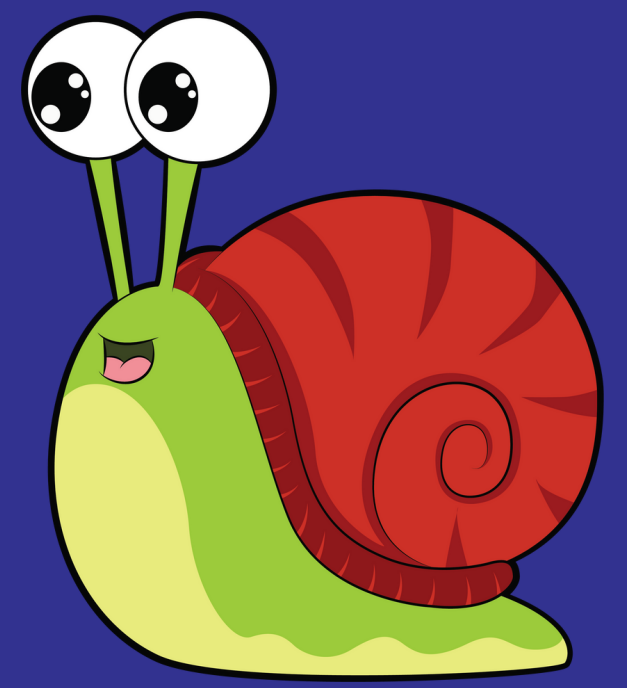


# PEM / PESE Info Sheet



## Definition, management, actions, resources

### Definition:

Post Exertional Malaise (PEM)

aka Post Exertional Symptom Exacerbation (PESE)

- Is a disabling, often delayed exhaustion or symptom that has increased disproportionate to the effort made.
- It is most often triggered by activity which includes day to day living tasks, physical activity or something that requires concentration or high emotion. PEM/PESE can occur hours up to days after engaging in an activity, and this response can last for days, weeks or even months.
- It is the unique identifying feature of ME/CFS and can be present in long COVID; the primary goal in management is to avoid it.
- Physiotherapy can support patients with many of the symptoms, particularly fatigue, breathlessness, sleep health and return to activity and exercise (when the time is right).

### The 4 Ps (Prioritise/Plan, Pacing, Pleasure)

Simply put, when you have PEM/PESE, doing too much can make you feel worse. There is a lot you can do for yourself to Prioritise, Plan, Pace and still have time in your schedule for Pleasure.

#### Prioritise / Plan

It's good to recognise what's important to you and understand your individual energy reserve. You can do this by using activity diaries. These diaries reflect the energy expenditure for activities which in turn helps you plan for repeated future activities, telling you when to rest and how to pace your day better.

#### Pacing - avoid the BOOM/BUST

Activity Diaries help identify your pattern of fatigue and show clearly where you have taxed your energy resources (BOOM) and left you without anything left for further activity (BUST!). Working out how to manage that energy resource better is called PACING.

As your symptoms improve you will experience less weakness and fatigue, but this journey might have many ups and downs. Learning to manage the down days is important, likewise don't be tempted to overdo it on the days when you feel good. You have the capacity to learn and control your energy envelope and avoid that bust.

It's good to adjust your expectations because on some days, more rest is required than others, Long Covid is characterised by an ebb and flow of symptoms, and this can be frustrating.

If you are well enough to do so, undertaking activities of daily living safely is important, you may have an underlying mobility or health condition or injury that may put your health at risk, using an aid or having help with a task or doing it with someone else around for safety maybe a good plan. Also try waiting at least an hour after a meal before doing the activity, drink plenty of water and avoid extremes of temperature as being too hot or too cold can increase unnecessary energy use.

Being realistic and flexible is helpful, spread your tasks and activities over the day, learn to say 'no', modify a task-can you do it sitting down? Invent some short cuts, use technology (and other people) to help you and avoid the temptation to do just a little bit more without rests, this is Pacing.

Whilst activity is an important part of daily life, and recovering your activity tolerance can seem slow, for those with PEM/PESE, activity within breathing and heart rate tolerances can ensure a more efficient day without the BOOM /BUST response and therefore is done safely.

#### Pleasure

It's important to prioritise something in your day or week that you love to do. Time spent with friends and family, attending social gatherings, doing crafts, taking a walk-in nature, whatever gives you pleasure. Recognising the activity as something worth preserving energy for is important to add colour your week. Reflecting the choice in your activity diary as you plan for it and pacing to get there is the trick. Reflecting on your week, focus on that accomplishment- you have done well, that is the key to success.



