



ME/CFS AND COVID19: WHAT'S THE CONNECTION?



Dr. Lucinda Bateman

Dir. Jaime Seltzer

JD Davids

Brian Vastag

Wilhelmina Jenkins

Terri Wilder

WELCOME!

JAI ME SELTZER
DIRECTOR OF SCIENTIFIC +
MEDICAL OUTREACH,
#MEACTION
she/her, they/them



What is #MEAction? (www.meaction.net)



- #MEAction is a global, 501(c) nonprofit advocacy organization
- Provides resources for advocacy actions with the support of hundreds of volunteers
- Advocates for public investment in research, healthcare, and medical education
- Resources include:
 - social media support groups
 - news articles
 - MEpedia
 - community calls,
 - informative emails with a reach of +35K people with ME and allies.
- Partnerships with other orgs for greater impact

#MillionsMissing fights for research funding and recognition



#MEAction led actions in over 100 cities worldwide for in-person protests to fight for better research funding for ME.

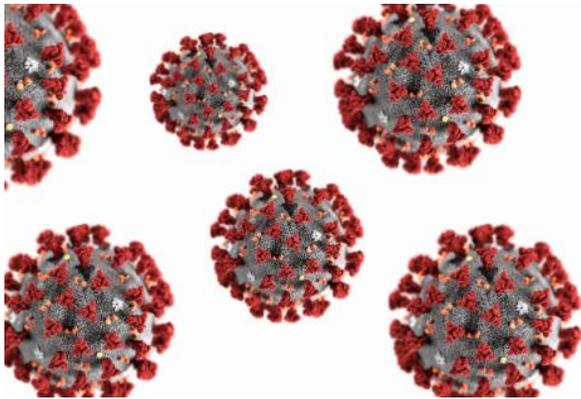
Protest demands for equitable research funding were delivered to the NIH with thousands of signatures.

As our most visible action, #MillionsMissing is often what #MEAction is known for.



BODY POLITIC

- Body Politic is a queer feminist group in NYC
- Explores the intersections of health and social justice
- Created a global support group for people with long COVID-19
- 50+ channels for support & advocacy work



COVID-19 Working Group – NY

is a coalition of doctors, healthcare professionals, scientists, social workers, community workers, activists, & epidemiologists committed to a rapid and community-oriented response to the SARS-CoV-2 pandemic.

TERRI L. WILDER,
MSW
she/her





ME/CFS and COVID-19

What's the connection?

**DR. LUCINDA
BATEMAN,
DIRECTOR OF
BATEMAN-HORNE
CENTER**
she/her



ME/CFS 101

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

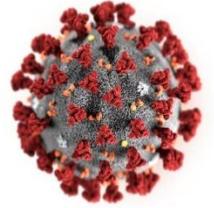
A chronic, debilitating, multisystem illness characterized by central and peripheral nervous system disease, immune manifestations, and impaired cellular metabolism.

ME/CFS is thought to be a post-viral or post-infection syndrome

LUCINDA BATEMAN MD

2020

What does ME/CFS have to do with COVID-19?



COVID-19: a pandemic caused by a novel coronavirus, SARS-CoV-2. Very contagious. Impacts almost all systems of the body. May be fatal in 1-4%, especially higher in high risk groups.

We are observing after the acute infection resolves that many “long haulers” are still struggling with chronic multisystem illness manifestations. It is too early to tell how much comes from the acute viral infection/inflammation, and how much is the development of **a chronic post-viral syndrome.**

- Fatigue, sleepiness and brain fog/cognitive complaints
- Musculoskeletal issues, pain, headaches
- Respiratory tract inflammation
- Heart inflammation: myocarditis, pericarditis, chest pains, palpitations
- Neurologic symptoms: dizziness, headache, confusion, loss of smell and taste, altered consciousness
- Hair thinning and others

Why does it matter?

