

Pacing Basics

Review - how to know when something causes PEM

What to Do About it

How to Do Activities in a Less Fatiguing Way

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Overview of Session

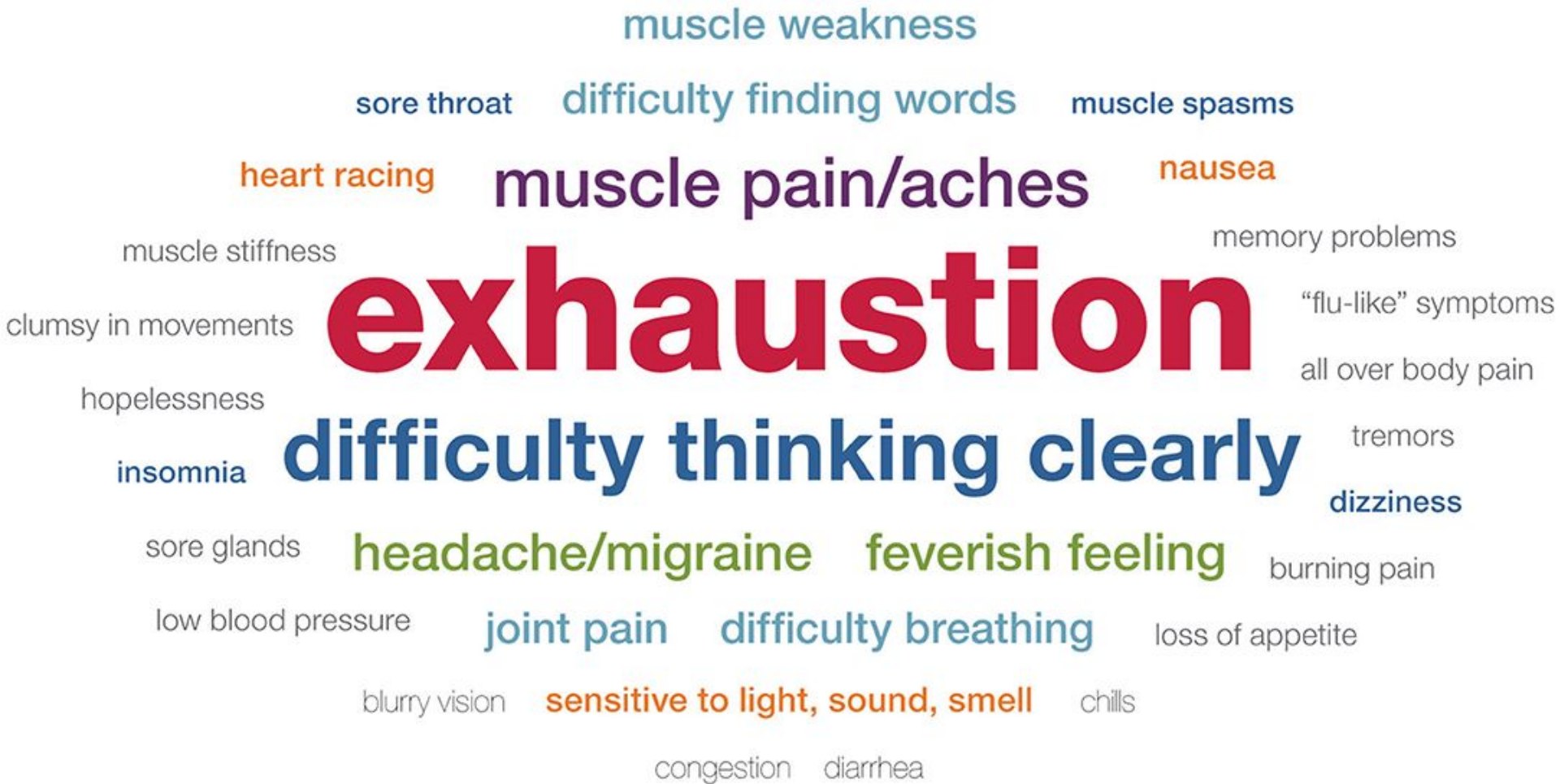
Who am I?

Ground rules

Review - How do you know if something is causing PEM

What to Do About it

Question and Answers - initially on topic of the week - then broader



Becoming a PEM Detective

Cut the Noise

Activity Diaries

Backtrack last 12-48 hours

Listen to your body and mind for clues

Tap into your experience of what might have caused issues before

Heart Rate Monitoring

Heart Rate Variability

Feedback from Others - Allies who understand about pacing and PEM

Listen to peers who also need to pace - what has caused issues for them?

Get help

What To Do When You Know Something Is Causing PEM

- Do Less - if it is more the general amount rather than specific things

Here are some things to help:

- Do it less often/avoid doing it where possible, stop doing it sooner
- Explore different ways of doing the task or achieving the benefit/need differently
- Get help from people or aids and adaptations
- Rest before and after task - if possible also rest during
- Ask for help from the community - others will have dealt with this situation before
- Break task down into different elements where possible
- Explore what can be done with environmental factors and other elements increasing the fatiguing / PEM causing elements
- Preemptive rest
- Switching

What Increases or Exacerbates Energy Used?

