HEALTH
UNIVERSITY OF UTAH

UNRAVELING THE COMPLEXITY OF CHRONIC PAIN AND FATIGUE

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SESSION #3

Effective use of
evidence-based clinical diagnostic criteria
and symptom management approaches
to improve patient outcomes

THE RATIONALE FOR USING EVIDENCE-BASED CLINICAL DIAGNOSTIC CRITERIA

- **Widespread pain amplification disorders**
  - 1990 ACR fibromyalgia
  - 2016 ACR fibromyalgia criteria
- **Orthostatic Intolerance Disorders**
  - POTS, NMH, OH, CAN, NOH…
- **ME/CFS 2015 IOM/NAM criteria**

PAIN AMPLIFICATION DISORDERS
EX: FIBROMYALGIA ACR 1990

Chronic (>3 months)

Widespread Pain (pain in 4 quadrants of body & spine)

and **Tenderness** (>11/18 tender points)

PAIN= stiffness, achiness, sharp shooting pains…tingling and numbness…light and sound sensitivity…in muscles, joints, bowel, bladder, pelvis, chest, head…

FATIGUE, COGNITIVE and SLEEP disturbances

are described in Wolfe et al but were not required for dx.

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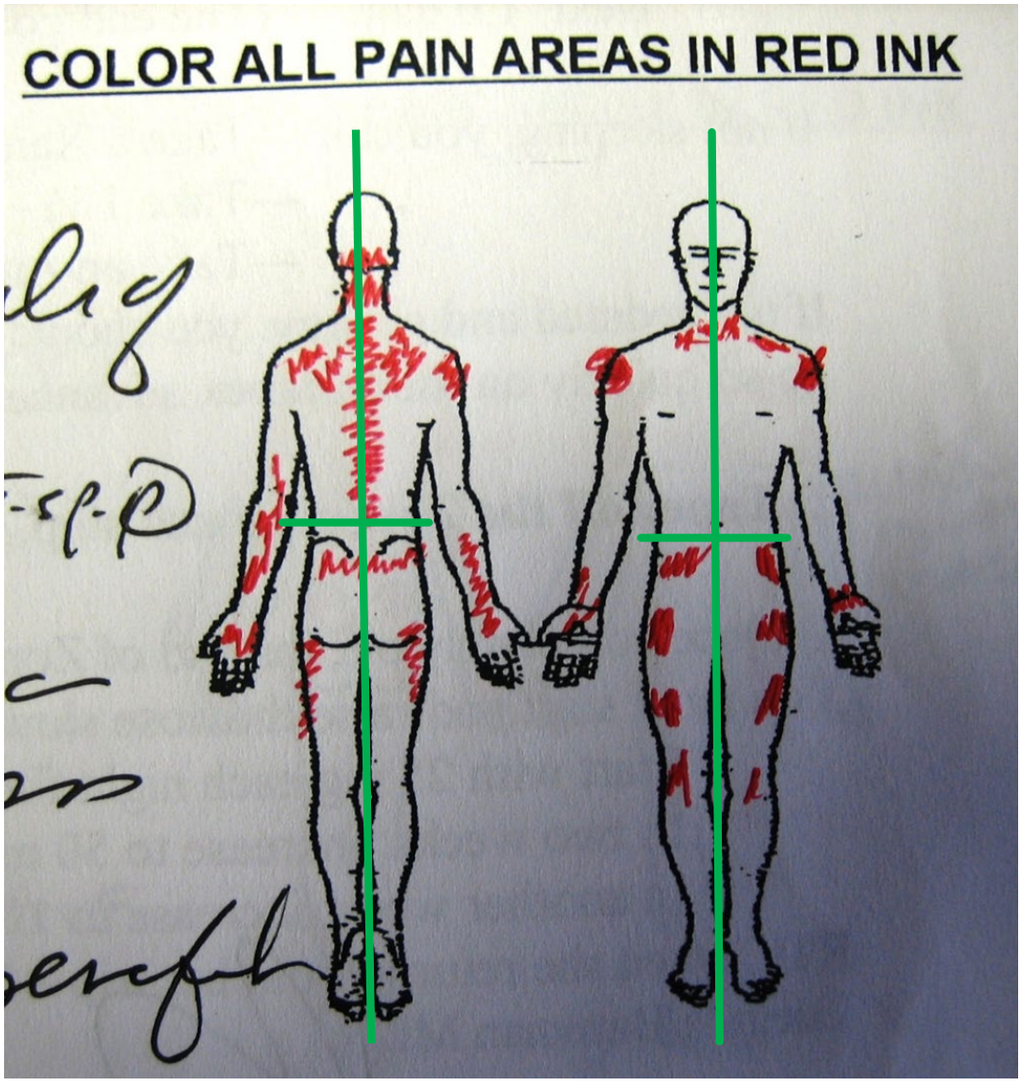
Wolfe F, et al. The American College of Rheumatology 1990 criteria for the classification of fibromyalgia: report of the Multicenter Criteria Committee. Arthritis Rheum 1990;33:160–72

FIBROMYALGIA 1990 ACR CRITERIA



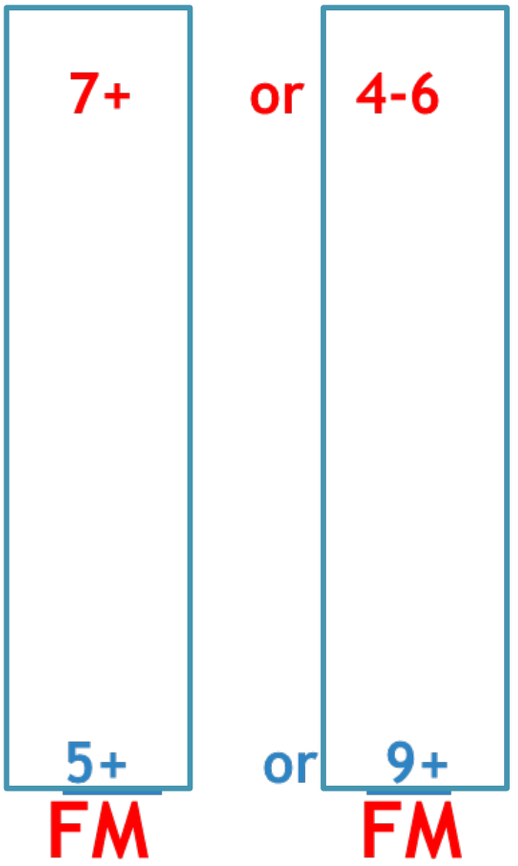
Pain in four quadrants and the spine

FIBROMYALGIA 2016 ACR CRITERIA

1) Widespread PAIN index (WPI)
(0-19 points—in 4 of 5 regions)

