

# Post-Exertional Malaise, Exercise And ME/CFS

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## Post-Exertional Malaise (PEM)

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The cardinal feature of ME/CFS is Post-Exertional Malaise (PEM), which is defined as an “exacerbation of some or all of an individual’s ME/CFS symptoms that occurs after physical or cognitive exertion and leads to a reduction in functional ability” (National Academy of Medicine, 2015, p. 78). Sometimes, PEM is misunderstood as being like the fatigue which healthy people experience after exercise, however PEM is much more than just fatigue. When experiencing PEM, the individual will have an exacerbation of any or all symptoms (eg: muscle pain, sore throat, sore lymph nodes, sensory sensitivity (sensitivity to sound, light or touch), difficulty with thinking or concentrating (“brainfog”), orthostatic intolerance (difficulty standing), just to name a few). The level of exertion which triggers PEM varies according to the level of severity of the individual’s illness. For some, it may be a short walk. For others, it could be brushing their teeth or even lifting their head off the pillow. Exertion which triggers PEM may also vary within the individual: what an individual can manage to do today without triggering PEM, may not be what they can safely do on another day. The onset of PEM is often delayed (commonly 24-48 hours after exertion, though it can be delayed more than this), and can last for days or weeks (or even longer).

It is important to understand that exertion not only worsens symptoms in the short term, but can also lead to an overall worsening of the individual’s illness on a more permanent basis. For this reason, pushing through when experiencing symptom exacerbation is not advised for people with ME/CFS. Instead, pacing activities and rest is recommended. Research has shown that those who stay within their energy limits (also known as the “Energy Envelope”) tend to experience less symptoms and have increased functional capacity than those who push themselves (Jason, Benton, Torres-Harding, & Muldowney, 2009; Jason, Muldowney & Torres-Harding, 2008). To learn more about pacing, visit our [Pacing Page](#).

## Graded Exercise Therapy (GET)

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Graded Exercise Therapy (GET) is one of two commonly recommended treatments for ME/CFS (the other being Cognitive Behaviour Therapy (CBT)). GET is recommended to people with ME/CFS based on the idea that ME/CFS is largely the result of deconditioning due to lack of activity. It is assumed that GET treatment will reverse this deconditioning, leading to a reduction in symptoms and even recovery. Despite the fact that the deconditioning hypothesis of ME/CFS is not supported by biomedical research, and GET studies do not show the high rates of recovery predicted by the deconditioning hypothesis, GET is still the treatment which people with ME/CFS are most likely to have recommended to them. For this reason, it is important to understand what GET is, as well as the potential risks it poses.

GET generally consists of two phases: an initial stabilisation phase (in which the focus is on stabilising symptoms and learning about pacing) and an exercise phase (in which the

individual is encouraged to gradually increase their exercise over time). The stabilisation phase, in which pacing strategies are learned, can be useful to help the individual understand how to live within their energy envelope and minimise PEM. (You can read more about pacing strategies on our [Pacing Page](#).)

However, the exercise phase of GET has the potential to cause harm (especially for those who are either newly diagnosed (and unaware of the importance of pacing) or who are more severely unwell). In surveys from around the world, people with ME/CFS commonly report experiencing harm from GET. For example, the UK's ME Association's patient survey found that 74% of survey respondents reported harm from GET (Geraghty, Hann, & Kurtev, 2017). Emerge Australia, in partnership with Federation University, undertook an Australian patient survey in 2015. Preliminary analysis of the results found that 89% of the 555 respondents indicated that increasing their level of exercise/activity resulted in a worsening of their symptoms.

Unfortunately, individuals who undertake GET for ME/CFS are often encouraged to ignore symptoms that they may experience following exercise, to not listen to their bodies, and may even be told that the symptom exacerbation they experience following exercise is a normal part of reconditioning. Whilst this may be true for healthy people, this is not true for people with ME/CFS. Misinterpreting signs and symptoms of PEM as part of reconditioning poses a real risk to the health of people with ME/CFS, as it can encourage them to push beyond their safe limits and can lead to a worsening of their overall health. It is important for people with ME/CFS to be encouraged to listen to their body, and to minimise or avoid activities which make their symptoms worse.

