

# Support for Long Covid and ME/CFS

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Navigating ME/CFS and Long COVID

# ME Support - Who Are We?

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- It is estimated that over 45,000 New Zealanders have ME/CFS (Myalgic Encephalomyelitis) or Long COVID. We are on a mission to provide much needed support for this community.
- ME Support (formerly ME Auckland) are a charity, initiated in 2013. Membership growth has been consistent. We are currently working with over 950 members.
- Our work is to provide free support, advocacy, community connection and illness management information to people with ME/CFS, Long COVID and related conditions such as Fibromyalgia.
- We do not receive Government funding for our services, so are reliant on funding from other sources and member donations.
- We exist to improve the lives of people with these illnesses, their family/whānau, carers and support persons. We support clients across Auckland and New Zealand.
- We offer members medical information, emotional support, advocacy and a support community (including support groups).

# Community Need for our Services

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Research indicates that in New Zealand between 25,000 to 40,000 people are living with ME/CFS, with 7,000 to 13,000 of those residing in Auckland (*note: these are older statistics*).

ME/Myalgic Encephalomyelitis (commonly known as Chronic Fatigue Syndrome) is a chronic and debilitating illness whereby the key symptom is overwhelming fatigue, often triggered by even minimal exertion.

New Zealand research shows that ME/CFS impacts quality of life as severely as Parkinson's Disease and Multiple Sclerosis/MS.

'Long COVID' is used as a generalised term describing the ongoing, or developing symptoms, that occur 3 months after an initial COVID-19 infection.

People with Long COVID often experience numerous, overlapping symptoms that can fluctuate and change over time.

It is estimated that 10% of people who get COVID will experience Long COVID. Using current COVID statistics this will equate to over 10,000 people in New Zealand being affected by Long COVID.

# Long COVID - The Background

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- Long COVID refers to the long-lasting symptoms experienced by individuals who have recovered from an infection of COVID-19.
- Census data found Long COVID symptoms adversely affected the day-to-day activities of 1.2 million people (67% of those with self-reported long COVID), with 346,000 (19%) reporting that their ability to undertake their day-to-day activities had been “limited a lot” (Census UK 2022 data).
- Due to illness similarities with ME/CFS, Long Covid has been referred to as a ‘sister illness’ to ME/CFS by Professor Warren Tate (Otago University, ME/CFS and Long Covid researcher)
- At present, there is no diagnostic blood test for either Long Covid or ME/CFS. The method of diagnosis of is very similar for both conditions in relation to a time frame for duration of symptoms being required. Along with the exclusion of other possible explanations for the symptoms.
- Research is ongoing to understand the causes and effective treatments for Long COVID.

# Diagnosis of ME and Long COVID

Long Covid has a number of common symptoms that overlap with a post-viral fatigue syndrome (PVFS) or ME/CFS. So a significant proportion of people with Long Covid have one or more symptoms that are consistent with a diagnosis of PVFS or ME/CFS. The time frames before diagnosis is possible, differ though.

## ME/CFS

### APPENDIX A

#### 1994 RESEARCH CASE DEFINITION CRITERIA FOR CHRONIC FATIGUE SYNDROME WORKSHEET\*

Patient name ----- Date -----

#### Major Criteria

----- Significant fatigue, relapsing or chronic, insidious or abrupt, of at least six months duration

----- Exclusion of other clinical conditions that plausibly explain this fatigue

#### Minor Criteria (A minimum of 4 out of 8)

Symptoms (must be concurrent, persisting or relapsing; and symptoms must NOT precede the onset of fatigue)

----- Sore throat

----- Painful lymph nodes (cervical, axillary, inguinal, or supraclavicular)

----- Generalized, new headaches

----- Myalgia or muscle discomfort

----- Migratory arthralgia

----- Fatigue worsens with exertion, plus post-exertional malaise

----- Neuropsychological (cognitive) complaints

----- Sleep disturbance

#### Fulfills:

----- Major Criteria ----- Four or More Minor Symptom Criteria

## Long COVID

A Delphi<sup>2</sup> study was conducted in the United Kingdom with a panel of primary and secondary care medical practitioners. Recommendations were generated relating to the investigation and management of long COVID by the panel. The recommendations that follow reflect the Delphi study.

