

US ME/CFS Clinician Coalition Consensus Statement: Diagnosing ME/CFS in People with Long COVID April 2023

In October 2020, we, a coalition of ME/CFS clinician experts, published a letter recognizing the development of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in patients with Post-COVID Conditions, also known as Long COVID or long-haul COVID (1). In that letter, we highlighted the overlap between the two conditions and its significance (2). As patients continue to develop these conditions, leaving millions unable to work, the intersection of ME/CFS and Long COVID has become even clearer (3-8). This highlights the need to consider a diagnosis of ME/CFS in those with Long COVID.

Before the COVID-19 pandemic, an estimated 90% of cases with ME/CFS were undiagnosed (9,10). It is likely that this number remains true – or may have even risen – with the addition of Long COVID. Historically, projected rates of recovery from ME/CFS have been close to 5% (11). These statistics are complicated by universally low recognition and diagnosis of early- or mild-stage ME/CFS, as well as lack of longitudinal studies. This could have major implications in patient outcomes as studies demonstrate a distinct difference in immunologic signature approximately three years after disease onset (12).

People with Long COVID are increasingly being seen by specialists in ME/CFS. Our clinical impression is that early diagnosis and management of ME/CFS may be critical in the trajectory of Long COVID. Most proposed ME/CFS criteria state a formal diagnosis of ME/CFS can be made at 6 months regardless of specific infectious agent or other cause. But a working diagnosis can be made at any time (10,13). We agree that this is reasonable in people with Long COVID who meet criteria for ME/CFS as well.

By proposing that ME/CFS be diagnosed by 6 months of illness in relation to symptom onset since acute COVID-19 infection, we aim to do the following:

- 1) Improve historically low diagnostic rates and prevalence estimates of ME/CFS
- 2) Initiate earlier therapy in those with ME/CFS following COVID
- 3) More accurately assess the initial ME/CFS state (<3 years), thereby improving opportunities for early intervention and recovery prospects

Early recognition of ME/CFS and its common comorbidities can expedite the use of helpful therapies in Long COVID (14,15). For example, patients with ME/CFS following COVID report improvement when pacing – a form of activity management based on symptom-contingent energy allocation to reduce flares – is implemented. Even if full ME/CFS criteria are not met, we still recommend that any Long COVID patient with classic signs of post-exertional malaise (post exertional symptom exacerbation) engage in paced activity to reduce exercise-induced progression (15).

We therefore encourage all clinicians seeing patients suffering with persistent post-exertional malaise and other symptoms after a COVID-19 infection to consider adding the diagnosis of ME/CFS (ICD-code G93.32) if those criteria are met (16). This will improve characterization, application of management strategies, and understanding of the disease trajectory in the Long COVID population (4,5,14).

References

1. [Long COVID or Post-COVID Conditions | CDC.](#)
2. [ME/CFS Clinician Coalition Letter MECFS and Long-Haul Covid.pdf. 2020. Google Drive](#)
3. [Long COVID is sidelining millions of workers from their jobs : NPR. 2022.](#)
4. [Why we need a deeper understanding of the pathophysiology of long COVID. The Lancet Infectious Diseases. 2023.](#)
5. [Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME/CFS\)-A Systemic Review and Comparison of Clinical Presentation and Symptomatology. Medicina. 2021. PubMed \(nih.gov\)](#)
6. [Long COVID Now Looks like a Neurological Disease, Helping Doctors to Focus Treatments. Scientific American. 2023](#)
7. [ME/CFS is common in post-acute sequelae of SARS-CoV-2 infection \(PASC\): Results from a post-COVID-19 multidisciplinary clinic. Front Neurol. 2023. PubMed \(nih.gov\)](#)
8. [Post-exertional malaise among people with Long COVID compared to ME/CFS. Work. 2023. PubMed \(nih.gov\)](#)
9. [What is ME/CFS? | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME/CFS\) | CDC](#)
10. [Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. US Institute of Medicine. 2015. PubMed \(nih.gov\)](#)
11. [A systematic review describing the prognosis of chronic fatigue syndrome. Occup Med. 2005. PubMed \(nih.gov\)](#)
12. [Distinct plasma immune signatures in ME/CFS are present early in the course of illness | Science Advances. 2015.](#)
13. [Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols: Journal of Chronic Fatigue Syndrome: Vol 11, No 1. 2003. \(tandfonline.com\) \(Link to full article\)](#)
14. [Long COVID: major findings, mechanisms and recommendations. Nat Rev Microbiol. 2023. PubMed \(nih.gov\)](#)
15. [Clinical management of COVID-19: Living guideline, 13 January 2023. World Health Organization](#)
Beginning on page 114, the guidance discusses PEM, also called post-exertional symptom exacerbation, in people with Long COVID. WHO refers to Long COVID as post-COVID condition
16. [ME/CFS: Essentials of Diagnosis and Management. Mayo Clinic Proc. 2021. PubMed \(nih.gov\)](#)