SEVERE ME WEBINAR

Caring well for patients with severe ME

A practical session

Presented by

Dr David Fineberg

General practitioner

PhD candidate, University of Melbourne

Founder, ME Research Clinic (MERC)

29 August 2026

WELCOME

Why this session

Many GPs feel on their own

Managing ME well is hard to learn in isolation. Tonight brings together practical, tested tools rather than theory alone.

Built for real practice

How to diagnose with confidence, when and how to refer, and how to make a home visit genuinely safe for the patient.

Written for two audiences

In plain language for GPs new to ME research, and for the people with ME and carers joining us live tonight.

A recording and transcript will be available afterwards, for anyone who cannot manage live viewing.

INTRODUCTION

Meet Dr Fineberg and the ME Research Clinic

Dr David Fineberg

Dr David Fineberg is a general practitioner and PhD candidate at the University of Melbourne. He founded the ME Research Clinic, where he combines clinical care with research into ME and Long COVID, including work on biomarker guided, individualised treatment through the TOTEM trial.

Research focus: precision medicine

Through the Melbourne ME/CFS Collaboration and the Open Medicine Foundation network, TOTEM uses each patient's own biomarker data to help predict which treatment is likely to work, moving ME care away from trial and error.

What MERC does

- Diagnostic confirmation and targeted investigations
- Referral coordination for patients and their treating GPs
- Research based patient profiling across cognitive, autonomic, immune and m
  help identify patient subgroups

COMMUNITY AND CONTACT

A community of practice for GPs

RACGP Energy Limiting and Post Infection Conditions group

Endorsed August 2025. Covers ME, Long COVID, POTS and fibromyalgia. Chaired by Associate Professor Bernard Shiu.

Offers case based learning, practical tools, evidence based resources, and a stronger GP voice in education and policy.

Join: RACGP interest form, or search the group on Facebook

General line: 1800 090 588, gpsi@racgp.org.au

Reach us directly

For referrals, clinical questions, or to connect about the special interest group.

Phone
(03) 9527 1216

Email
reception.merc@gmail.com

Four levels of severity

As defined by the ME International Consensus Primer

1

Mild

Meets diagnostic criteria, with a noticeable drop in activity from before the illness.

2

Moderate

Roughly half the pre-illness activity level. Often still able to manage some routine tasks.

3

Severe

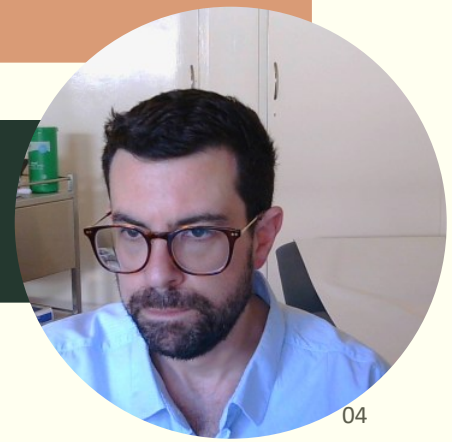
Mostly housebound. Leaving home is rare and comes at a real cost.

4

Very severe

Mostly bedbound. Needs assistance with basic daily functions.

Severe ME is not the same as having a severe episode of ME. It is a sustained state, not a temporary flare.



Very severe ME has its own spectrum

Recent research proposes an extremely severe category within very severe ME, describing a further progression rather than a single fixed state.

LESS AFFECTED END

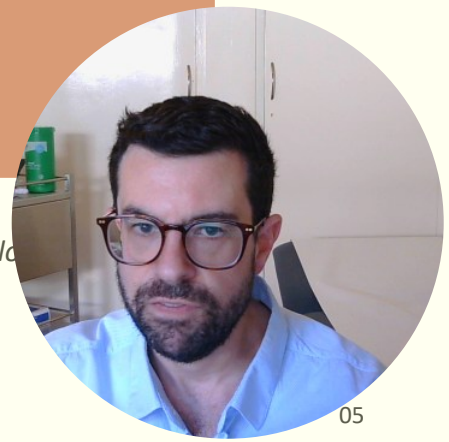
Still fully bedridden

Some patients at this end can still tolerate sound and music, use the internet, communicate in writing, and have people nearby without a flare.

