



Bateman Horne Center's Lunch and Learn

May 16, 2024

Staying within your Energy Envelope by modifying tasks

Presented by
Amy Mooney, MS OTR/L

www.OT4ME.com

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Myalgic Encephalomyelitis & Long COVID related ME



Photo by family



Photo by #MEAction

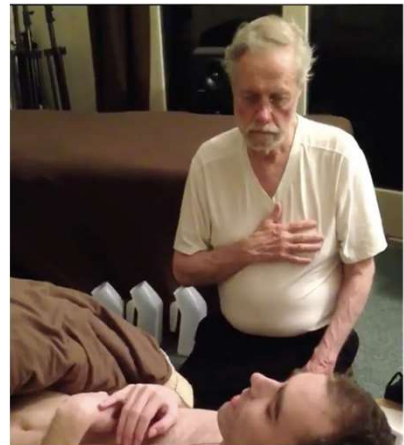



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PEM: so much more than fatigue

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Post-Exertional Malaise (PEM)

Post-Exertional Malaise (PEM), the hallmark symptom of ME/CFS, is an exaggerated response to exertion, characterized by both immediate and delayed effects.



Credit: Daniel Horowitz for NPR

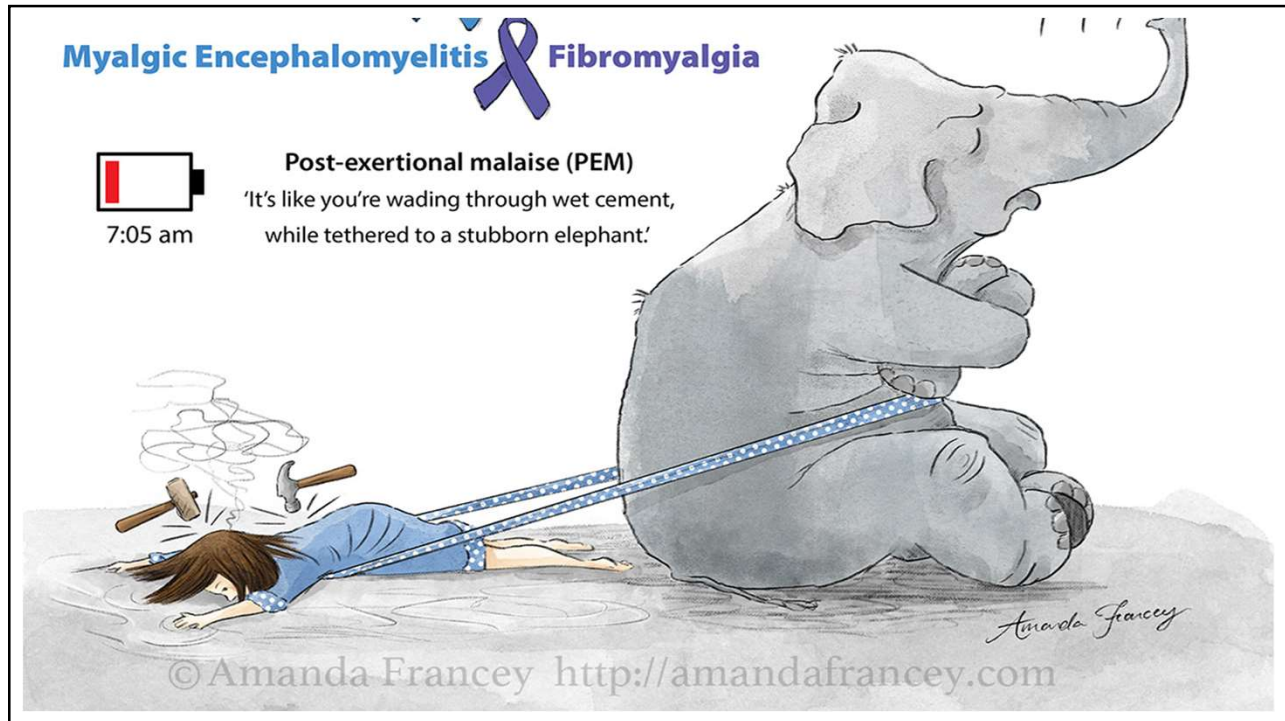
Crash, Relapse, Collapse

PwME describe PEM as having

- run a marathon,
- with the flu,
- a hangover,
- and then getting hit by a bus.

