Long COVID & Fatiguing Illness Recovery Program ECHO

Thursday, May 12, 2022

CDC Centers for Disease Control and Prevention
Family Health Centers of San Diego
University of Colorado Anschutz Medical Campus
UW Medicine School of Medicine
UNM Health Sciences
Project ECHO

History of ME/CFS

myalgic encephalomyelitis/chronic fatigue syndrome

Lucinda Bateman, MD

Bateman Horne Center

CDC Centers for Disease Control and Prevention

Family Health Centers of San Diego

University of Colorado Anschutz Medical Campus

UW Medicine School of Medicine

UNM Health Sciences

Project ECHO

Bateman Horne Center (BHC)

BHC is a 501(c)3 non-profit organization with a mission to improve lives through direct **clinical care,** facilitation of **research,** and dissemination of **educational** resources.

This specifically/exclusively includes the lives of people with:

- **myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)**
- fibromyalgia (FM)
- post-viral syndromes and
- related comorbid conditions (small fiber neuropathy, mast cell activation syndrome, hypermobile EDS, postural orthostatic tachycardia syndrome/POTS)

May 12th

International ME/CFS and FM Awareness Day

https://www.nih.gov/research-training/medical-research-initiatives/mecfs/me-cfs-fibromyalgia-international-awareness-day

CDC Centers for Disease Control and Prevention
Family Health Centers of San Diego
University of Colorado Anschutz Medical Campus
UW Medicine School of Medicine
UNM Health Sciences
Project ECHO

What is ME/CFS?
myalgic encephalomyelitis/chronic fatigue syndrome

- **A chronic, complex, debilitating, multi-system illness involving:**
  - **Brain** (neuroinflammation, abnormal stress response system, HPA-axis dysregulation)
  - **Peripheral nervous system** (especially small fiber nerves involving pain, sensation, and ANS function)
  - **Immune system** (impaired NK Cell fxn, abnormal T-cells, cytokines, autoimmune conditions, immune activation, mast cell activation)
  - **Circulatory system** (orthostatic intolerance, perfusion abnormalities)
  - **Impaired cellular metabolism**
- **Often a post-viral or post-infectious syndrome, but diagnosis is typically made so late (if ever) that evidence of the acute infection has been lost, or diagnostic studies of common potential pathogens were not done at illness onset.**
- Immune triggers may also be associated with onset of ME/CFS

US ME/CFS Clinician Coalition website: https://mecfscliniciancoalition.org/

Inflammation correlates with symptoms in chronic fatigue syndrome. Komaroff AL. Proc Natl Acad Sci USA. 2017 Aug 22; 114(34): 8914-8916. Published online 2017 Aug 15 . doi: 10 .1073 / pnas.1712475114 PM CID: PMC5576849

CDC Centers for Disease Control and Prevention · Family Health Centers of San Diego · University of Colorado Anschutz Medical Campus · UW Medicine School of Medicine · HSC Health Sciences · Project ECHO

ME/CFS can be triggered by a variety of pathogens

- Many **viruses** can cause a post-viral syndrome and have been associated with the onset of ME/CFS, including Epstein-Barr Virus, CMV and other herpesviruses, Parvovirus B19, West Nile Virus, enteroviruses, coronaviruses (SARS CoV1, MERS, SARS CoV-2) and other non-viral pathogens as well (giardia, Q-fever/Coxiella burnetii, Lyme/Borrelia burgdorferi, and more).

- ME/CFS may be caused by the body's complex reactions to certain acute infections, or viral reactivation, in combination with **an abnormal chronic immune/inflammatory response**. Genetic predisposition may play a role.

- People with ME/CFS **share the same core symptoms** but heterogeneity exists, likely due to the systems affected, disease duration and the development of comorbid conditions. This heterogeneous illness has been challenging to study.
- Post acute sequelae of COVID (Long COVID) may change that!

- **ICD-10 G93.3 Post-viral syndrome, myalgic encephalomyelitis.**

Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome. Komaroff AL, Lipkin WI. Trends Mol Med. 2021 Sep. PMID: 34175230

CDC Centers for Disease Control and Prevention · Family Health Centers of San Diego · University of Colorado Anschutz Medical Campus · UW Medicine School of Medicine · UNM Health Sciences · Project ECHO

ME/CFS historical background

ME/CFS is not a new illness.

Post-infectious illnesses of this nature and severity have been world-wide and multicultural.

Comparable illnesses have been documented for centuries (but historical comparisons are problematic).

ME/CFS historical background

- Illnesses like ME/CFS have historically been **described** many ways.

- Initial descriptions included *"epidemic neuromyasthenia,"* and later, ***"benign myalgic encephalomyelitis"*** first used in the 1950s. The syndrome usually applied to epidemic outbreaks, but sporadic cases were identified as well.

- In 1970, two *psychiatrists* in the UK reviewed 15 outbreaks and concluded these "were psychosocial phenomena caused by…***mass hysteria***…and conclusions were based on the higher prevalence in females and the lack of physical signs. They recommended the name *"myalgia nervosa"* reminiscent of the term *neurasthenia* from the 19th century.

