emerge australia

# Shared Decision Making

## PATIENT DECISION AID

## Exercise: What is right for me?

Supporting people with ME/CFS, long COVID and their health professionals

Volume 1

# CONTENTS

# WHAT IS SHARED DECISION MAKING AND PATIENT DECISION AIDS

## What is shared decision making?

Shared decision making is a collaborative conversation between a person and their healthcare professional about decisions relating to their care.

It brings together the available evidence, clinical expertise, and information about potential benefits, risks, and uncertainties with the person's preferences, circumstances, values, goals, and lived experience.

For people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and long COVID, this is particularly important because symptoms, functional capacity and post-exertional malaise (PEM) can vary significantly between individuals.

## What is a patient decision aid?

A patient decision aid is a resource that helps people understand a specific healthcare decision and prepare for a conversation with their healthcare professional.

It can help someone understand their options, consider potential benefits and risks, identify what matters most to them, and decide what questions to ask.

A decision aid does not make the decision for the person. Its purpose is to support informed choice and shared decision making.

## What a decision aid will not cover?

A patient decision aid is not a diagnostic, treatment or self-management guide. It will not:

- diagnose ME/CFS, long COVID or PEM;
- assess an individual's symptoms or severity;
- provide personalised medical advice;
- teach someone how to undertake an activity or exercise;
- tell someone how much activity they should undertake; or
- replace professional assessment or care.

## The goal

To support people with ME/CFS and long COVID to make informed healthcare decisions that are right for them, in partnership with their healthcare team.

## Who is this patient decision aid for?

This patient decision aid is for people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and/or long COVID who experience post-exertional malaise (PEM).

This decision aid will help you decide if exercise is right for you. It can also support discussions with your healthcare professionals (eg. your doctor, nurse, or allied health professional).

## Consider your health and wellbeing

Making decisions can take time and energy. You may need to read this in small parts, take breaks, or ask someone to help you. Think about your emotional wellbeing. For some people, decisions about exercise can bring up strong feelings.

## A note on graded exercise therapy

International guidelines from organisations such as the World Health Organisation, National Institute for Health and Care Excellence, and Centers for Disease Control and Prevention do not recommend fixed, progressively increasing exercise programs for people who experience post-exertional malaise (PEM), including those with ME/CFS and some people with long COVID.[1–3]

## If graded exercise therapy (GET) is not recommended, why is it included in this patient decision aid?

Some people are still offered or prescribed graded exercise therapy in clinical practice. This decision aid is designed to support informed, shared decision-making for those who are considering or have been advised to undertake this approach.

## When will graded exercise therapy be removed from this decision aid?

This option will be reconsidered as:

- Clinical practice changes and when it is no longer commonly presented as a treatment option to people with ME/CFS and those with long COVID who have PEM.
- People who seek care from their general practitioner (GP) report that they have been assessed for post-exertional malaise (PEM), and management options are in line with international recommendations.
- Access to clinicians with specific expertise in ME/CFS and long COVID is not limited due to availability, cost, or long wait times.

# HOW THIS PATIENT DECISION AID WORKS

This Patient decision aid will help you and your health care professional answer the following question.

**How much exercise, if any, is right for me if I have ME/CFS and/or long COVID?**

To help answer this question, the patient decision aid has **two parts**.

**Part one** gives information on four potential options for you to consider:

- Pacing and rest
- PEM-informed exercise
- Graded exercise therapy (GET)
- Maintain current management approach.

**Part two** guides you through five steps to help you choose what feels right.

**These five steps will guide you to:**

1. Read about what the research shows
2. Consider the potential benefits and harms
3. Think about what matters most to you
4. Prompts to help understand how the information applies to you
5. Consider your options and next steps

Your decision may change over time, and there is no right or wrong choice. You can revisit this decision aid at any time if you feel it is helpful.