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Making order out of *chaos*

Word Cloud:

headache/migraine memory problems
 muscle weakness sore glands
 difficulty finding words
muscle pain/aches
exhaustion
difficulty thinking clearly
 sensitive to light, sound, smell
 hopelessness
 low blood pressure insomnia sore throat

Etiology and Pathophysiology


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

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

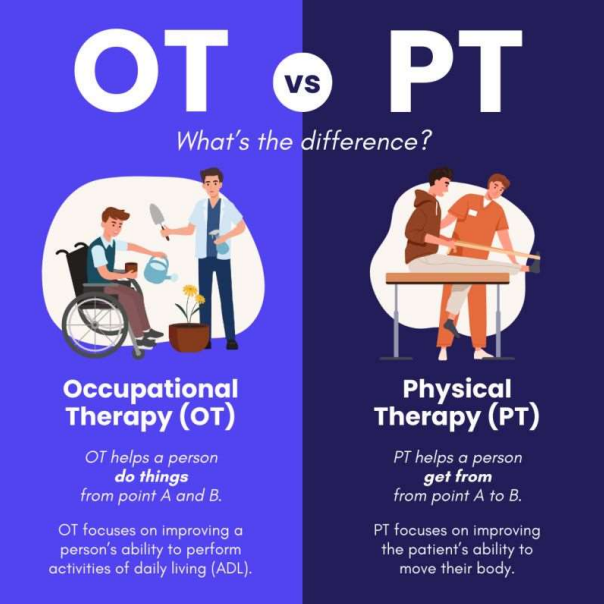
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Care for pwME

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OT vs PT
What's the difference?

Occupational Therapy (OT)
OT helps a person *do things* from point A and B.
OT focuses on improving a person's ability to perform activities of daily living (ADL).

Physical Therapy (PT)
PT helps a person *get from* from point A to B.
PT focuses on improving the patient's ability to move their body.


Occupational Therapy (OT)

- May involve **adapting the environment** to suit the individual's needs
- Aims to help patients **regain or develop skills** for daily living, including self-care, work, and leisure
- Practitioners work on **fine and gross motor skills** for specific daily tasks

Physical Therapy (PT)

- Often uses **exercises and techniques** to treat specific physical conditions or injuries
- Aims to **improve movement, strength, and range of motion**, as well as **decrease pain**
- Practitioners focus on **exercises that strengthen the body** and increase joint mobility

https://www.linkedin.com/posts/why-choose-ot_otspt-whychooseot-occupationaltherapy-activity-7148040767658196992-5XTO

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Conventional OT/PT Guidelines

without consideration for PEM

Improve/Increase activity + Restore health & function → Goal: Improve Quality of Life

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

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Pacing for PEM: Flip the Iceberg

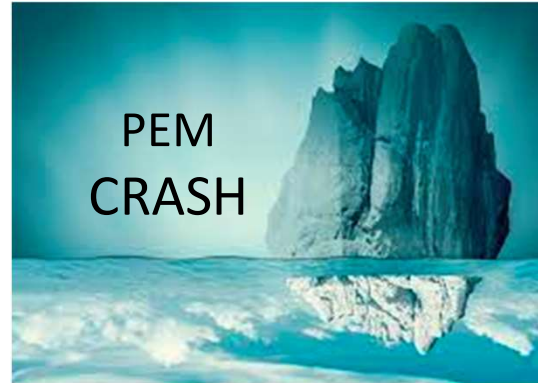
- Identify/determine immediate & delayed symptoms
- Prioritize/analyze activity within PEM limitations
- Manage pre-emptive and recuperative rest



Restore autonomy



Goal: Improve Quality of Life



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Pacing for PEM: Flip the Iceberg

Identify PEM

- Screen for PEM
- Identify symptoms
- Determine symptom time course

Core Occupations

Prioritize and plan meaningful and purposeful activities

Develop treatment plan w/in limitation of PEM:

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

Utilize Strategies

Frames of Reference (examples)

- Sensory integrative
- Proprioceptive Neuromuscular Facilitation
- Neurodevelopmental Treatment
- Biomechanical
- Cognitive-behavioral

Utilize Guidelines/Protocols

- Heart Rate Biofeedback
- Comorbid disease treatments

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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 strategies
- **Pacing for PEM**
Specialized strategy for managing tasks, exertion, & recovery over time

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Pacing for PEM

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Updated “energy envelope”



Which platform do you have?

What are the app demands?

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Updated “energy envelope”



What is your daily budget?

