Bateman Horne Center's Approach to Clinical Care for ME/CFS



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Marmot



CLINICAL CARE GUIDE

Managing ME/CFS, Long COVID, & IACCs

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MERC

IOM (NAM) 2015 ME/CFS Clinical Diagnostic Criteria

The IOM (now the National Academy of Medicine (NAM)) *demoted the term fatigue* and placed **impairment of function and PEM** as the leading diagnostic features.

Major Criteria (required for diagnosis):

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 (ANS dysfunction)

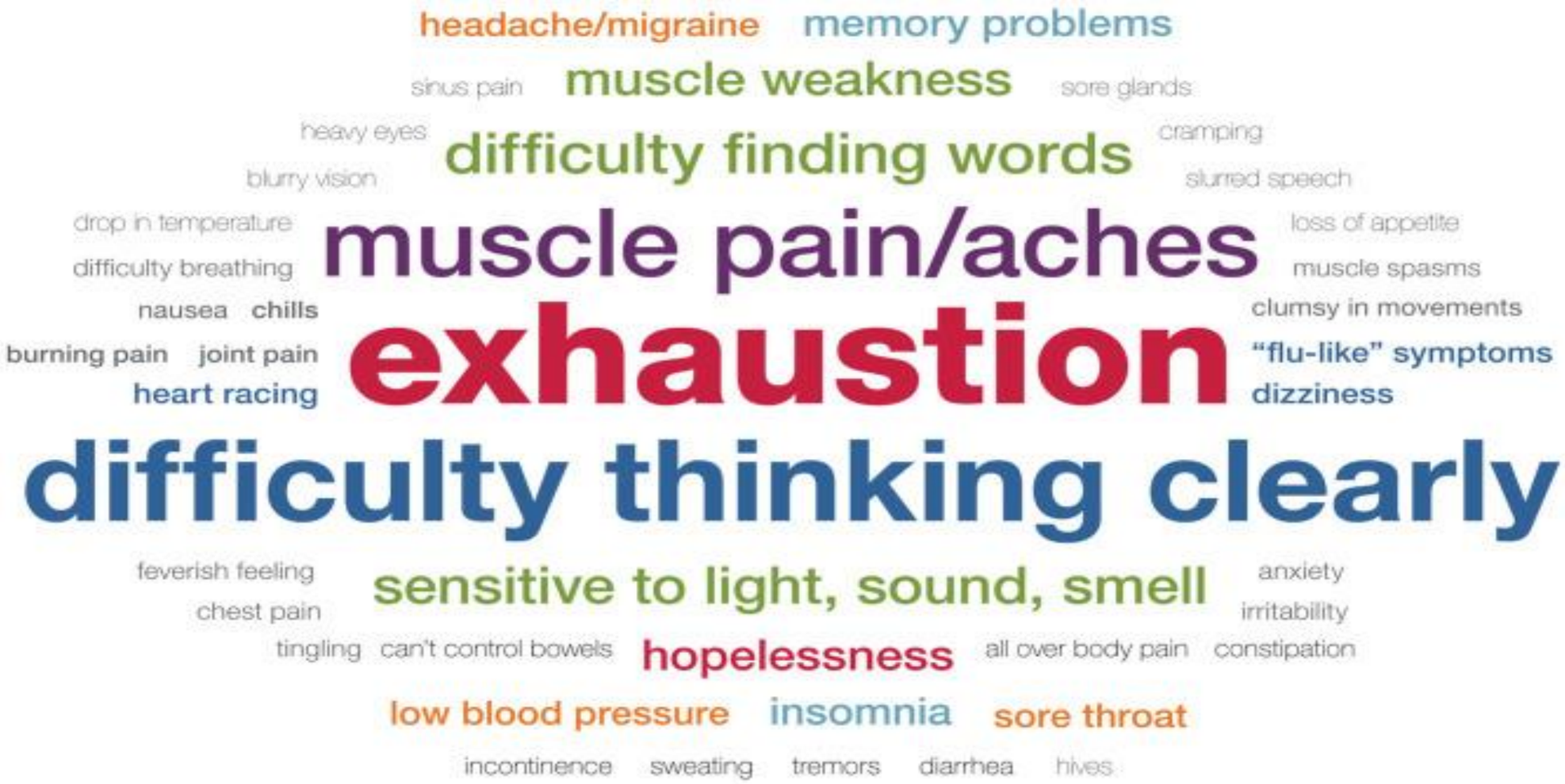
***Must be moderate-severe and present >50% of time**

Additional Common Features of Illness in the ME/CFS population:

- **Chronic pain** (headache, muscle and joint aches, hyperalgesia, central sensitivity)
- **Immune/inflammatory manifestations** (allergy, inflammation, chemical sensitivities)
- **Infection manifestations** (viral or atypical infections, sore throat, tender lymph nodes, low grade fevers)
- **Neuroendocrine manifestations –** HPA Axis dysregulation

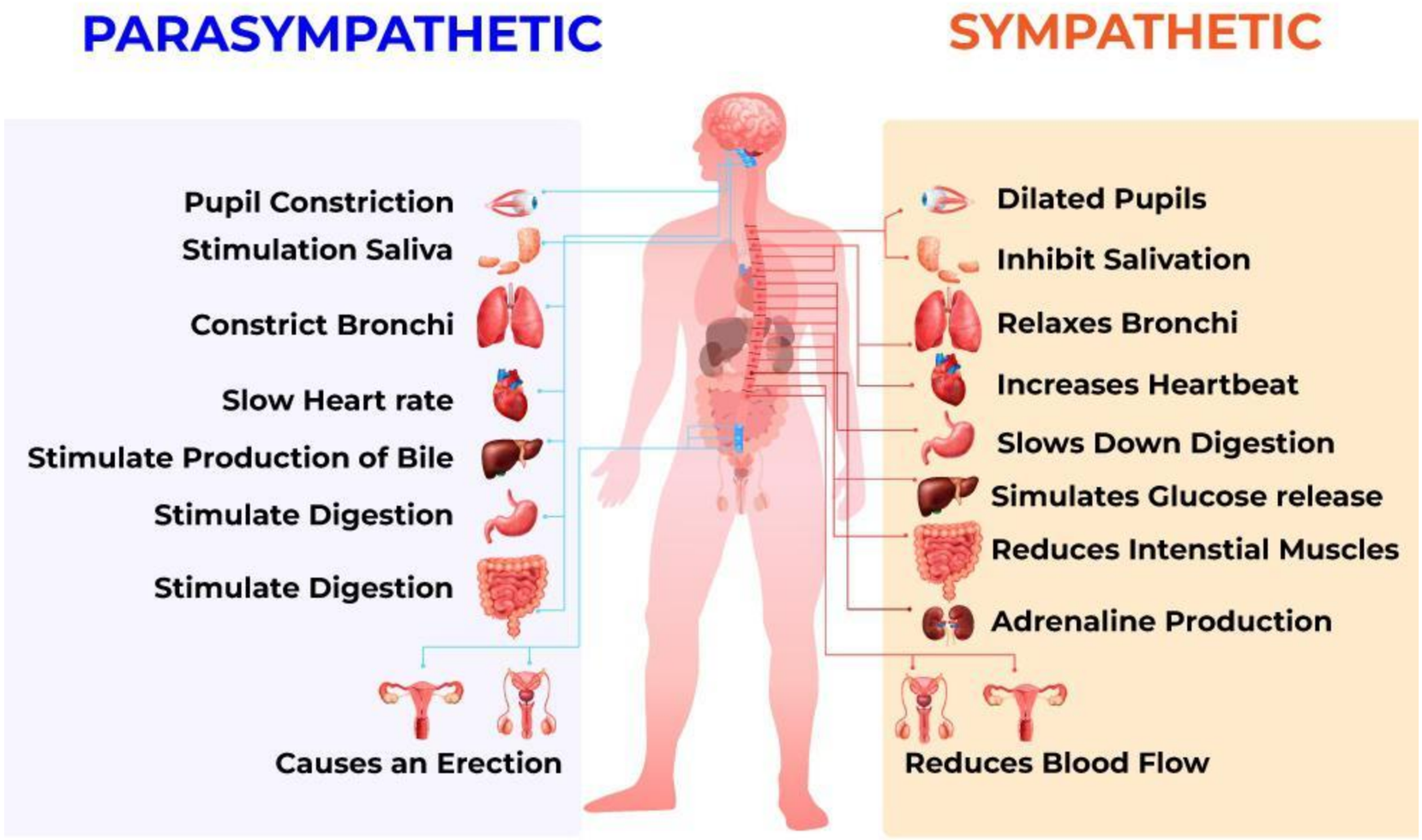
Beyond Myalgic Encephalomyelitis: Redefining an Illness. Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb 10. ISBN-13: 978-0-309-31689-7ISBN-10: 0-309-31689-8

The Experience of PEM



https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7530890/ Stussman B, Williams A, Snow J, ... et al.
Characterization of Post-exertional Malaise in Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.
Front Neurol. 2020 Sep 18;11:1025. doi: 10.3389/fneur.2020.01025. PMID: 33071931; PMCID: PMC7530890.