Recommendations	Grade
Consider a differential diagnosis of long COVID in anyone with a wide range of presenting features (not limited to fatigue and breathlessness) occurring 12 weeks or more after a confirmed or probable infection with COVID-19.	B
Undertake further investigation and specific therapies where there is:	B
<ul style="list-style-type: none"> <li>myocarditis</li> <li>multi-system inflammatory syndrome in children (MIS-C) or paediatric inflammatory multi-system syndrome temporally associated with Sars-Cov2 (PIMS-Ts) (find further information <a href="#">here</a>)</li> <li>postural orthostatic tachycardia syndrome (POTS)</li> <li>mast cell activation syndrome (blood disorder)</li> <li>hypoxia/desaturation</li> <li>chest pain</li> <li>palpitations</li> <li>histamine intolerance symptoms.</li> </ul>	

# Potential Mechanisms

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A number of causes of Long COVID have been suggested within the research, these include:

- Viral Persistence
- Dysregulated Immune Response
- Autoimmunity
- Microvascular Dysfunction (non-obstructive coronary artery disease that causes the small blood vessels feeding the heart muscle to not work as they should)

# Recent Research

An estimated 65 million people worldwide have Long COVID, with more than 200 symptoms identified, including impacts on multiple organ systems, the autonomic nervous system, and evidence of vascular and clotting abnormalities (Davis et al., 2023).

Many patients experience dismissal of Long COVID symptoms, prolonged diagnostic journeys, and lack of treatment options for Long COVID (Au et al., 2022).

Holistic assessment, early diagnosis, and supportive care from health practitioners all contribute to effective support and management of Long COVID (Koc et al., 2022).



# NZ Model of Care for Long Covid

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Currently: The Clinical Rehabilitation Guideline for People with Long COVID in Aotearoa New Zealand

- Personalised Community-Based GP and Self Care
- Long COVID Multi-Disciplinary Team, Hospital or Community-Based
- Specialist Care
- A PDF of the guidelines can be found here:
  - [https://www.health.govt.nz/system/files/documents/publications/clinical\\_rehabilitation\\_guideline\\_for\\_people\\_with\\_long\\_covid\\_13\\_dec.pdf](https://www.health.govt.nz/system/files/documents/publications/clinical_rehabilitation_guideline_for_people_with_long_covid_13_dec.pdf)



Our **Long COVID Support Tool** covers the basics of Long COVID and:

1. Related Conditions
2. POTS and Dysautonomia
3. Pacing
4. Nutritional Management
5. The Nervous System, Emotions, and Stress
6. Sleep
7. Pain Management
8. Common Treatments
9. Working with your Health Provider
10. Community Support

You can access the tool at:

<https://www.mesupport.org.nz/longcovidhelp>

## Long COVID Online Support Tool



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# Further Reading

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- Koc, H. C., Xiao, J., Liu, W., Li, Y., & Chen, G. (2022). Long COVID and its management. *International Journal of Biological Sciences*, 18(12), 4768-4780. <https://doi.org/10.7150%2Fijbs.75056>
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- Davis, H. E., McCorkell, L., Vogel, J. M., & Topol, E. J. (2023). Long COVID: Major findings, mechanisms, and recommendations. *Nature Reviews Microbiology*, 21, 133-146. <https://doi.org/10.1038/s41579-022-00846-2>
- ME Association. (2021). Long COVID and ME/CFS. <https://meassociation.org.uk/wp-content/uploads/LONG-COVID-AND-MECFS-ARE-THEY-THE-SAME-MAY-2022.pdf>
- Friedburg et al. (2014). ME/CFS: A primer for clinical practitioners. <https://www.healthnavigator.org.nz/media/6520/me-cfs-clinical-diagnostic-criteria-worksheet.pdf>
- Smart Talk. (2022). Dr. Anna Brooks on the looming crisis of Long COVID. [https://www.rnz.co.nz/national/programmes/smart\\_talk/audio/2018855602/dr-anna-brooks-on-the-looming-crisis-of-long-covid](https://www.rnz.co.nz/national/programmes/smart_talk/audio/2018855602/dr-anna-brooks-on-the-looming-crisis-of-long-covid)

# Support for Long Covid and ME/CFS

## ME Support

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