PACING AND MANAGEMENT GUIDE FOR ME/CFS

#ME ACTION

What is **PEM**?

The cardinal symptom of ME/CFS is **post-exertional malaise (PEM).** PEM is a flare of symptoms and/or the appearance of new symptoms after exertion, often presenting 24 hours after the triggering event. Physical activity, cognitive overexertion and sensory overload can all trigger PEM.

Post-exertional malaise is a unique symptom, incongruent with experiences of fatigue after overexertion in healthy individuals. It is not the same as being more tired than normal after activity.

What is **pacing**?

Pacing is a **self-management** strategy for activity. Patients who pace well are active when able, and rest when tired. They may plan extra rest ahead of strenuous activities.

Graded exercise is a gradual increase in activity over time as directed by a clinician, until the patient returns to a healthy activity level. While graded exercise may be useful in patients who are deconditioned after surgery or a severe illness, graded exercise does not address the metabolic changes and atypical reactions to activity that lead to symptoms in people with ME.

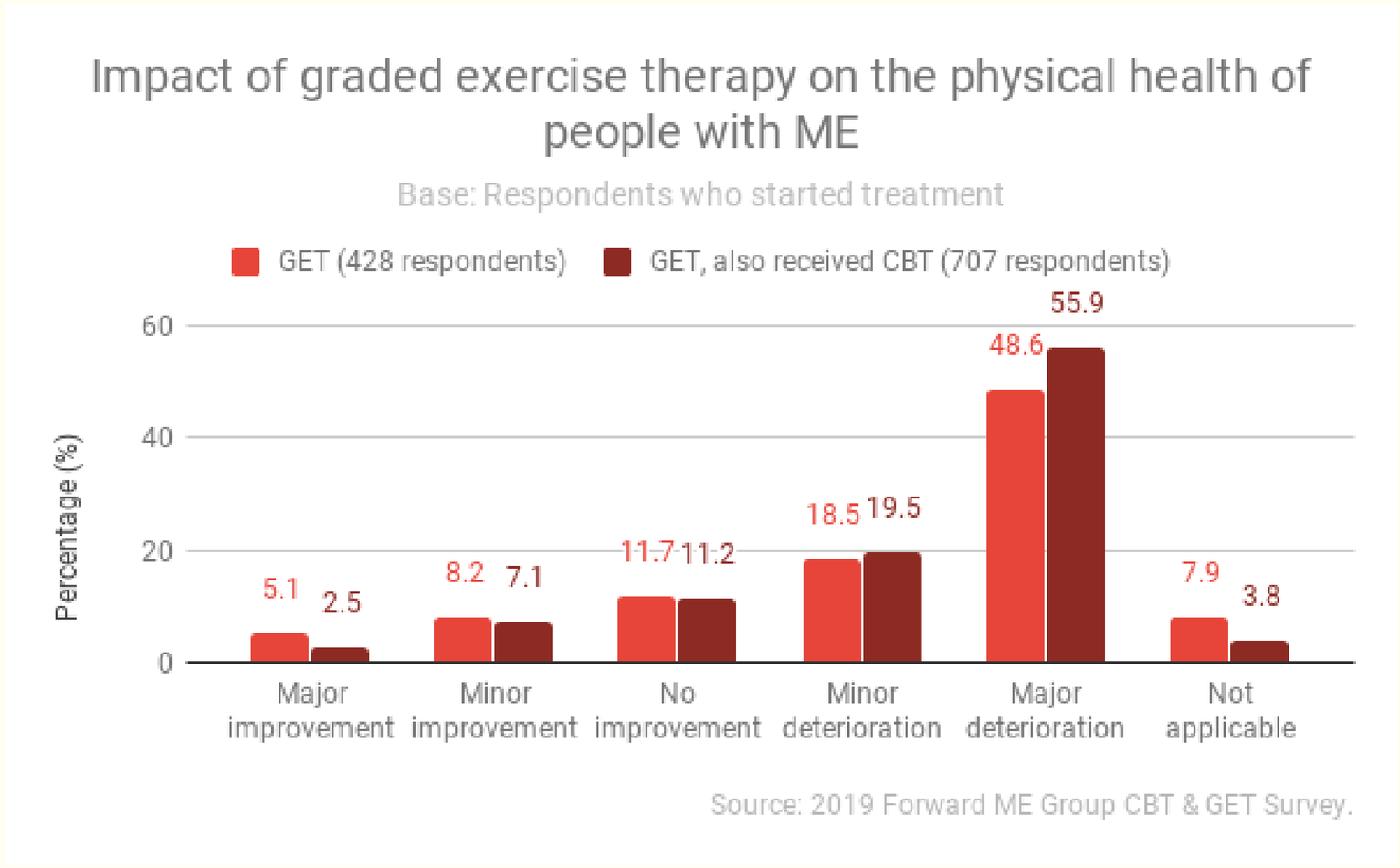
Because post-exertional malaise is the hallmark symptom of ME, programs that gradually increase exercise may do more harm than good. A recent, large-scale survey found that ~80% of people with ME found no benefit or significantly worsened on graded exercise regimens.