Autonomic Nervous System



Dysautonomia – often the low hanging fruit

ASSESS

Listen for history that suggests dysautonomia and orthostatic intolerance

10-Minute NASA Lean Test

Orthostatic Intolerance Questionnaire

COMPASS 31questionnaire – dysautonomia symptoms

Cognitive function

Heart Rate Variability and Resting Heart Rate trends

Sleep - Deep sleep trends, types and causes of sleep disruption



TREAT

Vascular volume support and vascular compression

Heart Rate and BP Management

Improve blood flow back to the heart and cerebral perfusion

Disrupted sleep – autonomic dysfunction, neuroinflammation, pain, MCAS

Vagal nerve stimulation - mediation, resonant breathing, neuroplasticity programs. *These techniques help to stimulate the parasympathetic nervous system*.

Mast Cell Activation Syndrome (MCAS)



ASSESS

Listen for symptoms of and screen patients for MCAS

- Symptom screen – multi-system involvement
- Laboratory evaluation – low sensitivity so frequently negative

Have a low threshold for suspicion for MCAS

Reassess frequently – this can begin to emerge, especially after PEM

Listen for MCAS symptoms as part of their PEM symptoms



TREAT

Educate patient to avoid triggers

Try empiric therapy – often diagnostic

Start one therapy at a time.

Consider use of compounded medications as much as possible – reduces excipient reactions.

Establish strategies for MCAS flares

Involve a trusted allergist/immunologist as needed

Pain

Pain in infection-associated chronic conditions (IACCs) such as ME/CFS, Long COVID, fibromyalgia (FM), and hypermobility syndromes arise from a complex interplay of neuroinflammation, autonomic dysfunction, impaired pain modulation, and musculoskeletal instability.

Types of Pain

- Widespread body pain, diffuse and moves – think FM
- Nerve pain – burning, tingling, numbness – think SFPN/FM
- Joint pain, subluxations, dislocations – think hypermobility
- Treatment resistant/intermittent pressure headaches – think hypermobility, venous congestion syndromes.

Pain (cont.)

ASSESS

- Fibromyalgia
  - 2016 ACR Fibromyalgia Questionnaire
  - Tender point +11/18 required
- Small Fiber Polyneuropathy – primarily a clinical diagnosis but can get skin bx, QSART test
- Hypermobility/CTD
- Imaging and other diagnostics as appropriate for the pain presentations

TREAT

- Pain reduction interventions
  - Treat what can drive pain
    - Pacing and PEM avoidance is key!
    - Improve autonomic function – fluids, compression, dysautonomia treatment
    - Manage MCAS – antihistamines, mast cell stabilizers
    - Optimizing sleep – Low dose TCAs, melatonin, dysautonomia treatment,
  - Address central sensitization – LDN, TCAs, SNRIs, antiseizure agents/GABA analogs – gabapentin & pregabalin
  - Utilize standard pain medications
  - Refer to pain management as appropriate

Hypermobility/Connective Tissue Disorder

Presentation

- Musculoskeletal Manifestations – joint pain, subluxations, dislocations, overuse injuries
- Autonomic Dysfunction & Dysautonomia
- MCAS
- Frequent headaches – base of skull, pressure, positional, worse with PEM, unresponsive to usual h/a medications

ASSESS

- Beighton Score assesses for hypermobility
- Brighton Criteria – Used to diagnose hEDS
- Five-point questionnaire for joint hypermobility
- Genetic testing for CTD – no genetic markers for hEDS but testing will eval for other genetic variations.
- Brain, spinal, and venous imaging as indicated

TREAT

- Aggressive management of PEM, Dysautonomia and MCAS to reduce inflammation
- Pain management
- Have PT evaluate to aid in diagnosis and management
- Refer to orthopedics, neurology, vascular and/or neurosurgery as indicated

Referrals

- Identify trusted referral sources for these patients.
- Be clear as to why you are referring. Many specialists will deny referrals if they think you want them to manage LC or ME/CFS.
  - Ask for evaluation of specific issues
  - Rule out possible concerns
  - Specific testing or treatments
- Most common referrals we make
  - **Physical Therapy –** make sure PT understands about PEM or they can do more harm than good.
    - Reconditioning with PEM in mind
    - Hypermobility evaluation and management
    - Provide strategies for pacing and exertional recovery
    - Pelvic Floor PT can help with core strengthening and urogyn/tethered cord issues
  - **Occupational Therapy –** can be immensely helpful with more severely ill patients and with pacing within the home, life, etc.
  - **Speech Therapy –** Communication Specialists can diagnose and treat disorders of communication and cognition, as well as voice, speech, and swallow dysfunction. Can help with cognitive processing and memory.
  - **Allergy/Immunology –** Evaluate for and manage more complex immune issues, prescribe omalizumab for MCAS.
  - **Neurocognitive Specialist** for cognitive testing – primarily for disability but also in helping with cognitive processing and memory.