- Medical establishment **focused on acute illness**, especially COVID-19, and **generally unfamiliar with post-viral syndromes**, especially those that do not resolve in a few months.
- We know from SARS and MERS, two smaller coronavirus epidemics, that many “recovered” patients have chronic post-viral symptoms.
- Recognizing a **pattern of post-viral illness**, especially if there are known criteria and supportive treatment approaches, is empowering and restores some control of your life.
- **Early intervention may improve long term prognosis**
- People recovering from COVID-19 have been victims of **insufficient medical resources, huge uncertainty/fear, and unprecedented isolation and loneliness**. COVID victims and their caregivers may suffer emotional consequences (anxiety and depression) or develop Post-Traumatic-Stress-Disorder (PTSD). Chronic stress alters the neuroendocrine (HPA) and immune systems.
- Not feeling “believed” when experiencing debilitating illness symptoms is a crushing and destabilizing experience emotionally. **Some physiologic symptoms can be misdiagnosed as anxiety or depression.**

ME/CFS Historical Background (abbreviated)

- ME/CFS is associated with many other names, including:
 - Neurasthenia--- The Diseases of the Nervous System, 2nd ed. New York, Appleton, pp.529-38. Hirt, L. (1899)
 - Icelandic disease (1946-47 outbreak of polio-like illness)
 - ME – “Benign” Myalgic Encephalomyelitis (1950s)
 - Post-Viral or Post-Infectious Fatigue Syndromes
 - Chronic mono or Chronic Epstein Barr or Chronic EBV (1980s) [the role of EBV remains controversial]
 - CFS - Chronic Fatigue Syndrome (1988 in the US)
 - CFIDS- Chronic Fatigue Immune Dysfunction Syndrome (a term adopted by advocates to replace “CFS”)
- ME/CFS is not a new illness.
- ME/CFS is world-wide and multicultural.
 - Comparable illnesses have been documented for centuries but historical comparisons are problematic.
- **ME/CFS is a description of a chronic multisystem illness, likely post-infectious, with neurologic, immune and metabolic dysregulation.**

ME/CFS can be triggered by a variety of pathogens

- Many viral infections are capable of causing a postviral syndrome; and a number have been associated with the development of ME/CFS, including Epstein-Barr Virus, West Nile Virus, enteroviruses, and coronaviruses such as SARS.
- ME/CFS may be caused by the body's complex reactions to certain infections in combination with an abnormal chronic immune/inflammatory response.
- Each infection may result in unique illness features due the variety of organ systems targeted by different viruses: liver and lymph nodes by EBV; respiratory and nervous systems by SARS-CoV-2, for example.
- People with ME share the same **core symptoms** but may have additional and **varied symptoms** due to the systems affected and the development of comorbid conditions.

Canadian Consensus Criteria 2003 CFS/ME Case Definition

Expert consensus definition intended for clinical use...

1. **Substantial reduction in activity** level due to new onset, unexplained, persistent **fatigue** (at least 6 months in duration)
2. **Post exertional malaise** [payback symptoms], delayed recovery (>24 hrs)
3. **Sleep dysfunction** [wide range]. Unrefreshing or altered rhythm.
4. **Pain – myalgia/arthralgia, headaches...**
5. **Neurologic/Cognitive manifestations** (concentration, short term memory, “sensory overload,” disorientation/confusion, ataxia ...)
6. At least one symptom from two of the following:

Autonomic manifestations e.g. orthostatic intolerance, POTS, IBS, vertigo, vasomotor instability, respiratory irregularities...

Neuroendocrine manifestations e.g. temperature intolerance, weight or appetite changes, reactive hypoglycemia, low stress tolerance...

Immune manifestations e.g. tender lymph nodes, sore throat, flu-like symptoms, allergy symptoms, hypersensitivities...

