

U.S. ME/CFS MYALGIC ENCEPHALOMYELITIS
CHRONIC FATIGUE SYNDROME
CLINICIAN COALITION

**US ME/CFS Clinician Coalition Letter: Post-COVID “Long Haulers” and ME/CFS
October 30, 2020**

Weeks to months after an acute COVID-19 infection, a significant number of patients, even those with an initially mild infection, are reporting ongoing debility and a range of symptoms (1, 2). Referred to as “Long Haulers” or “Long COVID,” some of these patients have evidence of organ damage and others remain ill without obvious organ damage (3). Some, according to NIH’s Dr. Fauci, have a post-viral syndrome that is “highly suggestive” of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (4), a disease frequently preceded by an infectious illness (5, 6). For instance, in a four-year evaluation following SARS infection in Hong Kong, Lam found that 27% of people qualified for a diagnosis of ME/CFS (7). Given the similarity in symptoms and the preceding infectious illness, we recommend that you consider a diagnosis of post-viral fatigue syndrome or ME/CFS (ICD-10 93.3) in the differential diagnosis of those patients who remain ill for an extended time following a COVID-19 infection and meet established ME/CFS criteria.

ME/CFS is a chronic, debilitating, multi-system illness affecting more than a million Americans (5). It is more prevalent in women and adults but affects people of both sexes and all ages, ethnicities, nationalities, and socioeconomic backgrounds and may be more prevalent in people of color (5, 8). ME/CFS is associated with neurological, immunological, autonomic, and energy metabolism impairment (9). The hallmark of the disease is post-exertional malaise (5), a systemic intolerance to previously tolerated exertion. Other common symptoms include a substantial impairment in function, profound exhaustion, unrefreshing sleep, cognitive impairment, orthostatic intolerance, widespread pain, flu-like symptoms, and sensory sensitivities. COVID Long Haulers have reported a number of these symptoms including the hallmark intolerance to exertion (2). Some Long Haulers additionally report other symptoms not typically seen in ME/CFS.

Historically, ME/CFS has been misunderstood and dismissed, leaving patients struggling to obtain an accurate diagnosis and appropriate clinical care (5). COVID Long Haulers are experiencing similar problems and dismissal. ME/CFS patients have also reported harms from graded exercise therapy and cognitive behavioral therapy, commonly recommended therapies that assume the debility of ME/CFS is due to deconditioning caused by the patient's fear of activity (10). But exercise can trigger the systemic intolerance to exertion characteristic of ME/CFS and worsen the patient’s condition.

The ME/CFS field has changed substantially in the last 5 years. In 2015, the National Academy of Medicine published an extensive evidence review and new clinical diagnostic criteria that focus on the core features of the disease (5). In parallel, GET and CBT studies have been widely criticized for study conduct issues that inflated claims of efficacy and safety (11). As a result, CDC and other clinical guidance providers have removed recommendations for these therapies and incorporated updated ME/CFS diagnostic criteria and guidance (12). Recently, we, a clinician coalition of ME/CFS experts, published a website with information for medical providers on how to diagnose and manage ME/CFS along with links to available CMEs and other resources (13). Many coalition members are available for consult or referral.

We encourage you to consider post-viral fatigue syndrome and ME/CFS in your differential diagnosis for patients, including Long Haulers, who present with the symptoms of ME/CFS described above and on the Coalition website. While there is not yet a commercially available diagnostic test or FDA approved treatments specific to ME/CFS, there are a number of actions you can take to validate the patient’s illness and help reduce the disease burden and improve the quality of life for both existing ME/CFS patients and for any COVID-19 patients who go on to develop ME/CFS (14).

The US ME/CFS Clinician Coalition
Website: MECFSClinicianCoalition.org

References

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<https://pubmed.ncbi.nlm.nih.gov/31041108/>
11. One example of criticism of CBT/GET studies is this special Issue in *The Journal of Health Psychology* discussing the PACE trial, the largest trial of cognitive behavioral therapy and graded exercise therapy - <http://journals.sagepub.com/toc/hpqa/22/9>
12. CDC ME/CFS website - <https://www.cdc.gov/me-cfs/index.html>
13. ME/CFS Clinician Coalition website and a handout on the basics of diagnosis and treatment. MECFSClinicianCoalition.org and <https://drive.google.com/file/d/1SG7hIJTCSDrDHqvioPMq-cX-rgRKXjfk/view>
14. In addition to the diagnosis and management resources on the ME/CFS Clinician Coalition and CDC websites, the following resources for post-acute COVID-19 and post-viral fatigue syndrome may be useful
 - a. Shepherd C. ME Association’s pamphlet on Covid-19 and Post-viral Fatigue Syndrome. (includes discussion of ME/CFS)
<https://meassociation.org.uk/2020/04/covid-19-and-post-viral-fatigue-syndrome-by-dr-charles-shepherd-30-april-2020/>
 - b. Greenhalgh T, Knight M, A’Court C, Buxton M, Husain L. Management of post-acute covid-19 in primary care. *BMJ*. August 2020. 370:m3026
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