2) Symptom Severity Score (SSS):
0=none, 1=mild, 2=mod, 3=severe

Chronic fatigue	(0-3)
Unrefreshing sleep	(0-3)
Cognitive complaints	(0-3)
Headaches	(0-1)
Lower abd pain	(0-1)
Depression	(0-1)
Max SSS = 12	



> 3 months in duration and without other apparent explanation

2016 Revisions to the 2010/2011 fibromyalgia diagnostic criteria, Seminars in Arthritis and Rheumatism. Volume 46, Issue 3. www.semarthritisrheumatism.com/article/S0049-0172(16)30208-6

FM IS OFTEN FOUND COMORBID WITH OTHER CONDITIONS

Examples of the prevalence of fibromyalgia by 1990 criteria among various groups:

General population → **2%**
Women → **4%**
Healthy Men → **0.1%**
IM & Rheum clinics → **15%**
IBS → **13%**
Hemodialysis → **6%**
Type 2 diabetes → **15-23%**
Behcet's syndrome → **80%**
Bipolar Disorder → **21%**

Prevalence of fibromyalgia and co-morbid bipolar disorder: A systematic review and meta-analysis. J Affect Disord. 2015 Dec 1;188:134-42. doi: 10.1016/j.jad.2015.08.030. Epub 2015 Sep 2. Kudlow PA1, et al.

Prevalence of fibromyalgia in general population and patients, a systematic review and meta-analysis. Heidari F et al. Rheumatol Int. 2017 Apr 26. doi: 10.1007/s00296-017-3725-2.

COMMON MANIFESTATIONS OF SENSORY AMPLIFICATION DISORDERS (FM)

- Muscle and joint pain and tenderness
- Migraine and tension headaches, TMJ/TMD
- Paresthesia (numbness and tingling)
- Restless legs syndrome
- Irritable bowel syndrome, IBS-D, IBS-C
- Irritable bladder, interstitial cystitis, painful menstruation, pelvic pain, vulvodynia
- Sensory (light, noise, olfactory, chemical, etc) sensitivities
- Sicca syndrome (dry eyes and mouth)
- Heart palpitations, sinus tachycardia, low HRV

UNCOMPLICATED FM RESPONDS TO BASIC TARGETED INTERVENTIONS

- Restorative sleep
- Reduction of pain using meds helpful for neuropathic pain or musculoskeletal disorders
- Mental health support
- Low impact exercise and strength training

Improved symptoms and function are the goal. Symptoms can easily flare without ongoing behavioral and medical management.

OPIOIDS

- Opioids used daily for pain amplification syndromes become ineffective due to tolerance and can INCREASE hyperalgesia over time
- It is particularly difficult for opioid-dependent patients with pain amplification syndromes to reduce their doses or taper off opioids due to increased hyperalgesia during withdrawal

Opioid Use in Fibromyalgia: A Cautionary Tale. Don L. Goldenberg, MD, et al. Mayo Clinic Proceedings. May 2016. Vol 91, Issue 5, Pgs 640-648.

OFF LABEL DISCUSSION: **LDN**

naltrexone hydrochloride is an opioid receptor antagonist, FDA approved for treatment of alcohol and opioid dependence (50 mg)

Low dose naltrexone (LDN): (1-5 mg) may

- paradoxically decrease pain due an increase in the release of endogenous opioids with transient blockade
- calm microglial cell activation in the CNS (anti-inflammatory or neuroinflammatory agent)

LDN provides a viable alternative to use of opioids in patients with hyperalgesia and allodynia.

LDN is under study and used for many conditions of inflammation and neuroinflammation, including FM, SFPN, and many others

LDNresearchtrust.org

Low-dose naltrexone for the treatment of fibromyalgia: findings of a small, randomized, double-blind, placebo-controlled, counterbalanced, crossover trial assessing daily pain levels. Younger J1, Noor N, McCue R, Mackey S. Arthritis Rheum. 2013 Feb;65(2):529-38. doi: 10.1002/art.37734

The use of low-dose naltrexone (LDN) as a novel anti-inflammatory treatment for chronic pain. Younger J, Parkitny L, McLain D. Clin Rheumatol. 2014 Apr;33(4):451-9. doi: 10.1007/s10067-014-2517-2. Epub 2014 Feb 15. Review.

SMALL FIBER POLYNEUROPATHY (SFPN)

It is possible that 40-50% of adults and 90% of adolescents meeting FM criteria have a SFPN

Where are these small nerve fibers? (C-fibers)

- **Sensory nerves** and **autonomic nervous system (post-ganglionic) nerve fibers**
  - Sensory nerves to the skin, heart, organs
  - Efferent nerves to smooth muscle (including constriction, dilation of blood vessels)

Does knowing this change your perspective and approach?

Oaklander, AL Multiple publications on Pubmed

SELECT **SFPN** SYMPTOMS

- SENSORY
  - cold-like pain, tingling/needles, burning pain
  - transient electric shock–like pain
- Autonomic N.S.
  - dry eyes, dry mouth (Sicca Syndrome)
  - postural lightheadedness, fainting (OI)
  - abnormal excess sweating
  - nausea, vomiting, diarrhea, constipation, low appetite
  - difficulty with urinary frequency, nocturia, and/or voiding

SFPN: SMALL FIBER POLYNEUROPATHY

- Normal or near normal physical and neurologic examination [!]
  - Coordination, motor, and reflex exam will be **normal**.
  - Light touch, vibratory sensation, and proprioception may be **normal**
  - May have **decreased pinprick, thermal (heat), vibratory sensation**, or hyperalgesia in the affected region
  - **EMG** and **nerve conduction** may be **normal**
- Abnormal skin bx: The sensitivity (78%–92%) and specificity (65%–90%) of skin biopsy for diagnosing a small fiber neuropathy is fairly high across all studies
- Seek to find any **treatable/reversible causes** of SFPN, and there are many

Objective evidence that small-fiber polyneuropathy underlies some illnesses currently labeled as fibromyalgia. Oaklander AL, et al. Pain. 2013 Nov;154(11):2310-6. doi: 10.1016/j.pain.2013.06.001. Epub 2013 Jun 5.