- Cumulative amount we do - particularly if already used up everything “in the tank” . Equally if we did too much in the last few days everything can use more
- Duration
- Intensity

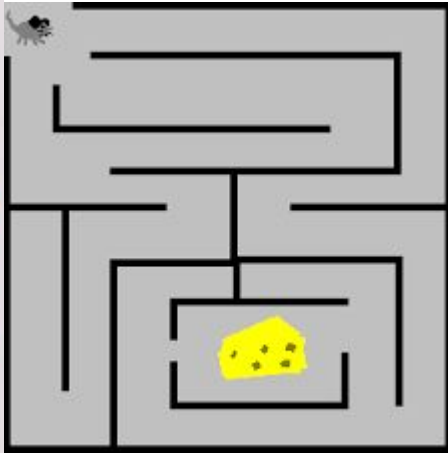
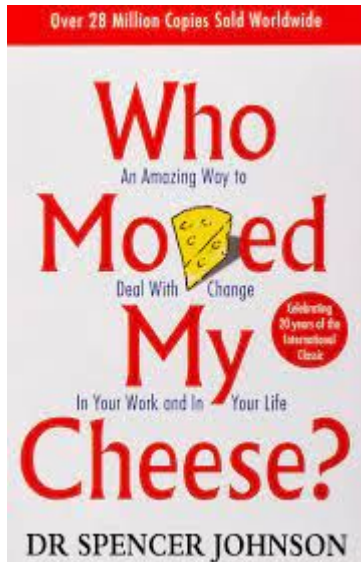
- Environmental
- Other health issues/requirements
- Stressors
- How well rested before and afterwards
- Multitasking and multi type activities e.g. with physical AND mental component

Safety and Risk Issues

- Do your own safety assessment
- Other causes - It isn't always PEM



If you have PEM/PESE - You might need to learn to do things differently. The typical or habitual way you do tasks might no longer be best



Recovery Matrix



Example - Cutting the Grass

Cut more often

Get others to do it

Cut first at higher setting as less fatiguing

Regular rests

Stop when signs of fatigue

Consider replacing grass if needed



Example - Completing Paperwork

- Environmental - noise, multitasking
- Aides, adaptations
- If this is particularly fatiguing look at why - it might be that there is resistance to doing the paperwork, it might be you are worried at sending emails that do not make sense (having someone check emails might help)
- Does it need to be done? If so does it need to be you?
- If 1 hour of paperwork leaves you particularly fatigued then consider pre-emptive rest, make sure rest before and after etc.

Meal Out

Aids and adaptations

Consider distance to where you are eating, and also how busy venue is

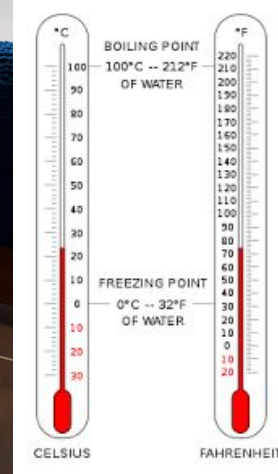
Consider fewer courses

Maybe have arrangements so you can leave for a rest in a car etc. if needed

Learn what foods might be more fatiguing for you and avoid

Having a Shower/ Washing

- Making sure you have enough energy
- Rest before & after
- Use aids as needed for safety and to lower effort
- Get help as needed and available
- See if temperature of water relevant
- Consider showering less often



Cleaning the House

Change standards and do less

Have others do more

Adapted Devices, light hoovers/ floor steamer, Hoover on each floor, different cleaning products

Change approach - Less vigorous, "Corner of a room"

A "paced" clean

Working a “9-5” Office job

Ergonomic assessment & Aids and adaptations

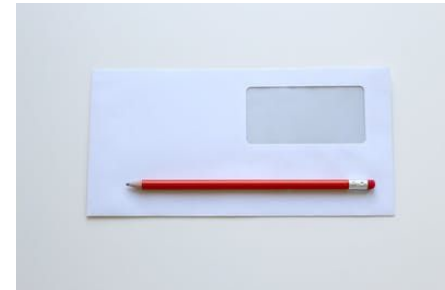


Negotiate “Reasonable Adjustments/ Accomodations with employer” - Getting Access Needs Met - Social Model of Disability



Negotiate some home working, flexible working, shorter hours, breaks in the day, Access to Work, Adjust work role and/or tasks allocated

Adjust what you do outwith work to reflect energy taken with work



Walking the Dog

- Shorter walks
- Can other people do walks
- Meet with other dog owners so dogs can exercise themselves
- Puzzles at home etc. Stick seats, rests and mobility scooters
- Dog training if needed
- Use HRM



Review - 10 Pacing Tips

- 1- Do less!
- 2- Add structured Rest Periods and Get Higher Quality of Rest
- 3- Get help - it is hard to learn and apply best to your life on your own
- 4 - Use HRM to help avoid exceeding your Aerobic threshold and monitor your activity levels
- 5 - Work out what is causing PEM and draining your energy
- 6 - If something is causing PEM stop doing it if you can and rest if possible. Later review how to deal with the situation in the future if it could happen again
- 7 - Avoid, delegate, ask for help and learn to do tasks that can be fatiguing in a more paced way
- 8- Adapt and adjust your day based on your energy level but try not to do too much more than you do on your bad days, even on good ones
- 9 - Make use of peer support - others will have found similar solutions to the ones you seek
- 10- Recruit those around you to assist or at least not act against your rest and pacing