

This review includes:

- Pacing management for ME/CFS: Lessons for Long COVID.
- Patient perspectives of Long COVID services.
- Water-based vs land-based exercise interventions with children.
- Return-to-work experiences and employer recommendations.
- Long COVID symptoms and diagnoses in primary care.

COMMENT:

Given the similarities between Long COVID and ME/CFS, it makes sense to learn from research on ME/CFS. The NICE ME/CFS guidelines provide recommendations for the diagnosis and management of ME/CFS, emphasising the importance of individualised care, symptom relief and a patient-centred approach, which can serve as a valuable framework for addressing similar management strategies for Long COVID.

Mātauranga Raranga

Long COVID Registry
Aotearoa New Zealand

<https://www.lcregistry.auckland.ac.nz/>

Kia ora koutou katoa.

Welcome to the 'Long COVID Literature Review' by Te Hikuwai Rangahau Hauora | The Health Services Research Centre. We aim to bring you monthly summaries of interesting literature concerning Long COVID. We prioritise Aotearoa New Zealand and Indigenous research and publications determined to be high-quality, evidence-based research.

A scoping review of 'Pacing' for management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Lessons learned for the Long COVID pandemic

(Sanal-Hayes et al., 2023)

[Find abstract here.](#)

SUMMARY:

This scoping review collates the type of, and outcomes of, pacing in people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). It also explores how these findings might apply to Long COVID. A total of 17 articles were used in the final synthesis. Five articles implemented their own pacing interventions, eight studies were observational and four involved sub-analysis of results of the PACE trial. All intervention studies were analogous to the 'Energy Envelope Theory', which suggests people with ME/CFS should moderate their activity levels and practice energy conservation. Eleven studies reported positive effects on symptoms, such as fatigue or Post-Exertional Malaise [PEM], quality of life, self-efficacy, and depression and anxiety, while four reported no effect and two had adverse effects. Given the similar symptoms in ME/CFS and Long COVID and the lack of effective treatments, pacing appears to be the primary strategy for managing Long COVID. However, as found in this review, variable study designs and outcome measures, allied with poor-to-fair methodological quality, make it difficult to draw clear conclusions. The authors recommend future research using randomised control trials and digital patient-reported outcome measures (e.g., applying mHealth approaches and outcome measures agreed upon by the British Association of CFS/ME Professionals [BACME]) to better understand the effects of pacing for both ME/CFS and Long COVID.

LONG COVID REVIEW

Swept under the carpet: A qualitative study of patient perspectives on Long COVID, treatments, services, and mental health

(Hawke et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study aims to understand Long COVID treatment and the healthcare experiences of individuals experiencing mental health and quality of life challenges. It involved 47 individuals with Long COVID from Canada, some of whom had pre-existing mental health concerns prior to contracting COVID-19. The study found that when accessing Long COVID services, patients experienced (1) systemic barriers to accessing care, including long wait times, financial burdens and geographical distance; (2) challenges navigating the unknowns of Long COVID due to knowledge gaps regarding Long COVID, inadequate Long COVID services and illness invalidation from service providers; (3) negative impacts on patient wellbeing and recovery, including feeling abandoned and self-stigma. Patients called for improvements in Long COVID healthcare services, focussing on (1) developing Long COVID-specific knowledge and services with up-to-date information and holistic care; (2) enhancing support for financial wellbeing, daily living and building a Long COVID community, including access to assistive devices and support; (3) improving awareness and the public representation of Long COVID, such as engaging in educational training programmes for service providers, patients, families and employers, with information sessions to help recognise symptoms.

COMMENT:

These results from Canada resonate with experiences in Aotearoa New Zealand. The absence of a national coordinated response to Long COVID in Aotearoa New Zealand has resulted in inadequate services and support from healthcare providers. This insufficient support and often experiences of syndrome disbelief have caused emotional distress and hesitancy among those with Long COVID when seeking healthcare. This study identifies three critical areas for improving Long COVID care.



Effect of water-based vs. land-based exercise intervention (postCOVIDkids) on exercise capacity, fatigue, and quality of life in children with post COVID-19 condition: A randomised controlled trial

(Ogonowska-Slodownik et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study examines water-based (AQUA) and land-based (LAND) training programmes on exercise capacity, fatigue and health-related quality of life in children aged 10 to 12 with Long COVID. Children who met the study inclusion criteria were randomly assigned to one of three groups: AQUA, LAND or CONTROL (no exercise). The AQUA and LAND exercise groups had supervised 45-minute sessions twice a week for eight weeks, designed to match intensity in terms of duration and muscle group training. Each session included a warm-up, ten aerobic exercises (each consisted of one minute of activity followed by a 15-second rest), and a cool down. The results indicate that exercise capacity is improved after both exercise programmes, with the most significant improvement in maximal oxygen uptake (VO_2 max) observed following water-based exercise training. No significant differences were found in fatigue scores or individual fatigue symptoms (i.e., decreased vitality, mental overload and somatic symptoms). Overall health-related quality of life significantly improved only in the LAND group of parents.

COMMENT:

The study found that neither training programme improved fatigue scores. However, it did show that VO_2 max values improved in children, with water-based training improving to a greater degree than land-based training.