Carruthers BM et al. (2003). "Myalgic encephalomyelitis/chronic fatigue syndrome: Clinical working definition, diagnostic and treatment protocols" (PDF). Journal of Chronic Fatigue Syndrome 11 (1): 7–36. doi:10.1300/J092v11n01_02.

The Institute of Medicine (**IOM***) conducted a review of the scientific evidence (from 1950-mid 2014) and published **core clinical diagnostic criteria** for ME/CFS in Feb 2015 in **an effort to get doctors to recognize and diagnosis ME/CFS.**

A new name, **Systemic Exertion Intolerance Disease (SEID)**, was recommended **but not adopted** by federal agencies that sponsored the review.

The IOM report advised that the term “Chronic Fatigue Syndrome” should no longer be used.

<https://www.ncbi.nlm.nih.gov/books/NBK274235/>. Beyond Myalgic Encephalomyelitis: Redefining an Illness. Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb 10. ISBN-13: 978-0-309-31689-7 ISBN-10: 0-309-31689-8

ME/CFS 2015 Clinical Diagnostic Criteria:

CORE criteria (required for diagnosis) ***Must be moderate-severe and present >50% of time**

- 1) Impairment of normal function, accompanied by fatigue, persisting >6 months
- 2) PEM: post exertional malaise*
- 3) Unrefreshing sleep*
- 4) Plus at least one of the following:

Cognitive impairment*

Orthostatic intolerance (autonomic nervous system dysregulation)

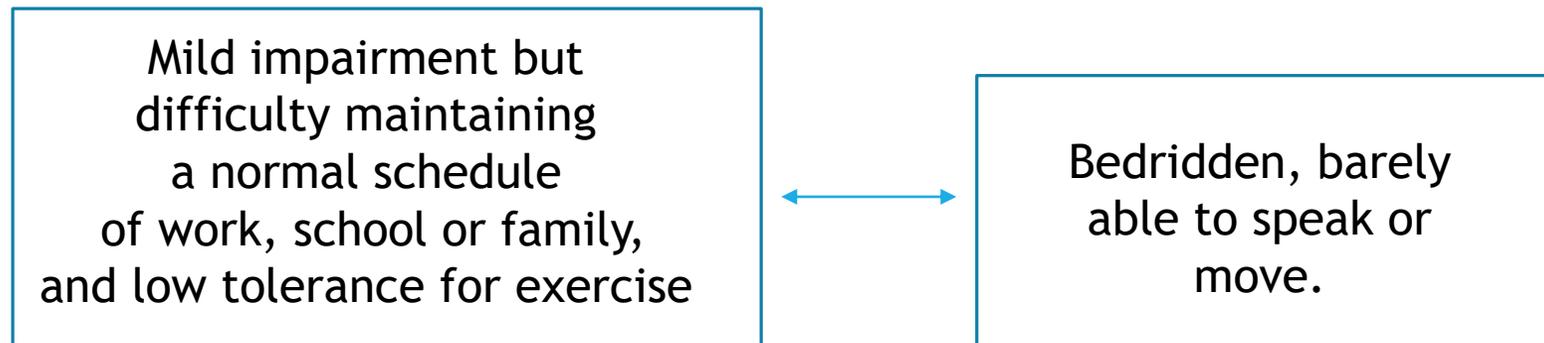
Additional common but not “CORE” features of illness in the ME/CFS population:

- Chronic pain (headache, muscle and joint aches, hyperalgesia, central sensitivity, tingling, burning...)
- Immune/inflammatory manifestations (allergy, inflammation, immunodeficiency, chemical sensitivities)
- Infection manifestations (viral or atypical infections, sore throat, tender lymph nodes, low grade fevers)
- Neuroendocrine manifestations (HPA-axis, stress response)

Beyond Myalgic Encephalomyelitis: Redefining an Illness. Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb 10. ISBN-13: 978-0-309-31689-7 ISBN-10: 0-309-31689-8

Lower activity tolerance and a low “threshold” for relapse from activity (physical, cognitive, etc.)

