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Shared Decision Making

PATIENT DECISION AID

Orthostatic Intolerance: Should I be tested?

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

Volume 2

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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.



About this patient decision aid

If you live with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) or long COVID and feel dizzy or lightheaded, this patient decision aid may help you decide whether to talk with your healthcare professionals (eg. your doctor, nurse, or allied health professional) about getting tested for orthostatic intolerance (OI).

There are several different forms of OI, and you may have heard of all or some of them, like:

- Postural orthostatic tachycardia syndrome (POTS)
- Orthostatic hypotension (OH)
- Neurally mediated hypotension (NMH)

Who is this patient decision aid for?

This patient decision aid may be helpful if you:

- Have been diagnosed with ME/CFS or long COVID.
- Experience post-exertional malaise (PEM).
- Are unsure whether some of your symptoms may be caused by orthostatic intolerance.

Consider your health and wellbeing

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



This patient decision aid has two parts.

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

- Option 1: Start with a simple assessment (NASA Lean Test or active stand test).
- Option 2: Have formal testing now (Tilt Table Test).
- Option 3: Wait and monitor symptoms.

This patient decision aid may help you consider each option in relation to what it is, who it might suit, its possible benefits and harms, and the reasons for each option.

Part two guides you through four steps to help you choose what is right for you at the time. Your decision may change over time, and there is no right or wrong choice.

These four steps may guide you to:

1. Make notes on the benefits and harms of each option based on what the research says.
2. Think about what matters most to you.
3. Reflect on what you have learnt.
4. Decide your next steps.



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.[1] 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.[2]

There are currently no approved treatments for ME/CFS. Care focuses on managing symptoms and using your energy to support daily life.[3] Some people with long COVID also experience symptoms like people with ME/CFS such as PEM, cognitive difficulties and fatigue like ME/CFS.[4–6]

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.[6,7]

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.[6,7]

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 (PEM), like people with ME/CFS. People with long COVID also have a higher risk of heart disease, stroke, diabetes, kidney problems, and mental health disorders.[6,7]



Definitions

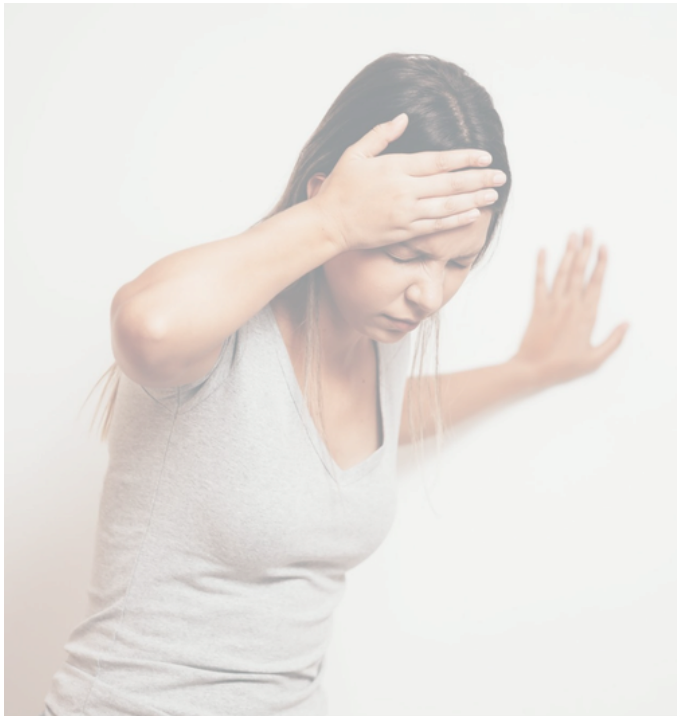
Before we introduce orthostatic intolerance, there are a few definitions that can help while learning:

- **Autonomic nervous system:** Your autonomic nervous system controls all your bodily functions you don't need to think about, such as heart rate, blood pressure, breathing and digestion.
- **Hypotension**: low blood pressure.
- **Orthostatic**: an upright posture, either sitting or standing.
- **Tachycardia**: fast heart rate.

What is orthostatic intolerance (OI)?

Orthostatic intolerance (OI) means your body has trouble adjusting to being upright, such as sitting or standing. This can affect blood flow, heart rate and blood pressure.