- These ideas were refuted for decades by a dedicated physician, Dr. Melvin Ramsay, who eventually published the first definition of **Myalgic Encephalomyelitis** in 1986.

ME/CFS historical background

- The term **Chronic Fatigue Syndrome (CFS)** was first published in 1988 to replace the misnomer *"Chronic EBV."* The paper described a post-infection or post-viral syndrome and proposed a research case definition.

- It was revised in 1994 but proved too broad, encompassing many other causes of "chronic fatigue" (including fibromyalgia and some mental health conditions).

- Very descriptive clinical criteria for ME/CFS were published in 2003 by expert clinical consensus, eventually called the **"Canadian Consensus Criteria,"** but the publication wasn't widely accessible to practicing clinicians. These criteria were revised, updated and published in 2011 as the **"International Consensus Criteria"** for ME. Both are widely used outside the U.S.

- Many other definitions and criteria have been published as well.

Holmes GP, et al. Chronic fatigue syndrome: a working case definition. Ann Intern Med 1988;108:387-9

Fukuda et al, Annals of Internal Medicine, Vol. 121, December 15, 1994, pp. 953-959

ME/CFS historical background

- After an *evidence-based review* the Institute of Medicine/IOM (now the National Academy of Medicine/NAM) proposed clinical diagnostic criteria in 2015 based on the **common core** symptoms of ME/CFS*.

- The IOM/NAM report is readily available: **https://pubmed.ncbi.nlm.nih.gov/25695122/**

**The term Systemic Exertion Intolerance Disease (SEID) was suggested but not adopted*

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

ME/CFS "Key Facts" of the 2015 NAM report

- 836,000 to 2.5 million Americans affected, and many more worldwide.
- Women > men. Most patients currently diagnosed are Caucasian, but some studies suggest it is more common in minority groups.
- 25% bed-bound or house-bound at some point of illness.
- 75% are unable to work or attend school. Symptoms can persist for years, and most never regain pre-illness level of health or functioning.
- Loss of productivity and medical costs contribute to a total economic burden of $17-24 billion annually in the U.S. [this has recently been revised to $36-51 billion]

Institute of Medicine. 2015. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, DC: The National Academies. PMID: 25695122. DOI 10.17226/19012 https://pubmed.ncbi.nlm.nih.gov/25695122/

Updating the National Academy of Medicine ME/CFS prevalence and economic impact figures to account for population growth and inflation, L.A. Jason & A.A. Mirin. 28 Jan 2021. https://doi.org/10.1080/21641846.2021.1878716

2015 ME/CFS Clinical Diagnostic Criteria:

(IOM/NAM)

CORE criteria (required for diagnosis)

1) **Impairment of normal function** accompanied by fatigue**, >6 months duration**

2) **PEM: post exertional malaise***

3) **Unrefreshing [dysregulated] sleep***

4) Plus at least one of the following:

Cognitive impairment*

Orthostatic intolerance (autonomic nervous system dysregulation)

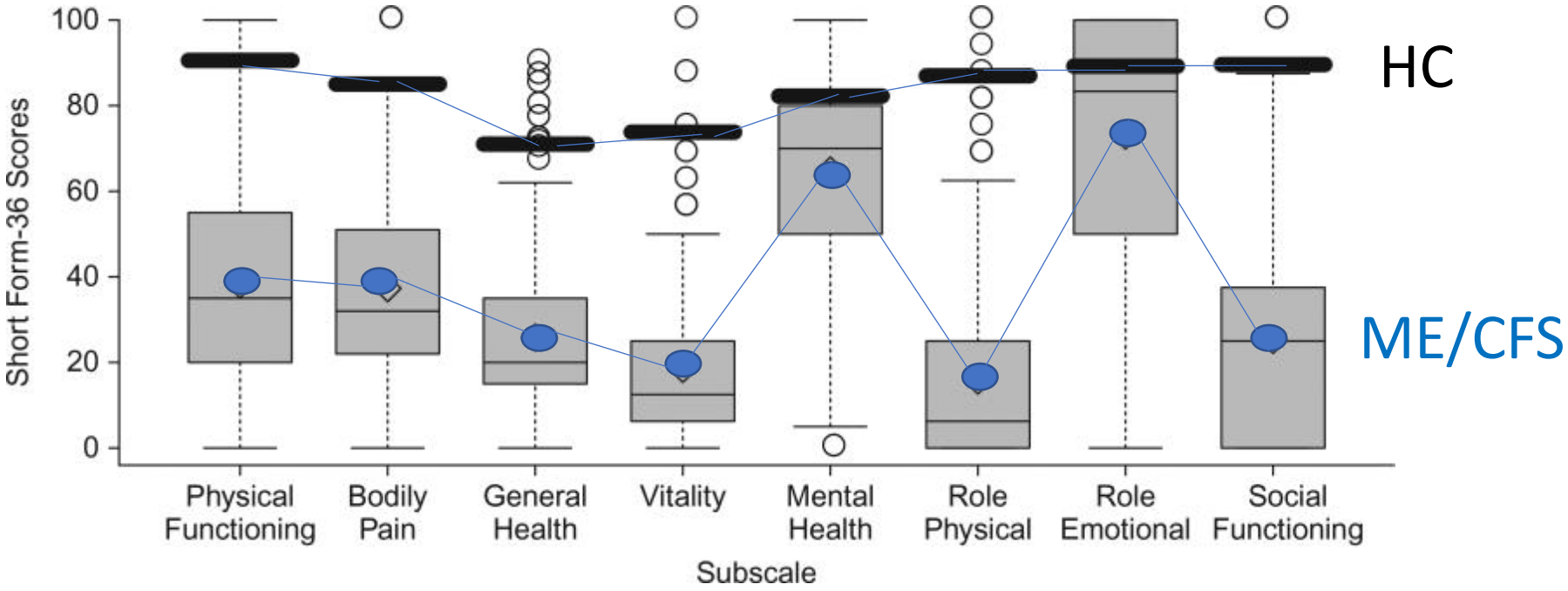
***Must be moderate-severe and present >50% of time**