## What is myalgic encephalomyelitis /chronic fatigue syndrome (ME/CFS)?

ME/CFS is a complex chronic condition that affects many parts of your body, including the brain, muscles, digestive system, immune system, and circulatory system, among others.[2] ME/CFS can cause mild to severe symptoms and disability, limiting how much energy you have and how sick you feel. A key feature is PEM.[4]

There are currently no approved treatments. Care focuses on managing symptoms and using your energy to support daily life.[5] Some people with long COVID also experience symptoms like people with ME/CFS such as PEM, cognitive difficulties, and fatigue like ME/CFS.[6–8]

## What is long COVID?

Most people recover after a COVID-19 infection, but some continue to experience symptoms for weeks, months, or longer. Around 6 in 100 people who get COVID-19 develop ongoing symptoms known as long COVID. Symptoms may begin during the initial illness or appear days to weeks later.[6,9]

Many people gradually improve within 4 to 9 months, but some remain unwell after 12 months. Long COVID can range from mild to severely disabling and includes more than 200 reported symptoms.[6,9]

Some people experience symptoms that commonly occur together, such as dizziness, palpitations, feeling faint when standing, and difficulty tolerating exercise. Others experience post-exertional malaise, like people who live with ME/CFS. People with long COVID also have a higher risk of heart disease, stroke, diabetes, kidney problems, and mental health disorders.[6,9]

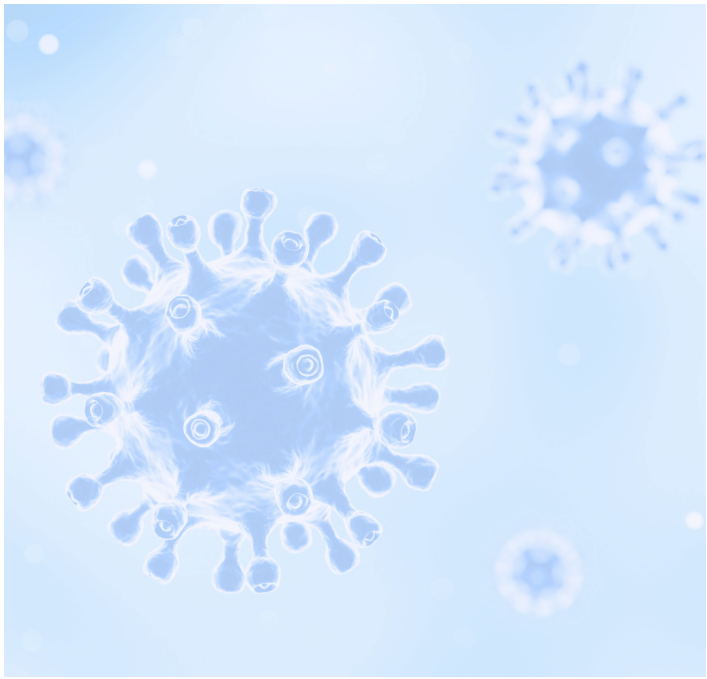
## What is post-exertional malaise (PEM)?

PEM is a worsening of symptoms after physical, mental, or emotional activity. The amount of activity that triggers PEM varies from person to person. Some people have enough energy to work, care for themselves and even exercise. Some people are too unwell to complete all activities of daily living or leave the house or bed. Many people with ME/CFS have much lower energy limits than before they became unwell.[10–12]

## Key features of PEM include:

- Delayed onset: Symptoms may get worse straight away or up to 72 hours later.[13,14]
- Multiple symptoms: This can include fatigue, pain, thinking difficulties, poor sleep, and flu-like symptoms.[15]
- Unpredictable recovery: Symptoms may last for days, weeks, or longer.[15]

PEM is different from normal tiredness, fatigue or being unfit. Understanding this difference is important when deciding about exercise or activity levels.[16]



# PART 1

## About Part 1:

This section will cover four options to help you consider how much exercise, if any, is right for you if you have ME/CFS and/or long COVID.