It can sometimes be caused by a problem with your **autonomic nervous system**, called dysautonomia.[8] You may feel worse when sitting upright, standing, taking a hot shower, or walking. When you lie down, your symptoms may improve or even go away, but for some people, they may not completely stop.[8]



Symptoms may include, but are not limited to:

- Feeling like your heart is skipping beats, racing or pounding.
- Dizziness, weakness, unsteady on your feet
- feeling faint.
- Sick in the tummy (nausea).
- Feeling like it's hard to get enough air when breathing.
- Pain in your chest .
- Problems concentrating.
- Your feet or hands become red or a little bit purple.
- Feeling thirsty even after drinking lots of water.[9]

Important facts:

- **95% of people with ME/CFS and 66% of people with long COVID[9,10] have orthostatic intolerance**
- Orthostatic intolerance symptoms can range from **mild to very severe.**[9]

In people with orthostatic intolerance, symptoms may occur because:

- Blood builds up in the lower part of the body.
- Blood struggles to move to the brain and back to the heart properly.
- There is less blood volume moving around the body.[8,11,12]

Before we move on, let's briefly review the three common types of orthostatic intolerance.

- Postural orthostatic tachycardia syndrome **(POTS)**: an inappropriate increase in heart rate when standing or sitting.
- Orthostatic hypotension **(OH)**: an inappropriate drop in blood pressure when standing or sitting, usually within a few minutes.
- Neurally mediated hypotension **(NMH)**: an inappropriate drop in blood pressure after prolonged standing or sitting.

PART 1

Part one instructions

This section will cover three options to help you consider if you should be tested for orthostatic intolerance if you have ME/CFS or long COVID.

Option 1: Start with a simple assessment - NASA Lean Test or Active Stand Test.
Option 2: Have formal testing - Tilt Table Test.
Option 3: Wait and monitor symptoms.

On the next page, you will see 2-3 sentences about each option: what the option is, whom the option might suit, possible benefits, possible harms and the reasons for this option.

While you read, consider asking yourself:

Does this option feel right for me?

- [ ] Yes
- [ ] No
- [ ] Unsure



Option 1: Start with a simple assessment (NASA Lean Test)

What is a simple way to test for orthostatic intolerance?

This option means talking with your GP about your symptoms and doing a simple test at the clinic, such as the NASA Lean Test. This may be done on the same visit or a separate appointment, sometimes with a nurse or another doctor.[12,13]

What happens during the NASA Lean Test?

First, you lie down and rest for about 5 minutes and have your blood pressure and heart rate measured. Then, you will stand and lean against a wall for up to 10 minutes. A doctor or nurse will check your heart rate, blood pressure, and ask you about your symptoms every minute for up to 10 minutes. After the test, they will review the results and discuss the possible next steps with you.[13]

The active stand test is similar, except without leaning on the wall.

Who might it suit?

The NASA Lean Test may suit if you:

- Have ME/CFS, long COVID, mast cell activation syndrome, or hypermobility spectrum disorder.
- Want an easy and low-cost assessment that may help understand if you have orthostatic intolerance.
- Feel dizzy, lightheaded, or have a fast heartbeat when standing.
- Feel the symptoms affect your daily activities.
- Are interested in exploring strategies to manage these symptoms.[9,10,14,15]

Possible benefits of NASA Lean Testing

- Not expensive.
- Quick test done in a clinic.
- Does not need special equipment.
- Can be done at home with instruction and at multiple time points.
- May help explain symptoms, such as dizziness or a fast heart rate, when standing.
- May guide next steps for treatment, both non-pharmacological and pharmacological, or referral to specialist services.

Possible harms

- May make symptoms worse during or after the test (eg. fatigue or PEM).
- Results may not always be clear or give a diagnosis.
- Symptoms may not occur during the test, so the results may not reflect your usual experience.
- You may still need more tests later
- May require a separate appointment or a longer appointment.
- May not be accessible for people with more severe symptoms as they may be too unwell to leave the house or bed.
- Your doctor may not be familiar with this test, which could affect how the results are understood or what happens next.

Rationale for NASA Lean Test

Some people choose this option to better understand how their body responds to standing. It can give useful information about your symptoms without needing complex or more expensive tests. It may help you and your doctor decide if further testing or treatment is needed.[16]

.

Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐

OPTION 2: HAVE FORMAL TESTING

What is formal testing?