Given that PEM is a hallmark feature of ME/CFS, and that Emerge Australia's own research has found that people with ME/CFS have reported harm from GET, Emerge Australia does not recommend GET as a treatment for ME/CFS.

## Why is GET recommended?

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GET is a controversial treatment. It has become a standard treatment for ME/CFS because several studies have appeared to show that it is effective. However, these studies have each had many (or all) of the following issues (taken from [Post-Exertional Malaise & Graded Exercise Therapy in ME/CFS](#)).

1. Diagnostic criteria used in ME/CFS research should ensure that all participants selected experience PEM, in order to ensure that this key aspect of the condition is being studied. However, there are currently no GET studies which have used ME/CFS diagnostic criteria which require PEM for diagnosis. These studies are therefore drawing conclusions about the safety and effectiveness of GET for people who experience PEM, whilst being unable to determine how many of the participants in their sample actually experience PEM. Despite this, results of GET studies are routinely applied to people with ME/CFS, who do experience PEM.

The US Agency for Healthcare Research and Quality (AHRQ) conducted a review of the evidence for GET in 2016. When excluding studies which used the broadest diagnostic criteria (which do not require PEM), the agency downgraded evidence for GET to

insufficient (Agency for Healthcare Research and Quality, 2016).

2. GET studies frequently use only subjective measures to measure the results of GET. Such measures are subject to bias (especially when used in non-blinded trials). However, when objective measures (like actimeters or pedometers, 6 minute walk test, return to work or welfare rates) are used, results do not support the use of GET for ME/CFS, nor do they support the deconditioning model of ME/CFS. In other words, objective measures tend to show that GET does not result in increased activity levels (even though the deconditioning model would suggest that it should).

3. GET studies have been criticised for inadequate reporting of harm experienced from the intervention. Such inadequate reporting has led to the conclusion that GET is safe for people with ME/CFS, however patient reports tell a different story. Doctors and patients should be aware of the risk of GET worsening ME/CFS. Blanket recommendations of GET for ME/CFS are likely to be harmful.

4. Despite these flaws in the GET research, both the treatment, and the deconditioning model on which it is based, have been the dominant approach to ME/CFS for decades. As a result, ME/CFS is often seen as a non-permanent condition, that is treatable with GET, despite there being no objective evidence of reversal of the condition following GET interventions. GET studies tend to include only participants with mild forms of ME/CFS, but GET interventions are recommended to patients regardless of their illness severity. All of this has implications for people seeking to access support services like Disability Support Pension (DSP) and National Disability Insurance Scheme (NDIS).

To learn more about the flaws associated with GET research, and the consequences of this for Australians with ME/CFS, please read [Post-Exertional Malaise & Graded Exercise Therapy in ME/CFS](#).

Given the evidence to support the physiological nature of PEM as a core feature of the condition, the risk of harm for people with ME/CFS from GET interventions, and the lack of evidence to support the effectiveness of the treatment, Emerge Australia does not recommend GET as an appropriate treatment for ME/CFS.

## What is Pacing?

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It is common for people with ME/CFS to find themselves in a “push-crash” cycle (also referred to as a “boom-bust” cycle). This is when the individual pushes themselves on their good days, going outside their energy envelope, and triggers PEM (the crash). One of the most commonly used management strategies for ME/CFS is pacing.

Emerge Australia endorses the view of patients that pacing and rest are the most efficacious management approaches for ME/CFS available at this point in time. Pacing involves taking required daily activities – mental/cognitive and/or physical, dividing them up into manageable portions and undertaking only those that fit with the energy available for that day (the “energy envelope”). By avoiding going into energy deficit, the aim is to gradually increase the energy reserves available over time.

For more information about pacing, please visit our [Pacing Page](#).