SFPN AND AUTONOMIC DYSREGULATION

- 32 year old woman with chronic fatigue, low function, severe migraines, widespread pain amplification, depression and dizziness unresponsive to standard therapies for any of the above. Everyone had given up on her. **SKIN BX= +SFPN**

- Take a look at her orthostatic testing→

FEMALE AGE 32: 10 MIN NASA LEAN TEST

Supine rest (10-15 min in quiet room):

Supine vital signs: BP: 116/60 Pulse: 85 **PULSE PRESSURE: 56** (SBP-DBP)

Standing straight with shoulder blades against the wall and feet 6" from the wall

Standing 0 minute BP:	104/80	Pulse: 85	
Standing 2 minute BP:	96/70	Pulse: 116	
Standing 4 minute BP:	98/78	Pulse: 120	*Arms "feel like they are tingling"*
Standing 6 minute BP:	91/73	Pulse: 125	*Lightheaded and dizzy (as if "spinning")*
Standing 8 minute BP:	96/74	Pulse: 122	*Increased lightheadedness, nausea*
Standing 10 minute BP:	93/80	Pulse: 120	*Increased "electrical buzz"*

PULSE PRESSURE: 13

Summary:

SBP -27 mmHg meets criteria for **systolic orthostatic hypotension** (> 20 mmHg)

HR +41 bpm meets criteria for **Postural Orthostatic Tachycardia Syndrome (POTS)**
(OI symptoms plus >30 bpm increase for adults)

Pulse Pressure/SBP should be >25%. This case: PP/SBP at 10 min is 14%

ORTHOSTATIC INTOLERANCE (OI)

- Orthostatic intolerance (OI) is the development of symptoms during upright posture that are relieved by reclining

- Orthostatic intolerance is:
  - Measurable (heart rate, blood pressure)
  - Treatable or at least manageable

OI can exist in someone who has low, normal or high blood pressure in the seated position

ORTHOSTATIC INTOLERANCE (OI)

- OI can be caused by drugs and acute or chronic medical or neurologic conditions
- **Chronic OI** may be related to pathology involving of the autonomic nervous system
  - Toxic causes (e.g. vincristine chemotherapy)
  - Autoimmune or CTD (e.g. Sjogrens, **hEDS**)
  - Post-viral, post-infection syndromes
  - Small fiber neuropathies
  - Mast Cell Activation Syndrome

MEASURING OI

- Tilt Table test (Gold Standard but not always available or standardized)
- Brief orthostatic tests are inadequate
  - 1, 3, 5 min measures of BP and HR standing*
- 10 min NASA Lean Test (rest supine/lean)
  - Practical and valuable in the office setting
- FitBit, AppleWatch or other HR tracking devices can track heart rate as an indicator of exercise effort, and are also an indirect measure of orthostatic intolerance

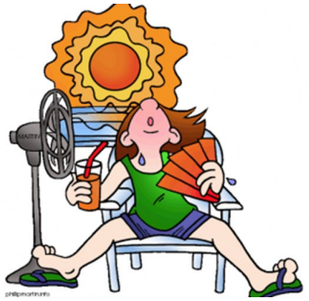
*Low Sensitivity of Abbreviated Tilt Table Testing for Diagnosing Postural Tachycardia Syndrome in Adults With ME/CFS. van Campen CLMC, Rowe PC, Visser FC. Front Pediatr. 2018 Nov 16;6:349. doi: 10.3389/fped.2018.00349. eCollection 2018. PMID: 30505831

SYNDROMES OF ORTHOSTATIC INTOLERANCE

- **Orthostatic hypotension**, either Systolic OH (a drop of 20 pts or more) or Diastolic OH (a drop of 10 pts or more)
- **Postural Orthostatic Tachycardia Syndrome (POTS)** Varied definitions, but basically an increase of 30 bpm in adults, or 40 bpm in adolescents, with OI symptoms
- **Neurally Mediated Hypotension (NMH)** or similar descriptive terms of sudden syncope during orthostatic testing

TREATMENT OF OI SYNDROMES

- The substantial Evidence-Based literature for **POTS, OH and NMH** can be applied to most OI syndromes
- OI can be worsened by
  - Becoming overheated or dehydrated
  - Prolonged bedrest and deconditioning
  - Medications
  - Prolonged standing or sitting with feet on floor



Vanderbilt University Autonomic Dysfunction Center
https://ww2.mc.vanderbilt.edu/adc/4787

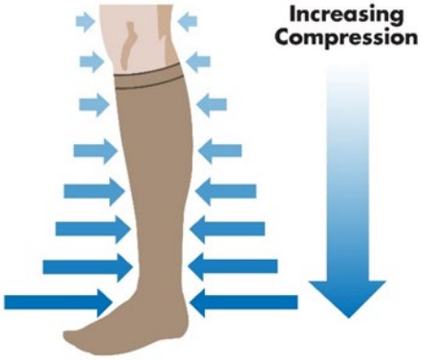
http://dysautonomiainternational.org/

PRACTICAL INTERVENTIONS FOR OI

Increase intravascular volume

- Consume extra **water/fluids** to expand blood volume: >1 gallon or >2 liters daily as a foundation
- Increase **salt intake** to retain water in the circulation and tissues. Must match the fluid intake. 2-5 gms daily (1/2 to 1 tsp)
  - MONITOR BP
- **Fludrocortisone 0.1 mg** in the am (consider potassium supplementation) Indicated for OH
- Rapid water ingestion (16 oz) helps reduce OI within 15 minutes (chugging) and lasts an hour

PRACTICAL INTERVENTIONS FOR OI



External compression or internal constriction of blood vessels

- Compression socks, pants, sleeves, abdominal binder
- Midodrine, a peripheral alpha-1 receptor agonist (stimulates the receptor). Indication: OH
  - Alpha-1 adrenergic receptors are in blood vessels of the skin, GI, GU and brain (but midodrine doesn't cross the blood brain barrier). Midodrine constricts arterioles and veins and raises blood pressure.
  - Short half-life requires 3x/day dosing, 10 mg every 3-4 hours, for continuous benefit.
  - Goosebumps, scalp tingling, cold hands and feet are common
  - Monitor for supine hypertension

PRACTICAL INTERVENTIONS FOR OI

Control an abnormally rapid heart rate response or orthostatic stress

- Low dose beta blockers: propranolol (10-20 bid), metoprolol (12.5-50 mg q hs), atenolol (12.5-25 mg)
  - Beta blockers can slow the HR too much, drop BP further, or block B2 receptors in the lung needed for asthma rescue with bronchodilators (B2 agonists). Varied indications based on the drug, broadest for propranolol.
- Clonidine (off label use) especially in combination with anxiety or insomnia
- Others…

