



SEVERE ME/CFS:

Medical Panel Webinar

Resource Guide

December 4, 2024



The content provided by Solve M.E. and the Bateman Horne Center in this guide is for informational purposes only and does not constitute medical advice. Readers are encouraged to consult with qualified medical professionals for specific advice tailored to their individual circumstances.

Journal Articles Focused on Severe and Very Severe ME/CFS

Special *Healthcare* issue: [ME/CFS – the Severely and Very Severely Affected](#)

The special *Healthcare* issue includes 25 published papers about severe and very severe ME/CFS. The following paper was highlighted by Dr. Bateman during the webinar.

[“Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome”](#)

Citation

Montoya, J. G., Dowell, T. G., Mooney, A. E., Dimmock, M. E., & Chu, L. (2021). Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Healthcare*, 9(10), 1331. <https://doi.org/10.3390/healthcare9101331>

References for the Impact of Graded Exercise Therapy (GET)

People who did graded exercise were less likely to get back to work.

- [Evaluation of a survey exploring the experiences of adults and children with ME/CFS who have participated in CBT and GET interventional programmes](#)

2,274 people responded to a survey on CBT and GET, of that data a subset had GET. With GET on its own, the majority of responders reported not completing the course (61%), of those that started the course 81% reporting worsening of symptoms. Approximately seventy nine percent of people reported no improvement (11.7%) or deterioration (67.1%) in physical health. Seventy nine percent of people reported that GET led to no change (25.5%) or worsening (53%) of mental health after GET.

- [Work Rehabilitation and Medical Retirement for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. A Review and Appraisal of Diagnostic Strategies - PMC](#)

In the PACE trial (n = 641) by White et al. [148], lost employment remained the same (84%) after CBT and increased from 83% to 86% after GET. The number of participants on income benefits increased from 10% to 13% (CBT) and from 14 to 20% (GET); disability benefits increased from 32% to 38% (CBT) and from 31% to 36% (GET); payments from income protection schemes or private pensions increased from 6% to 12% (CBT) and from 8% to 16% (GET) [150]. Evaluation of the efficacy of CBT and GET in the Belgian CFS knowledge centres (n = 655) showed that employment status decreased from 18.3% to 14.9% and sickness allowance status increased from 54% to 57% [141].

Collin and Crawley [111] analysed the efficacy of treatments provided by 11 CFS/ME specialist services in the UK (n = 952). These services treated patients with CBT, GET, a combination of both or activity management which was more effective in fatigue reduction at 12 months follow-up than CBT and GET. Also, there was no change in employment situation after treatment in the NHS clinics in 47.2 % cases. 18.0% were able to return to work or increase their hours and 30.0% stopped working or reduced their hours because of ME/CFS. Therefore, the net effect was that 12% stopped working or reduced their hours after NHS treatment.

Bateman Horne Center Resources Mentioned

[ER Care Considerations Handout](#): The intention of this handout is to provide basic advice and medical/scientific information about ME/CFS that can inform medical decisions in urgent, emergent, or hospital settings.

[Healthcare Professional Continuing Medical Education \(CME\)](#): This document provides a range of CME opportunities for medical practitioners. Highlighted topics include the intricacies of “Long COVID and Post-Viral Syndromes,” where practitioners can deepen their understanding of post-COVID conditions and their implications. Another notable module delves into “Post-Exertional Malaise (PEM),” a unique finding associated with ME/CFS. Each module offers specific AMA PRA Category 1 credits, ensuring professionals not only enhance their knowledge but also earn valuable continuing education credits. This document serves as a vital resource for those aiming to stay updated in these emerging medical areas.

[Low Dose Naltrexone \(LDN\) Information Sheet](#): LDN is used for ME/CFS and post-COVID conditions. At these low doses, there is reduction in glial inflammatory response and upregulation of endogenous opioid signaling by transient opioid receptor blockage.

[Communication Cards](#): During a crash, it can be difficult for patients to communicate with others. These downloadable and printable communication cards help to communicate needs. Consider keeping these in a bedside Crash Care Kit or on an electronic device to point/show a caregiver, loved one, or support services.

[Medication Sheets](#): Organizing medications into a list and schedule on these printable and downloadable sheets can help to streamline daily medication routines.

Bateman Horne Center Medical Education Program Summary

Medical Education Resource Center Program Overview (2022–2024)

The Open Medicine Foundation-supported Medical Education Resource Center (MERC) accomplished the following:

2022-2024 Impact Overview

- Healthcare Professionals (HCPs) Reached:

- o 2022: 2,810 HCPs
 - o 2023: 3,370 HCPs
 - o 2024: 7,244 HCPs
 - o Total: 13,424 HCPs reached across 45 states and 89 countries
- Accredited CME:
 - o MERC offers five enduring CME courses, including the only CME focused on post exertional malaise (PEM). These courses have educated healthcare professionals across 29 medical disciplines and are available through 2025. (linked in section above)
- [Project ECHO](#):
 - o 2022: 14 ECHO sessions focused on breaking down the diagnostic criteria for ME/CFS and related comorbid conditions.
 - o 2023–2024: 11 sessions addressed care management using a case-based approach.
 - o MERC also participated in six additional nationwide and international ECHO programs.
- Professional Training & Education
 - o Hosted four residency rotations, three observerships, one visiting fellowship, two master’s capstone projects, and one doctoral capstone project, totaling 1,130 hours of clinical training.

2024 Impact Overview

MERC has achieved significant progress in broadening its reach, expanding educational offerings, and strengthening its global presence.

Healthcare Professional Reach:

- 5,783 HCPs reached (Jan–Oct 2024) — surpassing the total reach from previous years combined.
- Global Impact: Educated healthcare professionals across 89 countries and 45 U.S. states. Partnerships with leading organizations such as the CDC, NIH (RECOVER), Israeli Ministry of Health, Centre hospitalier de l'Université de Montréal (CHUM),

Emerge Australia, ICanCME, and the EDS Foundation of Canada further amplified MERC's international influence.

CME Programs:

- MERC's CME offerings have reached a global audience through platforms like VuMedi and Medscape, continuing to shape medical practice worldwide.

Influencing Medical Governing Bodies:

- BHC is working with the Federation of State Medical Boards (FSMB) and United States Medical Licensing Exams (USMLE) to integrate ME/CFS content into board exams and curricula.
- Contributed the comorbid conditions chapter to a special issue of Health Sciences Review, focusing on infection-associated chronic illnesses and related conditions.

Lectures & Conferences:

- Delivered 47 lectures
- Notable presentations include:
 - o NIH RECOVER (RECOVER Neuro & all of RECOVER)
 - o Schmidt Global Initiative ECHO
 - o American Physical Therapy Association National Conference
 - o University of Utah Family Medicine Department Grand Rounds
 - o International Conference of Clinical & Scientific Advances in ME/CFS and Long COVID (Lisbon)
 - o Unite2Fight (global conference)
 - o Emory University's Long COVID ECHO
 - o University of Utah Pediatric ECHO
 - o EDS Foundation of Canada annual conference
 - o University of Rochester Medical Center Grand Rounds (Internal Medicine & Neurology)