

# The Myalgic Encephalomyelitis Update

CHRONIC FATIGUE SYNDROME

ROTORUA 2021 GP CME

**C**linical guidelines for diagnosis and treatment of ME/CFS have changed. Formerly recommended treatments are now contraindicated. This newsletter aims to assist health professionals in updating their clinical practice.

## In This Edition

- Diagnosing ME/CFS
- The Hallmark of ME/CFS: Post-Exertional Malaise
- Learn & Earn CME points
- Quality of Life in ME/CFS
- Managing ME/CFS

## Diagnosing ME/CFS

The challenge of diagnosing a patient presenting with multi-systemic symptoms can be reduced by applying the IOM (NAM) diagnostic criteria for ME/CFS.

These require

- **post-exertional malaise,**
- **a substantial reduction in the ability to engage in pre-illness levels of activity (accompanied by profound fatigue),**
- **unrefreshing sleep, and**
- **cognitive impairment and/or orthostatic intolerance.**

Additional symptoms may be present and relevant for a treatment plan but are not diagnostic.

**Scan the QR code to read more about *diagnosing ME/CFS*.**



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**NEWS IN BRIEF: Graded exercise therapy (GET) is NO LONGER RECOMMENDED for ME/CFS.**



*ME/CFS patients often look deceptively well, including during clinic visits. With PEM the picture changes. This is Nicky, before and then during PEM.*

## The Hallmark of ME/CFS: Post-Exertional Malaise

**Post-exertional Malaise (PEM) is required for a diagnosis of ME/CFS; it is key to distinguishing ME/CFS from other diseases.**

PEM is a pathological response to trivial physical or cognitive exertion. Exertion as minor as brushing teeth or talking can trigger major symptom exacerbation.

**Scan the QR code for guides to *PEM for both clinicians and patients*.**

PEM differs from other forms of exertion intolerance. PEM involves a wider range of symptoms, onset is typically delayed by hours to days, and return to previous function takes days, weeks or longer; in severe cases a return to previous function may not be possible.

PEM loss of function has been demonstrated in repeated CPET studies. However, CPET is not recommended in the clinical setting due to the risk of harming the patient.

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[www.m.e.awareness.nz/gpcme-rotorua](http://www.m.e.awareness.nz/gpcme-rotorua)

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Long COVID is affecting an increasing number of patients and, as after other viral infections, a subset are likely to develop ME/CFS. Now is a good time to get up-to-date with the recent changes to clinical guidelines for diagnosis and treatment of ME/CFS.

## Learn & Earn CME points

Accredited by RNZCGP.

- Think GP - Module 1 "Busting the myths and redefining ME/CFS"
- Think GP - Module 2 "Ensuring a patient-centred approach to care for people living with ME/CFS".
- ELearning with NZ Doctor "How to Treat ME/CFS"

Scan the QR code for additional resources.

## NEWS IN BRIEF: Cognitive behavioural therapy (CBT) is NO LONGER RECOMMENDED as a treatment for ME/CFS\*.

\*Some patients may wish to access counselling to assist with adjustment to living with a debilitating chronic illness.

## Managing ME/CFS

### Treatment

ME/CFS has no cure or approved treatment. Symptoms such as pain, sleep issues, and orthostatic intolerance, as well as any comorbid conditions, can be addressed conventionally with a start-low, go-slow approach as patients may be sensitive to medications.

### Support

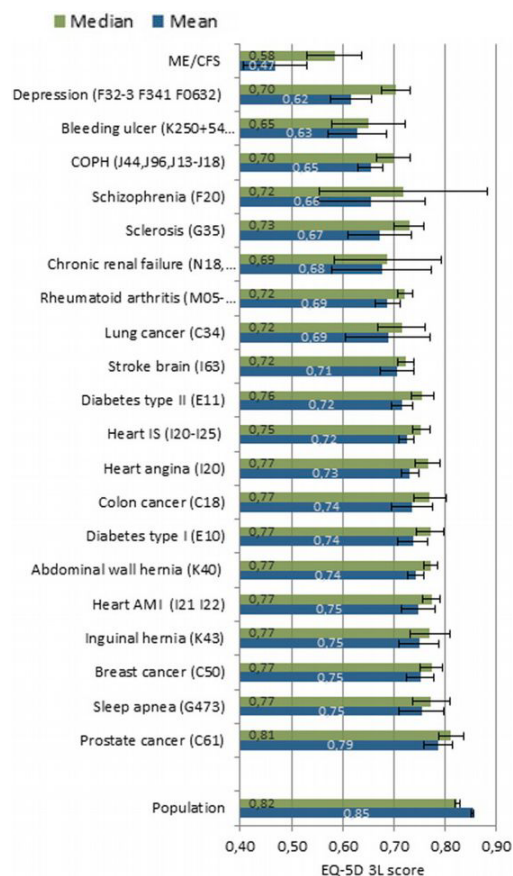
Equally important to QoL is validation and supporting applications for financial support or for employment or study accommodations.

### Pacing

Pacing is a way to manage activity and rest within a restricted energy envelope. Pacing helps minimise post-exertional malaise (PEM) and increase quality of life. The aim is for a stable level of activity that doesn't trigger PEM, not an increase in activity. Predicting what may trigger PEM is complicated by the delay between the triggering exertions and resulting symptom exacerbation.

Scan the QR code for information on *managing ME/CFS*.

## HRQoL of ME/CFS



"The EQ-5D-3L-based HRQoL of ME/CFS is significantly lower than the population mean and the lowest of all the compared conditions."

From: *The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS)*. PLoS One. 2015. © 2015 Falk Hvidberg et al.



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