LONG COVID REVIEW

Return-to-work with Long COVID: An Episodic Disability and Total Worker Health analysis

(Stelson et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study aims to identify participants' return-to-work experience using Total Worker Health and Episodic Disability frameworks. The Total Worker Health framework focuses on how work and larger social environments shape worker health and wellbeing. For Long COVID, it helps to identify individual, interpersonal, organisational and social factors that affect an individual's ability to return to work. The Episodic Disability framework considers the variability of disability and how it impacts daily life and social and economic inclusion. It applies to Long COVID, as symptoms vary and worsen with physical, mental and cognitive exertion. From an internet survey of 510 individuals without geographical restriction, four main work-related themes emerged: (1) a strong desire and need to return to work motivated by a sense of purpose and financial need; (2) diverse and episodic Long COVID symptoms intersect with the organisation of work and home life, with specific work-related tasks, such as having to read work-dense information, screen-time and engaging in meetings contributing to worse symptoms; (3) pervasiveness of disbelief and stigma at work and medical settings, this largely influenced participants' ability to access workers' compensation, support and workplace accommodations and; (4) the importance of supportive medical providers for a successful return to work. This article suggests that workplaces should consider an iterative and circular return-to-work model, which includes future check-in dates at which point, employers and employees re-evaluate support and adjustments as needed. To improve the return-to-work experience for people with Long COVID, this article provides six actionable and worker-centric recommendations: employers should (1) not require documentation of COVID-19 infection for support and benefits due to barriers to accessing this documentation; (2) accept self-identified Long COVID symptoms and related diagnoses due to lags in many medical providers' understanding of the illness; (3) collaborate with workers to tailor job responsibilities to manage symptoms; (4) offer remote work options to conserve workers' energy; (5) allow flexible work hours to help with pacing and; (6) set more extended deadlines to prevent burnout.

COMMENT:

When using the Total Worker Health framework, it becomes clear that debilitating symptoms of Long COVID affect not just the work environment but also home life and daily living. This article points out many participants had saved their energy for work, often spending their weekends or after work resting, relying on help from family/spouse, or even becoming bed-bound, reflecting a picture of survival rather than living. There are benefits to both employers and employees if the return-to-work process is suitable for those with Long COVID.



Long Covid Support
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Navigating ME/CFS and Long COVID

[ME Support](#)



[Complex Chronic Illness Support](#)



LONG COVID REVIEW

Glossary

Adjusted Hazard Ratio

[aHR] Used to compare the risk of event/outcome occurring between two (or more) groups, while taking into account for other factors that might influence results.

95% Confidence Interval

[95%CI] The range of values within which we can be 95% certain that the true value lies.



NEW WEBSITE LIVE

[Evidence-based management of Long COVID](#)

A three-year project funded by the Health Research Council of New Zealand.

For more literature concerning Long COVID, you can visit '[Lit COVID](#)', a website library for tracking up-to-date scientific information about COVID-19 and Long COVID.

Long COVID symptoms and diagnosis in primary care: A cohort study using structured and unstructured data in The Health Improvement Network primary care database

(Shah et al., 2023)

[Find abstract here.](#)

SUMMARY:

This study aims to compare symptoms in patients with and without a previous COVID-19 infection and examine symptoms associated with a general practice diagnosis of 'Long COVID'. This study analysed primary care records from 60,800 patients in the United Kingdom (England, Scotland and Wales) before COVID-19 vaccinations. This study found most symptoms [related to Long COVID] in the general practice records were in free-text formats (80%), with only 20% in structured data (i.e., clinical codes). A variety of symptoms were associated with Long COVID, including fatigue (adjusted Hazard Ratio [aHR]= 3.46, 95%CI: 2.87 to 4.17), shortness of breath (aHR= 2.89, 95%CI: 2.48 to 3.36), palpitations (aHR= 2.59, 95%CI: 1.86 to 3.60), and phlegm (aHR= 2.43, 95%CI: 1.65 to 3.59). Although no patients had a coded Long COVID diagnosis in their records, there were 818 mentions of suspected or confirmed Long COVID in the free-text. Among patients with confirmed COVID-19, 103 (0.9%) individuals had free-text entries related to confirmed or suspected Long COVID. The symptoms most frequently mentioned a week before the diagnosis of Long COVID were pain (68.3%, 95%CI: 62.5% to 73.8%), shortness of breath (66.2%, 95%CI: 60.3% to 71.7%) and fatigue (57.9%, 95%CI: 51.9% to 63.8%). Chest pain, cough and anxiety/depression were frequently mentioned. The study also found that patients were more likely to report Long COVID symptoms or receive a Long COVID diagnosis (via free text) if they were older, female or had been hospitalised during their initial COVID-19 illness.

COMMENT:

In this study, it is notable that no Long COVID diagnoses could be recorded, as relevant SNOMED CT codes were not available for most of the study period. The authors highlight the need for future research to investigate how general practitioners record diagnoses using structured and unstructured data.

If you or your family member has Long COVID and are interested in being involved in future Long COVID research, please contact us at:



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