# Using a Heart Rate Monitor for Pacing

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One of the most effective ways to minimise and avoid PEM, is to use a heart rate monitor (HRM) with pacing. The intention with using HRM for pacing is to find the safe level of activity which the individual can undertake without triggering PEM. This involves keeping the heart rate (HR) below either the anaerobic threshold (AT) (if a cardiopulmonary exercise test (CPET) has been undertaken) or below 50-60% of the maximum heart rate. The formula for calculating the safe heart rate threshold is as follows:

Using 60% of maximum:

$$(220 - \text{age}) \times 0.6$$

For example:

Sarah is 30 years old, so her maximum safe HR threshold would be:

$$(220 - 30) \times 0.6 = 114 \text{ beats per minute (bpm)}$$

For Sarah, 114 bpm is the threshold at which she is highly likely to trigger PEM, so Sarah should aim to keep her HR below this threshold as much as possible. This may mean making adjustments to daily living in order to accommodate these limits: doing activities in short bursts with rests in between, moving slowly rather than quickly, finding ways to do activities sitting or lying down, using mobility aids where necessary. Sarah should also be aware that 114 bpm is the upper limit of her safe zone, and it isn't ideal for her to spend most of her day with her HR close to 114 bpm. Ideally, Sarah should aim to have a significant portion of her day as rest, which means keeping her HR within 35-45% of max (which, for Sarah, would be 66-85 bpm).

## Safe Exercise

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Exercise may be possible with ME/CFS, provided the program is based on an understanding of PEM,

and includes appropriate safety measures. Note: exercise should only be attempted once the individual has stabilised their health, and is already living within their safe HR zone and minimising PEM. Exercise should be approached with caution, and is not a cure for the illness.

The following is taken from [Post-Exertional Malaise & Graded Exercise Therapy in ME/CFS](#):

Very few (if any) GET programs include the sufficient safeguards which are recommended for people with ME/CFS. So-called "safe" exercise programs, which do include safeguards, differ from GET in key ways:

1. They are based on the assumption that deconditioning is a consequence (not cause) of the condition.
2. They are intended as an adjunctive treatment. These exercise programs are a management approach to help improve functional strength, rather than an active

treatment to address the underlying dysfunction.

3. They focus on building functional strength whilst avoiding triggering PEM, working within the limits of a dysfunctional energy production system.
4. They encourage adequate rest both within and between exercise sessions. Heart rate monitoring is used within the session to ensure the patient stays below their anaerobic threshold and avoids PEM.

These safe exercise programs are based on the same principles of pacing with a HRM.

This approach to safe exercise consists of:

- Wearing a heart rate (HR) monitor, to ensure that the HR stays within safe limits (below 50-60% maximum heart rate).
- Focusing on building functional strength, rather than aerobic exercise (which is more likely both to result in the HR exceeding safe limits, and to trigger PEM).
- Exercising in a recumbent (lying down) position.
- Exercising for very short sessions (initially no longer than 30 seconds), with significant rest afterwards (3-6 times the duration of the exercise session). Session duration may be even shorter, depending on illness severity (eg: for individuals who are severely ill, exercise may consist of lifting the head off the pillow, or rotating wrists, or even less, as necessary).
- Rest, which is an integral part of this approach to exercise. Rest is encouraged both during and after exercise sessions. Exercise is initially undertaken only twice weekly, to ensure several rest days between sessions.
- Unlike GET, where symptom exacerbation is often framed as a normal part of reconditioning, with this approach, the emphasis is for the individual to experience no symptom exacerbation after exercise. The amount of exercise (& frequency of sessions) is tailored to the individual's physical capacity and to ensure that PEM is not triggered.
- Unlike GET, pushing through is not advised with this approach to exercise. Morning Resting Heart Rate (MRHR) can be used as a proxy measure of PEM. When the MRHR is more than 10% above or below the individual's usual MRHR, the individual is advised to not exercise that day, but to rest instead. (MRHR can be taken first thing every morning, by lying quietly for 10 minutes and noting the average HR over a 10 minute period. Tracking MRHR is a useful method for monitoring the individual's health over time.)

## Resources

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["When Working Out Doesn't Work Out"](#) by Dr Christopher Snell, Dr Mark VanNess and Staci Stevens

["A Realistic Approach to Exercise and Rehabilitation in ME/CFS"](#) by Dr Mark VanNess (Workwell Foundation) (30 minute video):

For those unable to watch videos, you can read [a summary](#) of Dr VanNess' presentation and concepts:

## References

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