

# Diagnosing ME/CFS

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Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) has traditionally been a diagnosis of exclusion. But in 2015, the Institute of Medicine established new evidence-based clinical diagnostic criteria, which focus on identifying the core hallmarks of the disease.

## ***Recognizing the Distinctive Symptoms of ME/CFS***

The core symptoms of ME/CFS include:

- Substantial reduction or impairment in ability to engage in pre-illness activity that persists for 6 months or more and is accompanied by fatigue. The fatigue is profound, not lifelong, not the result of ongoing exertion, and not alleviated by rest.
- Post-exertional malaise (PEM) in which physical or mental activities result in a delayed exacerbation of symptoms and reduction in functioning.
- Unrefreshing sleep
- Either cognitive impairment and/or orthostatic intolerance

These core features of illness must be moderate to severe and present at least 50% of the time; this is key to separating ME/CFS from other common causes of chronic fatigue.

PEM is the most distinctive symptom of ME/CFS and can help differentiate it from other diseases. It has been objectively associated with impaired aerobic energy metabolism and orthostatic stress. For some patients, reading, getting out of bed, or taking a shower can exacerbate all their symptoms and cause them to “crash” the next day. Other symptoms include widespread pain; immune impairment; light, noise, and chemical sensitivity; sore throat; and tender lymph nodes; and gastrointestinal and genitourinary issues. The IOM Clinician’s Guide provides further explanation and guidance on how to identify the core symptoms and the frequency of additional symptoms such as chronic pain, immune and neuroendocrine manifestations.

**Lab Tests:** While there is no single diagnostic test for ME/CFS, labs are used to differentiate between ME/CFS and other diseases. Orthostatic intolerance can be assessed with a tilt table test or a monitored 10 minute Lean Test. Some lab tests are used to identify key features such as immune impairment but these are typically not commercially available. Beyond diagnosis, lab tests can also be important in developing treatment plans.

***The Importance of the Differential Diagnosis:*** While ME/CFS is no longer a diagnosis of exclusion, a differential diagnosis is still important to distinguish between ME/CFS and diseases with similar presentation because treatment of these conditions could improve or resolve the patient’s symptoms. These include primary sleep disorders such as sleep apnea or periodic limb movement disorder, autoimmune diseases such as rheumatoid arthritis, endocrine disorders such as thyroid disease, infectious diseases such as Lyme disease, neurological diseases such as multiple sclerosis, and primary psychiatric disorders such as major depression.

***Identifying and Treating Comorbid Conditions:*** The IOM criteria recognize that other conditions can be comorbid with ME/CFS. While treating these comorbid conditions will not resolve ME/CFS, it may improve the patient’s quality of life. Some of the most common comorbid conditions include fibromyalgia, primary sleep disorders, postural tachycardia syndrome (POTS), Ehlers-Danlos syndrome, mast cell activation disorder, irritable bowel syndrome, secondary depression, hypothalamic pituitary adrenal axis dysregulation, Celiac disease and allergies.

## **Basic Facts**

- ME/CFS affects an estimated 836,000 to 2.5 million Americans but an estimated 84 to 91 percent of people with ME/ CFS have not yet been diagnosed,
- At least one-quarter of ME/CFS patients are bed- or house-bound.
- Symptoms can persist for years, and most patients never regain their pre-disease level of functioning.
- ME/CFS affects women more often than men.
- Most patients currently diagnosed with ME/CFS are Caucasian, but some studies suggest ME/CFS is more common in minority groups.
- The average age of onset is 33, although ME/CFS has been reported in patients younger than age 10 and older than age 70.
- ME/CFS patients experience loss of productivity and high medical costs that contribute to a total economic burden of \$17 to \$24 billion annually.
- The cause of ME/CFS is unknown, although the disease often follows an infection.
- There is no cure for ME/CFS but symptom treatment can improve the patient's quality of life.

## **Resources**

1. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. National Academy of Medicine, previously the Institute of Medicine. February 10, 2015.
  - Report - <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>
  - Clinician Guide -  
<http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2015/MECFS/MECFScliniciansguide.pdf>
2. Chronic Fatigue syndrome/Myalgic Encephalomyelitis. Primer for Clinical Practitioners. 2014 Edition. International Association for Chronic Fatigue syndrome/Myalgic Encephalomyelitis  
[http://iacfsme.org/portals/0/pdf/Primer\\_Post\\_2014\\_conference.pdf](http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf)
  - Page 15 includes a table of diseases to consider in differential diagnosis and Page 16 includes a table of comorbid conditions
3. Rowe, P et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer. Frontiers in Pediatrics. June 2017.
  - Information on comorbid conditions and differential diagnosis is provided on pages 8-12 and includes information on differentiating from primary psychiatric illness.
4. CDC ME/CFS Website <https://www.cdc.gov/me-cfs/index.html>

## **About the Authors**

*Lucinda Bateman, MD* is board certified in Internal Medicine, has been seeing ME/CFS patients for over 20 years, and is the Medical Director of the Bateman Horne Center in Utah. Dr. Bateman was a member of the panel that produced the 2015 Institute of Medicine report on ME/CFS and is a member of Health and Human Services' Chronic Fatigue Syndrome Advisory Committee (CFSAC).

*Susan Levine, MD* has been seeing ME/CFS patients in her clinical practice for over 30 years. She is board certified in Internal Medicine and Infectious Diseases and has served as past Chairperson of the Chronic Fatigue Syndrome Advisory Committee (CFSAC).

Dr. Bateman and Dr. Levine are both participating in the 5-year, \$35M Collaborative Research Centers recently awarded by the National Institutes of Health.