MOST AFFECTED END

Complete isolation

Loss of communication and internet access, and an inability to tolerate anyone else in the room. Severe nutritional deficiency can require a feeding tube and a PICC line.



In between, sensory intolerance increases step by step, until even one other person in the room becomes unbearable. Source: Grach et al, Frontiers in Immunol

What very severe ME can look like

1

Speech. Light. Sound.

Even these can each trigger a lasting flare, along with something as small as being turned in bed.

2

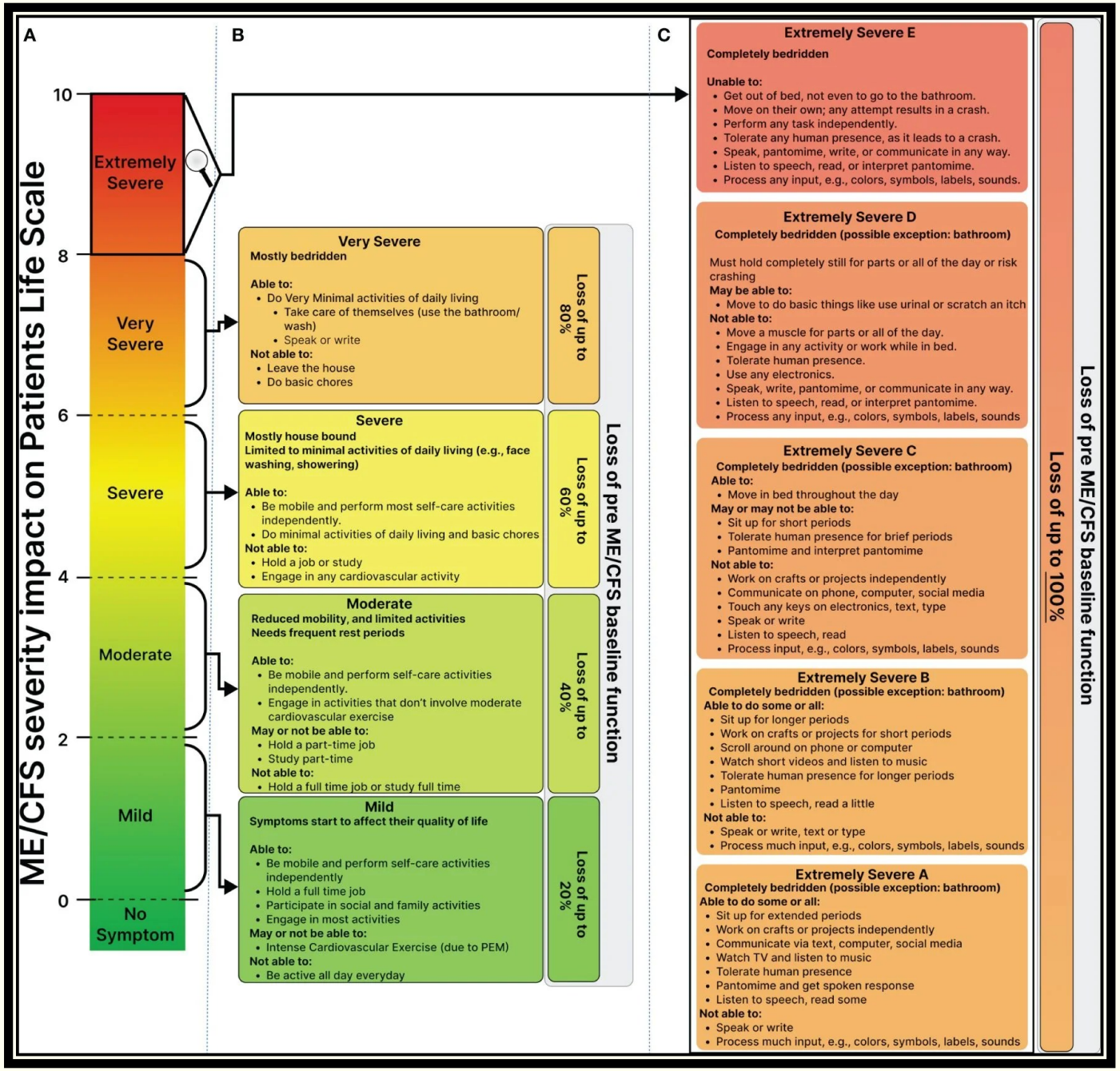
Once a month, or less

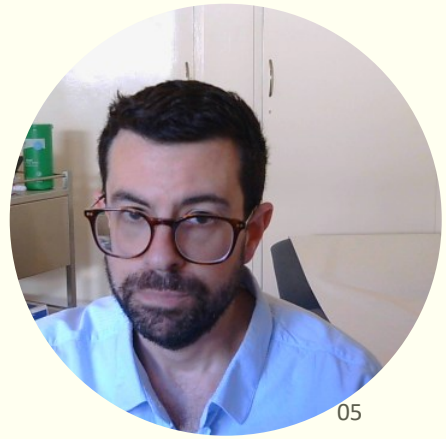
How often many very severely affected patients can manage a bath or shower.

3

Not avoidance

Malnutrition, dental problems and pressure injuries come from the ill
itself, not from psychological


A
B
C
ME/CFS severity impact on Patients Life Scale
10
8
6
4
2
0
Extremely Severe
Very Severe
Severe
Moderate
Mild
No Symptom
Very Severe
Mostly bedridden
Able to:
• Do Very Minimal activities of daily living
• Take care of themselves (use the bathroom/ wash)
• Speak or write
Not able to:
• Leave the house
• Do basic chores
Loss of up to 80%
Severe
Mostly house bound
Limited to minimal activities of daily living (e.g., face washing, showering)
Able to:
• Be mobile and perform most self-care activities independently.
• Do minimal activities of daily living and basic chores
Not able to:
• Hold a job or study
• Engage in any cardiovascular activity
Loss of up to 60%
Moderate
Reduced mobility, and limited activities
Needs frequent rest periods
Able to:
• Be mobile and perform self-care activities independently.
• Engage in activities that don't involve moderate cardiovascular exercise
May or not be able to:
• Hold a part-time job
• Study part-time
Not able to:
• Hold a full time job or study full time
Loss of up to 40%
Mild
Symptoms start to affect their quality of life
Able to:
• Be mobile and perform self-care activities independently
• Hold a full time job
• Participate in social and family activities
• Engage in most activities
May or not be able to:
• Intense Cardiovascular Exercise (due to PEM)
Not able to:
• Be active all day everyday
Loss of up to 20%
Loss of pre ME/CFS baseline function
Extremely Severe E
Completely bedridden
Unable to:
• Get out of bed, not even to go to the bathroom.
• Move on their own; any attempt results in a crash.
• Perform any task independently.
• Tolerate any human presence, as it leads to a crash.
• Speak, pantomime, write, or communicate in any way.
• Listen to speech, read, or interpret pantomime.
• Process any input, e.g., colors, symbols, labels, sounds.
Extremely Severe D
Completely bedridden (possible exception: bathroom)
Must hold completely still for parts or all of the day or risk crashing
May be able to:
• Move to do basic things like use urinal or scratch an itch
Not able to:
• Move a muscle for parts or all of the day.
• Engage in any activity or work while in bed.
• Tolerate human presence.
• Use any electronics.
• Speak, write, pantomime, or communicate in any way.
• Listen to speech, read, or interpret pantomime.
• Process any input, e.g., colors, symbols, labels, sounds
Extremely Severe C
Completely bedridden (possible exception: bathroom)
Able to:
• Move in bed throughout the day
May or may not be able to:
• Sit up for short periods
• Tolerate human presence for brief periods
• Pantomime and interpret pantomime
Not able to:
• Work on crafts or projects independently
• Communicate on phone, computer, social media
• Touch any keys on electronics, text, type
• Speak or write
• Listen to speech, read
• Process input, e.g., colors, symbols, labels, sounds
Extremely Severe B
Completely bedridden (possible exception: bathroom)
Able to do some or all:
• Sit up for longer periods
• Work on crafts or projects for short periods
• Scroll around on phone or computer
• Watch short videos and listen to music
• Tolerate human presence for longer periods
• Pantomime
• Listen to speech, read a little
Not able to:
• Speak or write, text or type
• Process much input, e.g., colors, symbols, labels, sounds
Extremely Severe A
Completely bedridden (possible exception: bathroom)
Able to do some or all:
• Sit up for extended periods
• Work on crafts or projects independently
• Communicate via text, computer, social media
• Watch TV and listen to music
• Tolerate human presence
• Pantomime and get spoken response
• Listen to speech, read some
Not able to:
• Speak or write
• Process much input, e.g., colors, symbols, labels, sounds
Loss of up to 100%
Loss of pre ME/CFS baseline function



