

# Pacing Basics 2

What is your Energy Envelope?  
What Uses Energy?

Rest and its Role in PEM  
Relaxation

Ben Wickens

# Overview of Session

Who am I?

Ground rules

Energy Envelopes - How Much Do We Have? What Happens If We Do Too Much?

What Uses Energy?

What Exacerbates/ Increases Energy Used

Why Is Rest Important

Tips on Rest

Relaxation

Dangers of Exercise and Doing Too Much

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

# Energy Envelope

We can only do so much because we have limited energy and need to stay within it.

Sometimes we might have energy for an activity but different activities can take different amounts of space



# Energy Envelope



Aside from experiencing PEM if we exceed our energy then the next day the envelope might shrink and the effort to do some activities might increase so we can no longer do them safely

# Energy Envelope

Bank Account analogy



Overdraft charges  
Credit Card  
Payday loan  
Loan Shark

A hard to break  
cycle



# The Spoon Theory

## How Many Spoons Do You Need Today?

The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

**If you only had 12 spoons per day, how would you use them?** Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.

- Get dressed
- Have breakfast
- Wash
- Have shower
- Make Lunch
- Eat Lunch
- Make Dinner
- Eat Dinner
- Walk Dog
- Cut grass



get out of bed



get dressed



take pills



watch TV



bathe



style hair



surf the internet



read/study



make & eat a meal



make plans & socialize



light housework



drive somewhere



go to work/school



go shopping



go to the doctor



exercise

The Spoon Theory was written by Christine Miserando, which you can check out on her website [www.butyoudontlooksick.com](http://www.butyoudontlooksick.com).

# What uses Energy?

Cognitive



Emotional



Physical



Social



Varies person to person what activities will have the biggest impact or “cost”. Often grouped in physical, emotional and cognitive. Can include digesting, watching TV, worrying about something. Environmental and other factors such as multitasking can increase the energy spent

# 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



# Rest

- Doing less can help stay within our “energy envelope”
- High Quality Rest can be recuperative increasing our “energy envelope” and assisting with recovery of PEM and other symptoms
- Can enable and contribute to “recovery”



# Six Tips for Resting Well With PEM

1. Understand what rest for you now is
2. Quality > Quantity    Rest does not always need to be for long periods
3. Schedule Regular Rests
4. Rest before, after and where possible during activities
5. Rest is Not the Same as Sleep
6. Listen to your body and mind and rest when needed for as long as needed

Bonus - Pre-emptive Rest - if you do an activity and need to rest afterwards. Next time try to stop 10-20 min BEFORE and rest for 5-10 minutes. See if it changes how PEM causing that activity is for you

# Recuperative Rest

Do you feel less symptoms afterwards?

Do you feel like you have more energy?

Are you able to do a little more without triggering symptoms so easily?

I find that for me the higher quality of rest the more recuperative it is. So for me this is:-

Lying down, no social interaction, not checking messages, few sound sources, no overly bright light, not thinking about something ( even something fun), not planning what I need to do. No worry, no strong emotions, no distractions

# Overcoming Barriers to Good Quality Rest

Do you want anything from the shops?

## Internal Resistance:

- “Rest is Boring!”
- Understanding and accepting need
- “You are worth it!”

Other Internal Barriers inc. habits

Circumstances and Environmental Challenges

- Noise and Light
- Family and other people
- Other environmental issues

I wonder if I have enough food in?

I wish my head didn't hurt!

What should I try next?



# The Value and Role of Relaxation Activities in Facilitating Rest

- Phasing in
- Can be less intimidating than just “resting”
- Can be naturally timed
- Many people with PEM are stress sensitive AND/OR Experience stress - relaxation exercises can LOWER stress levels enabling us to do more with less energy
- Can be enjoyable

Note - New Relaxation Activities are not always as restful initially as we are learning new approaches and techniques.



**Stop. Rest. Pace.**

## Dangers of Exercise and overdoing it

- Research shows only about 0.82% of people with Long COVID benefit from exercise <https://www.mdpi.com/1660-4601/19/9/5093>
- World Physiotherapy Briefing Paper 9 : Safe Rehabilitation Approaches for People Living With Long COVID: Physical Activity and Exercise <https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf>
- ME/CFS and Long COVID Patient community experience - potential for harm

# Relaxation Resources

- Apps - such as Calm, Buddhify, Dark Noise
- YouTube - Mediations, Music (relaxing e.g.Lars Danielsson “Liberetto”, E.S.T., Pachabel’s Canon, New Age Music, Rain Sounds ) and Lots of Relaxation Exercises
- Spotify - Lots of resources including Edward Charlesworth relaxation exercises
  
