5cvp8hCbPkungsFtgh_7y-ywIBC7)
- [Long COVID Basics | COVID-19 | CDC \(https://www.cdc.gov/covid/long-term-effects/index.html\)](https://www.cdc.gov/covid/long-term-effects/index.html)
- [Long COVID Patient Education - Bateman Horne Center \(https://batemanhornecenter.org/education/long-covid/\)](https://batemanhornecenter.org/education/long-covid/)

Helpful Tools for Monitoring patients with ME/CFS

- [FUNCAP \(https://www.funcap.no\)](https://www.funcap.no) – Accurately assessing functional capacity in patients with PEM
- [36-Item Short Form Survey \(SF-36\) | RAND \(https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form.html\)](https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form.html)
- [MFI-20 \(https://www.med.upenn.edu/cbti/assets/user-content/documents/Multidimensional%20Fatigue%20Inventory%20\(MFI\).pdf\)](https://www.med.upenn.edu/cbti/assets/user-content/documents/Multidimensional%20Fatigue%20Inventory%20(MFI).pdf)
- [Bell CFIDS Disability Scale for function | MEpedia \(https://me-pedia.org/wiki/Bell_CFIDS_disability_scale\)](https://me-pedia.org/wiki/Bell_CFIDS_disability_scale)

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