



Massachusetts ME/CFS & FM Association

Sunday Conversations

February 19, 2023

created by Amy Mooney, MS OTR/L

Pacing for PEM

An OT and PT perspective on what it is and how you can use pacing strategies in your daily life

Lead presenter:
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Contributing presenters:
Sallie Rediske, MPT
Melinda Maxwell, PT MA

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Presentation Outline

- OT & PT Traditional Guidelines
- Flipping the Iceberg for PEM
- Severity & Symptoms of ME/CFS
- Pacing for PEM
- Task & Activity Analysis

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ME/CFS is NOT the result of false beliefs, deconditioning

Cognitive Behavioral Therapy & Graded Exercise Therapy

Ignores 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

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Not All Fatigue is ME/CFS

Fatigue

Chronic Fatigue

Chronic Fatigue Syndrome

Post-Viral (infection) Fatigue

- Long COVID with Post-Viral Fatigue
- Long COVID with PESE (meeting diagnostic criteria for ME/CFS)

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ME/CFS Hallmark symptom Post-Exertional Malaise (PEM)



Credit: Daniel Horowitz for NPR

Crash, Relapse, Collapse

PwME describe PEM as
having run a marathon,
with the flu,
a hangover,
and then getting hit by a bus.

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ME/CFS is
NOT

- Being tired, worn out, or sleepy
- Deconditioned or out of shape
- Having fears or anxiety of activity

ME/CFS
is

- Exertion intolerance
- Worsening of symptoms following any stressor
- Inability to produce energy on a cellular level

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Occupational Therapy & Physical Therapy

What does OT & PT look like for pwME?

How can OT & PT support pwME?

Restore, Rebuild, Redefine
occupations lost due to the *unique*
characteristics of ME/CFS

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Goal of OT:

*participation in
meaningful &
purposeful
activities*

Occupation is **meaningful** when it allows an individual to fulfill a goal that is personally or culturally important.

Occupation is **purposeful** when it is determined by the individual's unique needs and interests in a particular environmental context.

<https://wfot.org/about/about-occupational-therapy>

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Goal of PT:
*preservation, restoration, or enhancement of **functional** & **personally relevant** movement*

PT addresses components and skills needed to perform **functional** tasks such as walking, standing, sitting, and transitions such as rolling and sit ↔ stand.

Goals should be patient-specific, addressing **personally relevant** movement for improved quality of life.

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***Uniquely* Occupational Therapy**

OT Evaluation

- Assess performance
 - Motor
 - Cognitive
 - Sensory
- Identify supports & barriers
- Determine **frames of reference** to set therapy guidelines

»»»

Frames of Reference (FoR)
 structure/foundation to guide therapeutic intervention

- Sensory Integration
- Neuro-Developmental Treatment
- Proprioceptive Neuromuscular Facilitation
- Biomechanical
- Cognitive-Behavioral

Goals

- Support the individual's meaningful & purposeful occupations
- Improving quality of life

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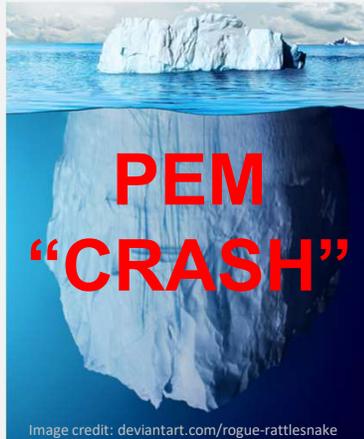
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Traditional OT & PT Guidelines

Improve/increase activity performance → restore health & functioning

Physical & Psychological Strategies:

- increase strength
- range of motion
- endurance
- coping strategies
- illness beliefs



PEM is out of view

- the “crash” is usually out of sight from providers post activity: hours, days, weeks
- patient too unwell to maintain therapy schedule
- therapist assumes patient is well & achieved goals, or is not motivated to continue

