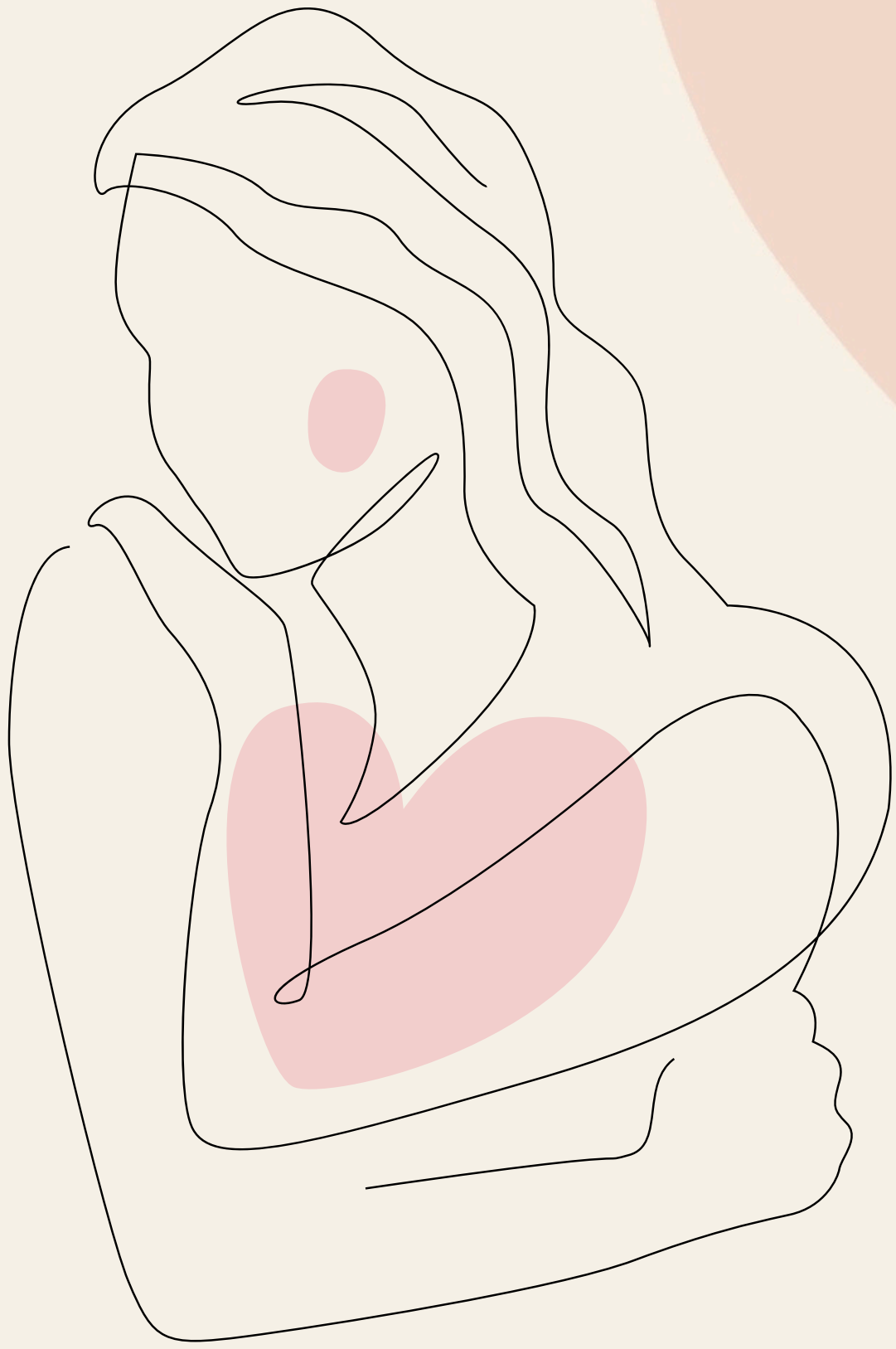
FREE GUIDE



Thriving with ME/CFS: A guide to wellbeing and balance

A note from Jemima

I’m an exercise physiologist from Canberra, Australia, with a lived experience of autism and ADHD, hypermobile Ehlers-Danlos syndrome (hEDS), postural orthostatic tachycardia syndrome (POTS), endometriosis, mast cell activation syndrome (MCAS), and fatigue. I’m passionate about helping people like myself find relief in their symptoms through therapeutic exercise and lifestyle management strategies.

I run my own virtual exercise physiology business, Visible Exercise Physiology. My vision is to improve access to allied health services for people living with invisible conditions and help them feel seen.

