

Pacing Basics 1

What is Post Exertional Malaise/Symptom
Exacerbation(PEM/PESE)?
And How Do You Know If You Have It?

Ben Wickens

Overview of Session

Who am I?

Ground rules

Overview and Format of the Sessions

Sneak Peek to Future Sessions

What Is Post Exertional Malaise/ Symptom Exacerbation?

What is Pacing?

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

A Look Ahead

Rest and Relaxation

Understanding and Challenging Resistance to Pacing

Heart Rate Monitoring for Condition Management

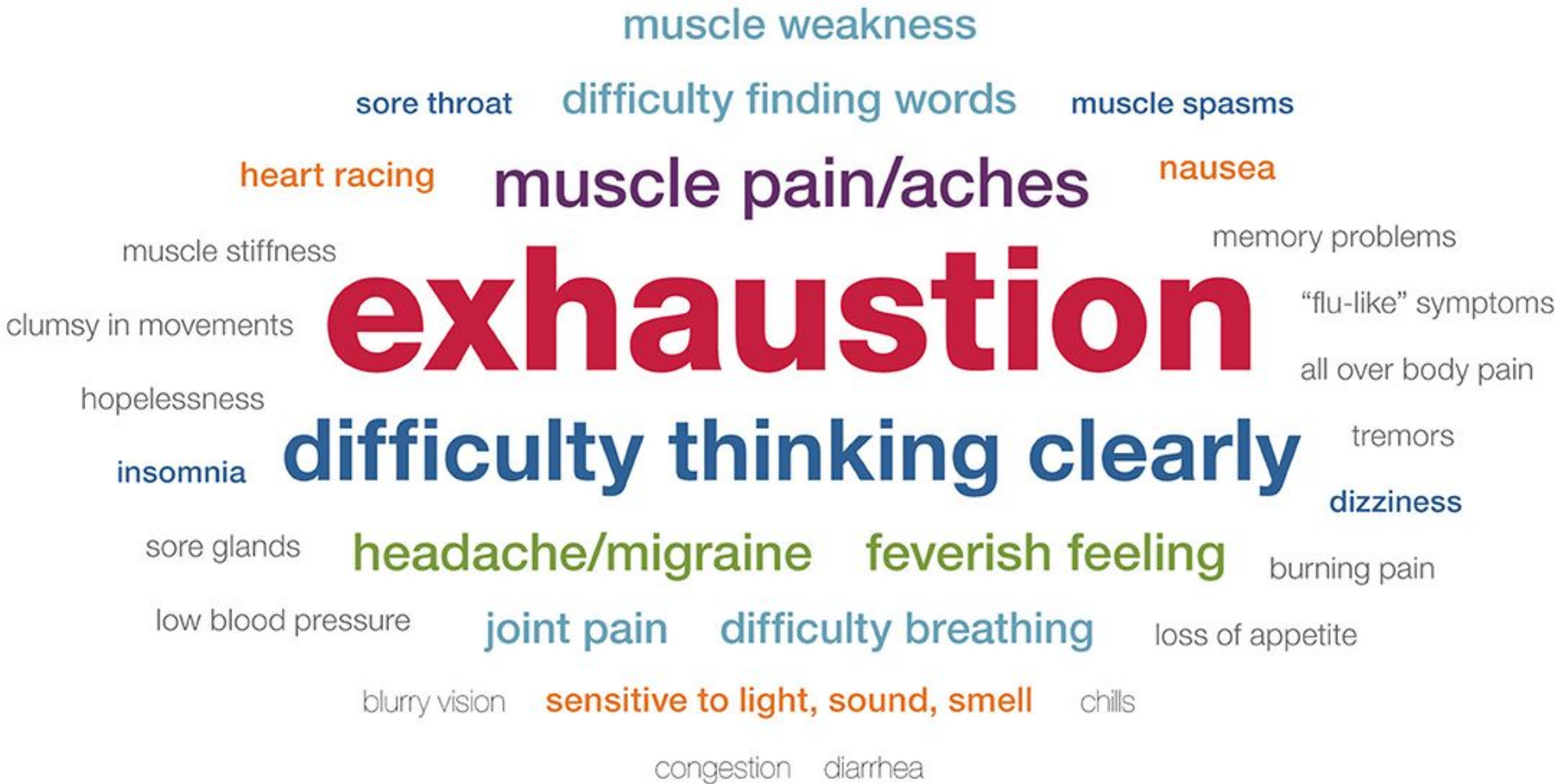
Becoming a PEM Detective

Activity Diaries - Their Importance and How to Use them

Coping with Challenges and Setbacks

Cognitive Pacing

Other Topics Requested by Participants



Key Points on PEM

- PEM/PESE - What's in an name - Why I will be using mainly PEM
- Considerable variability patient to patient
- “Exertion” triggers are not usually just physical
- Under-researched
- Symptoms can be very similar to a wide range of other conditions (With one crucial difference or Distinction)
- Present in ME/CFS and a small number of other conditions
- Usually a post viral complication
- Rarely the sole symptom/issue a patient experiences
- Present in up to 75% of patients with Long COVID at the 6 month mark
- No simple blood test to show you have it

How Do I Know If I Have PEM?