- Relaxation techniques including Progressive Relaxation, Deep Muscle Relaxation, Autogenic Relaxation, breathing exercises including 4,7,8,0 cycles, Aromatherapy, Adapted Yoga, Mindfulness
  
- Breathworks - <https://www.breathworks-mindfulness.org.uk/mindfulness-for-managing-long-covid>
- **Peer Recommendations** - not just for rest, relaxation but also low energy activities

**Invitation** - Try scheduling some more rest, try increasing quality of rest and try some relaxation activities over the next week or two. See if it helps

# Pacing Basics 3

Becoming a PEM Detective:  
Learning to Identify What is Causing your PEM/PESE  
(Post Exertional Malaise)

Ben Wickens



# Becoming a PEM Detective

Are you just doing too much?

Cut the Noise - The Boom Bust Cycle

## 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

# General Rule

We do not always have the same amount of energy each day. So if you have even something as simple as a cold then that might be using up some of your energy. If you are experiencing PEM from an activity a few days ago then you might have less energy today. So when assessing what you can do and what might/might not be causing PEM remember that you need to factor in what your energy levels were and also what else was going on at the time.

- Changes in your Heart Rate Variability and Resting Heart Rate can be indicative of having less energy

Week: 1 / 1

	Morning - a.m.											Afternoon/evening - p.m.												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

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Friday																								
Saturday																								
Sunday																								

Key: High energy activity (red), Low energy activity (yellow), Green (rest/sleep), Blue (sleep)

Adults Rest and Sleep Diary

Name: Joan Smith Date: Dec 26/11

Day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
No. of hrs. Sleep 7.00am - 6.00am	7.5	7.0	8.0	6.5	8.0	7.5	9.0
Sleep Quality	1 = very poor	2 = poor	3 = fair	4 = good	5 = very good		
Functional Capacity Scale at beginning of day 0 - 10 (see notes)	6	5	5	6.5	6	6.5	4
Activities (over 15 mins)	8:00 am wake up 9:00 am get ready 10:00 am dog walk 11:00 am get up 12:00 pm dog walk 1:00 pm pink up 2:00 pm training 3:00 pm dog walk 4:00 pm rest 5:00 pm veg 6:00 pm veg 7:00 pm veg 8:00 pm veg	8:00 am wake up 9:00 am get up 10:00 am dog walk 11:00 am get up 12:00 pm dog walk 1:00 pm dog walk 2:00 pm dog walk 3:00 pm rest 4:00 pm veg 5:00 pm veg 6:00 pm veg 7:00 pm veg 8:00 pm veg	8:00 am wake up 9:00 am get up 10:00 am dog walk 11:00 am get up 12:00 pm dog walk 1:00 pm dog walk 2:00 pm dog walk 3:00 pm rest 4:00 pm veg 5:00 pm veg 6:00 pm veg 7:00 pm veg 8:00 pm veg	8:00 am wake up 9:00 am get up 10:00 am dog walk 11:00 am get up 12:00 pm dog walk 1:00 pm dog walk 2:00 pm dog walk 3:00 pm rest 4:00 pm veg 5:00 pm veg 6:00 pm veg 7:00 pm veg 8:00 pm veg	8:00 am wake up 9:00 am get up 10:00 am dog walk 11:00 am get up 12:00 pm dog walk 1:00 pm dog walk 2:00 pm dog walk 3:00 pm rest 4:00 pm veg 5:00 pm veg 6:00 pm veg 7:00 pm veg 8:00 pm veg	8:00 am wake up 9:00 am get up 10:00 am dog walk 11:00 am get up 12:00 pm dog walk 1:00 pm dog walk 2:00 pm dog walk 3:00 pm rest 4:00 pm veg 5:00 pm veg 6:00 pm veg 7:00 pm veg 8:00 pm veg	8:00 am wake up 9:00 am get up 10:00 am dog walk 11:00 am get up 12:00 pm dog walk 1:00 pm dog walk 2:00 pm dog walk 3:00 pm rest 4:00 pm veg 5:00 pm veg 6:00 pm veg 7:00 pm veg 8:00 pm veg

# Activity Diaries

**Add your neutral activities**

**Log your daily activities**

**Log your energy drains**

**Log your energy refills**

**Log your energy levels**

**Track your energy levels**

# Key Points of Activity Diaries

Just keeping an activity diary can be using valuable energy so you need to make sure you get benefits.

