MassME

MASSACHUSETTS ME/CFS & FM ASSOCIATION

Health Equity Issues in ME/CFS and Long COVID

Gender: Women are two to four times more likely than men to be diagnosed with ME/CFS and Long COVID. Women are underrepresented in health studies and their physical complaints are often trivialized or psychologized. Diseases primarily affecting women are underfunded by NIH research programs.[1]

Demographics: People of color are disproportionately affected by these illnesses, with higher rates of persistent symptoms. Long COVID is more prevalent in people without a four-year college degree, Hispanic people, and sexual and gender minorities, especially those who identify as transgender.[2] These groups also encounter more significant barriers to care due to systemic inequities, including greater challenges in receiving diagnoses, and in accessing and navigating appropriate care for a complex health condition

> *"Diagnostic uncertainty is not neutral. It shapes who is believed, who gains access to care pathways, and whose suffering is recognized as real."*[3]

Disease Burden: The disease burden for ME/CFS is high: 25% of patients are housebound or bedbound, and up to 75% of people with ME/CFS qualify or would qualify for disability benefits. Yet this is the most underfunded disease in the NIH research portfolio. ME/CFS research would need *a 40-fold increase* to be commensurate with the disease burden.[4]

Barriers to Access and Diagnosis: There is no single lab test for ME/CFS; diagnosis is based on clinical evaluation which takes time and expertise. ME/CFS and Long COVID both affect multiple systems; these complex illnesses require many specialists as well as an informed clinical 'quarterback.' Many healthcare providers lack training or knowledge about ME/CFS, leading them to miss symptoms or misattribute them to psychiatric conditions.

> *"Long COVID has become a stress test for modern healthcare systems. Affecting multiple organ systems at once, it defies highly specialized, compartmentalized models of care."*

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[1] Mirin, A. Gender Disparity in the Funding of Diseases by the U.S. National Institutes of Health. *J. Womens Health*, 30, 7 (2021).

[2] Cohen, J., van der Meulen Rodgers, Y. An Intersectional Analysis of Long COVID Prevalence. *Int J Equity Health* 22, 261 (2023).

[3] Morgan, R., Azola, A. What Long COVID Reveals about Fragmented Care. *Science Politics* (2026).

[4] Mirin, A. A., Dimmock, M. E., & Jason, L. A. (2022). Updated ME/ CFS prevalence estimates reflecting post-COVID increases and associated economic costs and funding implications. *Fatigue: Biomedicine, Health & Behavior*, 10(2), 83–93.

RESOURCES AND LINKS

About ME/CFS

U.S. ME/CFS Clinician Coalition **Guide**

Bateman Horne Center ***Clinical Care Guide: Managing ME/CFS, Long COVID and IACCs***

Institute for Medicine Report (2015): ***Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness***

Mirin, A. A., Dimmock, M. E., & Jason, L. A. (2022**).** **Updated ME/ CFS prevalence estimates reflecting post-COVID increases and associated economic costs and funding implications**. *Fatigue: Biomedicine, Health & Behavior*, 10(2), 83–93.

About Long COVID and IACCIs

National Academies of Science, Engineering, and Medicine **definition of Long COVID** (2024).

A brief guide to **Infection-Associated Chronic Conditions and Illnesses** (IACCIs).

Ed Yong's essays in *The Atlantic* covered the gradual recognition of Long COVID, the devastating consequences, and the overlap with ME/CFS:

- **"Long COVID Has Forced a Reckoning for One of Medicine's Most Neglected Diseases"** (September 2022)
- **"Fatigue Can Shatter a Person"** (July 2023)

Health Equity

Mirin, A**.** **Gender Disparity in the Funding of Diseases by the U.S. National Institutes of Health**. *J. Womens Health*, 30, 7 (2021).

Cohen, J., van der Meulen Rodgers, Y. **An Intersectional Analysis of Long COVID Prevalence**. *Int J Equity Health* 22, 261 (2023).

Morgan, R., Azola, A. **What Long COVID Reveals about Fragmented Care**. *Science Politics* (2026).

Tan, H-L, Rosser, E., et al. **That's Not My Silo: Navigating Fragmented Long COVID Care in the Mid-Atlantic United States**. *SSM - Qualitative Research in Health* 9 (2026).