Additional common but variable and 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 dysregulation, impaired stress response)

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

Research…IMPAIRED FUNCTION with fatigue



SF-36 scores for patients in the CDC multisite clinical assessment of ME/CFS (MCAM)

Unger, E. R., Lin, J. S., Tian, H., et al. MCAM Study Group (2017). Multi-Site Clinical Assessment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (MCAM): Design and Implementation of a Prospective/Retrospective Rolling Cohort Study. American journal of epidemiology, 185(8), 617–626. https://doi.org/10.1093/aje/kwx029

Clinical tips…IMPAIRED FUNCTION with fatigue

We use simple **tools to communicate impaired function**

HUA: Hours of "Upright" Activity:

Report the # of hours spent with **feet-on-floor in 24 hours:** sitting, standing, walking

Must ask the question clearly to be sure
time spent sitting is considered in the total.

Clinical tips…IMPAIRED FUNCTION with fatigue

Typical HUA*

Hours of **U**pright **A**ctivity in 24 hours

- Normal healthy folks HUA 13-17
- Chronic Illness (MS, RA, CHF, COPD, FM) HUA 9-12
- ME/CFS HUA 0-8

Observational clinic data from BHC

CDC Centers for Disease Control and Prevention | Family Health Centers of San Diego | University of Colorado Anschutz Medical Campus | UW Medicine School of Medicine | UNM Health Sciences | Project ECHO

Clinical tips…IMPAIRED FUNCTION with fatigue

Good Day/Bad Day Questionnaires*

1) Average number of **GOOD**_____**BAD**_____ days per MONTH
2) Average **hours of UPRIGHT activity (HUA)** on a **GOOD**_____**BAD**_____ day:
   - *Sitting, standing, walking --- activities with FEET ON FLOOR*

   (Hours of upright activity + Hours of non-upright activity = 24 hours)
3) **Give examples** of activities/tasks you **CAN** do on a:
   - **GOOD day**_____
   - **BAD day**_____
4) **Give examples** of activities/tasks you **CAN NOT** do on a:
   - **GOOD day**_____
   - **BAD day**_____

"Unraveling the complexity of chronic pain and fatigue"
https://www.youtube.com/watch?v=7HJG-WlnxSg&t=69s

CDC Centers for Disease Control and Prevention | Family Health Centers of San Diego | University of Colorado Anschutz Medical Campus | UW Medicine School of Medicine | HSC Health Sciences | Project ECHO

Clinical tips…IMPAIRED FUNCTION with fatigue

Good Day/Bad Day Questionnaire Example

- On **GOOD days,** 4-5/mo, he can manage 8 HUA*
  - **Can:** read (<30 min), watch TV, listen to music, cook a meal, shower, walk one block, drive short distances
  - **Cannot:** walk more than 3 blocks, work, complete household chores exceeding 15 minutes, drive >30 minutes
- On **BAD days,** 25-26/mo, he tolerates **only 2 HUA***
  - **Can:** recline on the couch, microwave prepared food, have a short conversation (<5 min)
  - **Cannot:** read, listen to music, work, do household chores, take a shower, exercise, drive

***HUA**= **H**ours of **U**pright **A**ctivity (seated with feet on floor, standing, walking)

"Unraveling the complexity of chronic pain and fatigue"
https://www.youtube.com/watch?v=7HJG-WlnxSg&t=69s

What causes…IMPAIRED FUNCTION with fatigue?

