Post-Viral Syndromes: When Exercise Doesn't Help

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Patient cases are shared in this session for educational purposes. In some cases, the information does not relate to an individual, and instead represents a compilation of disease presentation.

In cases involving individual patient information, the patients have authorized the discussion of their case in this setting.

https://physicians.utah.edu/echo/long-covid

https://batemanhornecenter.org/providers/long-covid/project-echo/#long-covid-post-viral

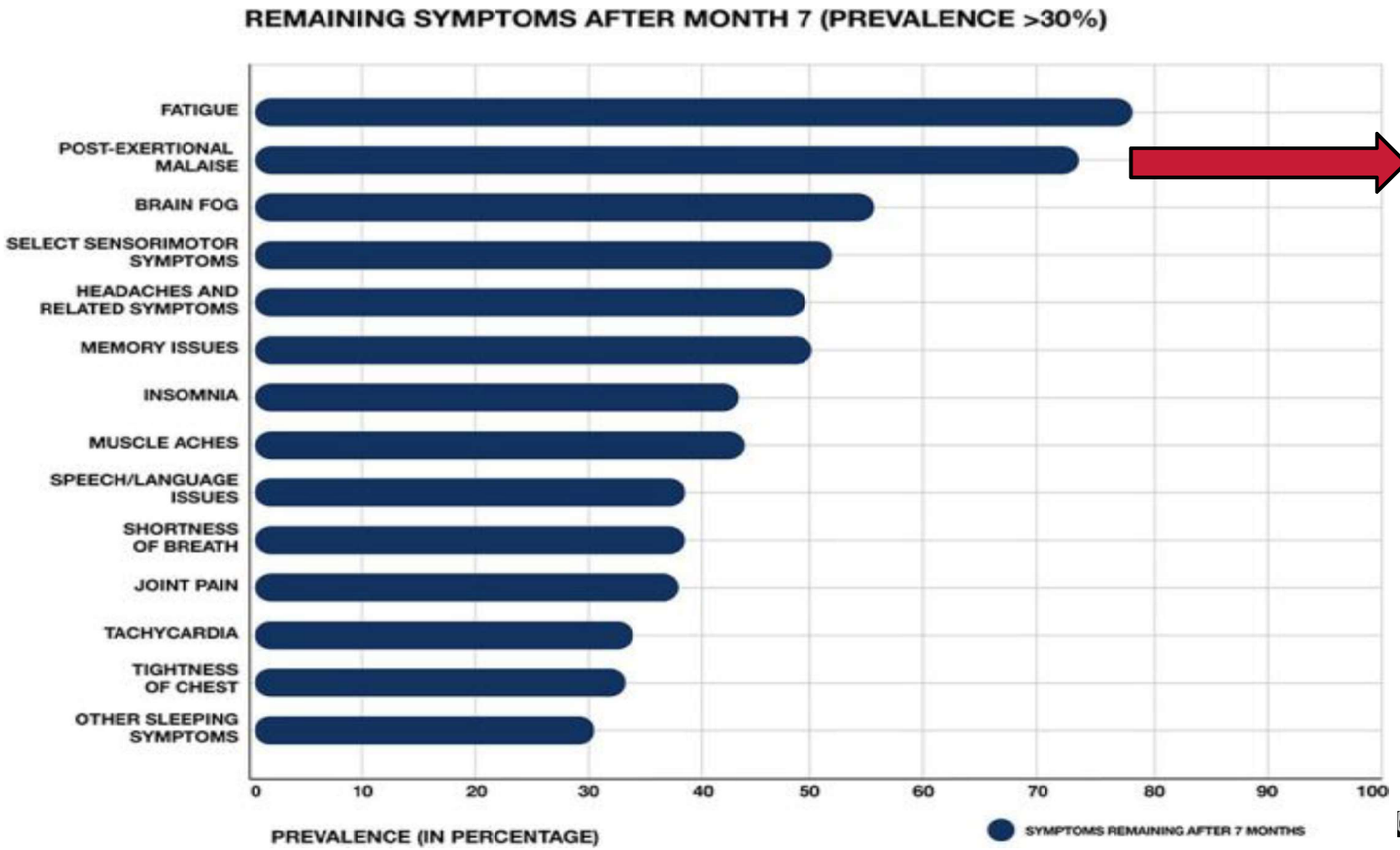
Learning Objectives

1. Acquire updated knowledge on post-exertional malaise (PEM) pacing and symptom management strategies for COVID-related ME/CFS

2. Acquire the ability to assess symptoms, formulate care plans, and provide resources for clinical support for patients with PEM

3. Elicit an engaging discussion on rehab practices for those with Long COVID with PEM/PESE

Long COVID Symptoms



Hallmark symptom of ME/CFS

Proal AD, VanElzakker MB. Long COVID or Post-acute Sequelae of COVID-19 (PASC): An Overview of Biological Factors That May Contribute to Persistent Symptoms. *Front Microbiol*. 2021;12:698169. Published 2021 Jun 23. doi:10.3389/fmicb.2021.698169

Clayton Powers, DPT 12/7/2023

PEM & Orthostatic Intolerance

High proportions of post-exertional malaise and orthostatic intolerance in people living with post-COVID-19 condition: the PRIME post-COVID study

Demi M. E. Pagen, Maarten Van Herck, Céline J.A. van Bilsen, Stephanie Brinkhues, Kevin Konings, Casper D. J. den Heijer, Martijn A. Spruit, Christian J. P.A. Hoebe, Nicole H.T. M. Dukers-Muijrers

doi: https://doi.org/10.1101/2023.08.17.23294204

Orthostatic Intolerance in Long-Haul COVID after SARS-CoV-2: A Case-Control Comparison with Post-EBV and Insidious-Onset Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients

by C. (Linda) M. C. van Campen * and Frans C. Visser

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Healthcare **2022**, *10*(10), 2058; https://doi.org/10.3390/healthcare10102058

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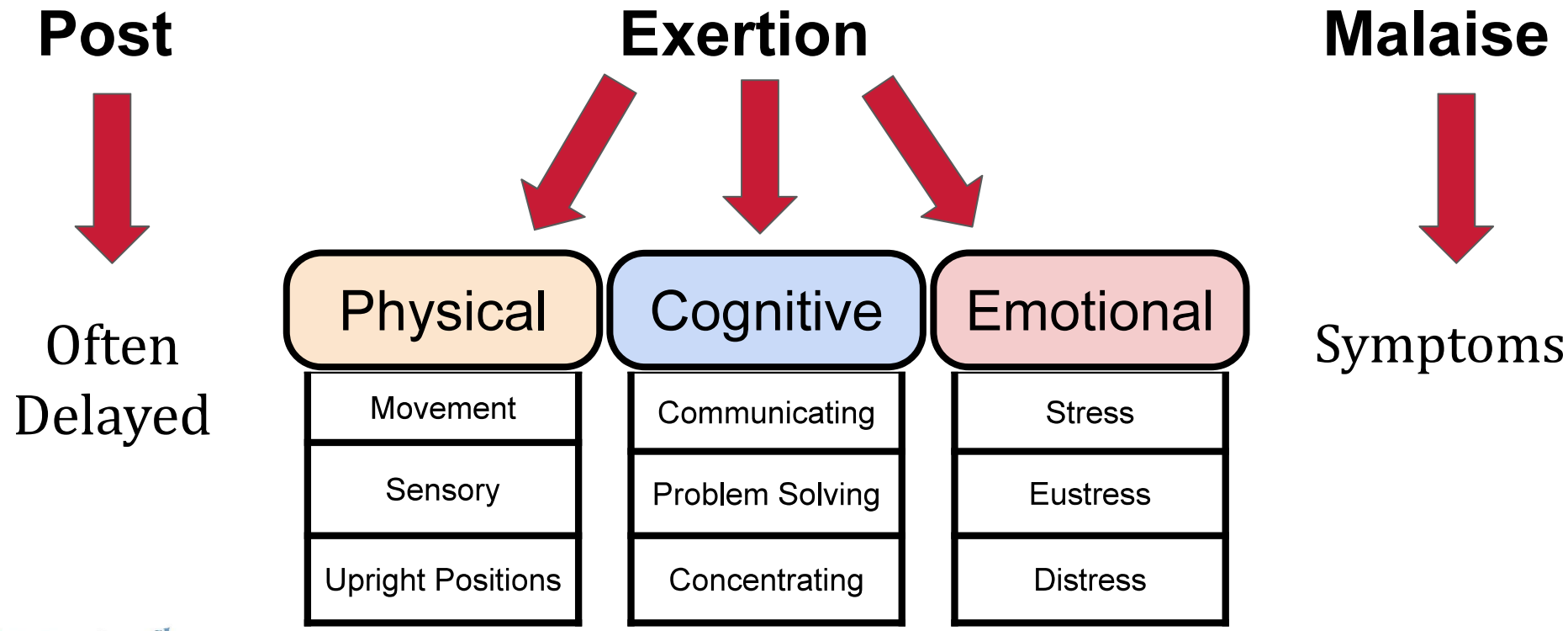
"**Conclusion:** OI symptomatology and objective abnormalities of OI (abnormal cerebral blood flow and cardiac index reduction during tilt testing) are comparable to those in ME/CFS patients. It indicates that long-haul COVID is essentially the same disease as ME/CFS."

Post-Exertional Malaise (PEM)[1,2,3,4]
Post-Exertional Symptom Exacerbation (PESE)

- Worsening of symptoms and function after physical, cognitive, emotional, sensory, and/or orthostatic exertion
- Symptoms are disproportionate to the level of exertion
  - Symptom severity, intensity, & character are unpredictable
- Can occur immediately or be delayed in onset by hours or days
- Prolonged recovery time lasting hours, days, weeks, or longer
- Usually triggered by a viral or bacterial infection. Can also be triggered by trauma, surgery, childbirth, stress, or allergic reaction.

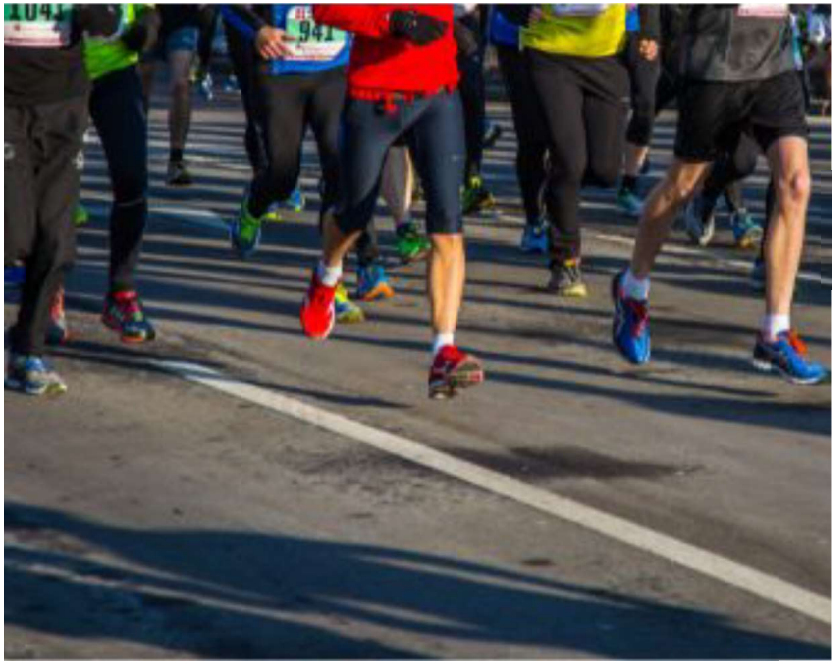
Post-Exertional Malaise (PEM)
Post-Exertional Symptom Exacerbation (PESE)



Common Theme

- **What do these patient examples all have in common?**
  - **The individual reports:**
    - 1 session of PT = 2-3 days of increased symptoms
    - 4x3 moderate resistance supine leg press = 3 days in bed, 1 week to baseline
    - 30 minutes at the gym = headache, sore throat, body aches
    - 1 day of skiing = 1 week in bed sick with flu-like symptoms
    - 1 hour socializing at a party = 2 days in bed sick
    - 12 minutes of biking hard = vomiting, diarrhea, flu-like for 7+ days
    - 4 hours of cooking = 1 week in bed vomiting and ill
    - 15 minutes vacuuming = 1-2 hours lying down to rest
    - 4 hours sitting at a concert = 1 visit to ER with paralysis symptoms
    - 15 min stationary bike 3x/week as recommended by PA = bedridden 2 month crash

Exercise



Hours to
Days Later

Abnormal Delayed Recovery

One day maximal cardiopulmonary exercise test

85% of sedentary controls recovered in 24 hours

0% of ME/CFS patients recovered in 24 hours

(Only 1 recovered within 48 hours)

VanNess JM, Stevens SR, Bateman L, Stiles TL, Snell CR. Postexertional malaise in women with chronic fatigue syndrome. *J Womens Health (Larchmt)*. 2010;19(2):239-244. doi:10.1089/jwh.2009.1507

Invasive Cardiopulmonary Testing

Researchers found:

"Exercise limitation is a common manifestation of post-COVID-19 syndrome months following resolution of mild acute COVID-19 illness."