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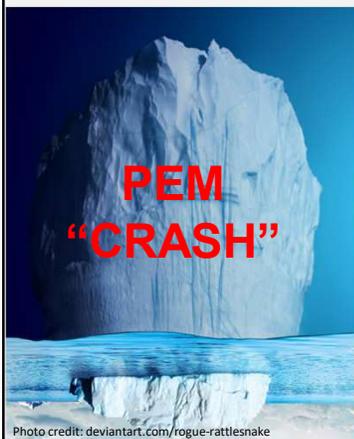
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Flipping the Iceberg for PEM

by Amy Mooney, MS OTR/L

Manage symptoms, manage activity within PEM limitations & restore autonomy →

Improved Quality of Life



Identify PEM

- Severity
- Symptoms

Core Occupations

Develop treatment plan w/in limitation of PEM

- Symptom management
- Pacing for PEM
- Modification & adaptations
- Patient & caregiver education

Utilize Strategies

- Frames of Reference
- Sensory integrative
- Proprioceptive Neuromuscular Facilitation
- Neurodevelopmental Treatment
- Biomechanical
- Cognitive-behavioral

Utilize Guidelines/Protocols

- Heart Rate Biofeedback
- Comorbid disease treatments

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Personalized Model of Care

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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>



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Identify PEM

Post Exertional Malaise

Determine Severity

- **Quantity**
 - What is the battery charge?
 - What is the threshold?
- **Quality**
 - How sensitive to exceed threshold?

Identify Symptoms

- “If you had a magic wand...”

Core Occupations

- How are the symptoms affecting the ability to perform purposeful and meaningful roles?

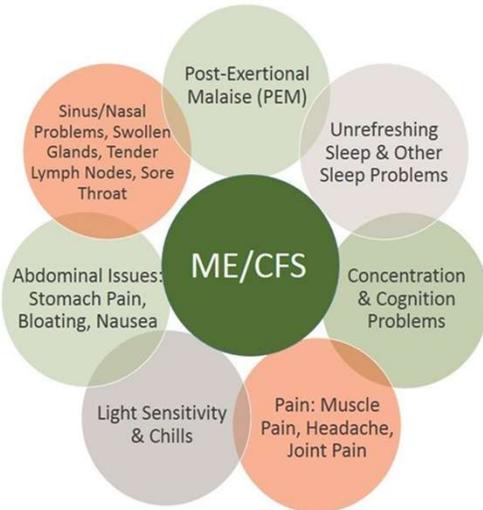


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ME/CFS Core Symptoms



Additional symptoms:
 Motor and Perceptual Disturbances
 Orthostatic Intolerance

Frames of Reference: example
 Sensory Integration
 NDT
 PNF
 Cognitive Disabilities
 Biomechanical
 Cognitive-Behavioral

<https://solvecfs.org/me-cfs-long-covid/about-the-disease>

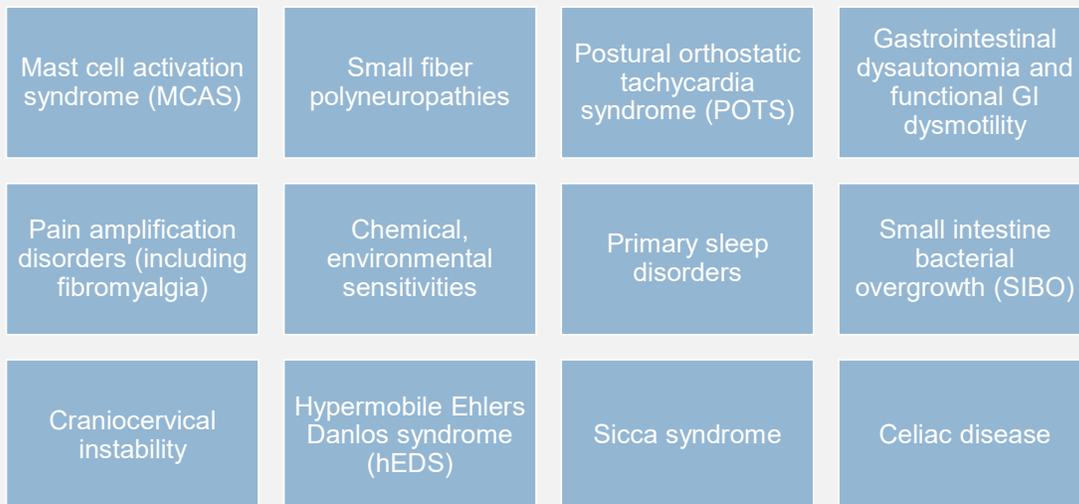


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Common Comorbid Conditions in ME/CFS



