

World ME Day puts the spotlight on the latest guidance for ME/CFS and other Post-Viral Illness

If you are a health professional, you very likely have patients in your practice who live with debilitating post-viral illness. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) most commonly occurs after an infection and affects an estimated 20,000 - 40,000 New Zealanders (estimated at 0.4-0.8%). On top of that the number of people with Long Covid is growing and they're looking for help.

This is why this May 12, on World ME Day, the World ME Alliance launches its #LearnFromME campaign. What we have learned from ME/CFS can now guide us in our approach to Long Covid, too.

Emeritus Professor Warren Tate and his research team at Otago University have contributed substantially to our improved understanding of post-viral illness.

Tate says “It was exciting to find molecular signatures in the immune cells of ME/CFS patients associated with dysfunctional energy production and showing instability in the epigenetic code that controls precise production of all our proteins, giving a clear indication of the biological basis for the illness... The fact that ME/CFS is so functionally debilitating, and is life-long in most cases, puts huge social and financial burdens on those affected, their families and their communities, and blunts the potential of highly productive people to contribute value to our society”.

The latest research evidence is reflected in the following resources.

Continuing Medical Education for ME/CFS

My Health Hub offers a CME-accredited webinar¹ about ME/CFS for New Zealand health professionals. Presented by Dr Cathy Stephenson, Clinical Lead - GPEP Southern, RNZCGP, the webinar was recorded in February 2022 and provides a practical approach to the understanding, assessment, and management of ME/CFS. It is eligible for 1 RNZCGP CME credit.

The *My Health Hub* webinar about ME/CFS covers:

- what we know (and don't know) about ME/CFS
- a systematic approach to diagnosis
- how to support a patient with ME/CFS
- resources for patients and whanau
- where to go to learn more

A number of other evidence-based CME modules and resources, along with regional HealthPathways, are now available to guide assessment, management and support of ME/CFS, a list can be found here [<https://m.e.awareness.nz/resources-health-professionals>]. Most use the IOM 2015 diagnostic criteria adopted by the CDC² in 2017 (Refer diagram 1).

¹ <https://myhealthhub.co.nz/myalgic-encephalomyelitis-chronic-fatigue-syndrome-2/>

² <https://www.cdc.gov/me-cfs/healthcare-providers/index.html>

Diagnostic Criteria for ME/CFS IOM 2015

1 Substantial impairment accompanied by profound fatigue

2 Post-exertional malaise
a disproportionate worsening of symptoms after physical or mental exertion

3 Unrefreshing sleep

4 Cognitive impairment and /or Orthostatic intolerance

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

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Clinical Guidance from NICE, CDC and Mayo Clinic

Following in the footsteps of the CDC, and after its own thorough evidence review, the National Institute for Health and Care Excellence (NICE, UK) produced their own new clinical guidance for ME/CFS³ in 2021. In the same year, Mayo Proceedings also published very similar consensus recommendations⁴.

All three health agencies have reversed previous recommendations for Graded Exercise Therapy and now state that GET is not appropriate therapy for ME/CFS. NICE also specifically advises against the Lightning Process programme or therapies based on it.

The new recommendations emphasise the need for patients to avoid Post-Exertional Malaise as much as possible, as it may lead to a more permanent worsening of ME/CFS. Patients need to be supported to adapt their level of activity to their personal energy limits by pacing their activities within their "energy envelope".

³ <https://www.nice.org.uk/guidance/ng206>

⁴ [https://www.mayoclinicproceedings.org/article/S0025-6196\(21\)00513-9/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext)

#LearnFromME ME/CFS experts suggest:

4 steps to support a person with ME



Validate the Patient's Experience

step 1

step 2

Assess Needs and Support



Teach Pacing

step 3

step 4

Treat Symptoms



Mayo Clinic Proceedings
ME/CFS Essentials of Diagnosis and Management

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Additional Resources

Additional CME and resources are listed on the websites of ANZMES⁵, Associated New Zealand ME Society, and M.E. Awareness NZ⁶.

To read more about the #LearnFromME campaign for World ME Day, visit <https://anzmes.org.nz/?s=learnfromme> and <https://www.facebook.com/LearnFromME.NZ>

⁵ <https://anzmes.org.nz/what-is-me/medical-professionals/>

⁶ <https://m.e.awareness.nz/resources-health-professionals>

Alternate - text only for Diagrams

| Diagnostic Criteria for ME/CFS - IOM 2015 |
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| 1. Substantial impairment accompanied by profound fatigue |
| 2. Post-exertional malaise, a disproportionate worsening of symptoms after physical or mental exertion |
| 3. Unrefreshing sleep |
| 4. Cognitive impairment and /or Orthostatic intolerance |
| Additional symptoms may be present and relevant for a treatment plan but are not diagnostic. |

| #LearnFromME ME/CFS experts suggest: |
|---|
| 4 steps to support a person with ME |
| Step 1 – Validate the Patient’s Experience |
| Step 2 – Assess Needs and Support |
| Step 3 – Teach Pacing |
| Step 4 – Treat Symptoms |
| Mayo Clinic Proceedings – ME/CFS Essentials of Diagnosis and Management |