"Our study confirmed that **vascular dysregulation and impaired oxygen extraction** are hallmarks of exercise dysfunction in these patients." [7]

Subjects "attained anaerobic threshold early"

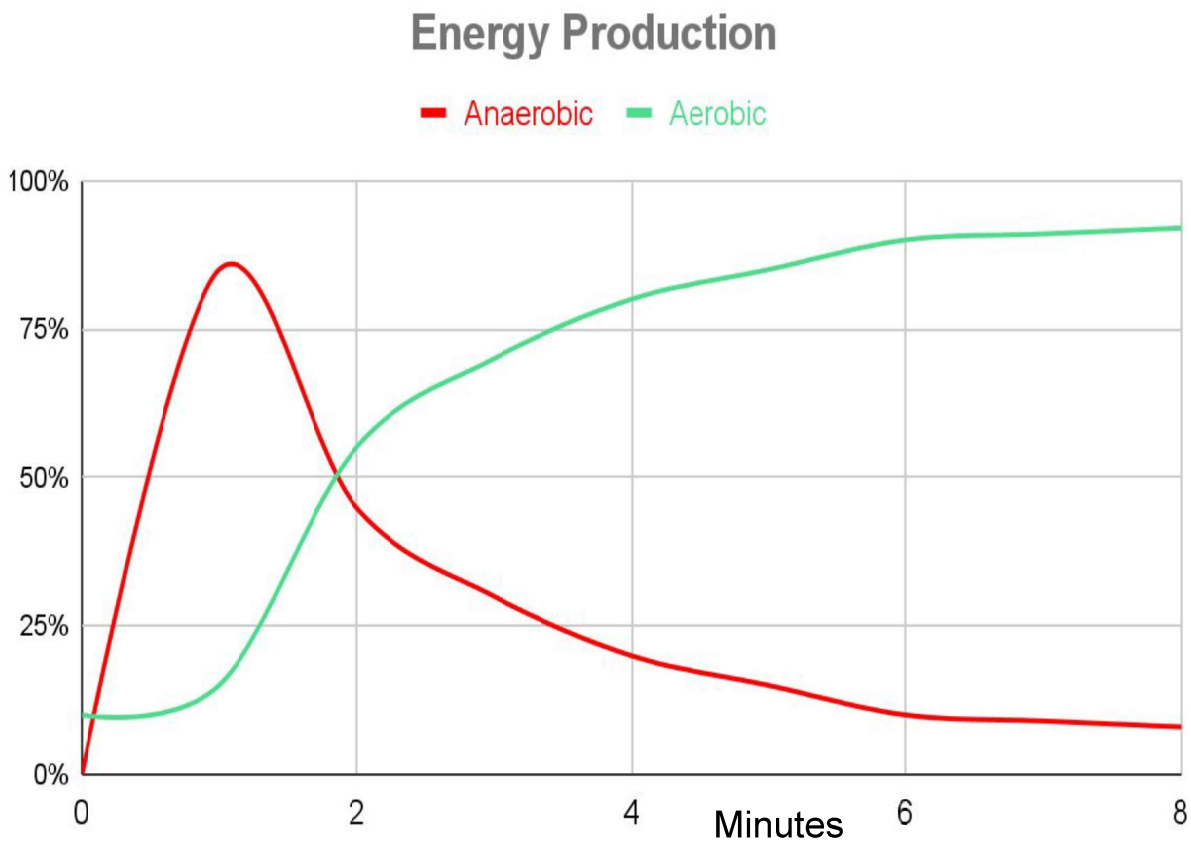
"Demonstrate a marked reduction in peak VO_2 from a peripheral rather than a central limit." [8]

https://www.brighamhealthonamission.org/2021/09/01/study-reveals-new-insights-into-source-of-certain-long-haul-covid-symptoms/

7. *Joseph P, Arevalo C, Oliveira RKF, Faria-Urbina M, Felsenstein D, Oaklander AL, Systrom DM. Insights From Invasive Cardiopulmonary Exercise Testing of Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Chest. 2021 Aug;160(2):642-651. doi: 10.1016/j.chest.2021.01.082. Epub 2021 Feb 10. PMID: 33577778; PMCID: PMC8727854.*

8. Singh I, Joseph P, Heerdt PM, et al. Persistent Exertional Intolerance After COVID-19: Insights From Invasive Cardiopulmonary Exercise Testing. *Chest*. 2022;161(1):54-63. doi:10.1016/j.chest.2021.08.010

Energy Systems



Dysfunction in how the body creates energy, especially the aerobic energy system

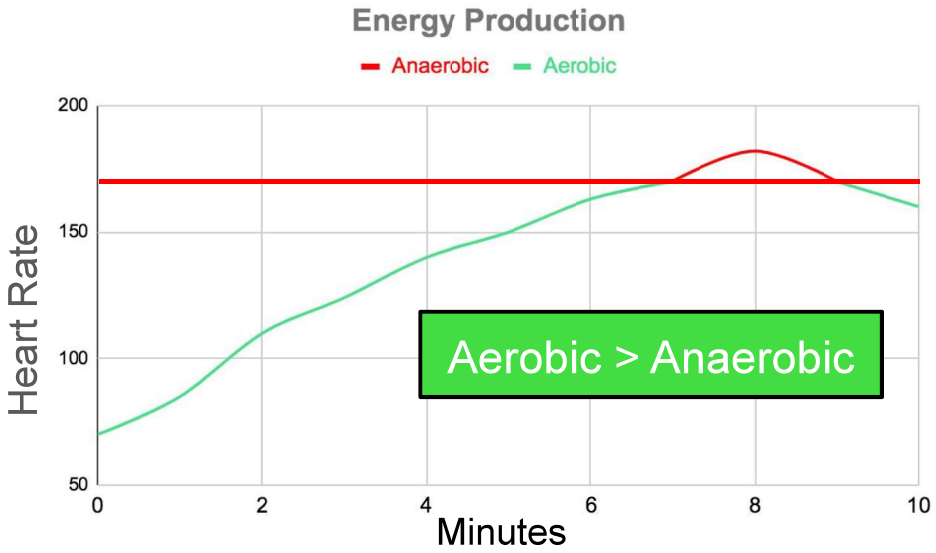
Snell CR, Stevens SR, Davenport TE, Van Ness JM. Discriminative validity of metabolic and workload measurements for identifying people with chronic fatigue syndrome. Phys Ther. 2013;93(11):1484-1492. doi:10.2522/ptj.20110368

Fluge Ø, Mella O, Bruland O, et al. Metabolic profiling indicates impaired pyruvate dehydrogenase function in myalgic encephalopathy/chronic fatigue syndrome. JCI Insight. 2016;1(21):e89376. Published 2016 Dec 22. doi:10.1172/jci.insight.89376

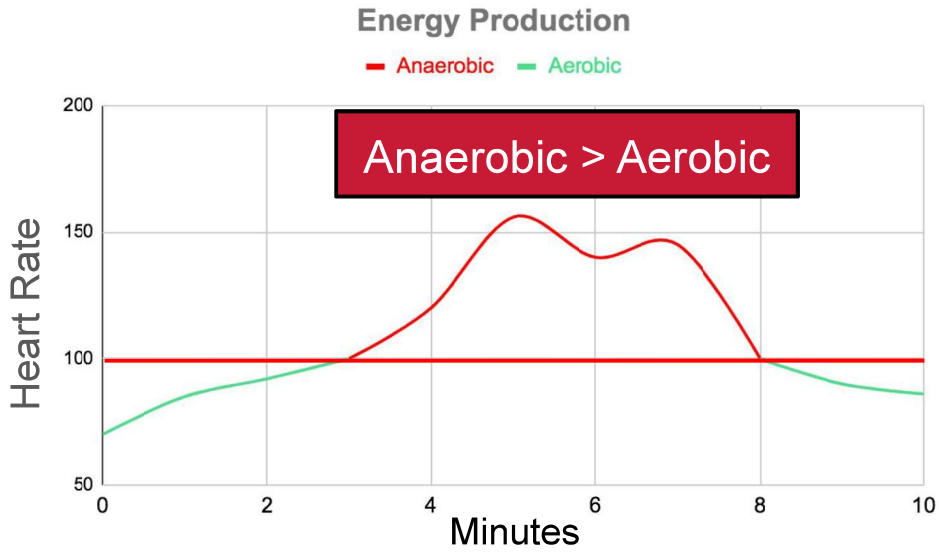
Keller BA, Pryor JL, Giloteaux L. Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to reproduce VO_2peak indicates functional impairment. J Transl Med. 2014;12:104. Published 2014 Apr 23. doi:10.1186/1479-5876-12-104

Energy Systems

Pre-COVID



Post-COVID



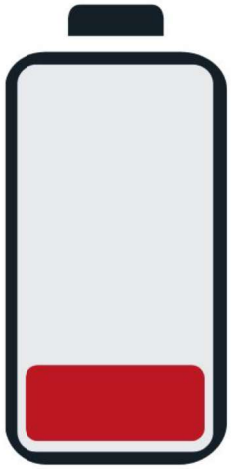
Patients with PEM use the anaerobic system at lower heart rates

Haunhorst S, Bloch W, Wagner H, et al. Long COVID: a narrative review of the clinical aftermaths of COVID-19 with a focus on the putative pathophysiology and aspects of physical activity. Oxf Open Immunol. 2022;3(1):iqac006. Published 2022 Sep 16. doi:10.1093/oxfimm/iqac006

Energy Systems Review

- Patients with PEM use the anaerobic system (AT) at lower heart rates[9,10]
- The anaerobic threshold is a strong predictor of endurance performance
- Activity above the AT is not sustainable[11]
- Once you go above AT, blood lactate levels rise[11]
- Going above this frequently or for too long will result in PEM
- Lactate builds in the bloodstream faster than it can be removed[11]
- Even resting lactate levels have been shown to be high in patients with Long COVID and ME/CFS[12,13]
- During PEM, they use anaerobic system at even lower heart rates[10]
- Activities of Daily Living (ADL's) are already putting them at high levels of strain and exertion
- You cannot add more strain to an already overly strained system
- Patients cannot tolerate exercise when their ADL's are already putting them above their anaerobic threshold

PEM/PESE



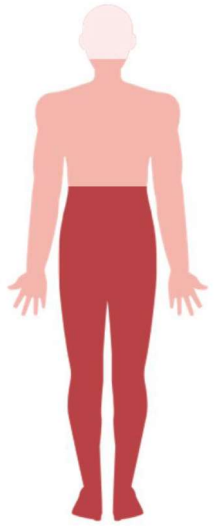
Long COVID

Cerebral Under-Perfusion Studies

- Measured cerebral blood flow in 429 patients with ME/CFS vs 44 Healthy Controls during a 30-minute head-up tilt table test using Doppler flow imaging of carotid and vertebral arteries
- In a subset of patients, cerebral blood flow was shown to be reduced without signs of hypotension or tachycardia.
- Cerebral blood flow reduction at end of tilt table testing
  - 7% decrease - Healthy Controls
  - 24% decrease - Patients with ME/CFS with normal HR/BP response (247 patients)
  - 28% decrease - Patients with ME/CFS with delayed Orthostatic Hypotension
  - 29% decrease - Patients with ME/CFS with POTS

A quantitative, controlled study using Doppler echography. van CampenCLMC, et al. Clin NeurophysiolPract. 2020 Feb 8;5:50-58. doi: 10.1016/j.cnp.2020.01.003. PMID: 32140630

- In a different study, it was found that cerebral blood flow remains reduced in a subset of patients even after returning to supine position for 5 minutes.
- In the more severely affected patients, it took much longer for cerebral blood flow to return to normal even after returning to supine position
- "The delayed recovery of cerebral blood flow was independent of the hemodynamic findings of the tilt test (normal heart rate and blood pressure response, POTS, or delayed orthostatic hypotension), or the presence/absence of hypocapnia"



Cerebral blood flow remains reduced after tilt testing in myalgic encephalomyelitis/chronic fatigue syndrome patients. van CampenCLMC, Rowe PC, Visser FC. Clin NeurophysiolPract. 2021 Sep 23;6:245-255. doi: 10.1016/j.cnp.2021.09.001. PMID: 34667909

Screen for PEM

- Physical therapists and other rehab providers need to screen for and help patients manage Post-Exertional Malaise (PEM) on a regular basis because:
- "Failure to address PEM roughly **doubled the risk of health deterioration**, following rehabilitation."
- "Not addressing PEM **substantially increased the probability of a decline in health and functioning** following the intervention and was **strongly associated with reduced perceived care quality, satisfaction, and benefit.**"
- "...failure to address PEM led to **ineffective, harmful healthcare** and respondents reported poor disease understanding of ME/CFS among healthcare providers and a lack of validation of their illness experiences."

Wormgoor M, Rodenburg S. Focus on post-exertional malaise when approaching ME/CFS in specialist healthcare improves satisfaction and reduces deterioration. *Front. Neurol.* Published December 1, 2023. Accessed December 1, 2023. https://www.frontiersin.org/articles/10.3389/fneur.2023.1247698/full

Key Points

- Rehab providers need to screen for Post-Exertional Malaise (PEM) on a regular basis
- If the patient has PEM, therapists need to provide an alternative treatment approach
- Graded exercise protocols like the Levine or CHOP protocols are **contraindicated**, and exercise can be **detrimental** for patients experiencing PEM [1,2,4]
- PT goals for patients experiencing PEM:
  - **Primary goal** = reduce, prevent, and manage PEM episodes
  - **Secondary goal** = help the patient improve their quality of life and function
- Many PT's still use graded exercise to try to "recondition" patients who have PEM
- The most effective treatments for PEM are:
  - Education
  - Activity pacing[1,5,6]
  - Energy conservation

The Ideal Therapy

- From start to finish, the patient experience should be taken into consideration to limit PEM, anxiety, stress, fear, and confusion.