Using HRM/ a smart watch can help and also do some of the job of activity tracking

I will do a later session on how to look at activity diaries yourself - I do feel ideally people should have someone else to help with this but I appreciate that isn't always possible

If no-one else is looking at it then it only needs to work for you

Ideally want to be able to log activities that last 10-15 min because even they can be really fatiguing

Ideally you want to fill it in as the day is going on so it isn't either a memory test nor overly impacted by any biases your memory might have

Listen and Feel

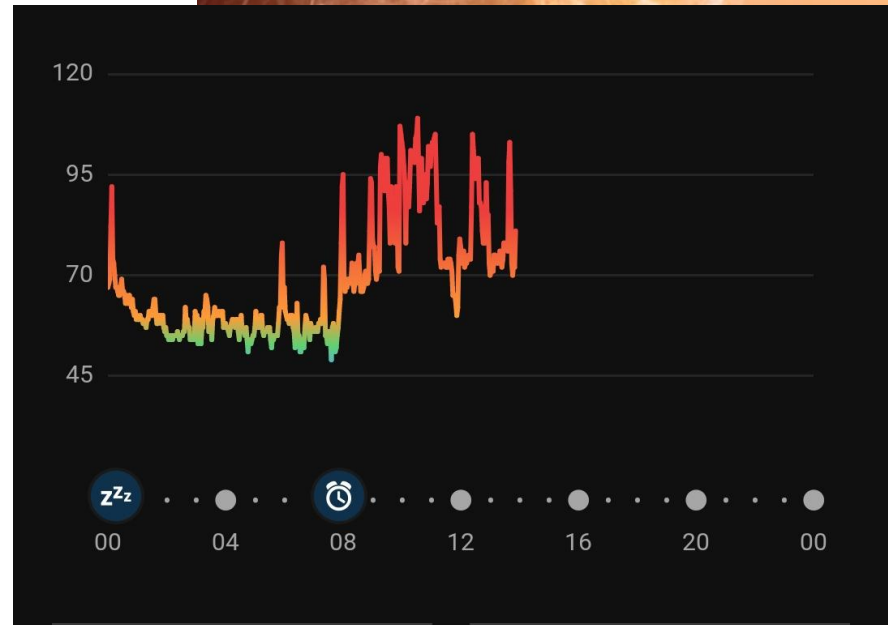


# Heart Rate Monitoring

The Workwell Foundation and others have explored the potential for using HRM for condition management.

Workwell have found that it is possible to calculate someone's aerobic threshold and when they exceed that they are potentially triggering PEM. Staying under this limit can reduce PEM.

Monitoring HRM data can also help you see if you have been balancing your activities well



## HRM (continued)

It is very easy to get bogged down in the calculations but it's “just” a educated guess. You can try one number and see how well it works for you in terms of warning you enough when needed and not being so frequent it just gets too annoying and ignored

Two types of formula are used:

- **Resting Heart Rate Based** such as Resting heart Rate plus 15
- **Age Based** such as  $208 - (\text{age} * .70) * 0.55$  ( usually more generous)

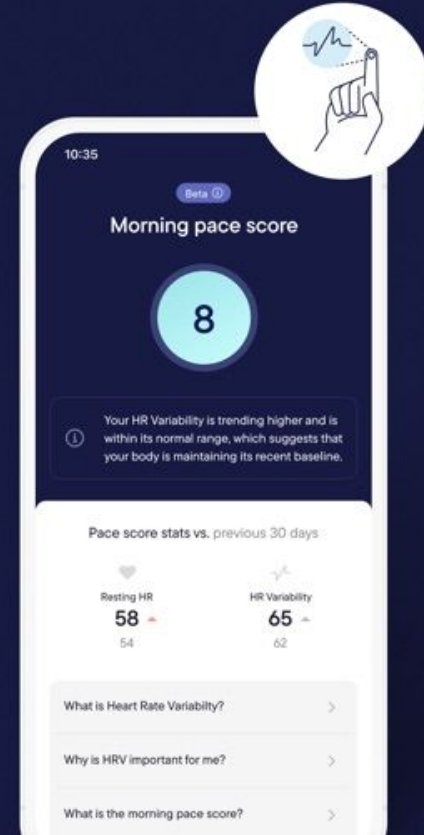
# Heart Rate Variability

An Emerging Area. Changes in HRV, particularly if you are regularly checking and recording data can show or suggest changes over time.

They can help assess how much you should do on a given day and potentially provide evidence of PEM from previous activities



## Measure your body's signals





# How Other People Can Help?

- Professionals
- Friends & Family
- Peers

## Red Herrings, Complications and Challenges

- Stimulants and Suppressors
- Euphoria and Denial
- Biases and Prejudice
- Other Medical Causes - e.g. dysautonomia
- The Noise - if still in boom/bust cycle or just too many other things going on

# What To Do When You Know Something Is Causing PEM

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

A whole session or more will look at this in much more detail:- 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