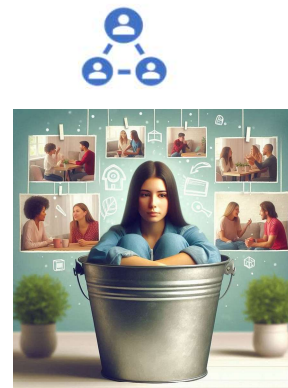
What is the cost for exceeding your balance?


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CUSTOMIZED THRESHOLDS: EACH BUCKET HAS ITS OWN TOLERANCE LEVEL

*How full is each bucket?
How quickly does the bucket drain?
What are the initial symptoms you experience?*



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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?

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IDENTIFY IMMEDIATE RESPONSE SYMPTOMS "STOP SIGNS"

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



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

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IDENTIFY DELAYED RESPONSE SYMPTOMS 24-48+ HOURS POST EXERTION

What 3 symptoms do you feel a day or two later?



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

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EACH BUCKET HAS AN INDIVIDUAL THRESHOLD FOR TOLERANCE

How full is each bucket?

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



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EXAMPLE PATIENT 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

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Task and Activity Analysis

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Activities of Daily Living (ADLs)			
ADLs involve self-care activities performed routinely to maintain one's well-being			
Tasks	Activities	Tasks	Activities
Personal hygiene and grooming	Oral care: tooth brushing, flossing, rinsing Facial care: clean, moisturize, make-up products Hair care: brushing, drying, styling Hair care: protective products, wraps, braids Shaving/trimming: facial hair, legs, underarms, pubic area Hand washing, moisturize, nail care Foot washing, moisturize, nail care applying deodorant	Toileting and toilet hygiene	assessing body functioning needs managing toilet hygiene adjusting clothes for before and after toileting transferring to and from toilet/commode caring for menstruation needs
Bathing/washing body	accessing washing location regulating water temperature washing the body rinsing the body drying off applying products	Dressing/undressing	selecting clothing obtaining clothing dressing/undressing upper body dressing/undressing lower body managing fasteners/closures applying/removing personal devices put on/take off compression garments
Cleaning/styling hair	preparing supplies/area wetting hair applying shampoo/conditioner rinsing hair drying hair combing/detangling hair styling hair	Feeding and eating	arranging/setting up eating space arranging/utilizing utensils bringing liquids to mouth bringing food to mouth chewing/swallowing cleaning up self/environment
		Bedroom mobility	adjusting position in bed for comfort, safety, and hygiene transitioning in and out of bed reaching and managing items near bedside
		Home mobility	moving from room to room transferring self from positions using stairs reaching, bending, squatting transferring/carrying items


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Instrumental Activities of Daily Living (IADLs)					
<p>IADLs contribute to daily life both at home and in the community. These activities are vital for fostering independence and facilitating individual's participation in meaningful occupations</p>					
Tasks	Activities	Tasks	Activities	Tasks	Activities
Care for others	physical care emotional support social engagement cognitive stimulation safety and advocacy	Meal preparation and cleanup	planning meal preparing the environment cooking serving clean up and store items	Safety and emergency maintenance	identifying and responding to hazards using safety devices and following safety procedures
Child rearing	provisions of basic needs emotional support and nurturing education and intellectual development role modeling and relationship building safety and advocacy	Housecleaning and home maintenance	routine cleaning deep cleaning laundry home maintenance yard work waste disposal	Religious and spiritual activities	participation in religious or spiritual practices maintaining personal and spiritual growth
Care for pets	managing nutritional needs cleaning and safety needs walking and exercising managing pet's medical needs	Driving and community mobility	trip planning vehicle operation public transit use pedestrian navigation community navigation safety procedures		
Communication management	sending and receiving information using communication devices manages written and digital communication	Health management and self-care	symptom and health monitoring medication management appointments and communication with medical team hair cut and self care maintenance nutritional management managing health insurance		
Social engagement	Family Interaction Peer Connection Community Involvement				
Shopping	planning and making list purchasing items carrying and transporting items organizing and storing decision making and budgeting	Financial management	budgeting and managing money paying bills and maintaining financial records banking and managing accounts		

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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


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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

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EXAMPLE PATIENT: GROOMING ACTIVITY