Jemima Minto

Accredited exercise physiologist

Understanding ME/CFS and post-exertional malaise (PEM)

What is ME/CFS?

ME/CFS, or myalgic encephalomyelitis/chronic fatigue syndrome, is a complex condition involving multi system dysfunction (neurological, immune, metabolic). Symptoms may include, but are not limited to, extreme fatigue, pain, brain fog, dizziness, and sleep issues.

What conditions are associated with CFS/ME?

Chronic Pain & Musculoskeletal Conditions

- Chronic low back pain
- Chronic pelvic pain
- Temporomandibular joint (TMJ) dysfunction
- Fibromyalgia
- Hypermobile Ehlers-Danlos syndrome (hEDS)

Neurological & Autonomic Conditions

- Migraine
- Dysautonomia
- Orthostatic intolerance / Postural orthostatic tachycardia syndrome (POTS)

Digestive & Urogenital Conditions

- Irritable bowel syndrome (IBS)
- Interstitial cystitis (bladder pain syndrome)
- Endometriosis

Environmental & Sensory Sensitivities

- Multiple chemical sensitivity (MCS)

What is PEM?

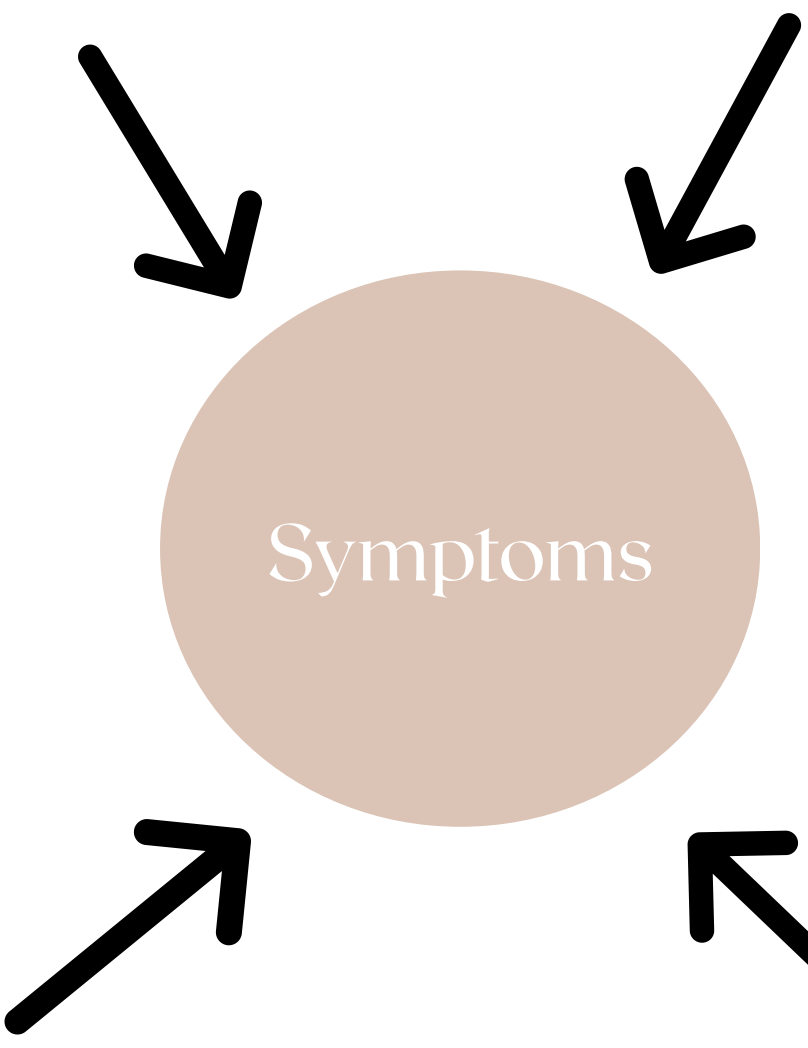
Worsening of symptoms after activity, or even minimal effort. PEM may be delayed for up to 72 hours. It is important to note that PEM is not a result of deconditioning.

Identify your triggers

Identifying your triggers is important as it helps reduce PEM, minimise and manage your symptoms, plan and pace your days more effectively, and most of all, helps you feel more in control. The chart below has an example of common triggers.

Physical
- Under or overexertion
- Medication
- Dehydration
- Diet
- Deconditioning
- Hormones (females)

Environmental
- Sensory overload
- Heat/cold
- Allergens
- Stressful environments



Cognitive
- Work/school
- Hobbies
- Social interaction
- Appointments

Emotional
- Stress
- Anxiety
- Depression
- Relationships
- Arguments

The "3 Ps" — Pacing, Planning, and Prioritising

1. Pacing

A self-management strategy to avoid overexertion and stay within your energy envelope.