**Option 1:** Pacing and rest.
**Option 2**: PEM-informed exercise.
**Option 3:** Graded exercise therapy (GET).
**Option 4:** Maintain current management approach.

Below, you will see 2-3 sentences about each option: what the option is, who the option might suit, possible benefits, possible harms and the reasons behind the option. You will then be asked to consider life factors that may influence your decidion.

While you read, consider asking yourself:

### Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐

## What is pacing and rest?

Pacing involves planning activity to stay within your energy limits. Rest is taken regularly to reduce the risk of overexertion.[17–19]

## Who it might suit?

People who experience PEM, fluctuating symptoms, or reduced energy, and want to focus on stabilising their symptoms.[2,19]

## Possible benefits:

- May reduce the frequency and severity of symptom flare-ups.
- May help maintain a more stable level of daily function.
- May help you understand and work within your energy limits.[17,20]

## Possible harms:

- Pacing can be difficult and frustrating because energy limits fluctuate. What someone can safely do one day may trigger PEM another day, when their energy limits are lower.
- Pacing may lead to unrealistic expectations of freedom from symptoms or even recovery, which can create unnecessary pressure and lead to disappointment. People with very severe symptoms may still experience PEM with minimal activity, even when pacing.
- Too much rest over long periods may lead to loss of strength and fitness, making daily activities more difficult.
- Pacing may be misunderstood or confused with other approaches. For example, the "PACE" trial studied graded exercise therapy, and some health professionals may inaccurately/incorrectly call the slow, gradual increase in exercise "pacing."[2,16,21]

## Rationale for pace and rest:

People with ME/CFS or long COVID who have PEM respond differently to activity and exercise compared to people without PEM. Pacing and rest often help people save energy and avoid setbacks by staying within their own energy limits. This may help reduce flare-ups and stablise health.[22–24]

## Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐

# OPTION 2 - PEM INFORMED EXERCISE

## What is PEM-informed exercise?

Exercise, in general terms, is any planned or structured physical activity that is done to improve or maintain health, fitness, or function. It can include things like walking, stretching, strength training, cycling and daily movement done in a deliberate, repeated way. When exercise is PEM-informed, it is planned, tailored, and adapted to stay within individual and fluctuating energy limits to avoid triggering PEM, causing harm.[2,25]

## Who might it suit?

People with ME/CFS or long COVID who experience PEM and understand how to manage their energy limits through pacing and rest.[17,26] Normally requires the support of a PEM-informed health care professional, such as a physiotherapist and/or exercise physiologist.

## Who does it not suit?

- People who are still learning about PEM, pacing and rest
- People who are in PEM
- People whose energy limits are not big enough to safely include exercise
- People whose energy limits are used supporting daily life needs such as personal hygiene, eating, cleaning, shopping, supporting others, working or any other activity.

## Possible benefits:

- May help maintain strength and range of movement.
- Can be tailored to your energy limits and preferences.
- May support participation in daily activities.[2,3,26]

## Possible harms:

- Physical activity may still worsen symptoms, even at low levels.
- PEM can be delayed (up to 72 hours), increasing the risk of overexertion.
- It can be difficult to identify safe activity levels.
- Symptoms may worsen if activity exceeds your energy limits.[13,14,27,2]

## Rationale for PEM-informed exercise:

PEM-informed exercise is based on the idea of tailoring exercise to stay within a person's energy limits to avoid triggering PEM, instead of pushing to do more. It uses pacing, rest, and small amounts of exercise. Exercise is adjusted based on the person's energy limits, life choices, and commitments. The goal is to exercise while reducing the risk of setbacks and helping people stay as stable as possible.