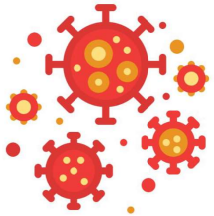
- Screen for PEM prior to appt & offer virtual appointment option
- Reduce paperwork and stress prior to appt – Provide paperwork prior to the appt
- Allow a quiet place to rest or lie down prior to appointment if able
- Offer private room with dimmable lights and place to lie down during appointment
- Thank the patient for attending the appointment
- Listen and believe your patient
- Validate the patient's experience
- Set expectations early of long-term management
- Limit paperwork, questions, movements, and testing if they have PEM
- Provide cognitive rest breaks during the appointment
- Provide educational materials in multiple formats
- Provide flexible scheduling options and telehealth options
- Provide assistance navigating out of the clinic (wheelchair if needed)
- Coordinate care with other providers
- Follow up after appointment to determine response to the appointment

Case 1: Long COVID with PEM - Virtual

Chart Review

- Female in her 30's became sick with COVID in 2021 and referred to multiple specialists

- **Treated by:**
  - Pulmonology
  - Immunology
  - Dermatology
  - ENT
  - Sleep Med
  - Long COVID Medical Team
  - Physical Therapy
  - Autonomic Neurologist



- **Diagnosed with:**
  - Asthma
  - Hypertension
  - GERD
  - Headache
  - Insomnia and sleep apnea
  - Tremor
  - Vertigo
  - Tachycardia & Heart Palpitations

- **Prior history of:** IBS, joint hypermobility, incontinence, anxiety

Case 1: Long COVID with PEM - Virtual

Chart Review

Testing Prior to Referral to PT

- **Cardiac Stress Test:**
  - No ECG evidence of exercise-induced myocardial ischemia
  - No arrhythmias
  - Appropriate heart rate response to exercise
- **Echocardiogram:**
  - Normal LVEF 55-60% (unremarkable ECHO)
- **Pulmonary Function Test (PFT):**
  - Normal spirometry
  - Normal total lung capacity by single breath gas dilution
- **EKG**
  - Normal
- **Chest CT:**
  - Negative for PE
- **Modified Barium Swallow:**
  - Normal
- **Brain and Spine MRI's:**
  - Normal
- **Autonomic Neurology Testing:**
  - "Very modest symptomatic orthostatic tachycardia on head-up tilt, suggesting a predisposition towards symptoms of orthostatic intolerance, though this did not meet criteria for Postural Tachycardia Syndrome (PoTS) today"

Case 1: Long COVID with PEM - Virtual

Chart Review

Medications

- Montelukast
- Cetirizine
- Albuterol
- Flonase
- EpiPen
- Labetalol and then switched to Carvedilol
- Hydrochlorothiazide
- Gabapentin

Other

- Water intake 2-3 x 40 oz
- Salt intake: salt tablets
- Compression leggings

Case 1: Long COVID with PEM - Virtual

Chart Review

- Prior to starting physical therapy:
  - Given Johns Hopkins COVID Rehab Handout
    - A graded exercise program that does not mention post-exertional malaise or pacing and is not helpful for those with PEM since it encourages working on graded activity and exercise.
  - Referred to COVID-19 Recovery Support Groups
  - Provided with videos on breathing exercises
  - Advised by some of her doctors to gradually increase her physical activity and exercise

Screen for PEM - Prescribe activity pacing instead

Case 1: Long COVID with PEM - Virtual

Chart Review

- One year later, referred to a PT specializing in POTS by cardiology with these instructions:
  - "The key treatment for POTS is exercise. This is the only research validated way to "recondition" your heart to react normally to postural changes, reduce symptoms and possibly cure POTS"
  - Follow the POTS exercise training program handout - CHOP Modified Dallas POTS Exercise Program

- Also referred to PT by autonomic physiologist with these instructions:
  - "Begin with graded therapeutic exercise program as indicated"

Referral to PT or OT: "Screen for Post-Exertional Malaise (PEM). Prescribe activity pacing, energy conservation, and ADL management."

Case 1: Long COVID with PEM - Virtual

Chart Review

- The patient completed 3 visits with the PT who "specializes" in POTS rehab

- The Physical Therapist noted:
  - "Exercise - attempted, but not gone well."
  - "ADLs - limited"

Minimize exertion-based examination
Focus on activity pacing instead

- The Physical Therapist performed:
  - 5-Minute Active Stand Test (Visit 1)
  - 6-Minute Walk Test (Visit 2) - 308 meters (LH, leg weakness; took break at 2:00; RPE 5/10; HR 113bpm)
  - 30-Second Sit to Stand Test (Visit 2) - 11 reps--4/10 RPE; HR 93bpm; legs felt weak and LH
  - Sensory Organization Test (Visit 3)
  - Set a goal to "progress HR by 5bpm or effort level to 4-5/10"

- The Physical Therapist prescribed:
  - Activity Pacing, HR Pacing, and Education on PEM
  - Recumbent strengthening exercises
  - Breathing exercises
  - An early version of the Utah ADaPT exercise protocol with these instructions:
    - "Cardio programming in reclined position with HR at 95-100bpm or RPE 3/10 x 20 minutes"

Case 1: Long COVID with PEM - Virtual

Subjective

- The patient was then referred to me 4 months later (17 months after onset)
- She said that she worked with POTS PT for 3 visits
  - Was instructed on PEM and pacing but encouraged to do recumbent leg cycling with heart rate below 105 bpm and to build the duration over time starting with 5 minutes
  - Instructed in recumbent strengthening
  - **She didn't feel that the exercises helped her symptoms**
  - Wearing compression and abdominal binder
  - Increasing electrolyte and fluid intake
  - Tracking her heart rate
  - She didn't tolerate ADL's, exercise, work, or recreational activities
- Goals for therapy:
  - Be able to do what she could before getting sick (walk farther, chores, go to amusement parks)

Case 1: Long COVID with PEM - Virtual

Subjective

- Symptoms:
  - Dizziness and Lightheadedness
  - Fatigue
  - Shortness of breath
  - Unrefreshing sleep, OSA using CPAP
  - GI symptoms: IBS and GERD
  - Headaches
  - Nerve pain and weakness in legs
  - Muscle/joint pain
  - Temperature intolerance
  - Asthma
  - Multiple allergies/allergic reactions
  - Chemical sensitivities
  - Brain Fog

Evidence-Based Screening Tool for PEM/PESE

Evidence-based Question	Patient/Client Response Indicating PESE
Does it take more than one day to recover to your usual baseline from activity?	"Yes."
Do you feel unwell, weak, don't sleep well, or have pain when recovering from activity?	"Yes" to at least one; diagnostic accuracy optimized for three or more.
Are you feeling limited in your ability to do your normal daily tasks after activity? Does exercise/activity positively affect you?	"Yes" to functional decrement and "No" to positive effect/mood.

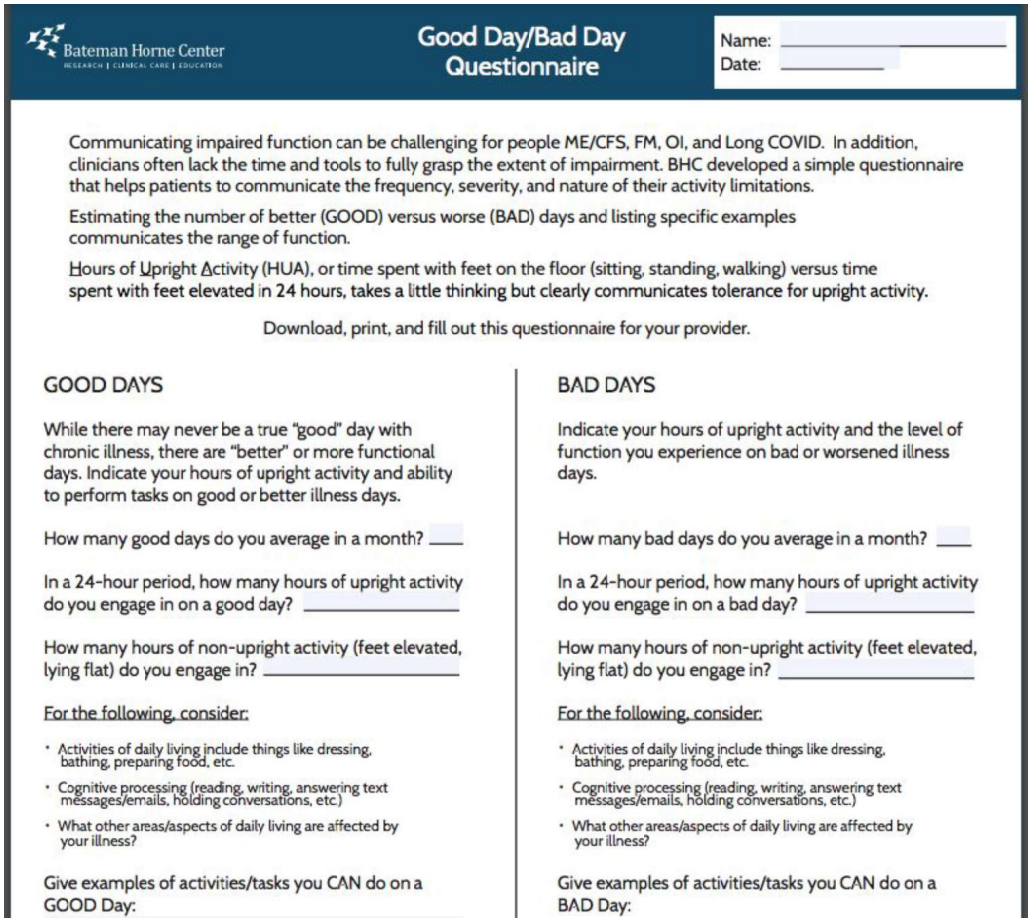
Case 1: Long COVID with PEM - Virtual

Screening

- **Post-exertional malaise:**
  - Several days to recover after physical, cognitive, social or emotional exertion
    - High PEM severity and irritability
  - Not positively affected by exercise/activity.

- **Mast Cell Issues:** subjective history
  - Feels inflamed with bread and dairy, yogurt
  - Asthma
  - Dermatographism
  - Multiple allergies
  - Chemical sensitivities
  - Sore throat or sores in mouth with hamburger & eating at a restaurant
  - Diarrhea with pineapple
  - Vomiting, hives, and diarrhea with alcohol
  - Overreaction to bug bites

Assessment



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Good Day/Bad Day Questionnaire

Name: _____
Date: _____

Communicating impaired function can be challenging for people ME/CFS, FM, OI, and Long COVID. In addition, clinicians often lack the time and tools to fully grasp the extent of impairment. BHC developed a simple questionnaire that helps patients to communicate the frequency, severity, and nature of their activity limitations.

Estimating the number of better (GOOD) versus worse (BAD) days and listing specific examples communicates the range of function.

Hours of Upright Activity (HUA), or time spent with feet on the floor (sitting, standing, walking) versus time spent with feet elevated in 24 hours, takes a little thinking but clearly communicates tolerance for upright activity.

Download, print, and fill out this questionnaire for your provider.

GOOD DAYS

While there may never be a true "good" day with chronic illness, there are "better" or more functional days. Indicate your hours of upright activity and ability to perform tasks on good or better illness days.

How many good days do you average in a month? ____

In a 24-hour period, how many hours of upright activity do you engage in on a good day? _____

How many hours of non-upright activity (feet elevated, lying flat) do you engage in? _____

For the following, consider:

- Activities of daily living include things like dressing, bathing, preparing food, etc.
- Cognitive processing (reading, writing, answering text messages/emails, holding conversations, etc.)
- What other areas/aspects of daily living are affected by your illness?

Give examples of activities/tasks you CAN do on a GOOD Day:

BAD DAYS

Indicate your hours of upright activity and the level of function you experience on bad or worsened illness days.

How many bad days do you average in a month? ____

In a 24-hour period, how many hours of upright activity do you engage in on a bad day? _____

How many hours of non-upright activity (feet elevated, lying flat) do you engage in? _____

For the following, consider:

- Activities of daily living include things like dressing, bathing, preparing food, etc.
- Cognitive processing (reading, writing, answering text messages/emails, holding conversations, etc.)
- What other areas/aspects of daily living are affected by your illness?