BatemanHorneCenter.org



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Mild ME/CFS

- 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

Photo source provided

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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

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Severe ME/CFS



Photo source provided



Photo source provided



Photo by ME/CFS South Australia Inc



Photo source provided

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



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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



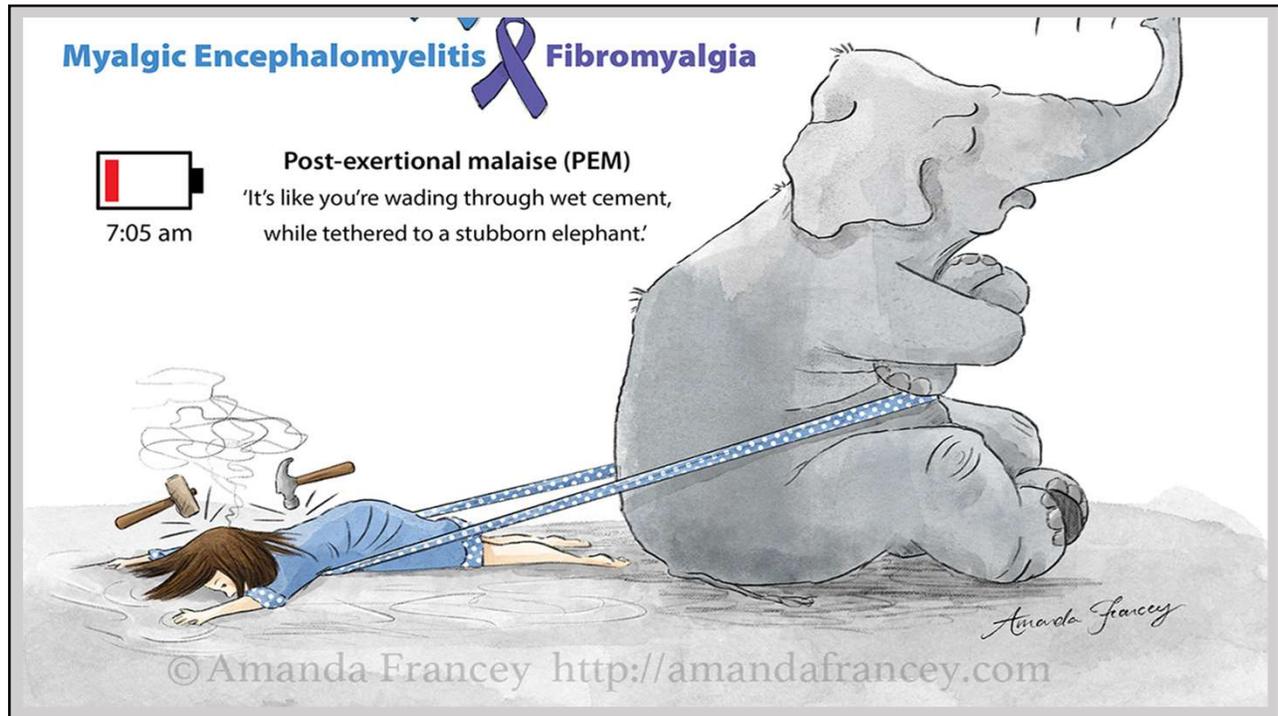
Photo source Anil van der Zee



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Pacing

A strategy used for managing exertion over time

3 Categories of Pacing

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

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Pacing for PEM



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

Plan

What will it take to get the activity done?