- **Impaired cellular metabolism**--- reduced ATP, reduced levels of many molecules, oxidative stress.
- Post exertional malaise (PEM)--- the consequences of exceeding physiologic capacity
- Orthostatic Intolerance
- Cognitive impairment and cognitive fatigability

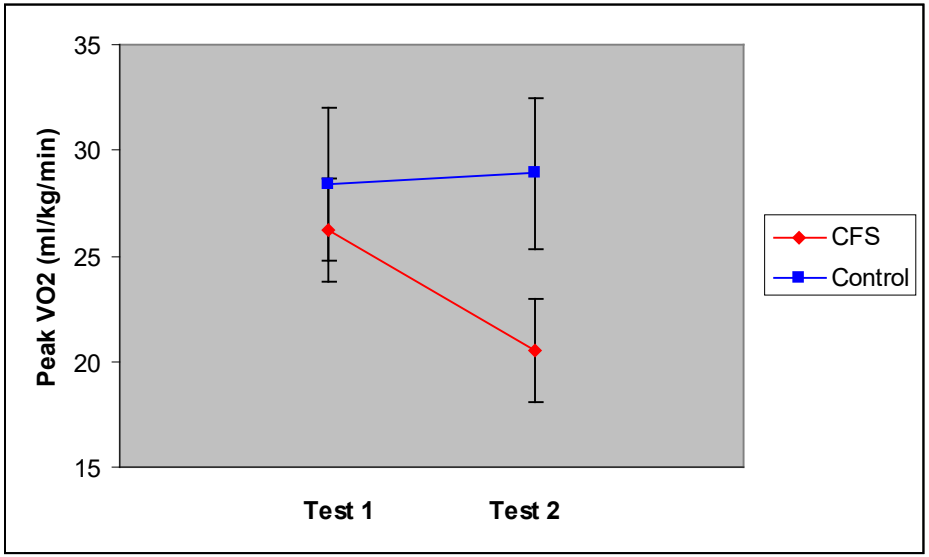
This is an important research question

Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome. Komaroff AL, Lipkin WI. Trends Mol Med. 2021 Sep. doi: 10.1016/j.molmed.2021.06.002. PMID: 34175230
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8180841/#b0005

Research…POST-EXERTIONAL MALAISE (PEM)

PEM is a distinctive exacerbation of the patient's symptoms and a further reduction in functioning after physical, cognitive, orthostatic, emotional, or sensory stressors.

- It is supported objectively by abnormal **cardiopulmonary exercise testing (CPET)** showing low anaerobic threshold, impaired aerobic metabolism, and inability to replicate the test results on serial days.



Using serial cardiopulmonary exercise tests to support a diagnosis of Chronic Fatigue Syndrome. VanNess, JM, et al. Med. Sci. Sports. Exerc. 38(5), **2006**.

CDC Centers for Disease Control and Prevention · Family Health Centers of San Diego · University of Colorado Anschutz Medical Campus · UW Medicine School of Medicine · HSC Health Sciences · Project ECHO

PEM: Two Day CPET Test confirmed

Test 1 = dark grey bars Test 2= light grey bars

22 ME/CFS subjects

Figure 1: ** p < 0.01, * p < 0.05 see Table 2

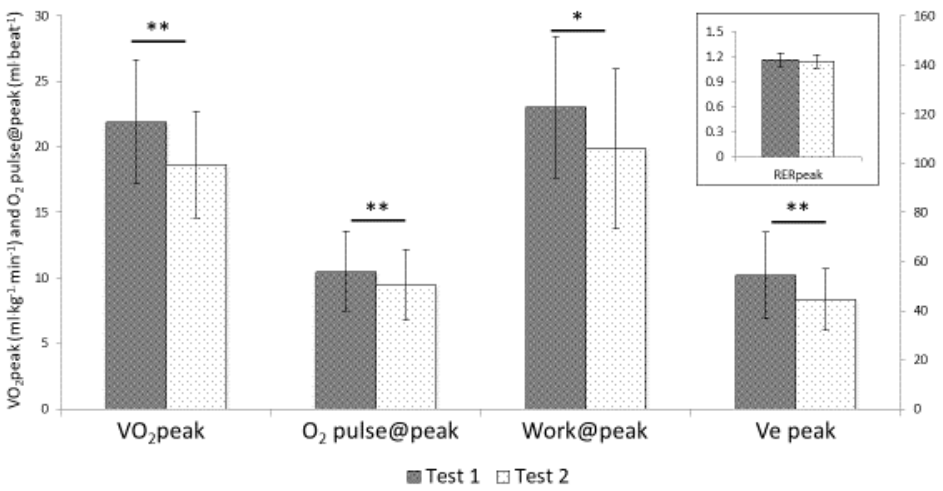
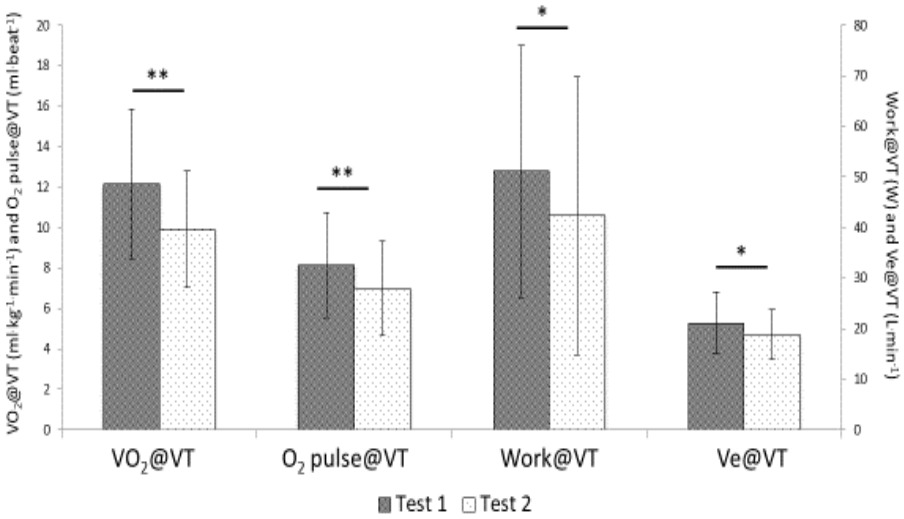