Illness severity and functional capacity ranges from:



PEM: post exertional malaise

(IOM Report Chapter 4, pp 78-86)

- Exacerbation (relapse) of symptoms after physical, cognitive, emotional, orthostatic or other stress.
- Typically delayed onset (24-48 hours)
- Duration: days, weeks, months...
- PEM has been objectively measured with CPET

Beyond Myalgic Encephalomyelitis: Redefining an Illness. Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb 10. ISBN-13: 978-0-309-31689-7 ISBN-10: 0-309-31689-8

Unrefreshing sleep and studies of sleep

Polysomnography (PSG) is non-diagnostic but usually abnormal in ME/CFS*

- Increased alpha waves (dozing, light sleep)
- Decreased delta waves (slow wave, deep sleep)
- Fragmentation
- Delayed onset

Abnormal **sleep architecture** may be a major presenting disturbance of ME/CFS

Sleep Structure and sleepiness in chronic fatigue syndrome with or without coexisting fibromyalgia. Arthritis Research & Therapy 10(3):R56. Togo 2008
Are patients with chronic fatigue syndrome just “tired” or also “sleepy”? Neu et al 2009. Journal of Sleep Research 17(4):427-431
Sleep abnormalities in chronic fatigue syndrome/myalgic encephalomyelitis. A review. Jackson et al 2012. Journal of Clinical Sleep Medicine. 8(6):719-728

Cognitive impairment

Neurocognitive manifestations (Chap 4, pp 96-107)

- Impairments in cognitive function are frequently reported
- Cognitive impairment can be measured. The strongest evidence demonstrates *slowed information processing*. There is some data to support *deficits in working memory* and *reduced attention*.

Beyond Myalgic Encephalomyelitis: Redefining an Illness. Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb 10. ISBN-13: 978-0-309-31689-7 ISBN-10: 0-309-31689-8

Orthostatic Intolerance



Orthostatic intolerance (OI) is the development of symptoms while **standing upright** that are relieved by **reclining**

Formally defined conditions of OI include:

- Orthostatic hypotension
- Postural Orthostatic Tachycardia Syndrome (POTS)
- Neurally Mediated Hypotension or
 - Neurogenic orthostatic hypotension, etc.



Orthostatic Intolerance proposed mechanisms

- 1) Venous pooling. Reduced pre-load, ventricular filling and stroke volume.
- 2) **Cerebral under-perfusion**
 - Lightheadedness, fainting, impaired cognition, disorientation, headaches, visual changes, unusual neurologic symptoms, exhaustion.
- 3) **Peripheral cardiovascular signs** from impaired autonomic nervous system response to standing
 - Palpitations, nausea, abdominal and chest discomfort, facial pallor, cold hands and feet, anxiousness, shortness of breath, sweating, tremor...

Worsened by heat, dehydration, prolonged standing, deconditioning and weakness, and immediately after exercise.

Tilt Table testing and 10 min Lean testing demonstrate OI in many ME/CFS patients.

Beyond Myalgic Encephalomyelitis: Redefining an Illness. Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb 10. ISBN-13: 978-0-309-31689-7 ISBN-10: 0-309-31689-8

Potential interventions

No FDA-approved drugs for ME/CFS; focus is on symptomatic relief and treatment of comorbidities

Post-exertional malaise

- Pacing and activity management

Orthostatic intolerance

- Beta-blockers, fludrocortisone, midodrine or pyridostigmine
- IV saline to increase blood volume

Pain and sleep

- NSAIDs such as Celecoxib or low-dose naltrexone
- Tramadol

Other ways to support people with ME/CFS:

- Check for nutritional deficiencies, including B vitamins, Vitamin D, and iron. While these do not cause ME/CFS, low levels may contribute to symptoms.
- Adaptations for sensory sensitivities include dark sunglasses, ear plugs, eye masks, and noise-canceling headphones.
- The use of wheelchairs and handicapped parking stickers can reduce PEM.