Give examples of activities/tasks you CAN do on a BAD Day:

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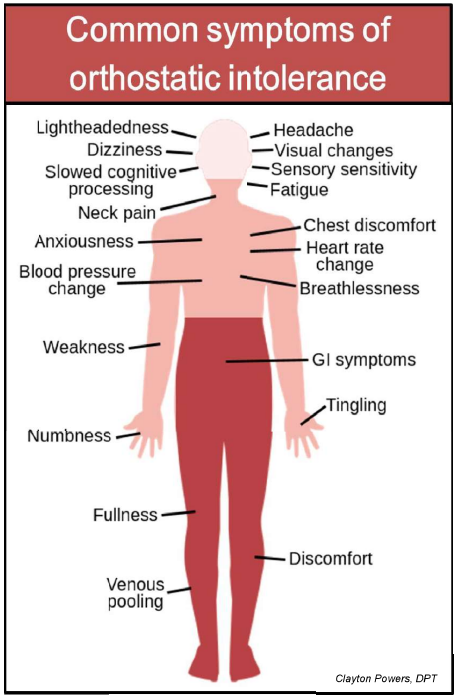
Good Day/Bad Day Questionnaire

https://batemanhornecenter.org/wp-content/uploads/filebase/education/top_resources/Good-Day-Bad-Day-Questionnaire-Fillable-V3-6_6_2022.pdf

Case 1: Long COVID with PEM - Virtual

Examination

- **Orthostatic Intolerance - Hours of Upright Activity:**
  - 12 hours on good days
  - 1-2 hours on bad days
- **Orthostatic Intolerance:** NASA lean not performed since patient already underwent tilt table testing.
- **Patient-Specific Functional Scale (PSFS)**
  - Key: 0/10 = unable, 10/10 = prior level of function
    - Light housework = 2-3/10
    - Walking >30 minutes = 1/10
    - Take laundry up & down stairs = 1/10



Case 1: Long COVID with PEM - Virtual

Evaluation

- **Impairments:**
  - Post-Exertional Malaise (PEM)
  - Orthostatic Intolerance
  - Multiple Allergies/Mast Cell Issues
  - Unrefreshing Sleep (OSA using CPAP)
  - Asthma
  - Heat Intolerance
  - Muscle/Joint/Nerve Pain and Weakness
  - Shortness of Breath
  - Dizziness and Lightheadedness
  - Fatigue
  - GI symptoms: IBS and GERD
  - Headaches
  - Chemical Sensitivities
  - Cognitive Impairment

- **Functional Limitations:**
  - Unable to walk for long distances
  - Unable to perform strenuous activity around the house
  - Unable to work without increased symptoms
  - Unable to participate in recreational activities with family and friends
  - Unable to tolerate going to amusement parks
  - Unable to tolerate going to concerts
  - Unable to tolerate going to athletic events for her children

Case 1: Long COVID with PEM - Virtual

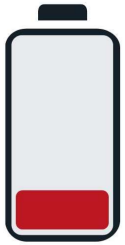
Interventions

First priority = reduce PEM episodes

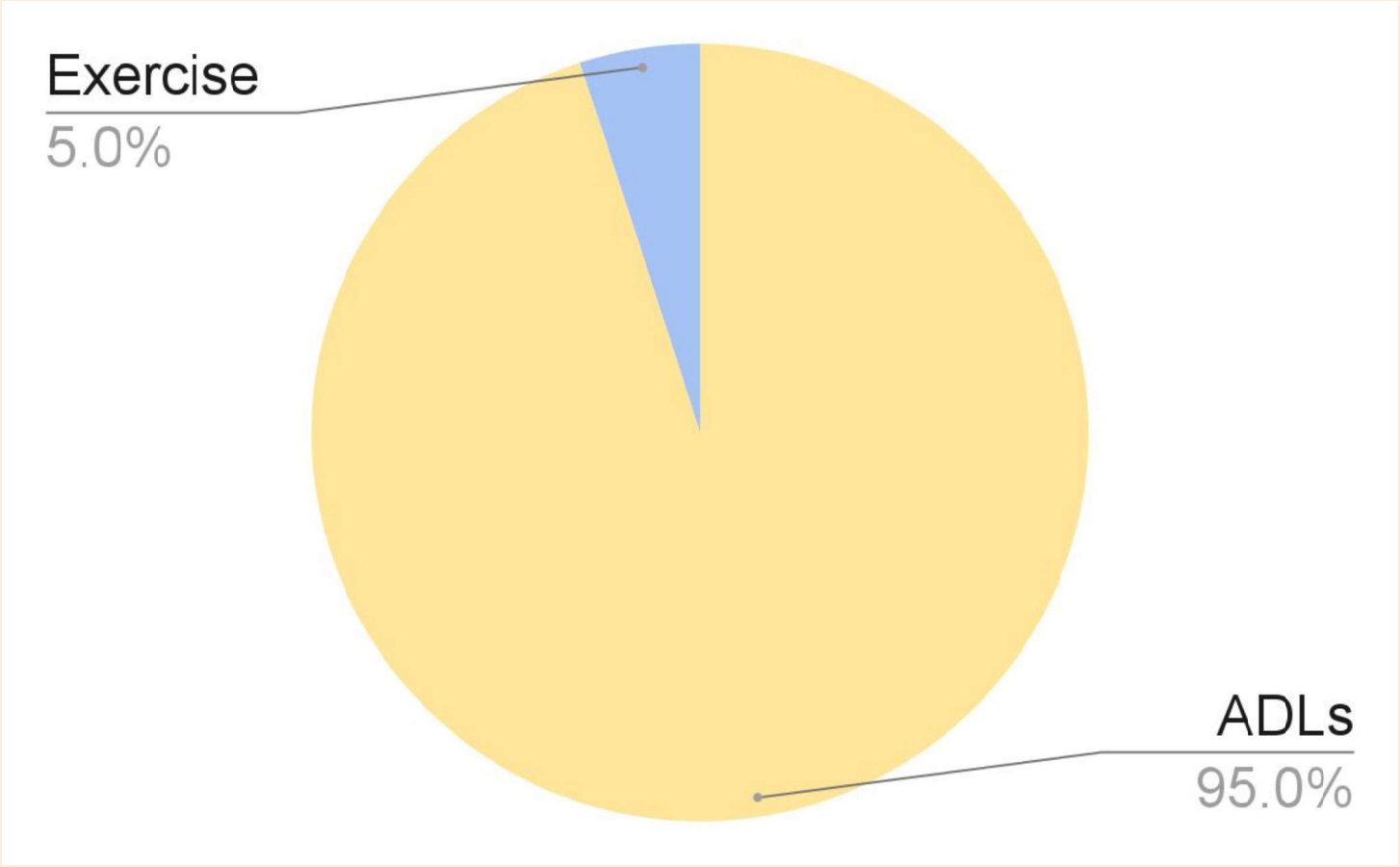
Case 1: Long COVID with PEM - Virtual

Interventions

- Education on PEM
  - Set expectations for rehab & prognosis
  - Cell phone battery analogy
  - Patient handouts and videos
- Advised patient to discontinue exercises - Utah ~~X~~DaPT
- Education on HR biofeedback pacing
  - Set HR alerts
  - "Stop and lower HR when you feel symptoms"
  - "Stop and rest when you feel an activity is hard"
  - Visible app for HRV monitoring
- Education on pacing upright activity
- Education on energy conservation strategies



Pacing > Exercise



Treatment for PEM: Energy Conservation

Physical Activity

- Exertion
  - Use a disability placard
  - Use a wheelchair or mobility aids or devices
  - Shower sitting down
  - Ask others for help
  - Learn to say "no"
  - Keep essential items nearby
  - Put chairs throughout your living environment to sit and rest whenever needed
  - Take rest breaks when talking
  - Use joint braces when needed
  - Prioritize & plan movements
- Orthostatic
  - Reduce time in upright positions
  - Lie down frequently
  - Elevate legs frequently
  - Increase fluid intake
  - Increase sodium intake (check with medical provider first)
  - Increase electrolyte intake
  - Wear compression clothing when upright (thigh-high or abdominal are most helpful)
- Physiological
  - Body temperature may fluctuate, have layers to put on and take off
  - Use cold packs on neck or other body parts to reduce overheating

Emotional Activity

- Positive & negative emotions use energy
- Minimize triggering stimuli
- Avoid emotionally charged interactions, conversations, or media
- Use calming techniques
- Observe your breathing
- Give yourself permission to rest







Sensory and Environmental Stimuli

- Sight/visual
  - Eye mask
  - Tinted lenses
  - Hat with visor
  - Dim electronics
  - Blue light glasses
- Sound
  - Earplugs
  - Noise-canceling headphones
  - Noise machines
- Touch
  - Loose clothing
  - Minimize abrasive linens and bedding
  - Weighted blankets (deep pressure can be soothing for some people)
  - Reduce contact with chemical products (e.g., hygiene or cleaning products)
  - Rest in comfortable positions that help you relax
  - Use joint braces or other supports when resting
- Odor
  - Minimize cooking odors
  - Avoid chemical odors
  - Reduce environmental odors
  - Minimize chemical products

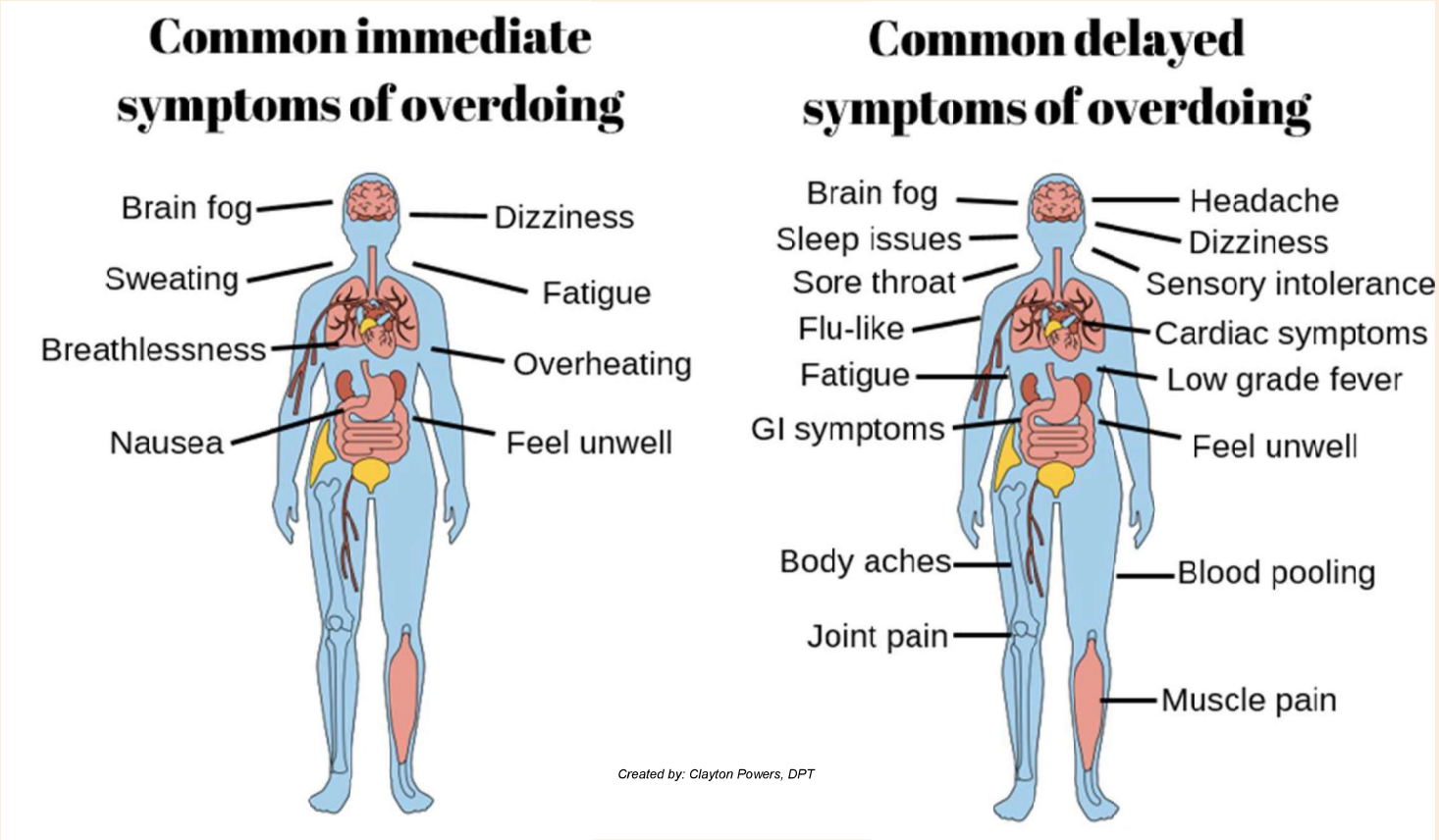
Cognitive/Brain Activity

- Prioritize & plan cognitive efforts
- Limit reading, speaking, texting, watching media (computer, TV, or phone)
- Avoid making big decisions in a crash
- Reduce or shorten periods of:
  - Problem solving
  - Concentrating
  - Multitasking

Clayton Powers, DPT

For more ideas for managing your symptoms, check out the BHC PEM Crash Survival Guide

Recognizing PEM



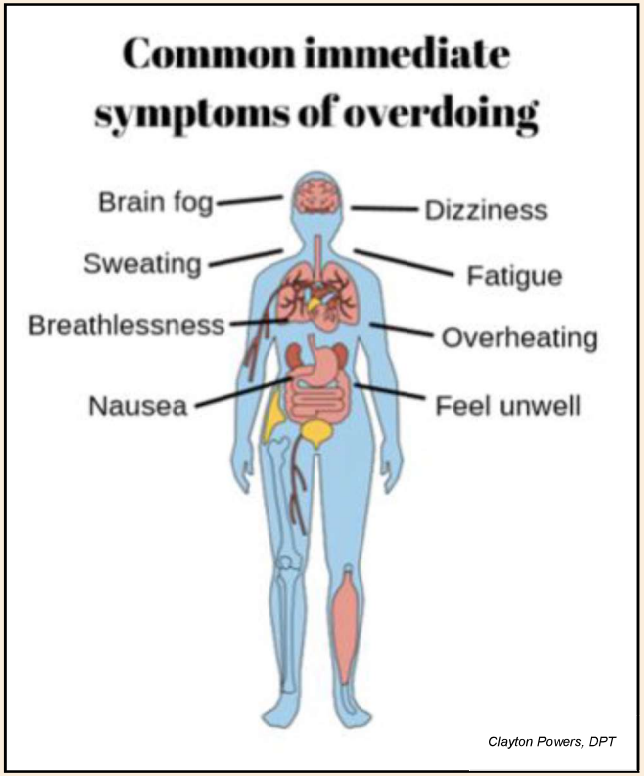
Treatment for PEM: Activity Pacing[5,6]

When you notice immediate signs of overdoing such as:

- Increased symptoms
- Increased difficulty with a task
- Shortness of breath

Then you need to:

- Stop - Do not push through the symptoms
- Rest
- Elevate your legs
- Lower your heart rate
- Slow your breathing
- Reduce sensory stimulation
- Put a cold pack on your neck



Heart Rate Biofeedback Pacing

Instruction:

- After determining resting heart rate over a 7-day period, Workwell Foundation recommends setting an alert at 15bpm above the resting heart rate to start and taper up over time until you determine a HR range that prevents PEM.
    - This is too conservative for some, especially for those with orthostatic tachycardia.
- Another method is to have the patient monitor at what heart rate they start to experience:
    - symptoms
    - increased difficulty doing an activity
    - when they experience shortness of breath
- Set an alarm to immediately alert you about 5-10bpm below the point that you begin to experience signs of overdoing

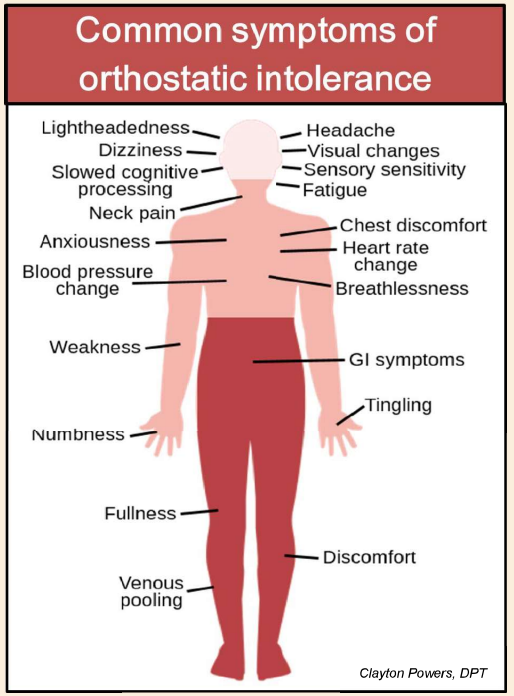
https://workwellfoundation.org/wp-content/uploads/2023/01/HRM-Factsheet.pdf

https://guidetolongcovid.com/trackers-wearables-devices-long-covid/

OI Treatment: Pacing Upright Activity

When you notice symptoms of orthostatic intolerance:

- Lie down
- Elevate legs above the level of your heart
- Wear compression clothing
- Increase intake of sodium, electrolytes, and water (if approved by medical provider)
- Use cold packs on abdomen or legs



Case 1: Long COVID with PEM - Virtual

Interventions

- Education about MCAS & Diet
  - Patient monitored reactions to foods
  - Referred to allergist and dietician
  - Reduced processed foods and sugar
  - Reduced foods that she reacted to
  - She started taking quercetin and started tracking food triggers

- Allergist put her on Montelukast, but she had a reaction
- Allergist put her on antihistamines and cromolyn sodium
  - Less GI symptoms and started experiencing more good days

Mast Cell Symptoms

- Rehab providers need to know about symptoms of mast cell activation symptoms because:
  - Exercise and other interventions can trigger mast cell degranulation[14,15,16]
  - Symptoms of mast cell degranulation can interfere with a patient's tolerance for therapy

Mast cell activation symptoms are prevalent in Long-COVID☆,☆☆,★

Leonard B. Weinstock[a,*], Jill B. Brook[b], Arthur S. Walters[c], Ashleigh Goris[d], Lawrence B. Afrin[e], Gerhard J. Molderings[f]

Mast Cell Symptoms Affecting Therapy Tolerance[17]

- **Constitutional**
  - Pain
  - Fatigue
  - Malaise
  - Temperature Dysregulation
  - Poor Healing
  - Inappropriate Sweating
  - Chemical/Physical Sensitivities
- **Integumentary**
  - Dermatographia
  - Skin Lesions, Rashes, Hives
  - Swelling
- **Musculoskeletal**
  - Bone/Muscle/Joint Pain
  - Joint Laxity/Hypermobility
  - Joint Swelling
  - Aneurysm
  - Osteopenia/Osteoporosis
  - Muscle Fasciculations/Cramping
- **Cardiovascular**
  - Heart Palpitations
  - Lightheadedness
  - Fluctuations of BP and HR
  - Chest Pain

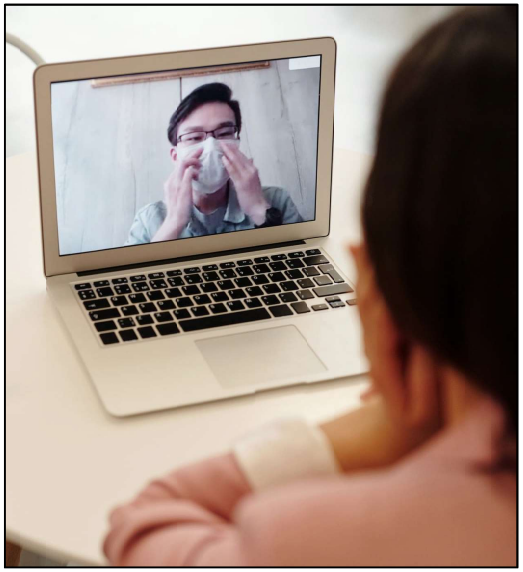
- **Neurologic**
  - Dysautonomia
  - Sensory Intolerance/Neuropathy
  - Pseudo-Seizures
  - Headache/Migraine
  - Dizziness and/or Vertigo
  - Visual Motion Sensitivity
  - Sleep Issues
  - Numbness/Tingling
  - Sensory Disruptions
  - Impaired Interoception
- **Vestibular**
  - Vertigo and/or Dizziness
  - Balance Deficits
- **Genitourinary**
  - Urinary and Fecal Incontinence
- **Pulmonary**
  - Dyspnea
  - Airway Inflammation
  - Cough
  - Sleep Apnea - leads to poor recovery
- **Ophthalmologic**
  - Sensitivity to Lights
  - Visual Impairment

- **Psychiatric**
  - Anxiety
  - Panic
  - Depression
  - OCD
  - Attention Deficits
  - Cognitive Impairment
- **Immunologic**
  - Hypersensitive
  - Poor Healing
  - Increased Infection Risk
  - Allergies/Sensitivities
- **Hematologic**
  - Anemia
  - Easy Bruising and Bleeding
  - Blood Clotting
- **Endocrinologic**
  - Blood Glucose Fluctuations
- **Lymphatic**
  - Swelling
- **Gastrointestinal**
  - Nausea
  - Abdominal Pain/Discomfort

Case 1: Long COVID with PEM - Virtual

Results

- 5 virtual appointments over 4 months
  - Patient discontinued exercises as per my recommendation
- More good days than bad days
- Fewer PEM episodes per month
- Increasing Heart Rate Variability (HRV) over time



- Perceived function at 1st appt = 50%
- Perceived function at 5th appt = 65-70%

- She continues to manage the symptoms, but now she has the tools to self-manage

Functional Assessment

PATIENT SPECIFIC FUNCTIONAL SCORE

Scoring scale is from 0 (unable to perform activity) to 10 (able to perform activity at pre-injury level)

Date	Eval	Visit 3	Visit 4	Visit 5
1. Light housework	2-3	2-3	2-3	5
2. Walking >30 minutes	1	3	3	3
3. Take laundry up and down stairs	1	5	5	6-7
4.				
5.				

Remember This!

PEM is not due to deconditioning

PEM is not due to laziness

PEM is not a psychological condition

PEM is much more than fatigue

PEM interferes with production of energy on a cellular level

Case 2: Long COVID with POTS

Subjective

- Female in her 40's became sick with COVID in 2022 and dx with POTS
- Started PT with me 15 months after getting COVID
- Medical provider diagnosed her with POTS using NASA Lean Test
- Exercises on rowing machine daily, but her endurance is low
- She doesn't notice worsening of symptoms after rowing, but she feels that she can't see progress
- Wears a Fitbit and Whoop
- Wears compression socks but not abdominal binder - upsets GI symptoms
- Changing positions quickly or standing for too long causes increased dizziness and fatigue
- Medications: tried multiple, no medications have helped
- Works full time - mostly sitting
- She has been pushing herself more with exercise to try to get better

Case 2: Long COVID with POTS

Subjective

- Symptoms:
  - Dizziness and Lightheadedness
  - Fatigue
  - Unrefreshing sleep
  - GI symptoms: intermittent bloating and GERD
  - Muscle/joint pain
  - Heat intolerance
  - Allergies to shellfish, latex
  - Seasonal allergies
  - Used to have asthma
  - Brain fog during crashes

PEM Screening

Post-Exertional Malaise/Post-Exertional Symptom Exacerbation Questionnaire:

1. Does it frequently take >24 hours to recover after activity or a busy day?
    a. How long does it usually take to recover from physical or mental effort?
    b. What's the longest that it has taken to recover from exertion/activity?
    c. What activities typically trigger your symptoms the most?
    d. What activities were once tolerated that you can no longer do without a 12-72 hour recovery?
2. Do you experience severe fatigue, brain fog, sleep disturbance, and/or pain after activity or a busy day?

Recumbent Exercise Decision Tool

3. If you are lying down, do you still have difficulty/symptoms with mental effort such as watching TV, having a conversation, or concentrating?
4. If you could do all of your activities lying down, would you be able to function at a much higher level?
5. Does exercise/activity positively affect you?
6. Have you tried exercise lying down?
    a. If yes: Did it improve your symptoms the next day?
7. Do your symptoms worsen with resting too much?
8. Does movement improve your symptoms more than being stationary?

Key: Yes to questions 1-3 and no to questions 4, 6a, 7, 8 = use energy conservation/pacing approach
No to questions 3 & 7 and yes to questions 4, 5, 6a, 8 = try pacing approach plus recumbent exercise

If you are unsure, use the energy conservation/pacing approach.

Case 2: Long COVID with POTS

Subjective

- 2-3 days to recover from crashes
- Crash symptoms:
  - Pain, brain fog, fatigue, weakness, poor sleep after excessive upright activity or strenuous exercise
- Exercise doesn't seem to help with fatigue
- Experiences syncope with deadlifts or standing up too quickly
- Cognitive symptoms when upright that resolve when lying down
  - "If I could live my life lying down, I would be able to function normally."
- Good day: go to work, exercise on rowing machine 30 minutes, make dinner, do chores
- Even on a good day: Unable to run, stand > 1 hour, sit > 30 minutes
- Symptoms worse if she rests too much or lies down >30 minutes
- Symptoms better with movement than being stationary

Case 2: Long COVID with POTS

Examination

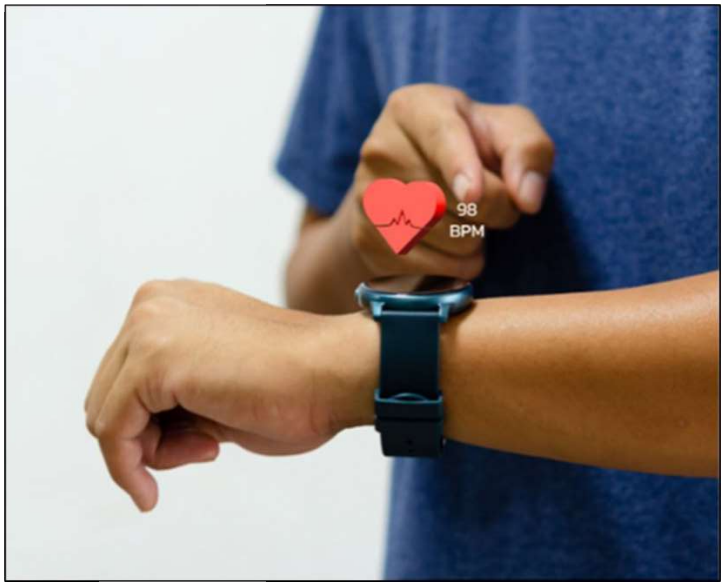
- **Orthostatic Intolerance - Hours of Upright Activity:**
  - 6 hours with feet on the floor on good days
  - <2 hours on bad days
- **Orthostatic Intolerance:** not performed
- **No evidence of joint hypermobility**
- **Patient-Specific Functional Scale (PSFS)**
  - Key: 0/10 = unable, 10/10 = prior level of function
    - Rowing 30 minutes = 6/10
    - Deadlift 140 lbs = 5/10
    - Work 5 hours mostly sitting = 5/10

Low severity, higher function and likely had a higher AT

Case 2: Long COVID with POTS

Interventions

- Education on PEM & Anaerobic Threshold
  - Stay below anaerobic threshold
  - Patient handouts and videos
- Education on HR biofeedback pacing
  - Set HR alerts at 120bpm and 130bpm
  - Keep heart rate below 130bpm during exercise
  - “Stop and lower HR when you feel symptoms”
  - “Stop and rest when you feel an activity is hard”
- Education on pacing upright activity
  - Set a timer to lie down or move every hour
  - Change positions or move when you have symptoms
  - Use cold on lower legs and abdomen



Case 2: Long COVID with POTS

Results

- Pacing upright activity helped substantially
- Performed physical fitness test and was able to lift 165lbs deadlift
- Scored higher on her physical function test for work than she had prior to COVID
- Uses a timer to get up and do squats every hour
- Rowing every other day at lower heart rate (<130bpm)
- Alternates weight lifting with rowing
- Feels better when she gets up frequently to move her circulation
- If she is in a crash, she doesn't do her workouts
- Her coworkers have noticed that she can do more
- She isn't needing to prioritize her activities or plan as much
- She is able to do more with her family

Case 2: Long COVID with POTS

Results

- 2 appointments over 6 weeks (follow up was virtual)
- More good days than bad days
- Decreased PEM episodes per month
- Hours of Upright Activity on Good Days: 6 → 7

- Perceived function at 1st appt = 70%
- Perceived function at 2nd appt = 95%

Functional Assessment

PATIENT SPECIFIC FUNCTIONAL SCORE

Scoring scale is from 0 (unable to perform activity) to 10 (able to perform activity at pre-injury level)

Date	Eval	Visit 2			Goal
1. Rowing 30 minutes	6	10			
2. Deadlift 140lbs	5	8			
3. Working 5 hours	5	10			

Total score = sum of the activity scores/ number of activities

MDC (90% CI) for average score = 2

MDC (90% CI) for single activity score = 3

Principles

- People tend to naturally increase their physical activity when they feel better
- You cannot add more strain to an already overly strained nervous system and expect that it will improve function

- If exercise/movement is medicine, then it needs to be cautiously dosed and carefully monitored.
- The primary goal of therapy is to reduce PEM episodes
- Patients who tolerate cognitive and physical activity lying down without PEM may benefit from exercise in reclined positions or in water as long as they are effective at pacing their upright activity.
- Pacing is more important than exercise in patients with POTS with PEM.