PRACTICAL INTERVENTIONS FOR OI

- Pyridostigmine (off label use—FDA approved for myasthenia gravis) raises acetylcholine, the neurotransmitter at the neuromuscular junction, but also much of the parasympathetic n.s. and at postganglionic sympathetic n.s. synapses. **15-60 mg q 4-6 hours - or - ER 180 mg q am.**
- A clinical trial is underway to understand the mechanisms better
  - The Exercise Response to Pharmacologic Cholinergic Stimulation in Preload Failure. ClinicalTrials.gov Identifier: NCT03674541
  - David Systrom, Brigham and Women's Hospital, Boston

Acetylcholinesterase inhibition improves tachycardia in postural tachycardia syndrome. Circulation. 2005 May 31;111(21):2734-40. Epub 2005 May 23. Raj SR1, Black BK, Biaggioni I, Harris PA, Robertson D

PRACTICAL INTERVENTIONS FOR OI

Improve the "muscle pump" of venous return

- Exercise with a goal to increase:
  - Muscular strength in legs and trunk/core
  - General circulation from light aerobic activity

PRACTICAL INTERVENTIONS FOR OI

Exercise tips

- Drink 500 cc cold water 15-20 minutes prior to exercise
- Wear compression socks, pants, abdominal binder
- Sit or lie down during exercise or movement activities
- Sit or lie down, elevate feet and hydrate immediately after exercising
- Work gradually into the cardio (walking) by doing very short bouts 2, 5, 10, 15 min. Avoid standing in place.
- Exercise in water! Easier on joints and low back. Cool water helps vasoconstriction. Warmer water helps widespread pain.
  - Hydrostatic pressure as water depth increases acts as "compression"
  - Swimming horizontal eliminates orthostatic stress

MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME (ME/CFS)

- In 2015 the Institute of Medicine (IOM), now the National Academy of Medicine (NAM), published evidence-based clinical diagnostic criteria for ME/CFS. www.ncbi.nlm.nih.gov/pubmed/25695122

- The report **"Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: Redefining an Illness,"** is intended improve clinical diagnosis and care and focuses on **common core features** of illness.

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb. The National Academies Collection: Reports funded by National Institutes of Health.

ME/CFS CLINICAL DIAGNOSTIC CRITERIA:

CORE criteria (required for diagnosis)

1) **Impaired function** manifest as fatigue persisting >6 months
2) **PEM: post exertional malaise***
3) **Unrefreshing sleep*** (a variety of sleep disturbances)
4) And either

- **Cognitive impairment*** and/or
- **Orthostatic intolerance/ANS dysfunction**

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

Other common but more variable features of illness:

- Pain (headache, muscle and joint aches, hyperalgesia, neuropathy)
- Immune manifestations (allergy, inflammation, sensitivities)
- Infection (symptoms viral reactivation or other infection sequelae)

www.ncbi.nlm.nih.gov/pubmed/25695122

ME/CFS CLINICAL DIAGNOSTIC CRITERIA:

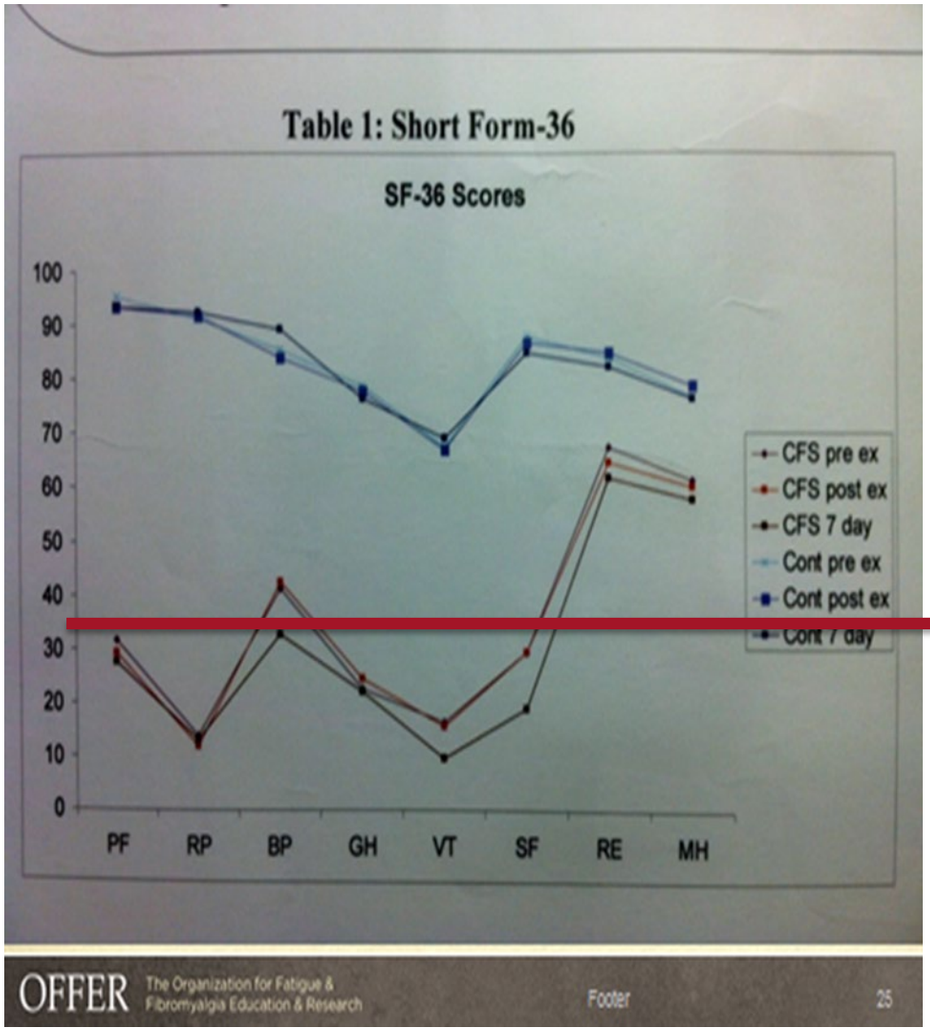
Describe a consistent clinical presentation or phenotype, but do not define the exact cause or underlying pathology. Many presenting with the ME/CFS phenotype are thought to have a post-infection syndrome with neurologic, metabolic and immune/inflammatory sequelae. It will probably prove to be more complicated than that…