#MEAction: *Diagnosis and Management of Myalgic Encephalomyelitis*, in association with *Unrest CME*

Selected common co-morbid conditions of interest

- ▶ Fibromyalgia, small fiber and peripheral neuropathies
- ▶ Allergies, chemical sensitivities, mast-cell activation syndrome, food intolerances
- ▶ Viral reactivation (shingles, herpes simplex, EBV, CMV, others)
- ▶ Celiac disease and gluten intolerance
- ▶ IBS, gastroparesis, SIBO (small intestine bacterial overgrowth)
- ▶ Chronic sleep disorders (“primary” and otherwise)
- ▶ Postural orthostatic tachycardia syndrome, orthostatic hypotension, dysautonomias
- ▶ Autoimmune thyroid disease, subclinical hypothyroidism, euthyroid-sick syndrome
- ▶ Sjogren syndrome/sicca syndrome (dry eyes and dry mouth)
- ▶ Vitamin/mineral deficiencies (Vit B12, B6, Vit D, ferritin, etc.)
- ▶ Neuroinflammatory disorders of the brain

BRIAN VASTAG
he/him





Pacing and Activity Management

Brian Vastag

Pacing - non-pharmaceutical illness management



- **Post-exertion malaise (PEM)** - worsening of symptoms after physical or mental exertion (a 'crash')
- **Pacing** = staying within an '**energy envelope**' physically, cognitively & emotionally

Pacing - non-pharmaceutical illness management



- **PAY ATTENTION** - listen to your body & your symptoms.
- If your symptoms get **worse**, you have exceeded your envelope
- **STOP** walking, working, reading before this point. Be conservative. Rest frequently.

Pacing - non-pharmaceutical illness management



- **Crashes** are often delayed 8, 24, 48 hrs after exertion
- **Symptom & activity diaries** can help you determine causes of PEM/relapses.

Pacing - non-pharmaceutical illness management

- **Activities** that used to feel effortless - reading - now require effort & need to be accounted for.
- Do **HALF or less** of what you think you can. **PLAN** for frequent downtime.

Pacing - non-pharmaceutical illness management

- Monitor heart rate - anaerobic threshold is key.

DO NOT EXCEED

$(220 - [\text{age}]) * 0.6 = 103 \text{ beats/min for me (48 yrs old)}$

- **Experience** will guide you. Go **easy** on yourself. **Learn** from your body.
- Using a **heart rate monitor** to prevent PEM in ME/CFS article:
<https://bit.ly/2DvyKGX>

JD DAVIDS
he/him





Advocating in Your Providers' Offices and Beyond

JD Davids, #MEAction, @TheCrankyQueer

Learn from Past Experiences with Crisis and/or Care

- Think about past crises/challenges. How do you act/react with people in power?
 - Do you tend to **fight**, take **flight**, **freeze** up, or **appease** (go along with what you think others may want?).
 - *This way you're less surprised when this happens in the provider's office!*
- Think about how you **work best with others.**
- Ask a close friend or loved one to help you **remember how you handle challenges.**

Set your Strategies for Your Care and Recovery

1. Identify Top Concerns, then Prioritize

What is both **important** and **easier** to take care of?

I had chronic dizziness as a central symptom, and there was a rehab 10 blocks from my workplace that treated it.

2. For each priority, list & track your strategy (in whatever way works for you):

- What is your current plan to address this priority?
- Who can help, including providers?
- Next steps and notes

Discuss your strategies with a key support person -- especially *before and after provider visits* -- bring them along if possible!