In this approach, the aim of the exercise isn't to treat ME/CFS or long COVID, but to support general health and wellbeing, without making symptoms worse. Some people cannot undertake any form of exercise safely, and each person should be assessed as an individual.[2,3]

## Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐

# OPTION 3 - GRADED EXERCISE THERAPY (GET)

## What is graded exercise therapy (GET)?

Graded exercise therapy involves starting at a low level of physical activity and gradually increasing it over time using a structured plan with set increases.[2]

## Who might it suit?

People who experience fatigue, feel deconditioned and avoid activity.[2]

## Who does it not suit?

People who experience PEM.[2]

## Possible benefits:

- May improve physical fitness and endurance.
- May help the body get stronger after a period of low activity.
- May support gradual return to activity.[29]

## Possible harms:

- PEM may be delayed by up to 72 hours after activity, which can lead to overexertion.[13,14,27,28]
- May cause symptom flare-ups, particularly in people with PEM.[24]
- Repeated activity beyond energy limits may lead to ongoing PEM and reduced overall function.[16]
- This approach may not be safe if you experience PEM.[2,30]
- It may be difficult to tell early on whether your symptoms are a temporary flare or a longer-term relapse.[2]

## Rationale for using graded exercise therapy (GET) for people without PEM:

Graded exercise therapy has been studied in people with long-term fatigue, and some research shows it may improve physical function and fatigue, particularly where reduced fitness or deconditioning is a contributing factor.[29]

## Concerns for people with ME/CFS and long COVID

Graded exercise therapy has been used in people with ME/CFS based on a psychological explanation of the illness. Science has shown this explanation to be incorrect.[31]

People with ME/CFS or long COVID who have PEM respond differently to activity than people without PEM. For many with PEM, activity can make symptoms worse and can make them feel very sick. Too much activity or exercise can lead to longer-term setbacks.

There are concerns about how safe and effective graded exercise therapy is for people with PEM. Because of this, it is not recommended internationally for people with PEM.[12,18]

## Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐

# OPTION 4
# MAINTAIN CURRENT MANAGEMENT APPROACH

## What is it?

Continue your current management approach to daily life, not making changes to energy management plans.

## Who might it suit?

People who:

- Are not ready to change their current approach
- Want more time to consider their options or to seek a second opinion
- Feel their current management plan is working well
- Are already undertaking options 1, 2 or 3.

## Who does it not suit?

- People who are in an ongoing cycle of feeling okay, then crashing.
- People who are new to ME/CFS or long COVID
- People with limited knowledge of PEM

## Possible benefits:

- If your current energy management is working well for you, there may be no need to adjust
- No need to focus energy on changing routines or trying new approaches
- May feel life is overwhelming and need to focus on other things in the short term.

## Possible harms:

- Symptoms may remain the same or worsen over time.
- Ignoring energy limits may increase the risk of symptom flare-ups.
- May lead to reduced function or participation in daily activities.[2]

## Rationale for maintaining the current management approach

Some people prefer to delay making changes. However, not adapting the activity to your condition may increase the risk of ongoing or worsening symptoms.[32]

## Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐

Now, consider the factors that may influence which of the four options above you choose. These influences can be complex. Some may be within your control, while others may not. The suggestions below are based on common concerns shared by the ME/CFS and long COVID communities.

## What other health, lifestyle and social factors may affect your choice?

Check any that apply and discuss your concerns with your health care professional.

| HEALTH CONDITIONS, FACTORS AND INFLUENCES | ✅❌ | HEALTH CONDITIONS, FACTORS AND INFLUENCES | ✅❌ |
|---|---|---|---|
| Access to disability support | | Gender roles | |
| Anxiety / Depression | | Healthcare expectations | |
| Athletic or fitness culture | | Hypermobility | |
| Beliefs about rest being “earned” | | Moving location or financial pressure | |
| Belief that hard work and pushing through is best | | Orthostatic intollerance (OI) and/or postural orthostatic tachycardia syndrome (POTS) | |
| Caring responsibilities | | Past experiences | |
| Connective tissue disorders | | Productivity - a worthwhile mindset | |
| Family expectations | | Religious or moral beliefs | |
| Fear of being judged | | Severity of ME/CFS and/or long COVID | |
| Fear of being judged that rest is lazy | | Stigma around illness | |
| Fibromyalgia | | Unable to afford allied health care | |
| Body weight | | Work or study | |
| Work ethic and perseverance values | | Other (specify) | |
| None of these apply to me | | | |

