



Solve M.E.

July 8, 2019

U.S. Access Board
1331 F Street NW, Suite 1000
Washington, DC 20004-1111

Public Comments – July 10th Meeting: Request for Further Research Regarding Current Guidelines Applicability for those Disabled by ME/CFS

Dear Members of the United States Access Board,

On behalf of the Solve ME/CFS Initiative (SMCI) and as a caregiver for a person with myalgic encephalomyelitis (ME), I am writing to share the experience of patients and their loved ones disabled by ME, previously called Chronic Fatigue Syndrome (CFS), and ask you to consider conducting additional research regarding current accessibility guidelines and their effectiveness in addressing the needs of up to 2.5 million Americans with ME/CFS.

First, please accept my thanks for your board's ceaseless efforts and transparency. Many other federal agencies can learn from the exceptional manner with which you have handled stakeholder input. It speaks volumes about your intentions that your agency has gone to such lengths to make the process inclusive and accessible.

Secondly, please allow me a moment to elaborate on the particular challenges of myalgic encephalomyelitis (ME), commonly known as chronic fatigue syndrome (CFS). ME/CFS is a complex disease with an array of debilitating symptoms including extreme exhaustion, orthostatic intolerance, unrefreshing sleep, memory loss, joint pain, inflamed lymph nodes, severe headache, sore throat, neurological abnormalities, and even complete organ system shutdown. The cause of ME/CFS is unknown, and there is no existing cure nor FDA-approved treatment for the disease. Here's a few facts about this prominent and often misunderstood condition from the 2015 Institute of Medicine Report "[Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.](#)"

- An estimated 836,000 to 2.5 million Americans have ME/CFS
- ME/CFS affects four times more women than men
- One quarter of ME/CFS patients will become house- or bedbound in their lifetime
- ME/CFS can strike anyone at any time; onset has been reported from ages 10 to 80
- Recovery from ME/CFS is rare and symptoms often persist for life

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- Many with ME/CFS have comorbid disorders, such as irritable bowel syndrome, dysautonomia, and fibromyalgia
- Patients with ME/CFS have the lowest median and mean quality of life scores of any disease tested, including lung cancer, rheumatoid arthritis, and brain stroke

In short, **ME/CFS is often a life-long disease** resulting in an extreme reduction of every-day function and **long term disability**. Many standard disability accommodations also benefit those with ME/CFS. But, there is no research and a very limited understanding about whether current accessibility guidelines are currently meeting the needs of those with ME/CFS.

ME/CFS patients struggle to access public and community spaces in many ways. The physical limitations of the illness make even the smallest physical exertions a significant challenge. Many patients have difficulty standing or even sitting upright for extended periods of time. Walking or similar types of physical activity is prohibitive. As a result, patients with ME/CFS are often isolated from their community and even from friends and family. Accessing many of the resources or protections for most individuals with disabilities is a unique challenge for those with ME/CFS.

One of the most significant barriers is the stigma and misunderstanding associated with this disease. Patients “look” healthy and are frequently denied basic accommodations in the workplace, school setting, or public spaces. What makes ME/CFS patients unique in the “invisible” illness category is what is commonly referred to as “post-exertional malaise,” a key symptom of ME/CFS. Dr. Anthony Komaroff of Harvard University described post-exertional malaise (PEM) as “**an illness within an illness**.” PEM is a debilitating onslaught of fatigue, pain, cognitive difficulties, sore throat, and/or swollen lymph nodes after a physical or mental activity. These symptoms can present as late as 48 hours after the activity which triggered them. This is a unique barrier because ME/CFS patients can participate in an activity as part of the community, but then suffer for weeks, months, or even years as a result. This unpredictability and variability of symptoms creates a false sense of “health” or “improvement” for those who only briefly interact with an ME/CFS patient, thus making many disability protections and accommodations extremely difficult to secure. It is all too common for patients to risk losing disability insurance, workplace/education accommodations, or public support just because they had a “good” day.

To fully understand these unique needs, I ask that the US Access Board consider conducting further research regarding accessibility for those with ME/CFS and to explore whether current guidelines are fully meeting the needs of the “millions missing” with ME/CFS.

I hope this information and insight into the lives of those with ME/CFS has been helpful and I hope the Board will consider further research to ensure our current regulations and guidelines are fully inclusive of the needs of this population. Please don’t hesitate to contact me or my organization if there is any way we can assist.

Sincerely,

Emily Taylor
Director of Advocacy and Community Relations
Solve ME/CFS Initiative