Understanding what Providers Need

- Recognize **what type of provider they are & limits of their role**
- **2-4 page life/medical history summary**
 - birth/birth trauma, key life trajectory/phases, any notable biological family history (if available)
 - Accidents, traumas, surgeries, chronic or major illness or permanent conditions
- **Current information:**
 - Full list of meds and supplements (Keep in 1 place and update, print out)
 - Current symptoms, in ranked order with *most severe/most relevant to you* up top
 - Recent tests, provider visits, with one line summary of results/recommendations

Understanding what Providers Need

- **Your Top 3 Questions for TODAY, in ranked order.**
 - What most impacts YOU according to your specific needs and priorities
 - For new providers, consider prioritizing this Q: **“how do you work with patients, what is the most effective way I can use my time with you?”**
- **#MEAction’s Hospitalization Kit**
(<https://www.meaction.net/covid-19/>)
 - **Intake form** (health history, etc.)
 - **What to bring**

Key Qs/Practices for Medical Mysteries/Miseries

- **Get copies of all reports (and scans, not just reports:** MRI on disks, etc) in 1 place (even if you never look at them!)
- **Learn:** What are **red flags** for urgent or emergency care? For calling provider?
- What seems to have **the most impact** on your well-being/coping?
- Are you noticing **cycles or patterns**?
- If you **change more than one factor at a time** (3 new meds, drinking more water AND taking naps), you can't discern which thing makes a difference.

Resources

Books:

- [How to Be a Patient](#): Sana Goldberg, RN -- *grew up going to hospital with her single mom, an MD!*
- [How To Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers](#): Toni Bernhard -- *author living with ME/CFS!*
 - **NEW!** There's a great [pocket version](#)! -- can be in the phone in your pocket if you get digital

Articles:

- [Beyond The Bullshit Of 'Too Bad, So Sad': On Life With Chronic Illness and Disabilities](#)
Asher Wolf, Medium
- [How Not to Track Symptoms, and Why, and When to Do It Anyway](#)
JD Davids, Cranky Queer Guide to Chronic Illness

**WILHELMINA
JENKINS**
she/her





Well-Being with Chronic Illness

Wilhelmina Jenkins

Well-Being with Chronic Illness



- This is not your fault
- Allow yourself to mourn your losses
- Don't compare yourself to anyone else
- Be kind to yourself - no shoulds!
- Proceed with caution

Well-Being with Chronic Illness



- Hold hope for the future while living in the moment
- Find an activity that makes you feel like yourself
- You are not alone
- Resource: **7 Tips for Making Peace With Chronic Pain and Illness**, by Toni Bernhard J.D.

Send to clinicians & clinical orgs:



Our clinical seminar on post-viral ME. Note there is a link to a downloadable flyer to share: www.meaction.net/seminar

Post-viral ME/CFS Clinicians' Seminar
SATURDAY, AUGUST 29, 3PM PST



Send your clinician to the *Unrest* CME: www.unrest.film/cme

Connect to #MEAction resources:



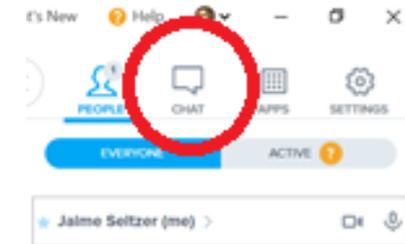
- Sign up for our mailing list, if you did not opt in when you registered; you'll get ME news and news about upcoming seminars.
- Our COVID resources: <https://www.meaction.net/covid-19/>
- If this seminar was valuable to you, please consider making a donation so we can continue to host seminars like these!
www.meaction.net/donate

Jaime Seltzer: jaime@meaction.net – science, medical, outreach
Terri Wilder: terri@meaction.net – #MEAction NY

Q & A



- **Type your question** in the chat box in the upper, right-hand corner of BlueJeans.



- **Address your question to a particular presenter:** “JD, can you tell me a little more about dealing with the flight response at the doctor’s?”

- **It’s ok to leave** if you feel exhausted. Remember that there will be a recording!





ME/CFS AND COVID19: WHAT'S THE CONNECTION?



with

BODY POLITIC