## Notes

_____

_____

_____

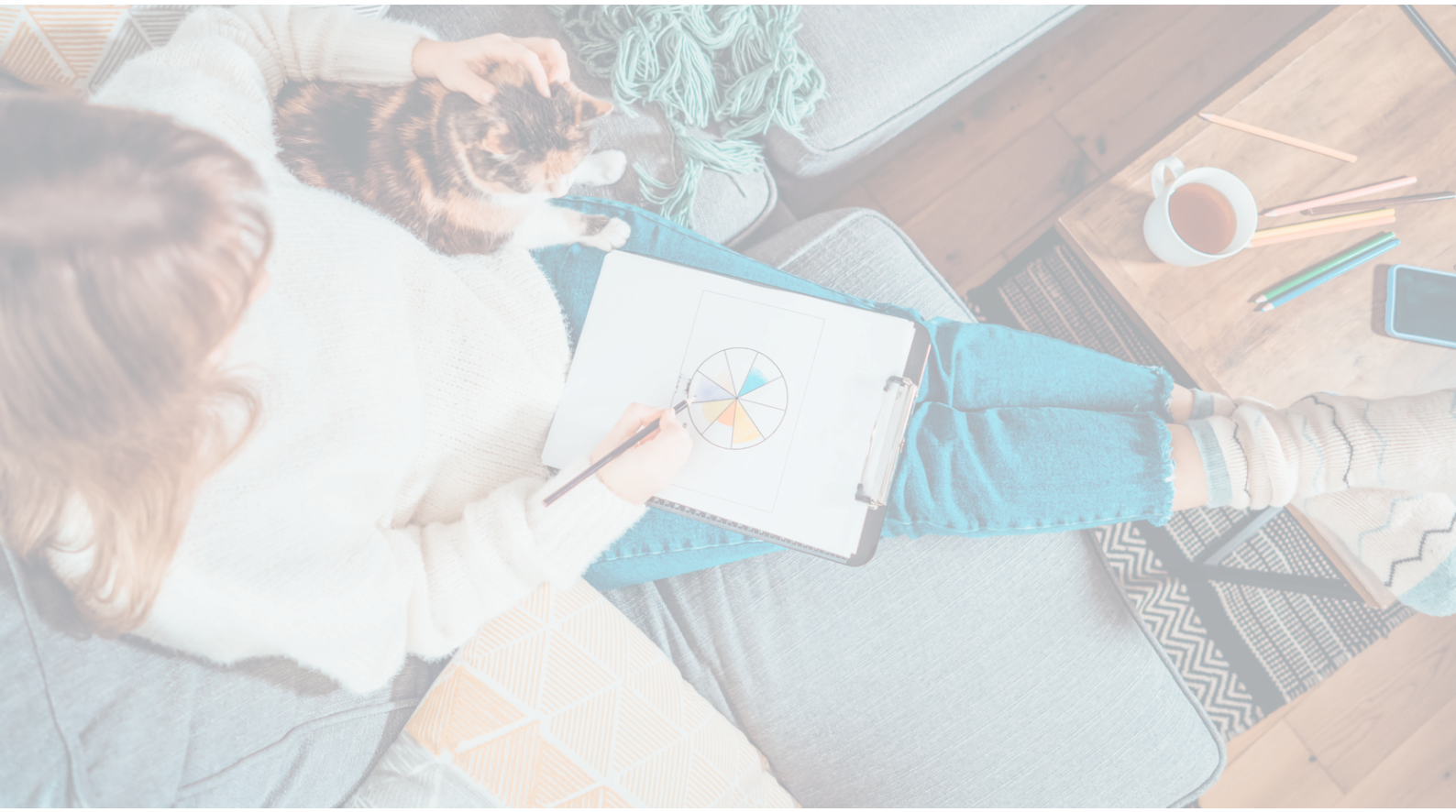
_____

# PART 2

## About Part 2

Now we will take the information from Part 1 and work through five steps to help you consider your options after reading the research.