Activity Analysis: Stressors

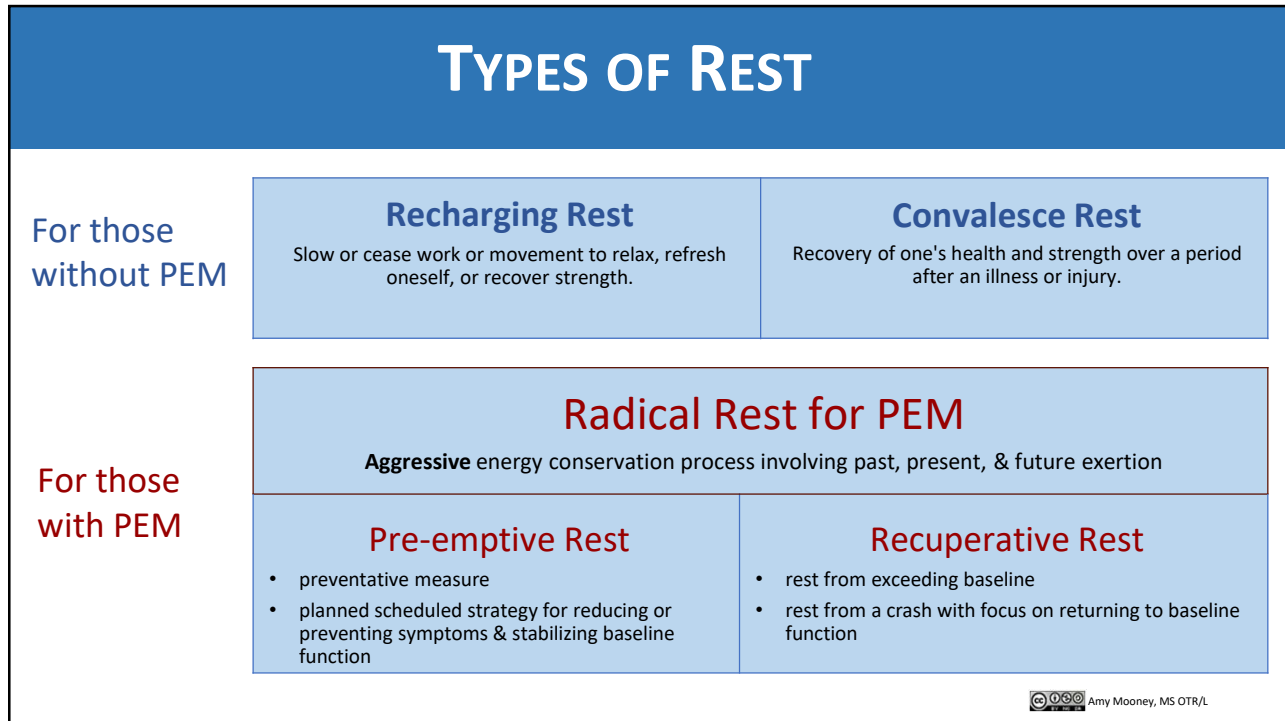
Time	Physical	Cognitive	Sensory	Emotional	Environmental
Frequency, duration, time of day, time between activity and rest	Biofeedback, location of performance, body mechanics, positioning	Perception, attention, processing, memory	Visual, auditory, olfactory, gustatory, tactile, vestibular, proprioception,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