Techniques:

- Heart rate monitoring (with help from an EP).
- Listen to your body. If this is difficult to keep track of, you can record your symptoms in apps or journals.
- Pre-emptive rest (not just reactive).

2. Planning

Energy mapping: You can divide days into high/medium/low energy activities. It may be tempting to do all your high priority tasks at once when you're feeling good, but this can lead to a flare-up in symptoms. Instead, spread out your activities throughout the week.

Task bundling: E.g. doing seated tasks together or meal prepping during a good window.

Visual planning tools: colour-coded planners (e.g., high/medium/low energy activity planning), spoon theory charts.

3. Prioritising

- "Must, should, could" lists.
- Delegation: recognising what doesn't have to be done by you.
- Values-based prioritising — what truly matters to you?

Tip: Instead of lumping all your high/medium energy activities close together, spread them out across the week with low-medium energy activities between. E.g., instead of doing your shopping after going to the gym, go to the gym in the morning and shopping in the evening, or do one of them the following day.

Movement benefits

Important note

Movement doesn't have to mean hitting the gym or going for a run. Gentle movement can be anything that feels good in your body—stretching in bed, a slow walk, even swaying to your favourite song. Movement is a tool, but it's most helpful when it's something you truly enjoy. For those with ME/CFS, it needs to be carefully tailored to your unique capacity and goals. When not adapted properly, even gentle activity can lead to setbacks. That's why it's important to work with a qualified professional who understands ME/CFS and can support you in finding a safe, sustainable approach.

Graded Exercise Therapy was once a standard recommendation for ME/CFS. However, it is no longer supported by clinical guidelines like NICE (UK, 2021) due to evidence that it can worsen symptoms, especially PEM.

This guide takes a different approach—one that respects your limits and centres pacing, nervous system support, and optional, adapted movement.

Benefits of cardiovascular exercise

- Improved circulation and oxygen delivery: May reduce orthostatic intolerance and support mild improvements in fatigue and dizziness for some individuals.
- Nervous system regulation: Gentle, rhythmic movement (like slow recumbent pedalling or walking) can help regulate autonomic function if tolerated.
- Mood and sleep: Light aerobic activity may support improved sleep patterns and mental health in those who can tolerate it.

Benefits of resistance training (low-load, short duration)

- Preservation of muscle mass: Helps reduce deconditioning in individuals who are mostly sedentary due to ME/CFS.
- Postural and joint stability: Especially helpful for those with hypermobility, orthostatic intolerance, or POTS.
- Improved function: Small strength gains can translate to easier daily movement (e.g. standing, walking to the bathroom, transferring from bed).

Therapeutic movement

Establish your baseline

How long can you walk/move for without needing more than 60 minutes rest afterwards?

- 20-50% guide
- If a 10-minute walk triggers a flare-up and requires extended rest, consider starting with a 'safe zone' that's just 20–50% of that time—around 2 to 5 minutes—to reduce the risk of post-exertional symptoms.

What could movement look like?

- Bed-based or reclined mobility work
- Gentle pilates
- Seated strengthening (e.g. resistance bands for upper limbs)
- Diaphragmatic breathing with relaxing music
- Most importantly: Anything that feels right for you

Key principles

- Start from a baseline that causes no flare-ups.
- Reassess tolerance over weeks, not days.
- Movement is optional — not mandatory.

Signs to pause or modify

- Increased fatigue or PEM 24–72 hours later.
- New symptoms (e.g. dizziness, pain).
- Decrease in function or cognitive energy.

Tip: if a short session is all you can manage, try adding 5–10 minutes of mindfulness or diaphragmatic breathing before and after. This can enhance the benefits for your fatigue. If mindfulness feels triggering or uncomfortable, feel free to modify the practice to suit your needs—or skip it entirely

Putting it all together

When to seek help

If you're noticing a worsening of symptoms, feeling unsure about how to safely explore movement, or feeling anxious about activity, it can be helpful to connect with an exercise physiologist who understands ME/CFS and can support you gently and safely.

Closing words

This guide is a starting point—not a fix—for supporting yourself on your health journey. With the right care and supports in place, many people with ME/CFS find more steadiness and predictability in their day-to-day life.

Need a hand getting started?

Putting the right supports in place and designing a movement plan that feels safe and manageable can be overwhelming—and sometimes even draining—when you're already dealing with symptoms. But you don’t have to do this alone. Let us take the guesswork out of it. Together, we can create a personalised, fatigue-friendly approach that helps you move towards more stability and symptom relief.

If you're ready for support that meets you where you are, book an appointment with a clinician who truly understands ME/CFS.

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