DIAGNOSIS

The ME-ICP diagnostic framework

International Consensus Primer for Medical Practitioners • tinyurl.com/meicp2012

PEM, the required core feature

The ME-ICP calls this post exertional neuroimmune exhaustion, or PENE. This session uses the more familiar term post exertional malaise, or PEM: a pathological inability to produce enough energy on demand, with delayed or immediate exhaustion after minimal exertion and a slow recovery, often 24 hours or more.

1

Neurological

At least one symptom from 3 of 4 categories: cognition, pain, sleep, and neurosensory.

2

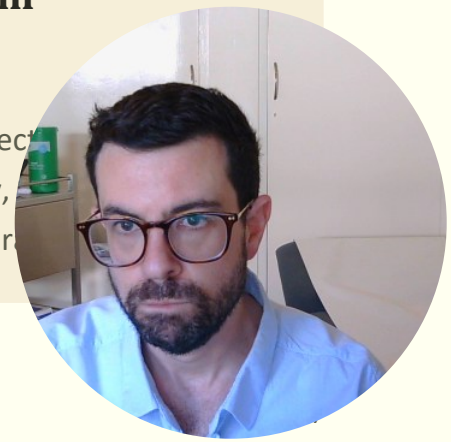
Immune, gut and urinary

At least one symptom from 3 of 5 categories, including flu like symptoms, viral susceptibility, GI, GU and chemical sensitivities.

3

Energy metabolism

At least one symptom affec
(including OI), respiratory,
thermoregulatory, temper



DIAGNOSIS

The ME-ICP diagnostic framework – A diagnosis of exclusion

International Consensus Primer for Medical Practitioners • tinyurl.com/meicp2012

Exclusion of alternate explanatory diagnoses is achieved by the patient's history, physical examination, and laboratory/biomarker testing as indicated. It is possible to have more than one disease, but it is important that each one is identified and treated. Primary psychiatric disorders, somatoform disorder and substance abuse are excluded

DIAGNOSIS

Other criteria you will see referenced

In practice, the combination of NICE criteria and Canadian Consensus Criteria are strong and unquestionable.

NICE, NG206 (UK, 2021)

- Fatigue that is not explained by another condition and is not simply the result of excessive exertion
- PEM, often delayed, disproportionate to the activity, and slow to resolve
- Unrefreshing sleep or sleep disturbance
- Cognitive difficulties, such as trouble finding words or slowed thinking
- Suspected at 6 weeks in adults, confirmed at 3 months

Canadian Consensus Criteria

- Fatigue, PEM, unrefreshing sleep, and pain, all four required
- Plus at least 2 neurological or cognitive symptoms, such as concentration or sensory disturbance
- Plus at least 1 symptom from 2 of 3 systemic categories: autonomic, neuroendocrine, or immune
- Symptoms persisting 6 months or more, 3 months in c

Every major framework agrees on one thing: post exertional symptom worsening, commonly called PEM, is the defining feature of ME.