- **Step 1:** Read what the research shows.
- **Step 2:** Consider the potential benefits and harms of each option discussed in Part 1, based on what the research shows.
- **Step 3:** Think about each option and use the template to record what matters most to you.2
- **Step 4:** Reflect on what you have learnt and use the prompts to help you understand how the information applies to you.
- **Step 5:** Consider your options and decide on your next steps.



Research on exercise, pacing and rest for people with ME/CFS and long COVID is limited and sometimes inconsistent. Many studies are small, use different ways to diagnose ME/CFS, and do not always ensure that people involved in the research experience PEM.

Because of this, there is uncertainty about the benefits and harms of different approaches, especially for people who experience PEM.[2,3,27,33,34]

## Graded exercise therapy (GET)

Some older studies in people with chronic fatigue syndrome (CFS) suggested that graded exercise therapy may improve fatigue and physical function.[35]

However, there are concerns about the quality of this research, including whether participants had PEM either before or during the research and whether harms were fully reported.

When PEM is considered, some reviews and clinical guidelines do not recommend graded exercise therapy for people with ME/CFS.[22,31,35,36]

Some health care professionals may still suggest graded exercise therapy. If it is used, it is important to monitor symptoms, particularly if there are concerns or uncertainty about whether PEM is being experienced.[2,3]

## PEM-informed activity or exercise

There is limited, high-quality research on exercise approaches specifically designed for people with PEM.

Some evidence and patient reports suggest that gentle, adapted activity may help maintain strength and function for some people.[26]

However, even low levels of activity can worsen symptoms in people with more severe disease, and PEM is often delayed by 12 to 72 hours, meaning it can be hard to decide how much exercise is safe for you.[21,22,33]

## Pacing and rest

Pacing is widely used as an energy management strategy for ME/CFS and long COVID. Some research and clinical guidance suggest it may help reduce the frequency and severity of symptom flare-ups.[17]

Guidelines: Clinical guidance from the US Centers for Disease Control and Prevention and the UK National Institute for Health and Care Excellence recommend staying within personal energy limits and adjusting activity based on symptoms.[2,3] Pacing is not a cure for ME/CFS or long COVID, and evidence on long-term outcomes is limited.[2]

# STEP 2:
# CONSIDER THE POTENTIAL BENEFITS AND HARMS

Based on what the research shows, consider the potential benefits and harms of each option discussed in Part 1.

| OPTIONS | BENEFITS | HARMS |
|---|---|---|
| 1. Pacing and rest | | |
| 2. PEM informed exercise | | |
| 3. Graded exercise therapy (GET) | | |
| 4. Maintaining current management approach | | |

Below, we have listed common reasons to choose each of the four options.
For each option, consider how much each factor matters to you using the scale from 0 to 5.

**'0' means it is not important to you. '5' means it is very important to you.**

| PACING AND REST | HOW IMPORTANT IS THIS TO YOU? RATE 0-5 | GRADED EXERCISE THERAPY (GET) | HOW IMPORTANT IS THIS TO YOU? RATE 0-5 |
|---|---|---|---|
| I want to reduce the frequency or severity of PEM flare-ups | | The concept of graduated increases in exercise appeals to me. I understand it is not recommended internationally for people with post-exertional malaise (PEM) | |
| I want to balance my physical, cognitive, emotional, and social activities with limited energy | | I am willing to watch for symptom worsening (PEM) while trying graded exercise therapy and accept the risk it may lead to symptom exacerbation, particularly if I experience PEM | |
| I want to protect my current function and quality of life | | I feel deconditioned and think my fatigue is due to low activity rather than PEM | |
| I prefer a conservative approach to avoid overexertion | | I want to improve my strength, endurance, or overall fitness and have weighed up the benefits and risks of graded exercise therapy | |
| **How important is PEM-informed exercise to you?** | | **Maintain your current management approach** | |
| I want to maintain or gently improve strength, flexibility, or range of motion | | I feel safer maintaining my current routine | |
| I want to learn what types and amounts of activity my body can tolerate | | I want to observe my symptoms before trying new strategies | |
| I want a personalised, PEM-informed approach | | I am unsure how exercise or activity will affect my symptoms | |
| I want to stay as active as possible without triggering worsening symptom and PEM | | I want to focus on other aspects of my life rather than changing my current activities | |