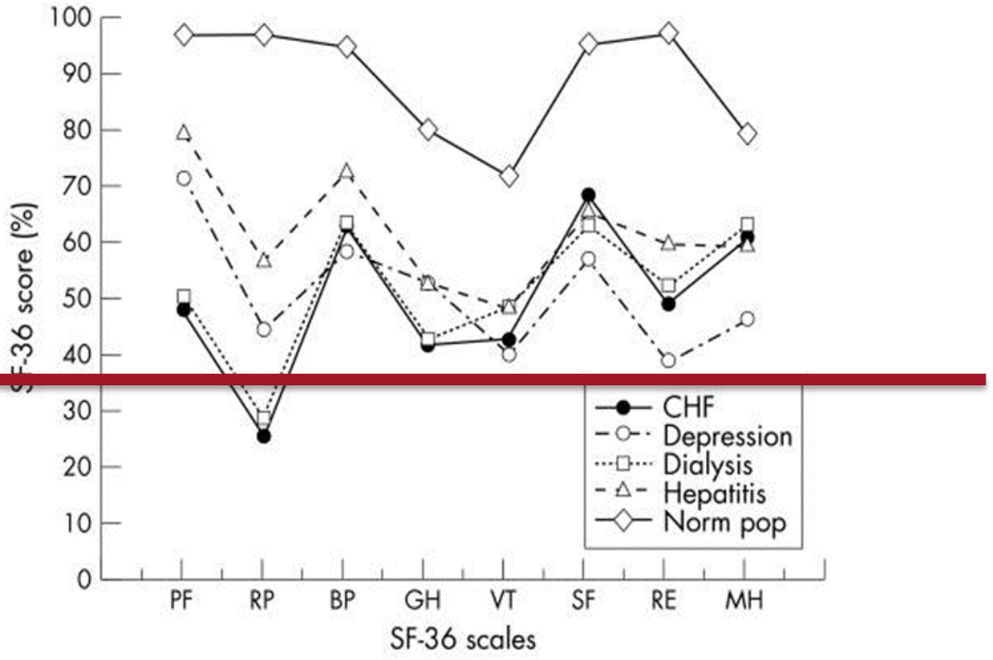
Many of the conditions addressed in Session 2 are common "comorbid conditions" in patients meeting FM or ME/CFS clinical diagnostic criteria: Small fiber neuropathies, migraine pathways, mast cell activation syndrome, hypermobile EDS, craniocervical instability and dysautonomias may be playing a role, as well as poorly defined auto-immune states (antibodies to adrenergic or muscarinic receptors).

www.ncbi.nlm.nih.gov/pubmed/25695122

CORE: IMPAIRED FUNCTION WITH FATIGUE

RAND-36/SF-36 scores are profoundly lower in ME/CFS than other chronic diseases, and show relatively preserved MH.





Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. Juenger J. Heart. 2002 Mar;87(3):235-41

IMPAIRED FUNCTION WITH FATIGUE

During invasive Cardiopulmonary Exercise Testing (iCPET) ME/CFS subjects display

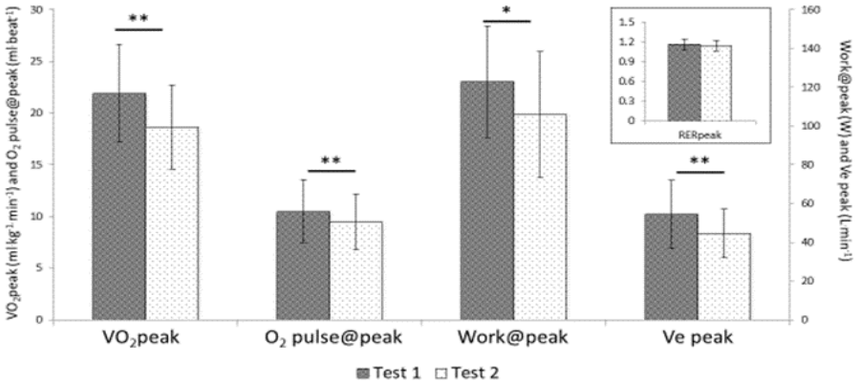
- Preload failure (inadequate ventricular filling)
- Impaired oxygen extraction

Unexplained exertional intolerance associated with impaired systemic oxygen extraction. Melamed KH, Santos M, Oliveira RKF, Urbina MF, Felsenstein D, Opotowsky AR, Waxman AB, Systrom DM. Eur J Appl Physiol. 2019 Oct;119(10):2375-2389. doi: 10.1007/s00421-019-04222-6. Epub 2019 Sep 6. PMID: 31493035

David M Systrom, MD, "Pathophysiology and treatment of exertional intolerance in ME/CFS: insights from cardiopulmonary exercise testing" NIH Accelerating Research on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Meeting. April 3, 2019.

ME/CFS subjects are unable to replicate CPET testing two days in a row because doing the test on day 1 impairs capacity to Function on day 2.

Figure 1: ** 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.

IMPAIRED FUNCTION WITH FATIGUE

Several peer reviewed publications suggest significantly altered cellular metabolism

- **Metabolic features of chronic fatigue syndrome**.
  Robert K. Naviaux et al. PNAS. September 13, 2016 vol. 113 no. 37 E5472-E5480
- **Metabolic profiling indicates impaired pyruvate dehydrogenase function in myalgic encephalopathy/chronic fatigue syndrome**.
  Øystein Fluge ... Olav Dahl, Karl J. Tronstad. January 3, 2017 JCI Insight. 2017;1(21):e89376
- **Metabolic profiling of a myalgic encephalomyelitis/chronic fatigue syndrome discovery cohort reveals disturbances in fatty acid and lipid metabolism**.
  Germain A, Ruppert D, Levine SM, Hanson MR. Mol. BioSyst., 2017 Jan 31;13(2):371-379. doi10.1039/c6mb00600k