ME/CFS

*Myalgic encephalomyelitis/ chronic fatigue syndrome (**ME/CFS**) is a neurological disease triggered by an infection in the majority of patients.*

It is a complex chronic disease with symptoms in multiple body systems, including neurological, immunological, endocrine, and metabolic.

One out of four people with ME are housebound or bedbound, with ~13% able to work full-time.



From a 2019 survey from Forward ME, a coalition of ME organizations in the US and UK

The core symptoms of ME are not due to deconditioning. Patients with minor presentation may have activity levels similar to that of healthy people, but still experience all the symptoms of ME, including post-exertional malaise (PEM) when they overexert.

EXERTION ≠ EXERCISE

Exertion is defined here as anything that **stresses or strains the system**. Some stressors are within the patient's control and some are not. Identifying triggers for post-exertional malaise is vital to a person with ME's physical and psychological well-being. Potential triggers include:

- **Physical** (exercise)
- **Orthostatic** (standing for long periods of time)
- **Cognitive** (long conversations, scholarly reading/writing)
- **Sensory** (loud, repetitive noises, bright or flashing lights)
- **Emotional** (challenging interactions, tragic events)
- **Environmental** (proximity to allergens, changes in weather, seasonal changes)

No trigger can be controlled all of the time. The goal of pacing is to **minimize** post-exertional malaise, rather than eliminate it. Keeping an **activity and symptom diary** each day can help identify triggering events.

Post-exertional malaise may be delayed by approximately 24 hours. Anecdotally, these delays are more common in long-standing disease and may increase on a circadian cycle with greater and greater distance between the triggering event and PEM. This is an important consideration when connecting PEM to a triggering event.

Jaime Seltzer
www.meaction.net

Beyond pacing: activity management

Radical rest

Some people with ME have found that being **inactive** before planned exertions, such as attending a wedding or giving a talk can help mitigate the effects of post-exertional malaise. This strategy is called **radical rest.**

Knowing that exertion is coming can help the patient plan for worsened illness before it occurs. Pre-making meals, asking friends or family for additional help, making sure water and crash-friendly snacks are nearby, making sure any medication is in reach, and planning on soothing, low-energy activities like shows to catch up on can mitigate the fallout after necessary exertions.

Cut activity in half

Decreasing activity by half to start with can help the person with ME find a baseline -- with the understanding that the baseline can become better or worse over time. While some people with ME have a progressive disease course, many may increase their baseline by avoiding PEM.

Monitor objective values like heart rate

A **symptom diary** can help identify activities that lead to PEM, and a **wearable device** can ensure your heart rate was recorded when engaged in those activities. Reducing activity to ensure your heart rate stays below this value can help prevent or mitigate PEM.

Some devices can be programmed to alert the wearer when their heart rate reaches a certain value. Program your device to alert you **below** the value you have identified as triggering PEM so that you can stop your activity in time.

Good pacing practice requires listening to your body and adjusting your practice accordingly. If you continue to develop PEM, you may have to decrease your activity until it no longer induces PEM. Likewise, you may be able to increase your 'safe' heart rate if you do not experience PEM at those values.

Break necessary activities into manageable tasks

Avoid ‘performing healthy’ -- sit down wherever you like, stop whenever you like, and speak up when you are with others. It's rare that an activity must be performed all at once.

- Fold a few laundry items at a time
- Do prep-work for meals, like chopping or measuring, the day before cooking
- If you are able to take a walk, sit frequently and wait for your heart rate to return totally to normal before resuming your activity

Jaime Seltzer
www.meaction.net

Prioritize activities you value & perform them differently

When faced with a challenging activity, consider its:

- → **Importance**:
  How necessary is it to complete this activity? What would happen if it were left undone?
- → **Difficulty**:
  How challenging would it be for you to do this activity on your own?
- → **Specificity**:
  Could others do this for you, or are you the only one who can?

After considering each, you may choose to:

- Drop this activity if it isn't necessary or isn't helpful
- Ask someone else to do this activity, either temporarily or for good
- Hire someone to do this activity, if that is within your means
- Do this activity, but less often than before, or only when absolutely necessary
- Do this activity, but adapt/change *how* you do it to support your current well-being

Example: meeting your friends at a coffeehouse

1. **Importance** Your well-being is important! It's important to have healthy social interaction when you can. If it's stressful rather than a positive social experience, it's may be time to drop the activity.
2. **Difficulty** Socializing in person may be challenging, but not impossible. Perhaps the café is noisy and sometimes you can't find a parking spot.
3. **Specificity** You're the only one who can carry out social activities for yourself.

Adapting this activity

1. Ask a friend to pick you up so that parking and walking isn't as much of an issue; they could drop you at the door.
2. Tell your friends beforehand that, as much as you love their company, you have a 'hard stop' after a certain amount of socializing time.
3. Stay in bed and still participate by asking a friend to call you when they arrive at your coffee meet-up and teleconference.
4. Wear earplugs or headphones if you have increased sensory sensitivity.

Jaime Seltzer
www.meaction.net