- Physical examination tests (e.g., strength, exercise, or exertion tests) are generally not recommended for patients who have PEM as this can result in PEM.
- It is abnormal for recovery to last >24 hours. If this occurs, it is a sign of PEM or overdoing.
- Pacing and energy conservation are the most important interventions for managing PEM.
- Exercise **can be harmful** to some patients with dysautonomia and should be prescribed by a healthcare provider that understands the complexities and complications of neuroimmune conditions and PEM.
- POTS can be comorbid with ME/CFS and PEM.
- Follow up with the patient the day or two after the session to assess how they responded to the treatments and session.

Recumbent Exercise Trends

Those who benefit from recumbent exercise tend to:	Those who do not benefit from recumbent exercise tend to:
○ Report substantial reduction in symptoms when lying down ○ Tolerate cognitive effort/activity/exertion lying down ○ Report worsening of function and symptoms with resting too much ○ Report that moving feels better on their body than being stationary ○ Report improvement the next day after recumbent exercise ○ Experience less tachycardia and orthostatic symptoms the day after recumbent exercise	○ Require >24 hours to recover after activity including recumbent cognitive or sensory exertion ○ Report only mild improvement in symptoms when lying down ○ Report difficulty or increased symptoms with cognitive effort even while lying down ○ Report improvement in function & symptoms with resting more ○ Report worsening of symptoms after even recumbent exercise ○ Report improvement of symptoms and function with cessation of exercise ○ Report improvement of symptoms and function with reduction in overall activity/exertion ○ Report improvement in POTS or orthostatic symptoms with resting more

Case Review

- **In both patient cases:**
  - Activity pacing and pacing upright activity were more important than exercise
  - Staying below the anaerobic threshold by using HR pacing reduced PEM episodes
  - Reducing the amount of aerobic exercise helped to reduce PEM episodes
  - Virtual/telehealth appointments were effective
  - Patient education was a vital aspect of rehabilitation
  - Improvement in symptoms and function can occur even >1 year after initial onset
  - Screening for PEM was essential in directing the rehabilitation approach
  - PT's can do more than just "exercise patients"
  - If the PT is not knowledgeable about PEM, they may cause more harm than good
  - Ensure that the PT you refer to understands PEM and how to provide effective treatments

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Occupational Therapy (OT)

Goal: Improve Quality of Life through participation in **meaningful** & **purposeful** activities

https://solidagovc.com/blog/a-closer-look-at-occupations-adlswhat-does-that-mean

Occupational Therapist's Toolbox

Frame of Reference (FOR): therapeutic basis for supporting strengths and deficits

FOR Examples:

- Sensory Integration (SI)
- Proprioceptive Neuromuscular Facilitation (PNF)
- Neuro-developmental Treatment (NDT)
- Biomechanical
- Compensatory
- Occupational Adaptation
- Model of Human Occupation (MOHO)

Conventional OT/PT Guidelines

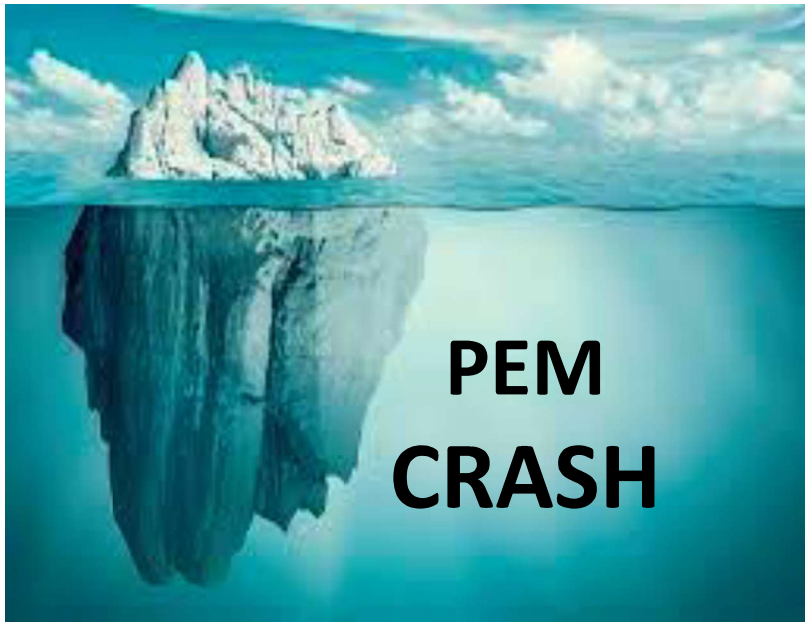
without consideration for PEM

Improve/Increase activity ✚ Restore health & function ➡ Goal: Improve Quality of Life

Physician's Referral: Occupational Therapy and Physical Therapy for assessment and treatment, incorporating graded exercise or activity as indicated for enhanced daily functioning.

OT/PT treatment strategies focus on "what is observed"

- Graded Exercise Therapy (GET)
  - Increase strength
  - Range of motion
  - Endurance
- Cognitive Behavioral Therapy (CBT)
  - Coping strategies



PEM is NOT the result of deconditioning or false illness belief

Graded Exercise Therapy(GET): promotes scheduled increases in aerobic activity even when doing so causes symptoms.

Cognitive Behavioral Theory (CBT): changes the false illness beliefs (**cognitions**) and promotes increased activity (**behavior**).

GET & CBT Assumption

- Ignores ME/CFS's broad evidence of neurological, immunological, autonomic, and energy metabolism impairment.
- Suggests that ME/CFS fatigue and disability are the result of inactivity and deconditioning.
- Fails to improve functioning and is detrimental to the health of this patient population.

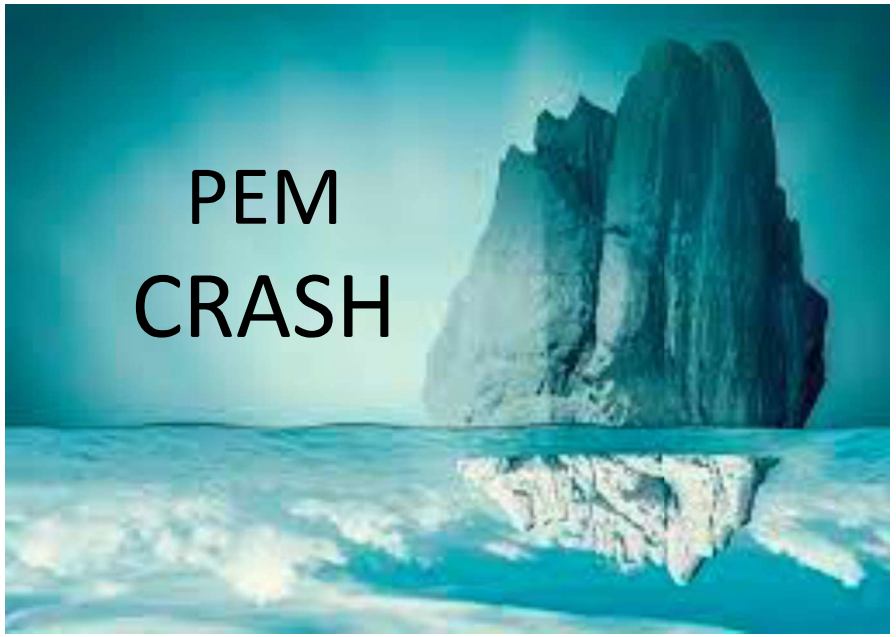
https://workwellfoundation.org/wp-content/uploads/2019/07/MECFS-GET-Letter-to-Health-Care-Providers-v4-30-2.pdf
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6482658/
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6482658/

Pacing for PEM: Flip the Iceberg

- Identify/determine immediate & delayed symptoms
- Prioritize/analyze activity within PEM limitations
- Manage pre-emptive and recuperative rest

+ Restore autonomy → **Goal:** Improve Quality of Life

Physician's Referral:
Occupational Therapy and Physical Therapy assessment to evaluate Post-Exertional Malaise (PEM), address symptoms, and implement pacing strategies for enhanced daily functioning.



Pacing

A strategy used for managing exertion over time

3 Categories of Pacing

- Pacing for individuals without significant health concerns
- Pacing for therapeutic strategies
- Pacing for PEM

SCREENING FOR PEM

What happens when you engage in normal (previously tolerated) physical/cognitive exertion/activity?

How much activity does it take to make you feel ill or trigger illness worsening?

How long does it take to recover from physical/cognitive effort?

Do you avoid or change certain activities because of what happens after you do them?

https://doi.org/10.1016/j.mayocp.2021.07.004

ME/CFS Severity

75% unable to work.

25% homebound or bedridden.

https://www.actionforme.org.uk/uploads/pdfs/functional-ability-scale.pdf

Functional ability scale

100% FULLY RECOVERED No symptoms, even following physical or mental activity. Able to study (or work) full time without difficulty, and enjoy a social life.	40% MODERATE TO SEVERELY AFFECTED Moderate to severe symptoms following any activity. Care must be taken not to overdo anything at this stage. Not confined to the house, but unable to walk much more than 50-100m, usually requiring aids such as walking stick/crutches. May manage a wheelchair trip to the shops on a quiet day, and 3 or 4 regular rest periods are needed during the day. Only one 'large' activity possible per day – eg. friend dropping by, or doctor's visit, or short home study (half hour at a time), with space usually requiring rest day/s between.
95% VIRTUALLY RECOVERED No symptoms at rest. Mild symptoms following physical or mental activity – tire rather easily but fully recovered next day. Able to study or work full time without difficulty, but social life is slightly restricted.	30% SEVERELY AFFECTED Moderate to severe symptoms at rest. Severe symptoms following any physical or mental activity. Usually confined to the house but may occasionally take a quiet wheelchair ride or very short, gentle walk in the fresh air. Most of the day resting. Very small tasks possible but mental concentration poor and home study difficult.
90% MILDLY AFFECTED No symptoms at rest. Mild symptoms following physical or mental activity - tire easily. Study/work full time with some difficulty. Social life rather restricted with gradual recovery over two/three days.	20% SEVERELY AFFECTED Fairly severe symptoms at rest. Weakness in hands, arms or legs may be restricting movement. Unable to leave the house except very rarely. Confined to bed/settee most of the day but able to sit in a chair for a few, short periods. Unable to concentrate for more than one hour a day but can read for about five to 10 minutes at a time.
80% MILDY AFFECTED Mild symptoms at rest, worsened to moderate by physical or mental activity. Full time study at school/college is difficult, as is full-time work, especially if it is a crowded, noisy or busy environment. Home tuition or part-time study without difficulty.	10% VERY SEVERELY AFFECTED Severe symptoms following any activity. Weakness and pain in arms or legs. In bed most of the time but feeling more stable and less dizzy. No travel outside the house. Concentration very difficult indeed. A friend can be seen for ten minutes or so.
70% MODERATELY AFFECTED Mild symptoms at rest, worsened to severe by physical or mental activity. Daily activity limited. Part time study at school/college is very tiring, and may be restricting social life. Part time work may be possible for a few hours in the day. With careful pacing of activities and rest periods, you may discover windows of time during the day when you feel significantly better. Gentle walking or swimming can be beneficial.	5% VERY SEVERELY AFFECTED Severe symptoms almost continuously, but may be possible to be propped up in bed for very short periods. Weakness and pain in arms or legs can give rise to paralysis; dizziness and nausea. Small, personal care may be possible (e.g. if washing equipment placed on the bed it may be possible to wash some parts of the body). As with 0%, sudden jerking movements can be a problem and what may be described as panic attacks are felt. No TV is possible but a little quiet music or audio book may be listened to for a few minutes. A friend can be seen for a minute for a hug and a few words.
60% MODERATELY AFFECTED Mild to moderate symptoms at rest. Increasing symptoms following physical or mental activity. Daily activity very limited. Study with others or work outside the home difficult unless additional support is available (such as use of a wheelchair/quiet room for a rest period). Short (I-2 hours) daily home study/work may be possible on good days. Quiet, non-active social life possible.	0% VERY SEVERELY AFFECTED Severe symptoms on a continuous basis. In bed constantly, feeling extremely ill even with permanent rest. Severe dizziness makes it almost impossible to be propped up in bed for longer than a few minutes at a time. Light and noise are very painful to the eyes and ears - curtains are closed and earplugs are needed. Severe pain almost anywhere in the body with the skin feeling very cold and extremely sensitive to touch. Unable to care for self at all; washing needs to be done a tiny bit at times throughout the day. Nausea and severe fatigue make eating extremely difficult. Liquid based food preferred– little and often. Occasionally, nasal feeding tubes are required when the energy to chew is completely spent. Any stimulus worsens the feeling of being severely ill, with no movement in the bedroom preferred. Any visitor to the room is almost impossible. Talking, even to the carer/family, is often impossible. This is often misread as being "selective mute." Severe adrenaline rushes felt with heightened sensitivity; sleep pattern often completely reversed.
50% MODERATE TO SEVERELY AFFECTED Moderate symptoms at rest. Increasing symptoms following physical or mental activity. Midday rest may still be needed. Simple, short (1hr) home study/home activity possible, when alternated with quiet, non-active social life. Concentration is limited. Not confined to the house, but may be unable to walk much beyond 100-200m without support. May manage a trip to the shops in the wheelchair.	