This option involves more detailed testing, such as a Tilt Table Test. This test requires a specialist referral by your GP to a cardiologist or neurologist who specialises in orthostatic intolerance and who has access to a Tilt Table.

What is a Tilt Table Test?

A Tilt Table Test helps assess how your body responds to being upright. It measures your heart rate, blood pressure, and symptoms as your body is moved from lying down to standing. It is normally performed by a specialist doctor and nurse.

What happens during the Tilt Table Test?

You lie flat on a special table and are safely strapped in. Your heart rate and blood pressure are measured. Then the table slowly tilted so you were upright while a doctor or nurse monitor your heart rate, blood pressure, and symptoms. The test may or may not involve the nurse giving medications as instructed by the attending specialist doctor. The test usually takes 20–45 minutes, and you will be supported throughout.

Who might the Tilt Table Test suit?

It may suit you if you have less severe, persistent, or unclear symptoms and want a more detailed assessment under the care of a cardiologist or neurologist who understands orthostatic intolerance.



Possible benefits

- Some specialists may prefer the Tilt Table Test over the NASA Lean Test for diagnosis.
- A written report of your results from the specialist may support your GP in managing your orthostatic intolerance.
- A specialist can help decide on management if the test is positive.
- May be required for certain insurance claims.

Possible harms

- Can be expensive
- .Rarely offered in public care, and public hospitals with a tilt table may have a long wait list.
- Symptoms may not happen during the test (for some, symptoms only happen later during a flare-up), so the results may not show the full picture.
- May make symptoms worse during or after the test (eg. fatigue or PEM).
- Not accessible for people with more severe symptoms, as they may be too unwell to leave the house or bed.

Rationale for having formal testing

Some people choose this option because it may provide a more detailed assessment to help confirm or rule out orthostatic intolerance. It may provide clearer information and help guide care, particularly when symptoms are unclear or the clinician chooses to use specific medication that needs cardiac monitoring during the standing test.

Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐

OPTION 3: WAIT AND MONITOR SYMPTOMS

What does it mean to wait and monitor symptoms?

This option involves tracking your symptoms over time and delaying testing unless your symptoms get worse or become more frequent.

People with orthostatic intolerance may experience symptoms that can affect daily life. Using a tool like the 12-item, Malmö POTS questionnaire may help you measure your symptoms at home and track when you feel at your best and worst.[17]

Waiting and monitoring symptoms may suit people who:

- Want to have a checklist of their symptoms before they go to their doctor.
- Have symptoms so severe that the Tilt Table Test or NASA Lean Test are not suitable because these tests may make their symptoms much worse and/or cause PEM.

Possible benefits:

- Monitoring can be completed before an appointment and within the person's energy limits.
- Symptom severity can be tracked over time (eg. when you are in a flare-up or at baseline).

Possible harms:

- Answers may not fully reflect symptoms, especially if they change day to day.
- The score may not capture all the relevant symptoms.
- Results could be misunderstood without support from a healthcare professional.
- Different health care professionals can interpret the results differently.[16]

Rationale for wait and monitor symptoms:

This approach allows time to observe symptom patterns before deciding whether testing is needed. Some people choose this option to avoid or delay testing, conserve energy, and reduce the risk of symptom worsening, including PEM. Monitoring can also provide useful information to guide future decisions about whether testing is needed.

Does this option feel right for me?

Yes ☐

No ☐

Unsure ☐



FACTORS THAT MAY INFLUENCE YOUR DECISION

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.

FACTORS AND INFLUENCES	
Access to disability support	
Access to testing centres	
Medical anxiety	
Caring responsibilities	
Fear of being judged or not believed	
Past negative or positive experiences within the healthcare system	
Severity of ME/CFS and/or long COVID	
Stigma around illness	
Unable to afford testing	
Unable to afford specialist care	
Other (specify)	
None of these apply to me	

Notes

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.
- **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.



What does the research show?

The table below show a "best estimate" of what may happen to **100 people** with ME/CFS or long COVID who choose each option.

These are estimates based on research. Your own experience may be different.