Criteria		US Centers for Disease Control 1988 (Holmes)	Oxford Criteria 1991	US Centers for Disease Control 1994 (Fukuda)	Canadian Consensus Criteria 2003	UK NICE Criteria 2007	ME International Consensus Criteria 2011	Institute of Medicine 2015	UK NICE Criteria 2021
Name used		CFS	CFS	CFS	ME/CFS	CFS/ME	ME	ME/CFS	ME/CFS
PEM required		No	No	No	Yes	No (2)	Yes	Yes	Yes
New Onset		Required	Required	Required	Required	Required	Required	Required	Required
Functional Impairment		50% Decreased	Substantial	Substantial	Substantial	Substantial	50% Decreased	Substantial	Significant
Minimum Duration (in adults)		6 months	6 months	6 months	6 months	4 months	No minimum	6 months	3 months
SYMPTOM REQUIREMENTS FOR EACH DIAGNOSTIC CRITERIA									
SYMPTOM CATEGORIES	Persistent Fatigue	Required	Required	Required	Required	Required		Required	Required
	Motor-Sensory disturbances	8 symptoms required from 11 specific symptoms across these 6 categories. Plus 2 of 3 physical signs			2 symptoms required from either category		1 symptom required from 3 of these 4 categories		
	Cognitive problems (CP)			Any 4 symptoms required from 8 specific symptoms across these 5 categories		1 symptom required from 10 specific symptoms from 7 categories, including GI and OI		Either CP or OI	Required
	Pain				Required				
	Sleep disturbances				Required			Required	Required
	Post-exertional malaise (3)				Required		Required	Required	Required
	Recurrent flu-like symptoms (4)				1 immune symptom required from these 3 categories (5)		1 symptom required from 3 of these 5 categories		
	Infection susceptibility								
	Sensitivities food/chemicals								
	Gastro-intestinal tract issues				1 autonomic symptom required from these 4 categories (5)	As above			
	Genitourinary problems								
	Orthostatic Intolerance (OI)					As above	1 symptom required from these 6 categories	Either CP or OI	
	Autonomic								
	Respiratory problems				1 neuroendocrine symptom required from these 4 categories (5)				
	Cardiovascular problems								
	Heat/cold Intolerance								
	Thermostatic instability								

Extracted from Open Medicine Foundation
https://www.omf.ngo/history-mecfs/ 21/8/24

Practice Points – The Home Visit

Preparation weeks prior

1. History and goal
2. Determine the aim of the visit outline the steps, minimise contact time

PPE

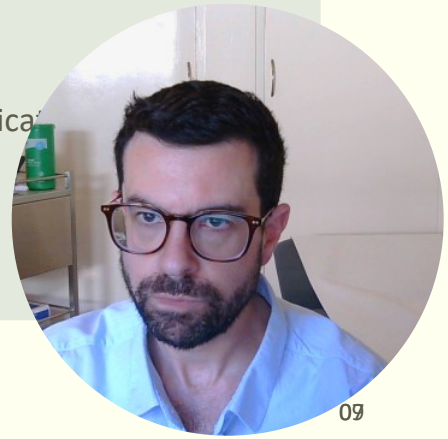
1. Mask
2. Alcohol hand rub
3. Ensure you are free of infectious illnesses

Rapid examination

1. Hydration status
2. Signs of malnutrition
3. Cardiac failure
4. Emerging neurodegenerative condition
5. Pressure injuries and skin integrity
6. Dental
7. Haem+GI

The aim is stabilisation

1. Interventions are a stressor
2. Involve carers after the visit in group communica
3. Agree on a paced plan
4. Set objective markers for deterioration
5. Stage and time interventions



REFERRAL

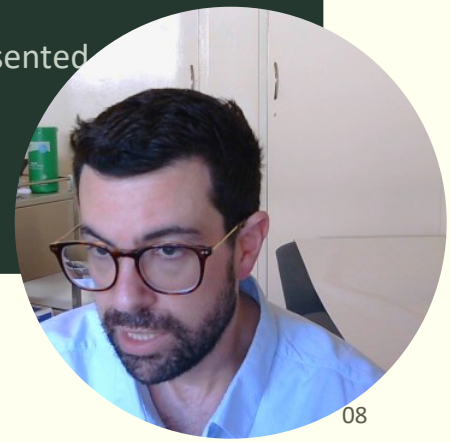
Referral pathways

What to include in a referral

- Full history and current severity level
- PEM (PENE) assessment and functional impact
- Current medications and doses
- Exclusion workup already completed

Who else to involve

- Allied health experienced in pacing, such as OT or physiotherapy
- Dietetics for nutrition and feeding support
- Psychology for support, not GET or CBT presented
- Complex care services for very severe cases



Is a GP diagnosis enough for NDIS and DSP?