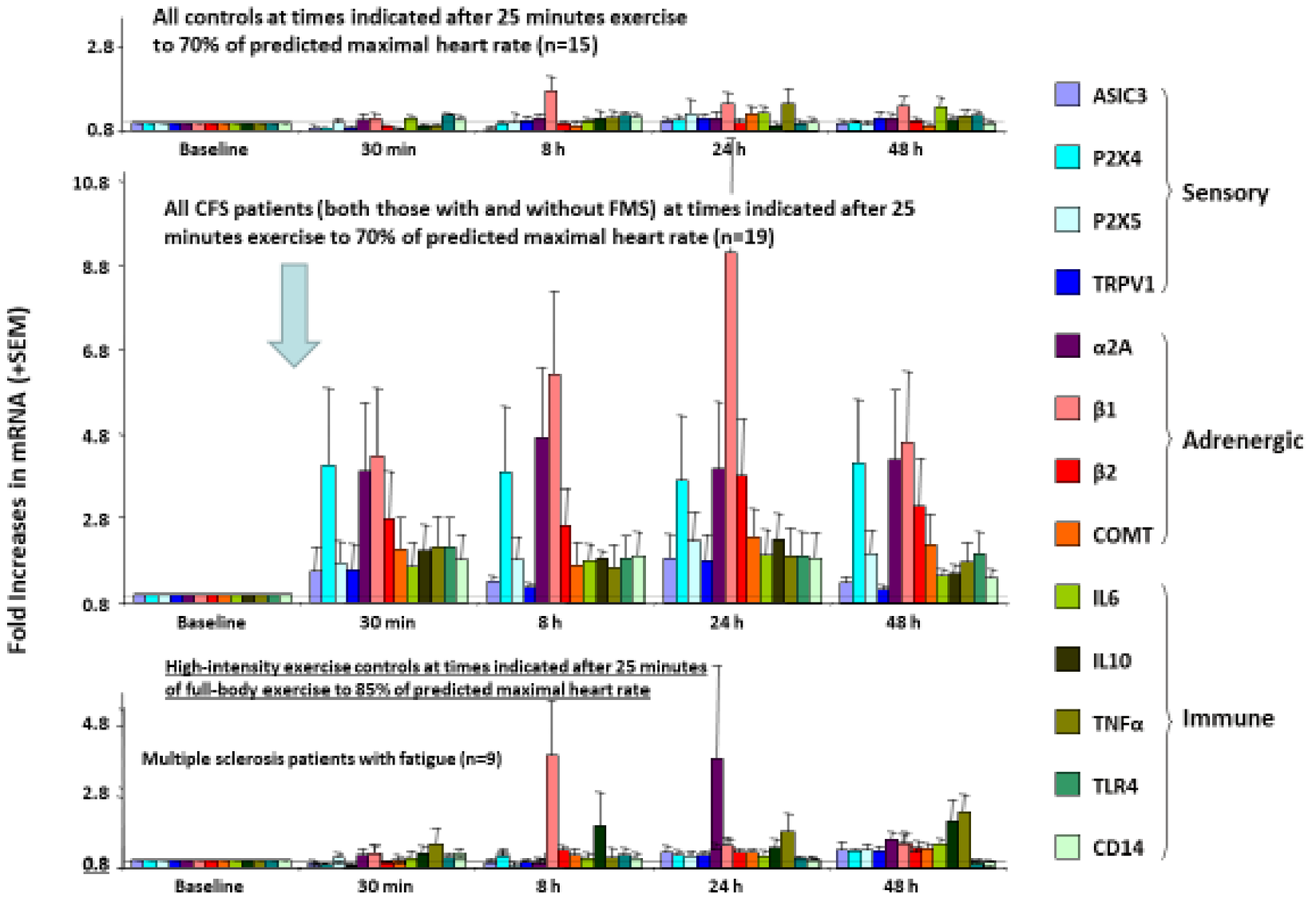
CORE: POST-EXERTIONAL MALAISE (PEM)

- Exceeding cellular energy capacity results in "payback" symptoms called Post Exertional Malaise or PEM
- PEM is physiologic and multisystem
- PEM is illness worsening

The key to ME/CFS management is to understand these physical and cognitive limitations, learn to "pace" all activity, and prevent severe or prolonged PEM.

CORE: POST EXERTIONAL MALAISE

Gene expression after an exercise challenge in a Utah study



Light A, et al. Journal of Pain. Nov 2010.

Moderate exercise increases expression for sensory, adrenergic, and immune genes in chronic fatigue syndrome patients but not in normal subjects. Light AR, White AT, Hughen RW, Light KC. J Pain. 2009 Oct;10(10):1099-112. doi: 10.1016/j.jpain.2009.06.003. Epub 2009 Jul 31. PMID: 19647494

IMPAIRED FUNCTION & PEM

The most important primary intervention for ME/CFS is activity management (**pacing**), which includes management of physical, cognitive, emotional and OI stress.

PACING is:

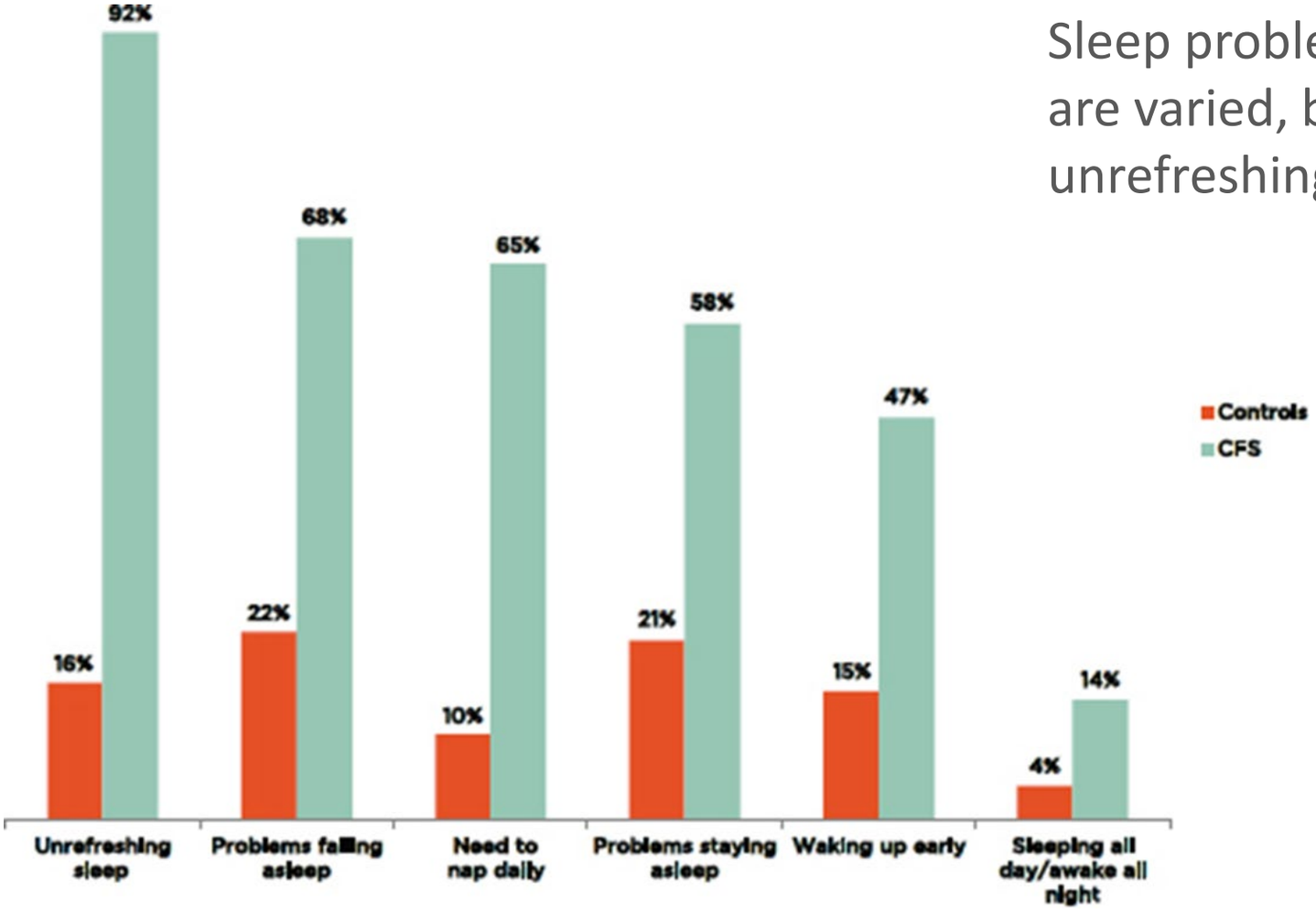
- Limiting activity to available energy
- Short activities spread out through the day
- Engaging in recovery behaviors between activities
  - Physical and cognitive rest. Supine position. Hydration.
- Avoidance of significant DEBT (PEM)
- An awareness that when debt accrues, it should be "paid off" asap and not allowed to accumulate
- Being mostly in a preventive, not rescue mode

