

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

**Press Release
For Immediate Release**

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Updated Clinical Guidance for ME/CFS May Also Help Long COVID Patients

SALT LAKE CITY, UTAH - Updated clinical guidance for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), produced by the US ME/CFS Clinician Coalition, may also help patients who remain ill with Long COVID after even mild cases of COVID-19. NIH's Dr. Anthony Fauci has said Long COVID is "highly suggestive" of ME/CFS. This is not surprising. For decades, scientists have observed a prolonged illness in some patients following an infection. More recent research suggests 10% or more of adults with acute COVID-19 may go on to develop ME/CFS. But patients with ME/CFS have long struggled to access clinical care as a result of a lack of accurate clinical guidance and provider knowledge. The influx of so many new cases of ME/CFS has created an urgent need for clinicians everywhere to learn about this disease.

The updated clinical guidance from the US ME/CFS Clinician Coalition focuses on adults and includes:

- New diagnostic criteria requiring post-exertional malaise and other key features to improve diagnostic accuracy
- Efficient use of interview questions, physical examination findings, and diagnostic testing
- Alternative diagnoses and co-existing conditions to consider
- Pharmacological and nonpharmacological treatments
- A discussion of why previously-recommended treatments—cognitive behavioral therapy and graded exercise therapy—can be harmful and are no longer recommended

There are no FDA-approved treatments for ME/CFS. Indeed, few therapies have been tested in large, randomized trials. Lacking a disease-modifying treatment, only five percent of patients fully recover. However, in the experience of the authors, improvement is possible with appropriate care. This report summarizes their consensus recommendations with a variety of available treatments.

Author Dr. Lucinda Bateman notes, "There are many steps clinicians can take now to improve the health, function, and quality of life of people with ME/CFS, including those newly ill with ME/CFS following COVID-19. This guidance may also help Long COVID patients, even if they do not fully meet criteria for ME/CFS."

ME/CFS is a chronic, multi-system disease that often follows a viral or other infection, including Epstein-Barr virus and SARS-CoV-1. It affects an estimated 836,000 to 2.5 million Americans of all ages, genders, ethnicities, races, and socioeconomic backgrounds. The hallmark symptom is post-exertional malaise, an exacerbation of symptoms and worsening of function following even minor exertion. In addition, ME/CFS causes substantial impairment in function, profound fatigue, unrefreshing sleep, cognitive impairment, and orthostatic intolerance along with other symptoms. Patients' neurological, immunological, autonomic, and energy metabolism systems are impaired, leaving an estimated 70% unable to work and 25% bedbound or homebound. Up to 91% of people affected by ME/CFS remain undiagnosed.

About Us: The [US ME/CFS Clinician Coalition](#) is composed of ME/CFS expert clinicians who have collectively spent hundreds of years treating many thousands of patients. They have been principal investigators for CDC and NIH-funded ME/CFS research, served on the Institute of Medicine and government-sponsored committees for ME/CFS, and authored clinical care primers for ME/CFS. Over the last year, they have been researching and caring for people affected by COVID-19.

The article has been published in Mayo Clinic Proceedings and can be found [here](#). An accompanying video by Dr. Lucinda Bateman can be found [here](#).

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