Many services are written as though a specialist must confirm the diagnosis. In practice, a GP diagnosis is accepted as evidence, but specialist reports are often given more weight, leaving a real gap for patients whose only accessible clinician is their GP.

What strengthens a GP letter

- Clear reference to the diagnostic criteria used, such as the ME-ICP (I always include 2 usually the CCC and NICE)
- Documented functional impact on daily life
- Expected duration and permanence of the condition
- Exclusion of relevant differential diagnoses
- A clear statement that graded exercise therapy and CBT as a cure are not appropriate, and may worsen the condition

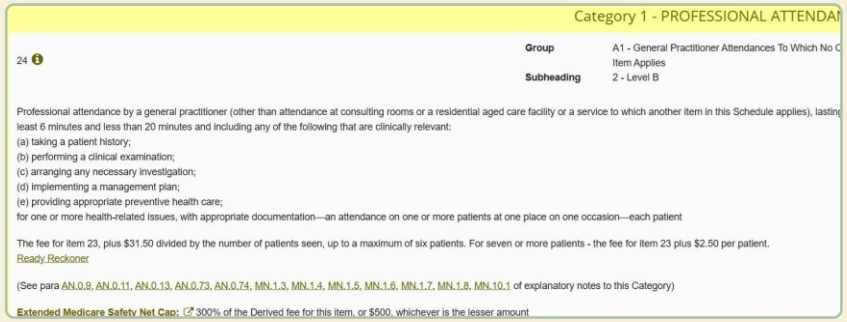
Home visits and Medicare item numbers

For patients who cannot get to a clinic, the home visit may be the only realistic way to access GP care.

Item	Level	Time	Fee
4	A	Brief attendance	$50.75
24	B	6 to 20 minutes	$74.60
37	C	20 to 40 minutes	$115.60
47	D	40 minutes or more	$155.80
5010 to 5067	A to D	After hours: evenings, weekends, public holidays	$88.35 to $191.95
585	Urgent	Restricted after hours windows only	$151.45

Schedule fees shown. Confirm current items and fees on MBS Online close to the day of your visit, as rates are indexed periodically.

From MBS Online



Category 1 - PROFESSIONAL ATTENDAN

24

Group: A1 - General Practitioner Attendances To Which No C
Item Applies
Subheading: 2 - Level B

Professional attendance by a general practitioner (other than attendance at consulting rooms or a residential aged care facility or a service to which another item in this Schedule applies), lasting least 6 minutes and less than 20 minutes and including any of the following that are clinically relevant:
(a) taking a patient history;
(b) performing a clinical examination;
(c) arranging any necessary investigation;
(d) implementing a management plan;
(e) providing appropriate preventive health care;
for one or more health-related issues, with appropriate documentation—an attendance on one or more patients at one place on one occasion—each patient

The fee for item 23, plus $31.50 divided by the number of patients seen, up to a maximum of six patients. For seven or more patients - the fee for item 23 plus $2.50 per patient.
Ready Reckoner

(See para AN.0.9, AN.0.11, AN.0.13, AN.0.73, AN.0.74, MN.1.3, MN.1.4, MN.1.5, MN.1.6, MN.1.7, MN.1.8, MN.10.1 of explanatory notes to this Category)

Extended Medicare Safety Net Cap: 300% of the Derived fee for this item, or $500, whichever is the lesser amount

The official descriptor for item 24, a Level B home visit, as published on MBS Online.

Each item has its own descriptor in this format. S
number at mbsonline.gov.au before billing.