ADL Functional Performance

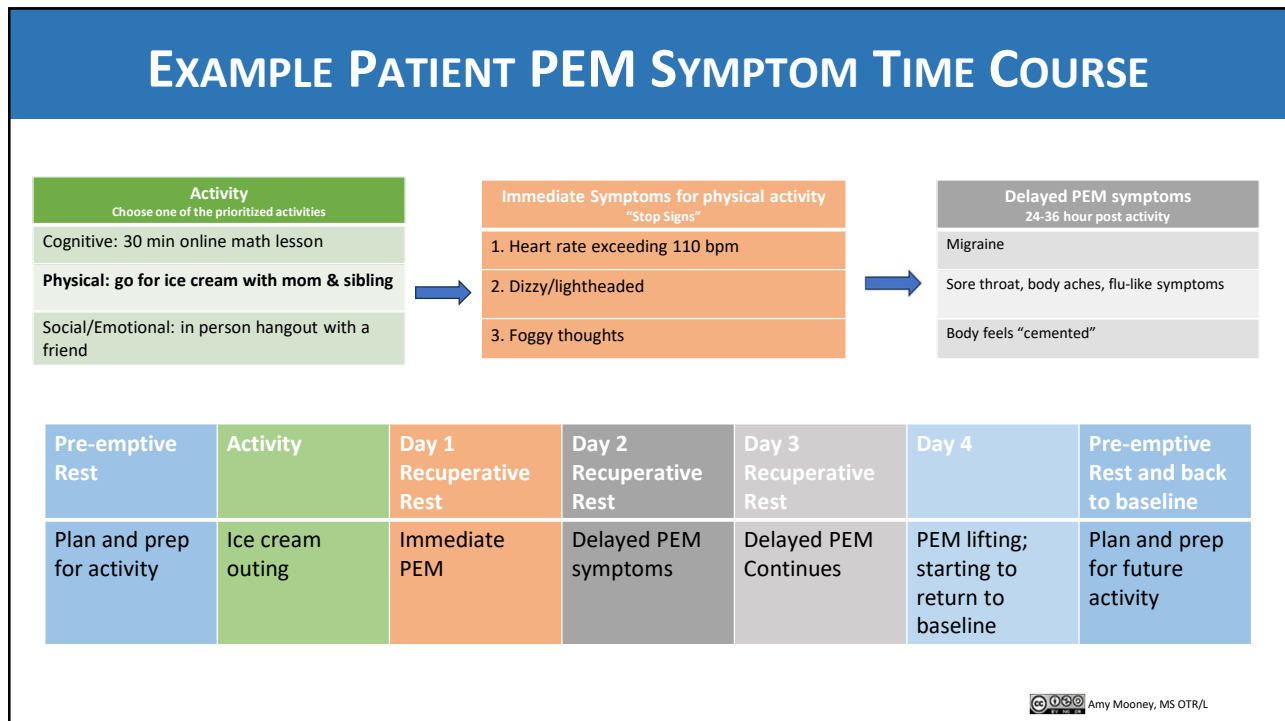
<p>Grooming: "Baseline"</p> <ul style="list-style-type: none"> Shower/bathe: 1-2 times per week. Uses a shower stool to sit for bathing tasks. Wash hair in separate task from body washing. Performs am/pm washing routine (face, teeth) 3-5 min seated activities with materials collected nearby. Wears lounge clothes/pajamas for home dressing; she wears easy to don/doff items with soft fabrics. E.P. keeps frequently worn items easily accessible and nearby. Independently uses the bathroom for bowel and bladder routines. Bathroom is 10 steps from bedroom. 	<p>Grooming: "Crash"</p> <ul style="list-style-type: none"> 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.
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NAME: _____ ACTIVITY: _____					
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
Symptom Stop Signs: 1. 2. 3.					
Functional Capacity: Plan and Pace					
Accommodations and Modifications based on the activity stressors: 1. 2. 3. 4. 5. 6.			Pre-emptive rest strategies: Recuperative rest strategies:		
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Pacing for PEM

Daily Activity Timeline

Tracking rest vs. activity levels: adjust based on symptom severity and exertion tolerance.
Implementing Pacing for PEM strategies: customizing activity and rest for managing PEM throughout the day.

Example: Functional Performance at Baseline

Wake up	Activity	rest	Lunch	rest	Activity	rest	Dinner	rest	Wind down
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Example: Functional Performance During Symptom Exacerbation or "Crash"

Wake up	rest	light meal	selfcare	rest	snack	selfcare	rest	light meal	rest	selfcare	snack	Wind down
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Pacing for PEM Weekly Activity Timeline

- Monitor levels of rest and activity.
 - Activity will vary depending on your symptom intensity and tolerance for exertion.
 - Provide sufficient time for delayed PEM and recuperative rest.

- Prioritize your activity based on how your symptoms present.
 - Take inventory of your symptoms.
 - Decide activity with attention to physical, cognitive, emotional stressors.

- The approach to pre-emptive rest, activity, and recuperative rest will differ from person to person and fluctuate based on the waxing and waning of symptoms.

Example of Balancing Activity and Rest: Tailoring Pacing Strategies for PEM over multiple days/weeks

Pre-Emptive Rest Baseline	Activity	Day 1 Recuperative Rest	Day 2 Recuperative Rest	Day 3 Recuperative Rest	Pre-Emptive Rest Baseline
Plan and prep for activity	STOP SIGNS Immediate PEM Symptoms of exertion	Immediate/delayed PEM	Delayed PEM	PEM lifting; starting to return to baseline	Plan and prep for activity


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Accommodations & Modifications

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Accommodations & Modifications

1. Focus on the **overall goals** and **functional outcomes**.
2. Evaluate symptoms that impact daily functioning
 - Utilize symptom checklists, daily logs and records.
3. Identify potential comorbid conditions such as POTs, EDS, and MCAS.
4. Always prioritize PEM when adhering to protocols for managing comorbid conditions.
5. Create the accommodation recommendations based on the individual's specific **symptom stressors** and **functional performance** needs.

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Thank you for
your attention

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