## Notes

# STEP 3:
# THINK ABOUT WHAT MATTERS MOST TO YOU

**Now, review the table on the previous page.**

Note the number of points each option has in the table below to help you determine/work out which option is best suited to your current situation.

| OPTION | WHICH OPTION HAS THE MOST POINTS? |
|---|---|
| Pacing and rest | |
| PEM-informed exercise | |
| Graded exercise therapy (GET) | |
| Maintain your current management approach | |
| I don't know what option is best suited to me | |

# STEP 4: PROMPTS TO HELP UNDERSTAND HOW THE INFORMATION APPLIES TO YOU

Use this to reflect on what you've learned from the patient decision aid. There are no "right" answers, just your understanding and perspective.

**Tick the answer that best reflects your current understanding.**

| OPTION | PACING AND REST | PEM-INFORMED EXERCISE | GRADED EXERCISE THERAPY (GET) | MAINTAIN YOUR CURRENT MANAGEMENT APPROACH | I DON'T KNOW |
|---|---|---|---|---|---|
| Which option is most likely to help you stabilise your symptoms? | | | | | |
| Which option is least likely to provide benefits? | | | | | |
| Which option is least likely to trigger PEM? | | | | | |
| Which option carries the highest chance of causing harm or symptom worsening? | | | | | |

**Now, find out how comfortable you feel about deciding.**

| DECISIONS | YES | NO |
|---|---|---|
| Do you know the benefits and harms of each option? | | |
| Are you clear about which benefits and harms matter most to you? | | |
| Do you have enough support and advice to make a choice? | | |
| Do you feel sure about the best choice for you? | | |

If you answered 'No' to any of these, discuss with your Health Care Professional

# STEP 5
# CONSIDER YOUR OPTIONS AND NEXT STEPS

**Tick the answer that best reflects your decision and make notes for discussion with your health professional**

| CHECK WHAT TO DO NEXT | YES | NO | NOTES |
|---|---|---|---|
| I have decided on an option | | | |
| I want to try the option ___ | | | |
| I have decided not to try option(s) ___ | | | |
| I need to discuss the options with my health care professional and family | | | |
| I need to read more about my options | | | |
| Other, please specify | | | |

## This information is not intended to replace the advice of a health care provider.

### Information about this document

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### Benefits and harms data taken from:

- Consensus Criteria / Diagnostic Definitions
- Original Research / Mechanistic Studies
- Systematic Reviews / Scoping Reviews / Meta-analyses
- Guidelines / Official Reports
- Patient Surveys / National Reports
- Commentaries / Perspective / Consensus Documents