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Mild ME/CFS

Photo source provided

Photo source provided

Photo source provided

Photo source provided

mobile and self-caring

able to manage light domestic & ADL tasks with modifications

employment & school duties performed with modifications

significantly reduced activity and frequent breaks

Moderate ME/CFS

- reduced mobility, may use mobility device for energy conservation
- 50% reduction in pre-illness activity
- unable to work or attend school full-time
- require many extended rest periods
- Home tethered

Photo source provided

Photo source MEAction UK

Photo source provided

Photo source provided

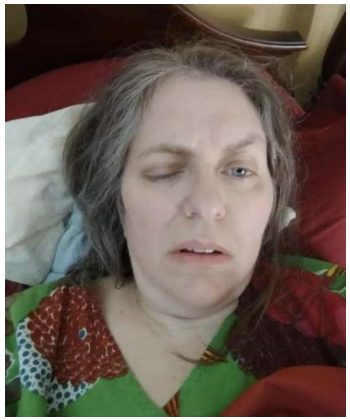

Photo source provided

Photo source provided

Photo by ME/CFS South Australia Inc

Photo source provided

Severe ME/CFS

able to carry out minimal ADLs with a moderate amount of assistance. Requires daily caregiver assistance

severe cognitive difficulties: decreased information retention and deficits in short-term memory and word-finding

may need support for positioning and movement

homebound and bed tethered

Very Severe ME/CFS

- unable to mobilize or carry out any ADLs for themselves
- needs assistance with basic functions and position care
- often extremely sensitive to stimuli
- bed ridden and limited bed mobility

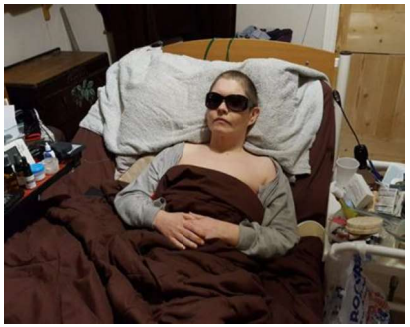

Photo source a journey through the fog

Photo source Janet Dafoe

Photo source provided

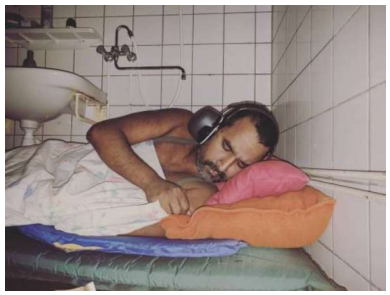

Photo source Anil van der Zee

PATIENT #1

40 yr. old female
lives with husband and dog in an urban city second-floor apartment
COVID Infection 2022

Prior to 2022 COVID infection	Medical history	Activity level:
	• Migraines	• Full time employment • No modifications or accommodations for active lifestyle

Current diagnosis:

- COVID related ME/CFS
- POTS
- EDS
- MCAS
- Migraine

Primary Symptoms:

- Fatigue
- Cognitive brain fog
- Headaches/migraines
- Difficult to transition into sleep/startles awake
- General body pain

Activity Level:

- **ADLs**: Baseline: Mild assistance for ADLs (set up and materials); Crash: moderate assistance for basic ADLs (bedside and support to walk between rooms)
- **IADLs**: Baseline: moderate support for single step IADLs (home care, food management, transportation); Crash: unable to perform IADLs
- All activities are planned, considering the necessary rest periods both before and after exertion.
- Delayed PEM is 24-36 hours post activity.

PATIENT #2

18 yr. old male
lives with parents, 14 yr. old sibling, and dog
bedroom is on the 3rd floor of a single-family home
illness onset: unknown infection 2021

Medical history

- Healthy childhood; occasional "bug" but no concerns
- Possible hypermobility but no functional concerns

Activity level:

- Full time highschool student
- Athlete in varsity swimming
- No modifications or accommodations for active lifestyle

Current diagnosis:

- Unknown illness related ME/CFS
- POTS
- EDS
- MCAS

Primary Symptoms:

- Fatigue
- Cognitive brain fog
- Abdominal pain
- Fluctuating sleep cycles: sleeps 14-18 hours; unable to transition into sleep.
- General body pain

Activity Level:

- **ADLs**: Baseline: Moderate assistance for self-care activities (bedside single step activities); Crash: not able to perform self-care activities (bowel and bladder functions are bedside with max assistance)
- **IADLs**: unable to perform
- **Communication**: Baseline: receptive and expressive communication are verbal with 10-15 interaction. Crash: expressive communication with hand gestures and non-verbal expression; receptive communication: picture charts and 1–2-word commands.
- All self-care activities, nutrition, bowel and bladder regimen are planned, considering the necessary rest periods both before and after exertion.
- Delayed PEM is 2-12 hours post activity; lasting days to weeks.

Making order out of *chaos*

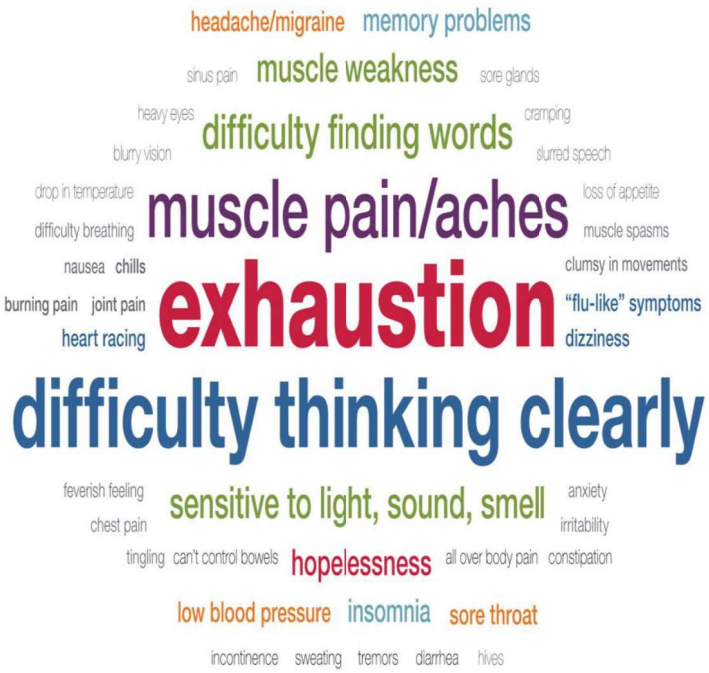

Image credit: https://www.ninds.nih.gov/news-events/press-releases/nih-study-details-self-reported-experiences-post-exertional-malaise-mecfs

Etiology and Pathophysiology

- Immunological changes, including autoimmunity
- Neurological and Cognitive Impairment
- Sleep Abnormalities
- Dysfunction of the Autonomic System
- Cardiovascular Abnormalities
- Mitochondrial/Energy Production Abnormalities

Symptom Time Course

Identify the varying patterns of symptoms and the time course of onset

Immediate symptoms: "doing too much", how much is in the battery before the symptoms present? These are the activity "stop signs".

Delayed symptoms: the "crash", how long does it take until I feel the impact?

Identify Immediate Response Symptoms "Stop signs"

What 3 symptoms do you feel when you have "done too much"?

Describe severity of symptoms
0 = no symptoms; 10 = very severe

Physical exertion	Cognitive exertion	Social/Emotional exertion
1.	1.	1.
2.	2.	2.
3.	3.	3.

PATIENT #1

IMMEDIATE PEM SYMPTOMS "STOP SIGNS"



Physical exertion	Cognitive exertion	Social/Emotional exertion
1. Heart rate exceeding 110 bpm	1. Head buzzing	1. Tinnitus (ears ringing)
2. Dizzy/lightheaded	2. Word find/slow expressive language	2. Headache
3. Foggy thoughts	3. Coat hanger pain in neck/shoulder	3. Slow thinking/hard to follow conversation

Task Analysis

must do, **might** do, **may** do

Prioritize: Where is this task on your To Do list?
Is this task meaningful and purposeful?

Activity Analysis
"Stressors"

Plan
What will it take to get the activity done?

Pace
How can **I** get this done with my energy & symptoms?

Adaptations & Modifications

Activity Analysis
Stressors

Time:
- Frequency
- Duration
- Time of day
- Time between activity and rest

Physical:
- Biofeedback (body's autonomic response)
- Location of performance
- Body mechanics
- Positioning

Cognitive:
- Perception
- Attention
- Processing
- Memory

Sensory:
- Visual
- Auditory
- Olfactory (smell)
- Gustatory (taste)
- Tactile (touch)
- Vestibular (balance)
- Proprioception (awareness of body positioning)
- Interoception (internal awareness)

Emotional:
- Eustress
- Distress

Environment:
- Weather
- Chemical/mold/pollution

Amy Mooney, MS OTR/L 12/7/2023

PATIENT #1

Activity Analysis: Stressors

Time	Physical	Cognitive	Sensory	Emotional	Environmental
Frequency, duration, time of day, time between activity and rest	Biofeedback, location of performance, body mechanics, positioning	Perception, attention, processing, memory	Visual, auditory, olfactory, gustatory, tactile, vestibular, proprioception, interoception	Eustress, distress	Weather, chemical, mold, pollution

ADL Functional Performance

Grooming: "Baseline"

- Shower/bathe: 1-2 times per week. Uses a shower stool to sit for bathing tasks.
- Wash hair in separate task from body washing.
- Performs am/pm washing routine (face, teeth) 3-5 min seated activities with materials collected nearby.
- Wears lounge clothes/pajamas for home dressing; she wears easy to don/doff items with soft fabrics. E.C. keeps frequently worn items easily accessible and nearby.
- Independently uses the bathroom for bowel and bladder routines. Bathroom is 10 steps from bedroom.

Grooming: "Crash"

- Brush teeth with material set up for bedside activity.
- Wash face with simplified 1-2 step seated activity.
- Change single layer clothing one time per 24 hours.
- Requires assistance/support for walking between adjacent rooms.

Types of Rest

For those without PEM

Recharging Rest

Slow or cease work or movement to relax, refresh oneself, or recover strength.

Convalesce Rest

Recovery of one's health and strength over a period after an illness or injury.

For those with PEM

Radical Rest for PEM

Aggressive energy conservation process involving past, present, & future exertion

Pre-emptive Rest

- preventative measure
- planned scheduled strategy for reducing or preventing symptoms & stabilizing baseline function

Recuperative Rest

- rest from exceeding baseline
- rest from a crash with focus on returning to baseline function

Patient #1 PEM Symptom Time Course

Activity Choose one of the prioritized activities
Cognitive: Online shopping for family gifts
Physical: In-person doctor visit (20 min 2-way transport)
Social/Emotional: At-home "date" with husband

→

Immediate Symptoms "Stop Signs"
Tinnitus (ear ringing)
Headache
Slow thinking/hard to process conversation

→

Delayed PEM symptoms 24-36 hour post activity
Migraine
Sore throat, body aches, flu-like symptoms
Body feels "cemented"

Pre-emptive Rest	Activity	Day 1 Recuperative Rest	Day 2 Recuperative Rest	Day 3 Recuperative Rest	Day 4	Pre-emptive Rest and back to baseline
Plan and prep for activity	At-home dinner date	Immediate PEM	Delayed PEM symptoms	Delayed PEM Continues	PEM lifting; starting to return to baseline	Plan and prep for future activity

Activity of Daily Living (ADL) & Instrumental ADL (IADL)

This summary will outline S.C.'s baseline functional capacity for activities of daily living and describe the repercussions of surpassing this exertion threshold, commonly referred to as the "crash."