IMPAIRED FUNCTION AND PEM

"Pacing" reduces the frequency and severity of PEM and improves both symptoms and function

- Ideally, engage in only the amount of activity that doesn't induce PEM in 24-48 hours
- The goal in pacing activity is feel "back to baseline" the following morning after sleep
- If PEM is induced, rest until it resolves
- Help patient develop a heightened sense of awareness about the threshold of relapse, and the consequences of pushing beyond it
- Help patient be less afraid---be more in charge

CORE: UNREFRESHING SLEEP



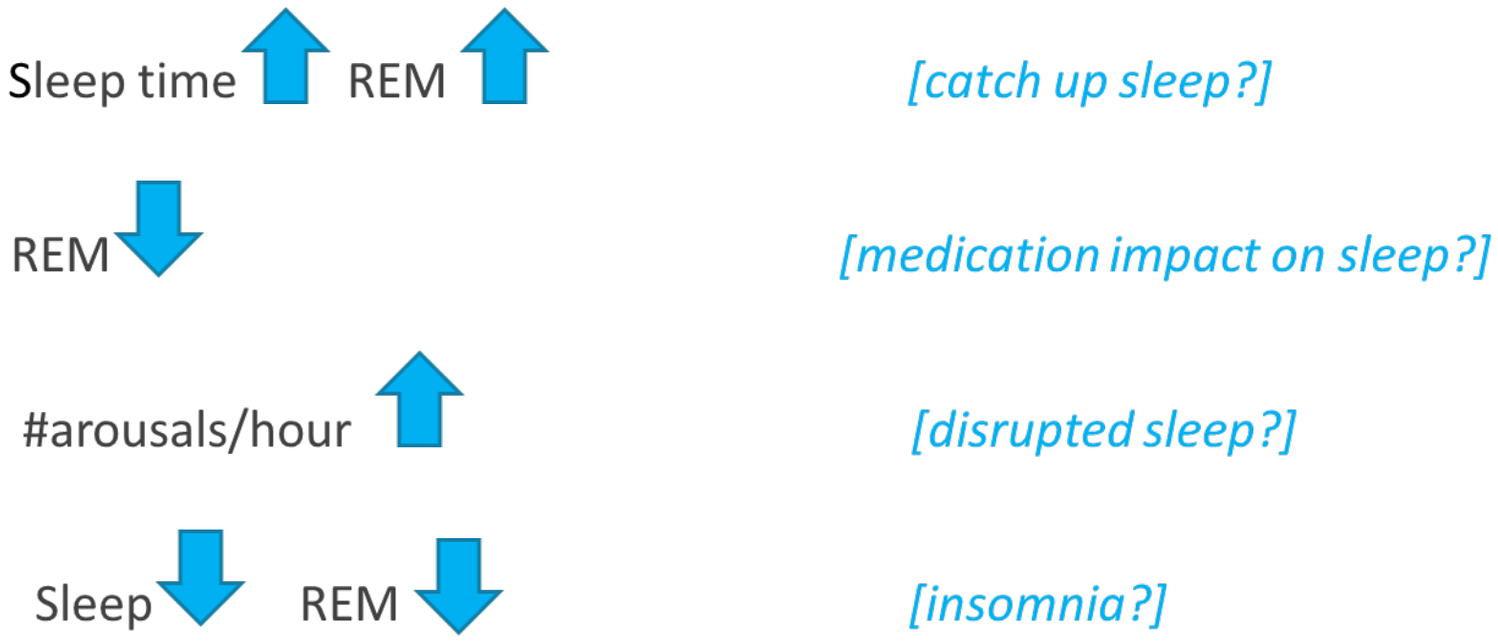
Sleep problems in ME/CFS are varied, but all result in unrefreshing sleep

FIGURE 4-2 Percentage of ME/CFS patients and healthy controls reporting sleep-related symptoms of at least moderate severity that occurred at least half of the time during the past 6 months. Jason et al., 2013b. IOM report 2015.

CORE: UNREFRESHING SLEEP

Polysomnography in 300 Dutch ME/CFS patients:
(those with primary sleep disorders were excluded)

Four types of sleep presentation (1 PSG):



Gotts ZM, Deary V, Newton J, Van der Dussen D, De Roy P, Ellis JG.
Are there sleep-specific phenotypes in patients with chronic fatigue syndrome? A cross-sectional polysomnography analysis. BMJ Open. 2013;3(6):e002999

CORE: COGNITIVE IMPAIRMENT

- ME/CFS cognitive impairment can be measured. The strongest evidence demonstrates **slowed information processing**. There are some data to support deficits in working memory and reduced attention*
- There is growing evidence of neuroinflammation in the brain of ME/CFS**

***Neural Consequences of Post-Exertion Malaise in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Brain Behav Immun. 2017 Feb 16. Cook DB1, Light AR2, Light KC2, Broderick G3, Shields MR4, Dougherty RJ4, Meyer JD4, VanRiper S4, Stegner AJ4, Ellingson LD5, Vernon SD6.**

****Neuroinflammation in Patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: An ^{11}C-(R)-PK11195 PET Study.** Nakatomi Y et al. J. Nucl Med. 2014 Jun;55(6):945-50. doi:10.2967/jnumed.113.131045. Epub 2014 Mar 24.