Figure 2: ** p < 0.01, * p < 0.05 see Table 2

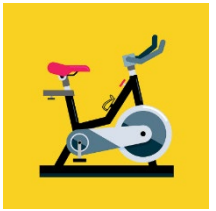


Inability of ME/CFS patients to reproduce VO2 peak indicates functional impairment. Keller B, et al. Journal of Translational Medicine 2014, 12:104.

CDC Centers for Disease Control and Prevention · Family Health Centers of San Diego · University of Colorado Anschutz Medical Campus · UW Medicine School of Medicine · HSC Health Sciences · Project ECHO

PEM and Invasive CPET (iCPET)

- Invasive CPET studies of people with ME/CFS and OI/POTS have demonstrated *"biologically plausible contributors to ME/CFS exertional intolerance."*
- 1516 upright invasive iCPETS were performed to investigate exertional intolerance.
- **Two types of peripheral neurovascular dysregulation were identified:**
  - **reduced cardiac output from impaired venous return**
  - **impaired peripheral oxygen extraction**



- They note the overlap of ME/CFS, POTS and FM, and suggest that in patients with small-fiber pathology, **neuropathic dysregulation** causing **microvascular dilation** may limit exertion by shunting oxygenated blood from capillary beds and reducing cardiac return.
- Similar findings are being seen in Long COVID

Also read: https://consultqd.clevelandclinic.org/unexplained-dyspnea-could-it-be-due-to-a-chronically-low-preload-state/

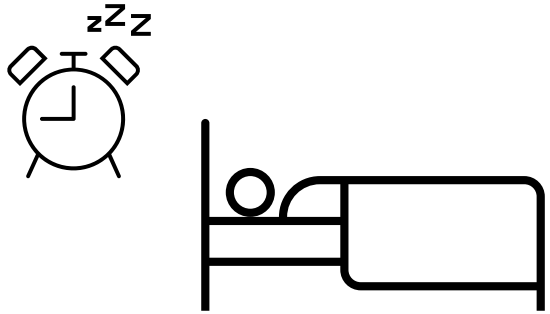
Insights From Invasive Cardiopulmonary Exercise Testing of Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Joseph P, Arevalo C, Oliveira RKF, Faria-Urbina M, Felsenstein D, Oaklander AL, Systrom DM. Chest. 2021 Aug;160(2):642-651. doi: 10.1016/j.chest.2021.01.082. PMID: 33577778 PMCID: PMC8727854 DOI: 10.1016/j.chest.2021.01.082

PEM take-home messages

- While we may not completely understand it, **exceeding *energy capacity* results in illness pathology—post-exertional malaise (PEM).** The severity and duration of PEM are relative to the energy expenditure.
  - A loose analogy is using HgA1C to measure the extent of glucose exertions in diabetes
- Energy expenditures include all types of physiologic stress—**physical activity**, **orthostatic stress, cognitive work, emotional exchanges**, responding to **environmental stress and sensory input**, etc.
- The threshold for triggering PEM varies day to day, at stages of illness, and from person to person with ME/CFS.
- In absence of a primary treatment for ME/CFS, the mainstay of treatment is **prevention of illness exacerbation** by carefully **"pacing"** activities to avoid significant PEM. *It isn't easy.*
- The better one prevents PEM, the more likely one is to stabilize and/or improve. The opposite is also true. Pushing into PEM may result in severe crashes and overall decline, sometimes permanently.

UNREFRESHING SLEEP--- known physiology

- **Sleep is variably disturbed and thus "unrefreshing".**
- **Nocturnal autonomic dysregulation** has been demonstrated as *reduced heart rate variability* from *increased sympathetic activity* relative to parasympathetic activity.
- **HPA-axis dysregulation** with *flattened* AM cortisol levels and throughout the day, rather than normal circadian changes, may play a role as well.