Referrals (cont.)

- **Neurology** – advanced w/u for unusual neurological findings, may be helpful in evaluation and treatment of increased intracranial pressure and head/neck venous congestion syndromes, other headache management.
- **Pain Specialist** – pain management interventions, Stellate Ganglion Blocks
- **Behavioral and Mental Health** –can be particularly helpful with processing medical and grief trauma, along challenges associated with chronic illness and chronic pain.
- **Cardiology** – for more advanced w/u, certain prescriptions

Adapting approach to care



- Strategic and flexible approach
- Partnership with the patient
- Expectations of cure vs management of a chronic illness – clinician and patient
- Medication strategies
- Clinician Comfort Zone with non-FDA approved strategies
- Frequent visits, utilizing Telehealth when possible
- Assessing needs for accommodations at work and school and potential need for disability.
- Assess needs for and access to social services, mental health services, and community support.

Patient Case - 31 yro woman

- Initial COVID infection 11/2020.
  - PMH: Migraines, Endometriosis, Iron Deficiency Anemia

- Presented at BHC 12/2021 with diagnosis of POTS and 6 months pregnant
  - Eval by cardiology, neurology, and GI
  - Treating POTS with aggressive H20 and dietary sodium and PRN propranolol, compression clothing.
  - Iron supplementation

- BHC work up
  - Met 2015 IOM criteria for ME/CFS with moderate to severe symptoms 50-75% of the time.
    OI was 75-100% of the time.
  - 10-min NLT positive for OI and very symptomatic with venous pooling, head pressure/headache, SOB, increased restlessness.
  - Lab evaluation prior had been extensive and was essentially normal
  - Pushed more aggressive sodium supplementation with electrolyte powders in addition to dietary. This helped.
  - Educated on pacing and PEM.
  - Was doing fairly well secondary to expanded vascular volume from pregnancy.

- Post-partum
  - Did well for the first 2 months but then started experiencing more “bone crushing fatigue”, dysautonomia, WSP, headaches - different from her prior migraines.
  - Repeat NLT not that different from the previous NLT.
  - Nursing her infant so medication options were very limited. Focused oral hydration/sodium and compression.
  - MCAS symptom screen was more positive now w/elevated histamine level. As she was nursing she wanted focus on low inflammatory/histamine diet and avoiding triggers as much as possible.

- **Lost to f/u for 14 months but pt reported she managed okay. Periods of PEM with recovery to baseline.**

- Returned to BHC 11/2023 with worsening and persistent PEM, brain fog, dysautonomia, unstable BP/HR, new MCAS diagnosis, sleep disturbances, widespread pain of FM, worsened IDA.
- Cardiology managing the IDA and iron infusions x3. Didn’t help that much.
- Self-referred to geneticist for hypermobile EDS evaluation who confirmed the diagnosis
- Repeat COVID infection 6/2024

Treatment Focus

- **Pacing and PEM avoidance** was top priority.
- **Dysautonomia** -Focused on managing dysautonomia and OI
  - OI - NLT more stable, +17 bpm, BP stable, PP/SBP < 25% (mild), symptoms of venous pooling, lightheaded.
  - Dysautonomia – poor sleep, anxiety, tremors, sensory sensitivity
  - Vascular volume support, vasoconstriction, HR control
  - Sleep management
- Diagnosed with **MCAS** per allergist and started on MCAS regimen – H1/H2 blocker and mast cell stabilizers.
- **Classical EDS** suspected per geneticist, genetic testing pending
- Pt focused on MCAS but not pacing → severe PEM November 2024, nearly bed bound.
  - Severe PEM management of IV fluids, controlling dysautonomia w/benzodiazepine, beta blockers, dextromethorphan, vagal nerve stimulation techniques, and aggressive rest and pacing.
  - Pt began to appreciate pacing and PEM as the foundation of management.
  - Took 1 month to stabilize, has gained control and function over the last 4 months with careful PEM avoidance and management of co-morbid conditions.

THANK YOU!