HOME VISITS

Preparing for a safe home visit

No fragrance

No perfume, scented hand sanitiser or deodorant. Scent sensitivity is common and can trigger a flare.

Low light, low sound

Avoid bright colours and overhead lights. Bring a dimmable torch and keep your voice low.

Involve carers

Brief carers and support workers ahead of time. They can relay history and manage the environment.

Consult first, then visit

Do the history and consultation by phone or video beforehand. Let the home visit itself f
on the examinatio
on parts of care

THE BIGGER PICTURE

A national gap, not a local one

Brisbane South PHN
White Paper

Homebound access to primary care

Unchanged since 2012

Medicare home visit funding has not kept pace, even as demand for home based care has grown.

The white paper uses severe ME as its lead example of what it calls fixed homebound status. Medicare's own billing data shows why home visits have become so rare.

Source: RACGP newsGP, analysis of Medicare data by A/Prof Joel Rhee, 2026. An 85 per cent fall over t
decades.

Homebound care currently relies on individual GP goodwill, rather than a de
with funding to match.

RESEARCH UPDATES

The MELLOW Study

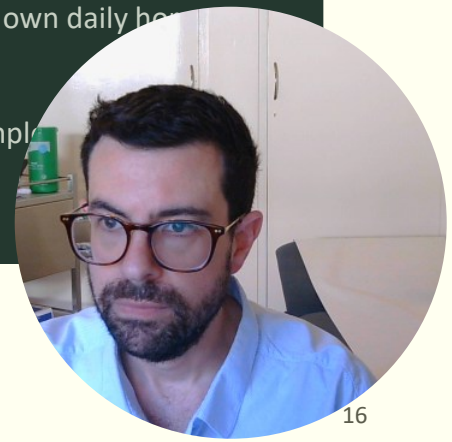
A Melbourne based study exploring how hormones across the menstrual cycle may contribute to ME/CFS and Long COVID symptoms, open to female participants aged 18 to 49.

What it's investigating

- Whether hormone fluctuations across the menstrual cycle contribute to ME/CFS and Long COVID symptoms
- A first of its kind at-home study combining daily hormone tracking with wearable physiological data
- Omics testing across metabolic, immune, and genetic markers, to find biological drivers
- Findings are intended to improve diagnosis and treatment for everyone, since all sexes produce these hormones

How participation works

- One full menstrual cycle of at-home tracking, no extra clinic visits required for monitoring
- A wearable device records heart rate and temperature throughout
- The Mira hormone tracker gives participants their own daily ho levels in real time
- Recruitment has started in Melbourne, due to sampl may expand more broadly later



MELLOW: could one of your patients take part?

20 participants

With ME/CFS, meeting NICE criteria

20 participants

With Long COVID, symptoms beyond 12 weeks, meeting NICE criteria

20 participants

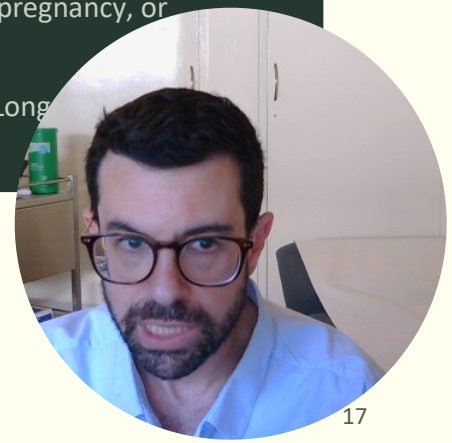
Healthy controls, no history of ME/CFS or Long COVID

Key inclusion criteria

- Female, aged 18 to 49
- Regular or semi-regular menstrual cycle, at least one bleed every two months
- Not using hormonal contraception during the study
- Willing to complete daily at-home tracking for one menstrual cycle

Key exclusion criteria

- Current use of hormonal contraception
- Absent or irregular cycles, for example menopause, pregnancy, or lactation
- Other major chronic illness unrelated to ME/CFS or Long could confound results



RESEARCH UPDATES

MELOPIS: imaging the ME/CFS brain

A Melbourne ME/CFS Collaboration project using MRI and PET scans to look for structural, blood flow, and biochemical differences in the ME/CFS, Long COVID, and POTS brain.