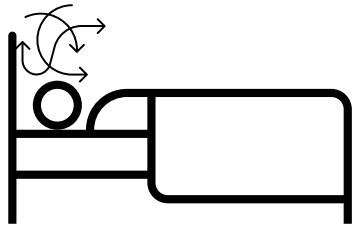


UNREFRESHING SLEEP---sleep studies

Polysomnography (PSG):

- 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



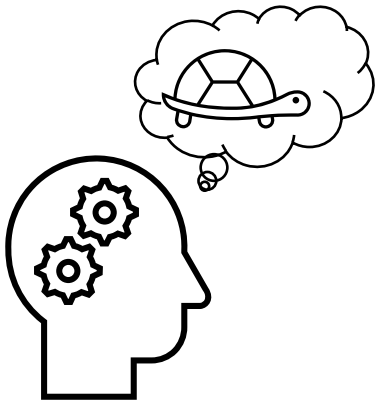
- Sleep Structure and sleepiness in chronic fatigue syndrome with or without coexisting fibromyalgia. Arthritis Research & Therapy 10(3):R56. Togo 2008
- Are patients with chronic fatigue syndrome just “tired” or also “sleepy”? Neu et al 2009. Journal of Sleep Research 17(4):427-431
- Sleep abnormalities in chronic fatigue syndrome/myalgic encephalomyelitis. A review. Jackson et al 2012. Journal of Clinical Sleep Medicine. 8(6):719-728
- Are there sleep-specific phenotypes in patients with chronic fatigue syndrome? A cross-sectional polysomnography analysis. Gotts ZM, ET AL. BMJ open 3: 1–7. 10.1136/bmjopen-2013-002

CDC Centers for Disease Control and Prevention · Family Health Centers of San Diego · University of Colorado Anschutz Medical Campus · UW Medicine School of Medicine · UNM Health Sciences · Project ECHO

COGNITIVE IMPAIRMENT

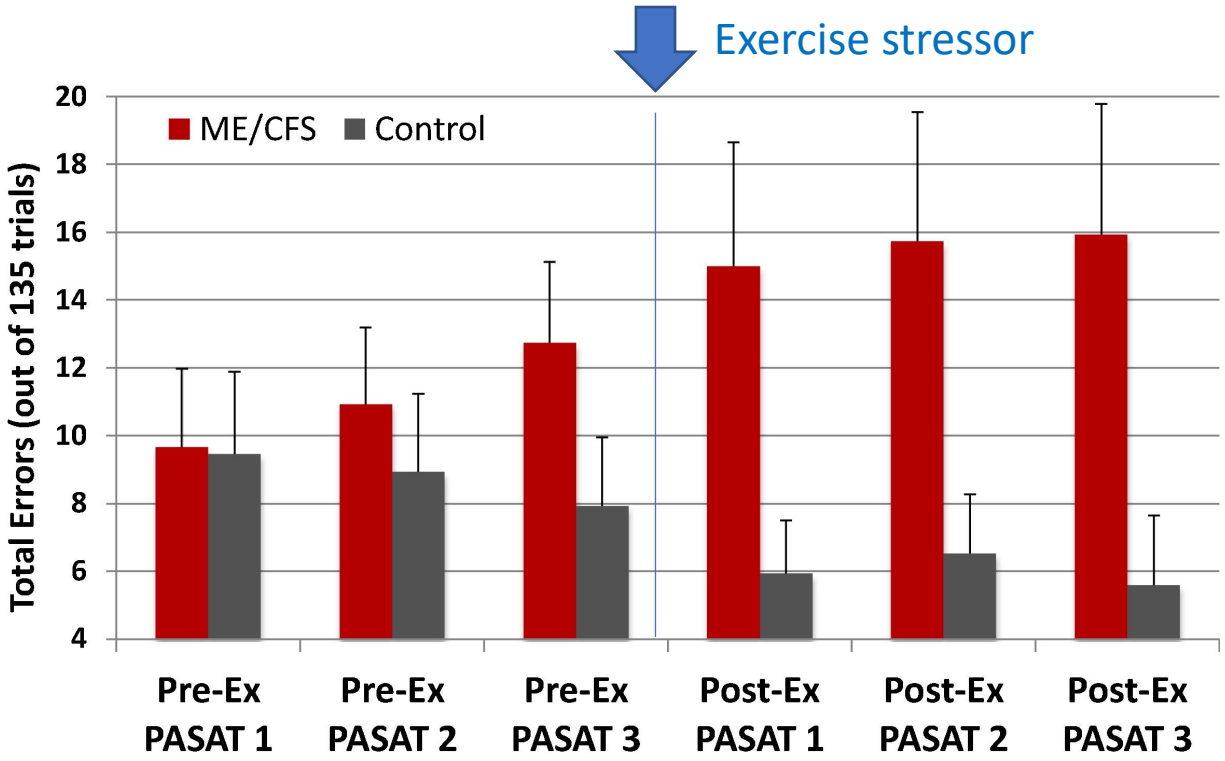
Cognitive Impairment:

- **Slowed information processing speed** is the most common cognitive deficit.
- Other abnormalities include **decreased working memory and attention**.
- Defects worsen when patients face deadlines, unrelenting demands, and multiple simultaneous tasks.



Total errors on PASAT testing (Paced Auditory Serial Addition Task)

Total errors represent both incorrect responses and missed responses (i.e. errors of omission). There was a significant Group by Time Interaction (F = 8.4, *p* = 0.007).