Navigating ME/CFS and Long COVID

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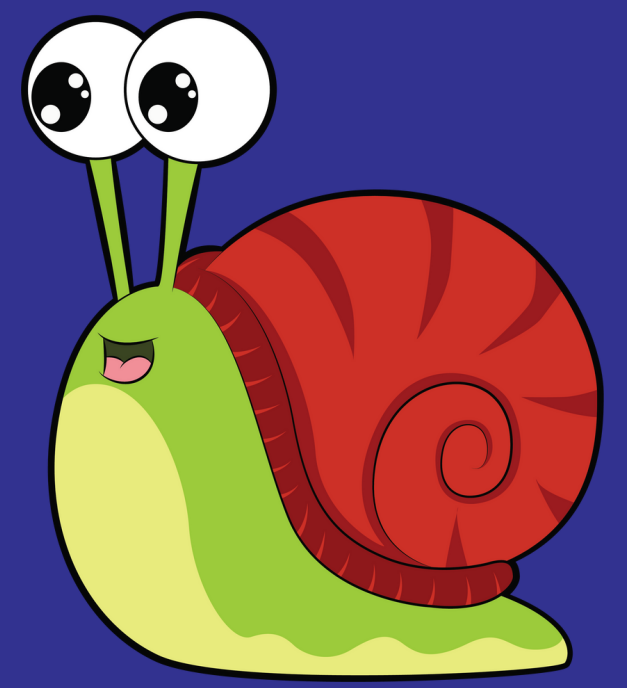
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Cardio-Respiratory Special Interest Group  
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# PEM / PESE Info Sheet



## Definition, management, actions, resources

### What is REST with PEM/PESE?

Understanding your energy reservoir is important- everyone is different and can change day to day.

Recognising how to boost what you have, and then use it wisely is the key to success.

Charging a cell phone is best done when you are not using it at the same time. A fast charge occurs when it is fully off and not receiving any information. A fast charge of our battery to fill our energy envelope is likely to be when we are fully resting, minimising all physical and mental activity, and in a low stimulation environment with minimal noise, light, activity around us.

This is a great place for a 2-minute meditation, a body check in, or a breathing exercise, something that follows a well-rehearsed routine so there is minimal thinking effort.

Some people like to set a timer- this is a short, recharging rest break and its ok to take as many of these as you need to increase that energy envelope.

Paced breathing with PEM/PESE

This is useful to practice when carrying out activities that might take more effort or make you breathless, like climbing the stairs or having a shower, hanging washing. It is important to remember that there is no need to rush.

Try breaking the activity down into smaller parts, does it all have to be done now?

Breathe in before you make the 'effort' of the activity, breathe out while making the effort.

Breathe in through your nose and out through your mouth and remember the talk test.

### If you feel any of the following symptoms, STOP and reconsider your plan:

- Nausea or feeling sick
- Dizziness or light headedness
- Severe shortness of breath
- Clamminess or sweating
- Chest tightness
- Increased pain

### The Talk Test - helping you to pace yourself

Fortunately, there is a simple tool to help guide your paced activity rate. Think about speaking a sentence: If you can speak the whole sentence without stopping and are not feeling breathless, then you can carry on; If you cannot speak at all or can only say a word at a time and are severely breathless, then you are working too hard.

Your response to activity may also be matched by your Heart rate. If it's right for you, your health provider can work with you to support assessing and monitoring your heart rate with activity. The goal for all these assessments and suggestions is to show you when is a good time to be doing activities and when you need to postpone the task for later.

Using the Talk test is a great way to tell you if you are doing too much.

### Useful Resources:

World Physiotherapy COVID-19 Briefing Paper "Safe Rehabilitation Approaches for People Living with Long COVID: Physical Activity and Exercise."

<https://world.physio/sites/default/files/2021-06/Briefing-Paper-9-Long-Covid-FINAL-2021.pdf>

Myalgic encephalomyelitis: International Consensus <https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-2796.2011.02428.x>

MEA-Research-Review-Assessing-PEM-in-MECFS-25.03.19.pdf <https://meassociation.org.uk/wp-content/uploads/MEA-Research-Review-Assessing-PEM-in-MECFS-25.03.19.pdf>

Work well foundation:

<https://workwellfoundation.org/wp-content/uploads/2020/03/WW-PEM-Timecourse.pdf>

<https://www.jospt.org/doi/10.2519/jospt.blog.20220202/full/>

Long Covid Physio: <https://longcovid.physio/pacing>

<https://longcovid.physio/post-exertional-malaise>

ME/CFS South Australia: <https://mecfssa.org.au/resources/post-exertional-malaise-pem>

CDC handout: [https://www.cdc.gov/me-cfs/pdfs/interagency/Managing-PEM\\_508.pdf](https://www.cdc.gov/me-cfs/pdfs/interagency/Managing-PEM_508.pdf)

WCPT handout: <https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet3-Fatigue-and-PESE-Final-A4-v1.pdf>

<https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet4-Pacing-Final-A4-v1a.pdf>



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