What it examines

- Brain blood flow, inflammation, metabolism, and hormonal markers, captured together in the same scan
- A scanning technique adapted from Alzheimer's disease research
- ME/CFS, Long COVID, and POTS studied side by side
- Led through the Melbourne ME/CFS Collaboration, with Dr Chris Armstrong and PhD student Ellen Xioayun Wan and Jamie Elliott

Early signals

- Healthy brains disengage cleanly from their resting network when starting a task, patients' brains may not
- Patients activate broader brain regions and use more energy to complete the same cognitive tasks
- Still recruiting ME/CFS, Long COVID, and healthy control parti[illegible] sessions run in Melbourne

These are early, not yet peer reviewed results, but they point to a measurable, physical basis for the fatigue and cognitive symptoms pati[illegible] describe.

Off-label prescribing in ME/CFS: why it needs a higher bar

Off-label prescribing is legal and common in general practice. It becomes the realistic option in ME/CFS and Long COVID, where the evidence base stays thin and approved options often fall short.

The legal test

- Rogers v Whitaker (1992) sets the consent bar: disclose any risk a reasonable patient would consider material
- Peer professional defence protects a supported minority view, but not a failure to warn of risk
- Every state's poisons legislation requires a demonstrable therapeutic need, not experimental guesswork

The AHPRA standard

- Weigh benefit against harm, and confirm a genuine expectation of efficacy before prescribing
- Obtain informed consent and document clinical reasoning in the patient record
- Recognise, act on, and reflect on any adverse event, per the section on adverse events

Off-label prescribing shifts the burden of justification onto the treating GP. A minority view is defensible when peer supported, isolated ar consented practice is not.

OFF-LABEL PRESCRIBING

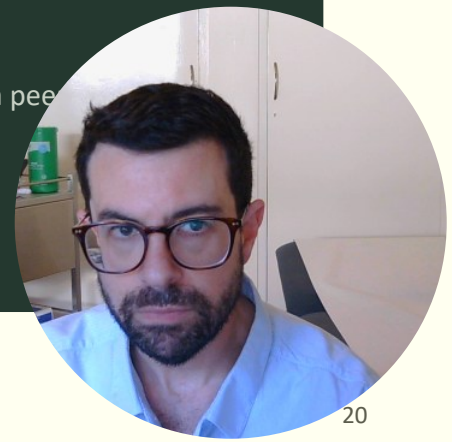
A practical framework: medicines and the MERC protocol

Medicines used off-label in ME/CFS

- Low-dose naltrexone: dosing plateaus near 4.5mg, well under the addiction-treatment dose, but titration can unpredictably trigger severe PEM
- CNS stimulants, such as modafinil, methylphenidate, and lisdexamfetamine: borrowed energy that can prompt overexertion and a later PEM crash
- Anticholinesterase inhibitors: repurposed from myasthenia gravis to manage comorbid POTS
- Nicotine patches: rapid recent uptake, but evidence is still limited to small case series

An example protocol, in brief

- Eligibility and assessment: confirm the diagnosis, document failed treatments, discuss the unknowns openly
- Risk and trial: stratify need by severity, start low and titrate as an N-of-1, recheck the evidence
- Governance and plan: seek a second opinion, build a pee
  the plan in writing, and re-evaluate periodically



IN DR FINEBERG'S WORDS

What keeps us going

We don't have all the answers yet, and that's alright. Our job right now is to be ready, so that when treatments do arrive, we can get that information out to patients in the community as fast as possible. That's what keeps us moving, one step at a time.

QUESTIONS AND CONTACT

Thank you for caring for patients with ME

ME Research Clinic	reception.merc@gmail.com
RACGP special interest group	Search Energy Limiting and Post Infection Conditions, or call 1800 090 588
ME-ICP diagnostic criteria	tinyurl.com/meicp2012
Brisbane South PHN white paper	Homebound access to primary care, available at bsphn.org.au

A recording of tonight's session will be shared afterwards.