### For more information on this patient decision aid:

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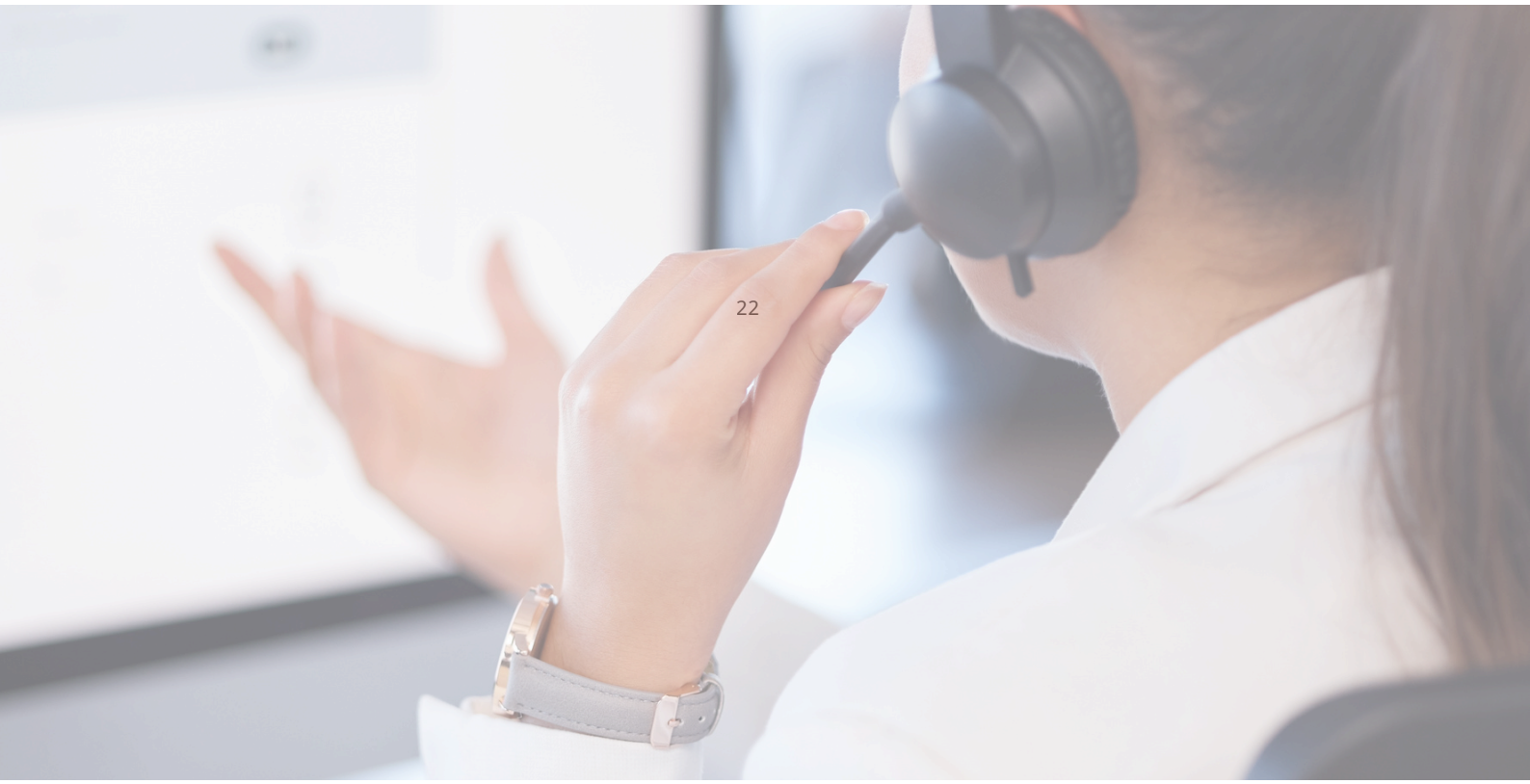

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## Education for your health professional

ME/CFS is not routinely taught in universities, making it hard for both health professionals and their patients to navigate.

Emerge Australia offers a range of FREE, online and RACGP-approved education for clinicians and allied health professionals.

## Education for you

Free online education & live education sessions - Self-paced modules and live sessions on topics such as post-exertional malaise, pacing and sleep.

## Information about ME/CFS, long COVID and PEM

Our website also offers clear, evidence-based information on ME/CFS and long COVID, including post-exertional malaise (PEM), diagnosis, and management.

## Position statements

Emerge Australia offers official position statements on specific subjects of relevance to the Australian ME/CFS and long COVID community and Health Professionals.

## Get involved in research

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This information is not intended to replace the advice of a health care provider

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