Grooming/self-care Bathing, toileting, dressing, haircare	At baseline S.C. undertakes basic grooming tasks, incorporating extra time and breaks for rest and symptom management. However, when her symptoms are heightened to a severe level, she loses the ability to independently perform any grooming activities and necessitates maximum assistance for basic tasks such as teeth and face washing, as well as clothing changes. • Shower/bathe: 1-2 times per week. Uses a shower stool to sit for bathing tasks. • Wash hair in separate task from body washing. • Performs am/pm washing routine (face, teeth) 3-5 min seated activities with materials collected nearby. • S.C. wears lounge clothes/pajamas for home dressing; she wears easy to don/doff items with soft fabrics. S.C. keeps frequently worn items easily accessible and nearby. • During baseline and a "crash", S.C. independently uses the bathroom for bowel and bladder routines. Bathroom is near bedroom. **FUNCAP55** questionnaire reports S.C. performs activities with functional consequences on a 0-6 scale. 0 = cannot do activity; 6 = unproblematic/does not affect other activities) • Shower seated with assistance: 4 limits other activities on same day. • Shower standing up: 3 can do little else on same day. • Getting up and staying out of bed/supine for approximately 1 hour: 4 limits other activities on same day. • Getting dressed in casual clothing: 5 rarely affects other activities. **FUNCAP55** Scores for upright positioning • Sitting in an upright chair with feet on floor for approx. 10 mins: 4 limits other activities on same day. • Sitting in an upright chair with feet on the floor for approx. 2 hours: 3 can do little else on same day. • Standing for approx. 5 mins: 4 limits other activities on same day. • Standing for approx. ½ hour: 1 capacity will be severely reduced for at least three days.
Time management Schedules, appointments, routines, events	S.C. organizes her schedule, incorporating upcoming events, appointments, and prioritized tasks. Following skills acquired during occupational therapy sessions, S.C. employs techniques to plan for rest periods both before and after activities, considering potential symptom exacerbation. S.C. adeptly identifies signs of symptoms in relation to various exertion stressors, enabling her to manage her schedule more effectively.
Food management Menu planning, shop, transport, prepare, eat, cleanup	S.C. and her husband use food delivery services for grocery shopping. Together with her husband, S.C. chooses items and plans menus for the upcoming week. S.C.'s husband manages grocery delivery, storing items, and preparing multi-step meals. At baseline, S.C. heats prepared foods, orders from restaurants, makes simple two-step meal. During a crash, S.C. requires all food items prepared and served by caregiver. **FUNCAP55** questionnaire reports S.C. performs activities with functional consequences on a 0-6 scale. 0 = cannot do activity; 6 = unproblematic/does not affect other activities) • Making a simple cold meal (sandwich, cereal): 5 this task rarely affects other activities • Cooking a simple hot meal: 4 S.C. limits other activities on same day. • Cooking a complicated meal from scratch: 0 S.C. is unable to do activity.
Caring for home laundry, cleaning, maintenance, financial management	At baseline, S.C. performs household responsibilities by assisting her husband with small tasks such as placing dishes in the dishwasher, cleaning the counter, and feeding the dog. All other household tasks are undertaken by her husband. During a crash, S.C. requires assistance for all aspects of home management. **FUNCAP55** questionnaire reports S.C. performs activities with functional consequences on a 0-6 scale. 0 = cannot do activity; 6 = unproblematic/does not affect other activities) • Light housework (dusting, tidying up): 2 S.C. can do little else on the same day and for one or two days after. • Heavier housework (washing floors, vacuuming): 0 S.C. is unable to do activity. • Laundry (sorting, folding): 2 S.C. can do little else on the same day and for one or two days after.
Transportation Driving, navigation, car maintenance	At baseline, S.C. drives to a familiar location within 10-15 mins from home for a single stop trip. S.C. requires a driver for all novel or longer distance trips. During a crash, S.C. requires full assistance for transportation; unable to navigate directions to familiar location, unable to operate a vehicle due to worsening symptoms. During a crash, outings or appointments are rescheduled or cancelled. **FUNCAP55** questionnaire reports S.C. performs activities with functional consequences on a 0-6 scale. 0 = cannot do activity; 6 = unproblematic/does not affect other activities) • Stepping outside home: 6 does not affect other activities • Going on a necessary errand (appointments): 2 S.C. can do little else on the same day and for one or two days after. • Shop for groceries: 0 S.C. is unable to do activity. • Riding as a passenger for 15 mins: 5 rarely affects other activities. • Using public transportation: 0 unable to do activity.
Hobbies/recreation	S.C. participates in a short in-person or virtual check-in visit with family or friends, lasting 15-30 minutes, occurring once or twice a month. She employs planning and pacing strategies for these social interactions, thoughtfully taking into account the timing, duration, and physical exertion involved, with considerations for positioning. These strategies offer support for S.C. to engage in social interactions while being mindful of her symptom limitations. In terms of physical activity, S.C. incorporates a routine of gentle stretching lasting 1-2 minutes, along with the movement necessary for self-care activities. **FUNCAP55** questionnaire reports S.C. performs activities with functional consequences on a 0-6 scale. 0 = cannot do activity; 6 = unproblematic/does not affect other activities) • Walking a short distance indoors, from one room to another: 5 rarely affects other activities. • Walking short continuous distance approx. 100 yds: 4 must limit other activities on the same day. • Walking approx. ½ mile mostly level terrain: 1 capacity will be severely reduced for at least 3 days. • Walking approx. ½ mile slight incline terrain: 0 unable to do activity. • Physical activity with increased heart rate for approx. 15 mins: 1 capacity will be severely reduced for at least 3 days. • Physical activity with increased heart rate for approx. ½ hour: 0 unable to do activity. • Doing enjoyable leisure activities (going to café, non-essential shopping): 0 unable to do activity. • Participating in organized leisure activities (classes, sports): 0 unable to do activity.
Sleep	S.C. takes medication and sleep hygiene strategies to aid in both the initiation and maintenance of sleep. Transitioning to sleep poses a challenge for her, and she frequently experiences disruptions throughout the night, struggling to remain asleep for extended periods. Achieving restful naps is also challenging and is often not realized.
Concentration/attention	S.C.'s main symptoms revolve around challenges in processing and expressing verbal and written communication, accompanied by brain fog, migraines, and tinnitus. These symptoms escalate with both physical and cognitive exertion. At baseline, S.C. can read and comprehend text for 10-20 minutes with light attention to detail, such as in social media and news reports. However, for more intensive reading, like academic or research material, she needs a focused environment with limited external sounds and stimuli for 5-10 minutes so not to exacerbate symptoms. If S.C. exceeded her baseline exertion threshold, she experiences an inability to process written and verbal communication, resulting in worsening of her symptoms. **FUNCAP55** questionnaire reports S.C. performs activities with functional consequences on a 0-6 scale. 0 = cannot do activity; 6 = unproblematic/does not affect other activities) • Reading a short text (text, social media): 5 rarely affects other activities. • Reading fiction/light reading: 4 limit other activities on same day. • Reading and understanding a non-fiction text (one page length text): 3 can do little else on same day. • Using social media to stay in touch with others: 3 can do little else on same day. • Watching entertainment show (30 min): 3 can do little else on same day.

 Amy Mooney, MS OTR/L 12/7/2023

Functional Capacity 27 and 55 Questionnaire

FUNCAP27. Questionnaire on functional capacity

This questionnaire evaluates your functional capacity for a range of activities. No days are the same. Base your response on an average day during the last month – not the worst nor the best. If a question concerns an activity that you have not performed, such as showering while seated because you always shower standing up, then score as you think this activity would have affected you.
Items described include necessary activities to perform them. Example: *"Going to a shop for groceries"* includes getting dressed and as necessary travelling.

It is a good idea to answer the questionnaire together with someone who sees you in everyday life.

What are the consequences for you if you perform the activities described below?
To what extent does this affect how much else you can do?

A to H: Scored 0-6:
0: I cannot do this
1: My capacity will be severely reduced for at least three days
2: I can do little else on the same day and for one to two days afterwards
3: I can do little else on the same day
4: I must limit other activities on the same day
5: This rarely affects other activities
6: Unproblematic – does not affect other activities

		0	1	2	3	4	5	6
A	**Personal hygiene / basic functions**							
1	Using the toilet (not bedpan or bedside commode)							
2	Showering standing up							
3	Getting dressed in regular clothes							
B	**Walking – moving around**							
4	Walking a short distance indoors, from one room to another							
5	Walking between approx. 100 m and 1 km on level ground (length of 1 to 10 football fields)							
6	Physical activity with increased heart rate, for approx. 15 min							
C	**Being upright**							
7	Sitting in bed for approx. ½ hour							
8	Sitting in an upright chair (dining chair) with feet on floor for approx. 2 hours							
9	Standing up for approx. 5 minutes, e.g. while queuing or while cooking							
D	**Activities in the home**							
10	Heavier housework (washing floors, vacuuming etc.) for approx. 1/2 hour continuously							
11	Cooking a complicated meal from scratch, approx. 1 hour of preparation							
E	**Communication**							
12	Having a conversation for approx. 5 minutes							
13	Participating in a conversation with three people for approx. 1/2 hour							
14	Participating in a dinner party, party or family event							
F	**Activities outside your home**							
15	Stepping right outside your home							
16	Going to a shop for groceries							
17	Using public transport (bus or train)							
18	Participating in organized leisure activities such as classes, sports etc.							
G	**Reactions to light and sound**							

		0	1	2	3	4	5	6
19	Staying in a room with normal lighting, without sunglasses, for approx. 1 hour							
20	Staying outdoors in daylight without sunglasses for approx. 2 hours							
21	Staying in a noisy environment, (shopping mall, café or open plan office) for approx. 1 hour							
H	**Concentration**							
22	Reading a short text, such as a mobile phone text message							
23	Reading and understanding a non-fiction text, such as an official document one A4 page long							
24	Using social media to stay in touch with others							
25	Focusing on a task for approx. 10 minutes continuously							
26	Focusing on a task for approx. 2 hours continuously							
27	Managing a full working day (non-physical work such as office work, classes or lectures)							

FUNCAP55. Questionnaire on functional capacity

This questionnaire evaluates your functional capacity for a range of activities. No days are the same. Base your response on an average day during the last month – not the worst nor the best. If a question concerns an activity that you have not performed, such as showering while seated because you always shower standing up, then score as you think this activity would have affected you. Items described include necessary activities to perform them. Example: *"Going to a shop for groceries"* includes getting dressed and as necessary travelling.

It is a good idea to answer the questionnaire together with someone who sees you in everyday life.

What are the consequences for you if you perform the activities described below?
To what extent does this affect how much else you can do?

A to H: Scored 0-6:
0: I cannot do this
1: My capacity will be severely reduced for at least three days
2: I can do little else on the same day and for one to two days afterwards
3: I can do little else on the same day
4: I must limit other activities on the same day
5: This rarely affects other activities
6: Unproblematic – does not affect other activities

		0	1	2	3	4	5	6
A	**Personal hygiene / basic functions**							
1	Using the toilet (not bedpan or bedside commode)							
2	Brushing your teeth without assistance							
3	Showering seated, with assistance							
4	Showering seated, without assistance							
5	Showering standing up							
6	Getting up and staying out of bed for approx. 1 hour							
7	Getting dressed in regular clothes							
B	**Walking – moving around**							
8	Walking a short distance indoors, from one room to another							
9	Walking a short continuous distance, approx. 100 m (length of a football field), in- or outdoors							
10	Walking between approx. 100 m and 1 km on level ground (length of 1 to 10 football fields)							
11	Going for a longer walk. Approx. 1 km (0.6 mile), mostly level ground							
12	Going for a longer walk. Approx. 1 km (0.6 mile), hilly or varied terrain							
13	Physical activity with increased heart rate, for approx. 15 min							
14	Physical activity with increased heart rate, for approx. ½ hour							
C	**Being upright**							
15	Sitting in bed for approx. ½ hour							
16	Sitting in an upright chair (dining chair) with feet on floor for approx. 10 minutes							
17	Sitting in an upright chair (dining chair) with feet on floor for approx. 2 hours							
18	Standing up for approx. 5 minutes, e.g. while queuing or while cooking							
19	Standing up for a long time – approx. ½ hour							
D	**Activities in the home**							
20	Light housework (dusting, tidying etc.) for approx. 1/2 hour continuously							

		0	1	2	3	4	5	6
21	Heavier housework (washing floors, vacuuming etc.) for approx. 1/2 hour continuously							
22	Laundry (sorting, hanging up to dry and folding)							
23	Making a simple cold meal, such as a sandwich or cereal							
24	Cooking a simple hot meal							
25	Cooking a complicated meal from scratch, approx. 1 hour of preparation							
E	**Communication**							
26	Speaking a few words							
27	Having a conversation for approx. 5 minutes							
28	Having a conversation for approx. ½ hour							
29	Writing a short message by hand							
30	Participating in a conversation with three people for approx. 1/2 hour							
31	Socializing with friends for approx. 1 hour							
32	Participating in a dinner party, party or family event							
F	**Activities outside your home**							
33	Stepping right outside your home							
34	Going on a necessary errand, such as a doctor's appointment							
35	Going to a shop for groceries							
36	Doing enjoyable leisure activities, such as going to a café, non-essential shopping etc							
37	Riding as a passenger in a car for approx. 15 minutes							
38	Using public transport (bus or train)							
39	Participating in organized leisure activities such as classes, sports etc							
G	**Reactions to light and sound**							
40	Staying in a room with dim lighting for approx. 1/2 hour							
41	Staying in a room with normal lighting, without sunglasses, for approx. 1 hour							
42	Staying outdoors in daylight without sunglasses for approx. 2 hours							
43	Staying in an environment with the sound of a few people in quiet conversation for approx. 1 hour							
44	Staying in a noisy environment, (shopping mall, café or open plan office) for approx. 1 hour							
45	Going to a cinema, concert etc. with high noise levels							
H	**Concentration**							
46	Reading a short text, such as a mobile phone text message							
47	Reading fiction/light reading							
48	Reading and understanding a non-fiction text, such as an official document one A4 page long							
49	Performing simple mental arithmetic							
50	Writing short messages on a smartphone or tablet							
51	Using social media to stay in touch with others							
52	Watching TV (series, news)							
53	Focusing on a task for approx. 10 minutes continuously							
54	Focusing on a task for approx. 2 hours continuously							
55	Managing a full working day (non-physical work such as office work, classes or lectures)							

https://www.frontiersin.org/articles/10.3389/fneur.2023.1247698/full?fbclid=IwAR2kfjA2ZBp5riRxahjCEubWk-8fnBXJ8DyKxV8rgwfKV4G-4aaV8FPI7IE