	Start with a simple assessment (NASA Lean Test)	Have formal testing (Tilt Table Test)	Wait and monitor symptoms
Possible benefit: Detecting orthostatic intolerance	About **55 out of 100** people who have a NASA Lean Test, may have orthostatic intolerance detected. This means that around **45 out of 100** people may not have orthostatic intolerance detected with this test.	About **65 out of 100** people who have a Tilt Table Test, may have orthostatic intolerance detected. This means that around **35 out of 100** people may not have orthostatic intolerance detected with this test.	About **10 out of 100** people who wait and monitor their symptoms may have orthostatic intolerance identified over time. This means that for many people, orthostatic intolerance may not be identified without testing.
Possible harms: Symptoms during or after testing, (such as: dizziness, PEM or fatigue).	About **20 out of 100** people who have a NASA Lean Test may feel worse during or after the test (for example, dizziness or PEM)	About **40 out of 100** people who have a Tilt Table Test, may feel worse during or after the test (for example dizziness or PEM). About **60 out of 100** people may not experience these effects.	About **5 out of 100** people who wait and monitor their symptoms may feel worse over time without testing or treatment. Most people will not experience worsening
Risk of additional consideration: Fainting during testing.	Fewer than **1 out of 100** people may faint during a NASA lean test.	About **10 out of 100** people may faint during a NASA lean test	N/A

The table above includes 'estimates' of what happens to a group of people using available research. The quality of the research for the:

- Benefits: +++ Moderate (further research may change the estimate)
- Minor Harm: ++ Low (further research is likely to change the estimate)

References for harms and benefits table

- Van Campen CLMC, Rowe PC, Visser FC. Orthostatic intolerance and haemodynamic abnormalities in ME/CFS
- Long COVID orthostatic intolerance study (n≈277): ~50–60% abnormal responses during standing tests
- National Institute for Health and Care Excellence. ME/CFS Guideline NG206 (2021).
- Freeman R, Wieling W, Axelrod FB, et al. Consensus statement on tilt table testing.

STEP 2: CONSIDER THE POTENTIAL BENEFITS AND HARM

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

OPTIONS	BENEFITS	HARMS
1. Start with a simple assessment (NASA Lean Test)		
2. Have formal testing (Tilt Table Test)		
3. Wait and monitor symptoms		

STEP 3: WHAT MATTERS MOST TO YOU?

Below, we have listed common reasons to choose each of the three 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.

SIMPLE ASSESSMENT (NASA LEAN TEST)	HOW IMPORTANT IS THIS TO YOU? RATE 0-5	FORMAL TESTING (TILT TABLE TEST)	HOW IMPORTANT IS THIS TO YOU? RATE 0-5
I want more information about my symptoms.		I want more detailed testing, and I am happy to wait.	
I want a quick test that my clinic can complete locally.		I want more detailed information, even if the process is more time-consuming or stressful.	
I want to avoid missing problems that could get worse.		I want results that help guide treatment decisions and medication choices.	
I want a quick, affordable test first before discussing medication or seeing a specialist.		I want a specialist to test my orthostatic intolerance.	

WAITING AND MONITORING SYMPTOMS?	HOW IMPORTANT IS THIS TO YOU?
I want to avoid or delay testing unless my symptoms change, or I feel testing is needed.	
I prefer to start treatment only if symptoms become worse.	
I want to minimise stress, travel, or medical appointments.	
I want to minimise the chance of PEM.	

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 DO YOU PREFER?
Start with a simple assessment (NASA Lean Test)	
Have formal testing (Tilt Table Test)	
Wait and monitor symptoms	
I don't know	

STEP 4:
WHAT ELSE DO YOU NEED FOR DECISION MAKING?

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

Tick the answer that best reflects your current understanding.

OPTION	START WITH A SIMPLE ASSESSMENT (NASA LEAN TEST)	HAVE FORMAL TESTING (TILT TABLE TEST)	WAIT AND MONITOR SYMPTOMS	I DON'T KNOW
Which option feels most appropriate for your current symptoms and circumstances?				
Which option seems least useful for you at this time?				
Which option seems least likely to worsen your symptoms or trigger PEM?				
Which option feels most likely to worsen your symptoms or be difficult for you?				

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.
(The SURE Test © O'Connor & Légaré, 2008)

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



ABOUT THIS INFORMATION

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:

- Guidelines
- Consensus Statement
- Narrative Review
- Observational
- Epidemiological Data
- Observational Study / Survey
- Clinical Guidance
- Instructional Protocol
- Score Development

For more information on this patient decision aid:

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ADDITIONAL INFORMATION

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.

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