Pace

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



Adaptations & Modifications



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Activity Analysis for PEM



Sensory

Visual
Auditory
Touch
Smell
Taste
Proprioception



Cognitive

Memory & Learning
Language
Executive Functions
Complex Attention
Social Cognition
Visual Perception



Physical

Gross Motor
Fine Motor
Autonomic Regulation
Positioning



Social Emotional

Meaningful
Purposeful



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Adaptation & Modification

Simplify the components of the activity

Flexible timeline/schedule

Outsource or eliminate work

Provide assistive technology, electric tools, remotes, timers, recording tools, disability placards

Positional support, adjustable bed, wheelchair, commode/bedpan/catheter

Nutritional support



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Time



Physical



Environment



**Adaptations
Modifications**

Activity Analysis



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Activity Analysis: Body Wash

(example for person with Severe ME)

Time	Physical	Environment	Adaptations/Modifications
<input type="checkbox"/> Daily/every few days <input type="checkbox"/> Weekly/every few weeks <input type="checkbox"/> One body area at a time with breaks (hours-days) <input type="checkbox"/> Determine optimal time of day/evening	<input type="checkbox"/> Bedside <input type="checkbox"/> Utilize bolsters/wedges positioning support <input type="checkbox"/> Individual body parts <input type="checkbox"/> Limit movement and touch <input type="checkbox"/> Use slow and consistent pressure/touch	<input type="checkbox"/> Light: lighting dim/filtered/off, blackout window shades, no glare, no lighting from screens <input type="checkbox"/> Visual: solid color (no patterns) towel/sheets/clothing for patient & caregiver, use visual communication cues <input type="checkbox"/> Sound: soft/muted, communicate only when necessary <input type="checkbox"/> Smell: scent free materials, limit caregiver's perfumes/lotions, limit scents from nearby environment <input type="checkbox"/> Temperature: warm water, cover all body parts not being washed	<input type="checkbox"/> Perform routine/predictable task, give cue for new touch/movement/method <input type="checkbox"/> Wash individual body areas (privates, armpits). <input type="checkbox"/> Use washcloth or body wipes <input type="checkbox"/> Unscented soaps, mild cleansers. <input type="checkbox"/> Short haircut, silk pillowcase or cap to decrease tangles/matting <input type="checkbox"/> Use pads to keep bed dry/water absorption. <input type="checkbox"/> Caregiver max assist for set up, positioning and task.

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Modifications/Adaptations: Grooming/Washing

Provide shower chair and grab bars.	A transfer board can be used to transfer patients from the chair to the tub.	Eliminate bathroom mats and rugs that pose a fall risk.	Use a tub with a pillow/neck support. Elevate feet and begin with lukewarm water temperatures.
Perform sponge bath bedside or in bed to conserve energy.	Wash body parts at separate times (e.g., face one day, hair another).	Use soaps with low fragrance and that are hypoallergenic.	Use dry shampoo. Consider short hair.
Examine skin integrity and look for any lesions while bathing.	Rest immediately after washing and before dressing if needed. Wrap in blankets, dry towel, or robe and return to bed.	Consider bathing every few days instead of daily.	Consider remodeling bathrooms to increase accessibility.

Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome <https://doi.org/10.3390/healthcare9101331>

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OT/PT Guidelines for PEM

Identify PEM	Identify Core Occupations	Develop treatment plan w/in limitation of PEM	Utilize protocols & guidelines of co-morbid conditions
<input type="checkbox"/> Severity <input type="checkbox"/> Symptoms	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> Symptom management <input type="checkbox"/> Pacing for PEM <input type="checkbox"/> Modification & adaptations <input type="checkbox"/> Patient & caregiver education	<input type="checkbox"/> <input type="checkbox"/>


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Pacing for PEM

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Symptoms and Activity Level

List your activity interfering symptoms and level of functional performance (minimum/moderate/severe)

1.		
2.		
3.		

Was there a past exertion for which you are still recovering?
Is there a future exertion for which you are saving up your energy?

Task Analysis

Prioritize your To Do List: (hour/day/week snapshot)

Must Do	May Do	Wish to Do

Activity Analysis

Time	Physical	Environment	Adaptation/Modification
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>


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Activity Analysis for PEM

Time	Physical	Environment	Adaptations/Modifications
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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The care for ME/CFS & Long COVID

Goal

- Improve Quality of Life

Treatment Focus

- Manage symptoms
- Manage activity w/in PEM limitations
- Restore autonomy

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Facebook Group for peer-to-peer support

Physical Therapist/
Occupational Therapist
Resources for Treating ME/CFS

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Thank you for your attention

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