According to World Physio up to 75% of people with Long COVID have PEM 6 months after initial COVID infection

Doctors will sometimes diagnose a patient with ME/CFS, PEM/PESE, say they need to pace or signpost them to a service where they will be supported to pace

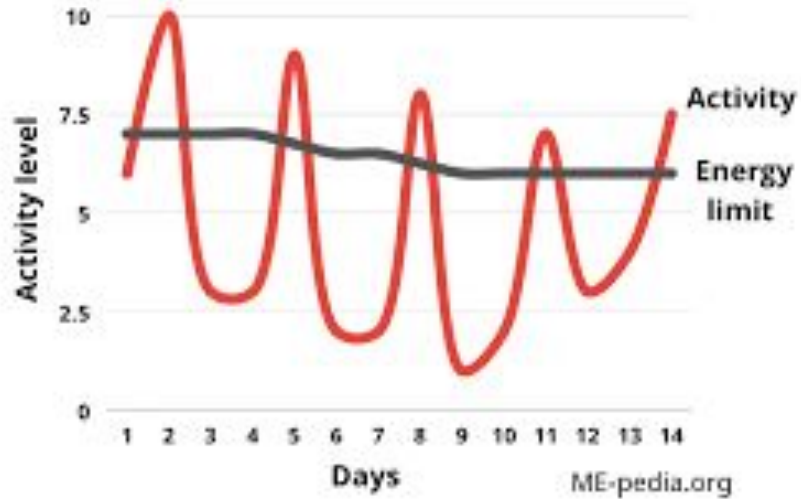
Can be issues with Doctors diagnosis as there are three key elements for someone to know they have PEM

- 1) Delayed or Prolonged Response to Exertion
- 2) Sufficient investigations carried out to rule out other causes
- 3) COVID infection triggered symptoms - OR alternatively ME/CFS route

Also - where PEM is present rest and “pacing” should help to alleviate symptoms and over time baseline energy levels tend to increase to some extent with effective condition management.

The Boom and Bust Cycle

Boom and bust cycle



Immediate

Symptoms after physical activity are the direct result of exceeding the anaerobic threshold. Examples include fatigue, **out of breath**, dizziness and nausea. For healthy individuals, immediate symptoms from exercise stress resolve quickly but for people with ME/CFS they begin to worsen.⁷

Short-term

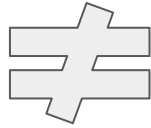
Lasts 2-4 days and reflects “overdoing activities” that exceed the anaerobic threshold for an extended period or multiple times per day exhausting the ability of the body to supply daily energy needs.⁸ Symptoms of short-term PEM include muscle/joint pain, **brain fog**, headache and sleep disturbance. These symptoms reflect dysfunctional neurological and cardiopulmonary responses.³

Long-term

Lasts 7 days or more and reflects a sustained immune response consistent with a damaged aerobic energy system.^{6,9} Signs may include weakness, a decrease in function, **flu-like** and cardiopulmonary symptoms.^{10,11}

What is “Pacing”

“Pacing” for
PEM



Pacing



- Energy Envelope Theory
- Pacing Theory
- Practitioner Feedback
- Patient Feedback
- Known Recovery Approach for a range of conditions



Shorthand for a condition management approach to reduce Post Exertional Malaise consisting of rest, activity planning, management and adjusting your activities based on feedback coming from yourself and others

- Non-optional if you have PEM
- Can be very hard to learn well and apply to your life on your own

Risk Issues

Relapse/Crash

PEM

Flare-up

Lowering of Baseline

Exercise

“Pacing Up” - Graded Exercise etc.

Medical Bias and lack of knowledge

Not adequately proven but common believe that sooner pacing and rest carried out the better the chance of a fuller recovery

Alternative Cause of Issues

Deconditioning

Resources

Weekly Sessions here
Notes - tied into training to follow

Action for ME Pacing Booklet



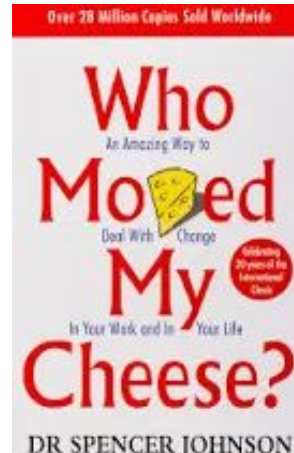
ME Association “Purple Book”, website and Long COVID Guide

The Workwell Foundation

Bateman Horne Centre

www.cfssselfhelp.org

Long Covid Physio



Lydia Rolley
THE FATIGUE BOOK

Chronic fatigue syndrome and long COVID fatigue:
Practical tips for recovery