Cognitive scores: IMPROVE with each attempt in healthy controls and WORSEN with each attempt in ME/CFS

Neural Consequences of Post-Exertion Malaise in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Brain Behav Immun. 2017 Feb 16. Cook DB, Light AR, Light KC, Broderick G, Shields MR, Dougherty RJ, Meyer JD, VanRiper S, Stegner AJ, Ellingson LD, Vernon SD.

COGNITIVE IMPAIRMENT

Research contributions from:

- Neurocognitive testing---deficits in attention, memory, and reaction time
- Spinal fluid studies--- increased WBC, abnormal proteins
- MRI, fMRI, PET scans--- hypoperfusion, glial cell activation, white matter changes
- Spectral analysis of EEG data can distinguish ME/CFS from HC and MD
- Neuroendocrine studies---abnormalities of the HPA-axis

Inflammation correlates with symptoms in chronic fatigue syndrome. Komaroff AL. Proc Natl Acad Sci USA. 2017 Aug 22; 114(34): 8914-8916. Published online 2017 Aug 15. doi: 10.1073/ pnas.1712475114 PM CID: PMC5576849

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5576849/

CDC Centers for Disease Control and Prevention | Family Health Centers of San Diego | University of Colorado Anschutz Medical Campus | UW Medicine School of Medicine | UNM Health Sciences | Project ECHO

ORTHOSTATIC INTOLERANCE

Orthostatic intolerance is the development of symptoms in **upright posture** that are relieved or partially relieved by **reclining.**

ORTHOSTATIC INTOLERANCE

Orthostatic Intolerance from Autonomic N.S. dysfunction:

1) **Cerebral under-perfusion** *symptoms and signs*

- Lightheadedness, fainting, impaired cognition, disorientation, headaches, visual changes, unusual neurologic symptoms, exhaustion

2) **Peripheral cardiovascular** *symptoms and signs*

- Sympathetic nervous system activation---palpitations, nausea, abdominal and chest discomfort, facial pallor, cold hands and feet, anxiousness, shortness of breath, sweating, tremor…

Worsened by heat, dehydration, prolonged sitting or standing, deconditioning and weakness, medications, and worsens during or immediately after exercise.

Chapter 4, pg 107; Chap 6, pg 185.

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

ORTHOSTATIC INTOLERANCE

Orthostatic intolerance and reduced cerebral blood flow are core manifestations of ME/CFS but BP & HR may not tell the whole story.

- **Cerebral blood flow is reduced** in ME/CFS during head-up tilt testing **even in the absence of hypotension or tachycardia**: A quantitative, controlled study using Doppler echography. van Campen CLMC, et al. Clin Neurophysiol Pract. 2020 Feb 8;5:50-58. doi: 10.1016/j.cnp.2020.01.003. PMID: 32140630

- **Cerebral Blood Flow Is Reduced** in Severe ME/CFS Patients During Mild Orthostatic Stress Testing: An Exploratory Study **at 20 Degrees of Head-Up Tilt Testing.** van Campen CLMC, et al. Healthcare (Basel). 2020 Jun 13;8(2):169. doi: 10.3390/healthcare8020169. PMID: 32545797

CDC Centers for Disease Control and Prevention | Family Health Centers of San Diego | University of Colorado Anschutz Medical Campus | UW Medicine School of Medicine | UNM Health Sciences | Project ECHO

ORTHOSTATIC INTOLERANCE

Can orthostatic intolerance testing be done by primary care providers? The 10 min stand/lean test can!

30-45 min
Cardiology

Head Up Tilt Table Testing

The Gold Standard

10 min stand/lean testing

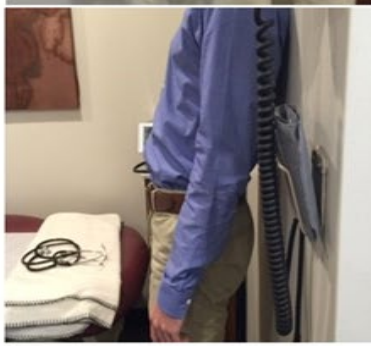
ORTHOSTATIC INTOLERANCE

A standardized clinic-based approach: the 10 min NASA Lean Test

10 minutes NASA Lean Test

Orthostatic Vital Signs/The NASA 10-minute Lean Test

	Blood Pressure (BP)		Pulse	Comments
	Systolic	Diastolic		
Supine 1 minute				
Supine 2 minute				
Standing 0 minute				
Standing 1 minute				
Standing 2 minute				
Standing 3 minute				
Standing 4 minute				
Standing 5 minute				
Standing 6 minute				
Standing 7 minute				
Standing 8 minute				
Standing 9 minute				
Standing 10 minute				



Hyatt, K. H., Jacobson, L. B., & Schneider, V. S. (1975). Comparison of 70 degrees tilt, LBNP, and passive standing as measures of orthostatic tolerance. Aviation, Space, and Environmental Medicine, 46(6), 801-808.