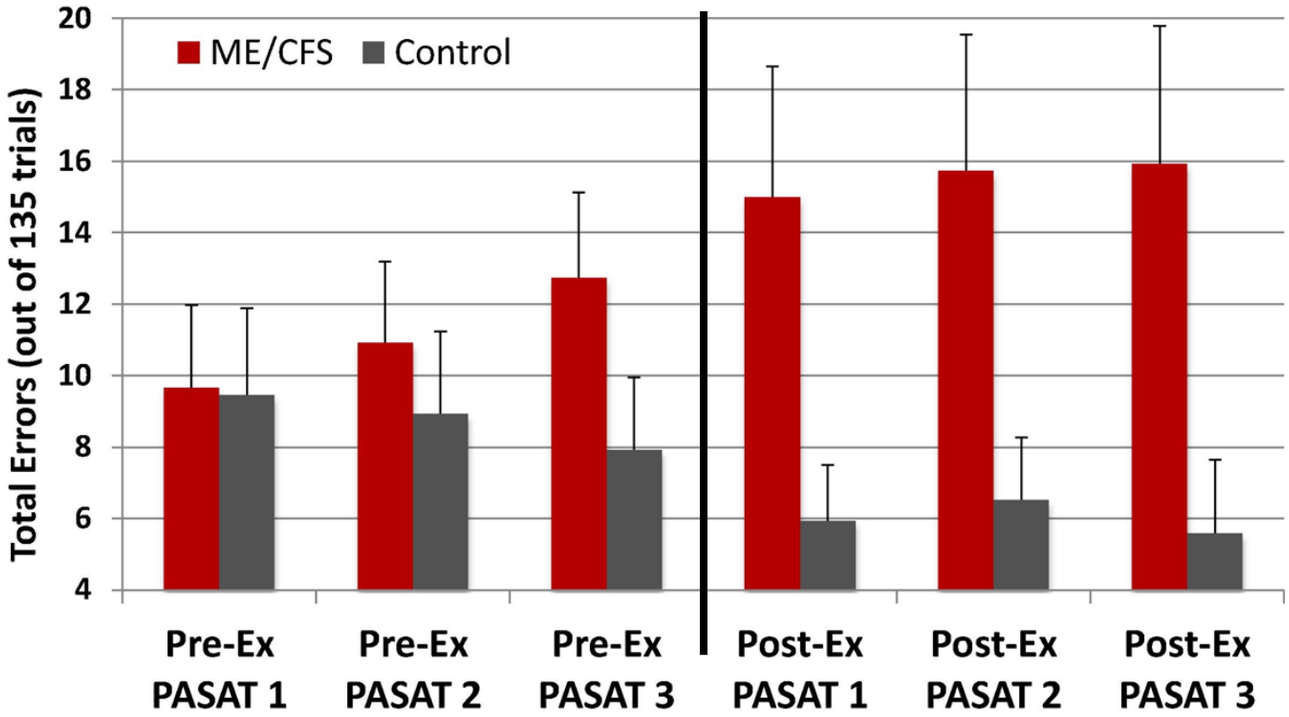
CORE: COGNITIVE IMPAIRMENT

Acute exercise exacerbated symptoms, impaired cognitive performance and affected brain function in ME/CFS patients

- 15 female ME/CFS and 15 female HC
- 30 min sub max exercise (70% peak HR) cycle ergometer
- fMRI during a fatiguing cognitive task: ***PASAT: paced auditory serial addition task***

Total errors on PASAT testing increased just from doing the cognitive test in ME/CFS.

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



Neural Consequences of Post-Exertion Malaise in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Brain Behav Immun. 2017 Feb 16. Cook DB1, **Light AR2, Light KC2**, Broderick G3, Shields MR4, Dougherty RJ4, Meyer JD4, VanRiper S4, Stegner AJ4, Ellingson LD5, Vernon SD6.

CORE: COGNITIVE IMPAIRMENT

- **Cognitive slowing, reduced executive function, cognitive fatigability and cognitive PEM** may be the most limiting aspects of ME/CFS illness, and a primary reason people with ME/CFS are unable to sustain employment or succeed in school.

- Cognitive impairments are aggravated by cerebral perfusion deficits due to OI.

CORE: ORTHOSTATIC INTOLERANCE/ANS

- OI is frequently missed or overlooked which is why we spent time discussing OI syndromes
- Supportive treatment for OI can improve both function and symptoms in ME/CFS

OTHER ME/CFS ILLNESS MANIFESTATIONS

- **Pain-** Common but highly variable in presence, nature and severity. Higher prevalence in more severely ill. Headaches, muscle and joint aches, hyperalgesia, spine pain and neuropathy.

- **Immune manifestations** (allergy, inflammation, sensitivities). Low NK Cell cytotoxicity (function) correlates with illness severity. Nonspecific T-cell abnormalities and cytokine patterns are documented.

- **Infection** - Symptoms viral reactivation or other post infection sequelae.

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Institute of Medicine. Washington (DC): National Academies Press (US); 2015 Feb.

SYMPTOM MANAGEMENT APPROACHES IN SYNDROMES OF CHRONIC ILLNESS

Identification of comorbid conditions opens the door to treatment interventions.

Still…lack of FDA approved drugs or Evidence-Based Treatment Guidelines does not mean

"I can't take care of you"

PALLIATIVE CARE IN CHRONIC ILLNESS AND WHY WE NOW HAVE INTEGRATIVE MEDICINE

What is palliative care?
www.multiplechronicconditions.org

Palliative care is the science and practice of symptom management. Chronic conditions produce accompanying symptoms – poorly managed symptoms contribute to disease exacerbations and frequent hospitalizations. The use and implementation of palliative care in the person with Multiple Chronic Conditions, promotes optimal quality of life, improves physical functioning and a reduces costly care.

CHRONIC ILLNESS IS, BY DEFINITION, INCURABLE

- But you can give the patient tools and confidence, partner with them in chronic management, listen, and improve QOL outcomes.

- It's OK to treat symptoms, but aim at primarily treating the cause as much as possible; keep the core underlying pathology and comorbid conditions in mind, and **do not** cause new problems.

CHRONIC ILLNESS MANAGEMENT GOALS

- **Improving function,** as illness permits, improves QOL
- **Symptom reduction** improves QOL
- **Cultivate realistic expectations**
  - Pain reduction, not pain free
  - Improved but maybe not former level of function
  - Treating or improving one aspect of illness may not cure the whole illness. But it's still progress.

BATEMAN HORNE CENTER

- We are a non-profit clinic, research and education center.
- Dedicated to creating equal access for all patients to evidence-based, high quality, compassionate medical care and scientific research.
- For more educational resources please contact our Education Director, Tahlia Dostal at tdostal@batemanhornecenter.org