CDC Centers for Disease Control and Prevention · Family Health Centers of San Diego · University of Colorado Anschutz Medical Campus · UW Medicine School of Medicine · UNM Health Sciences · Project ECHO

ORTHOSTATIC INTOLERANCE: 10 min NASA Lean

37-year-old disabled professional woman with ME/CFS

2-4 HUA/d. Sitting: BP 112/75. P-77

Lying down resting for 10-15 min:
Supine: BP 99/68 **P- 68**

Standing relaxed with shoulders against wall, feet 6" from the wall.
Standing at 0 minutes: BP 99/72 P- 90
Standing at 1 minute: BP 90/74 P-100 mild weakness, heavy feeling in legs
Standing at 2 minutes: BP 101/74 P- 94 dependent rubor, facial pallor
Standing at 3 minutes: BP 104/84 P-111 hands tingling
Standing at 5 minutes: *unable to measure*
Standing at 6 minutes: BP **88/62** P-**132** palpitations
Standing at 7 minutes: BP 94/64 P-115 palpitations, increased nausea
Standing at 8 minutes: did not register on B/P cuff

Tingling in face increased, tingling all over, sees "spots", muted sounds, legs gave way, vision blacking out. Assisted gently to the floor and legs elevated.

HR 68 → 132 (+64 bpm) just before near-syncope.

The 10 min NASA Lean test can diagnose OI, OH, POTS, orthostatic syncope

Hemodynamics during the 10-minute NASA Lean Test: evidence of circulatory decompensation in a subset of ME/CFS patients. Lee J, Vernon SD et al. J Transl Med. 2020 Aug. doi: 10.1186/s12967-020-02481-y. PMID: 32799889

Selected common CO-MORBID CONDITIONS of interest in ME/CFS patients

I'm defining a **co-morbid condition** as a known condition that can occur alone but also commonly occurs as a part of the ME/CFS clinical presentation.

Co-occurrence with ME/CFS generally makes a co-morbid condition much more difficult to treat. But still a worthy treatment target.

Selected common CO-MORBID CONDITIONS of interest in ME/CFS patients

- Fibromyalgia/pain amplification, central sensitivity
- Small fiber poly neuropathies (SFPN) and peripheral neuropathies
- Viral reactivation (VZV, HSV, HHV-6, EBV, CMV, etc.)
- Chronic sleep disorders ("primary" and secondary)
- Postural orthostatic tachycardia syndrome (POTS), orthostatic hypotension, other manifestations of dysautonomia
- Allergies, chemical sensitivities, mast-cell activation syndrome (MCAS), food intolerances
- Autoimmune thyroid disease, subclinical hypothyroidism, euthyroid-sick syndrome
- Celiac disease and gluten intolerance, IBS, gastroparesis, SIBO (small intestine bacterial overgrowth)
- Sjogren syndrome/sicca syndrome (dry eyes and dry mouth)
- Hypermobility and Ehlers Danlos Syndrome (the common type with no genetic markers)
- Craniocervical instability syndromes (high cord or brain stem compression syndromes)

These are conditions we can diagnose and manage with standard of care

CDC Centers for Disease Control and Prevention | Family Health Centers of San Diego | University of Colorado Anschutz Medical Campus | UW Medicine School of Medicine | UNM Health Sciences | Project ECHO

Managing ME/CFS (and Long COVID)

- Provide understanding and support.
- Teach **“pacing”** and activity management to prevent or reduce PEM.
- Identify and treat **“comorbid conditions”** but remember that it generally won’t be a magic bullet for the whole illness.
- **Address severe symptoms** sensibly, especially those that are “stressors”
  - Pain and headaches
  - Sleep disturbances
  - Orthostatic intolerance
  - Cognitive impairment
  - Anxiety, grief/loss (especially in the first 1-2 years of illness)
- Help patients build a “toolbox” of rescue medications and strategies to manage symptom flares and maintain some physical conditioning.
- Remember that any other medical problem can occur in someone with ME/CFS.

Useful links

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Institute of Medicine. 2015. Washington, DC: The National Academies. PMID: 25695122 DOI: 10.17226/19012 https://pubmed.ncbi.nlm.nih.gov/25695122/

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management. Mayo Clinic Proceedings, Consensus Recommendations: Vol 96, Issue 11, P2861-78. Nov 2021. https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext

US ME/CFS Clinician Coalition website: https://mecfscliniciancoalition.org/

Bateman Horne Center website and YouTube videos
BHC Quick videos

- **What is ME/CFS?** **[5 min]** https://www.youtube.com/watch?v=vQWVZdGm508&t=20s
- **Orthostatic Intolerance, Part 1. Diagnosis** **[6 min]** https://www.youtube.com/watch?v=X3Ym8rnYk_4&t=1s
- **Orthostatic Intolerance, Part 2. Management** **[5 ½ min]** https://www.youtube.com/watch?v=GIkS4w3tIg8&t=1s

CDC: https://www.cdc.gov/me-cfs/index.html
NIH: https://www.nih.gov/research-training/medical-research-initiatives/mecfs

CDC Centers for Disease Control and Prevention · Family Health Centers of San Diego · University of Colorado Anschutz Medical Campus · UW Medicine School of Medicine · UNM Health Sciences · Project ECHO