



Clinical Rehabilitation Guideline for People with Long COVID (Coronavirus Disease) in Aotearoa New Zealand

Revised December 2022

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Executive summary

Manatū Hauora (the Ministry of Health) has developed this clinical guideline to provide clinical guidance on the identification, assessment and diagnosis of long COVID and the best interventions, supports and care pathways for rehabilitation of people with long COVID. We recognise that long COVID imposes impairment on people affected and also affects their whānau.

Care pathways for rehabilitation are organised into 3 tiers:

- self-management
- supported management by a multi-disciplinary team of allied health professionals
- specialist care.

This guidance includes resources for health care practitioners and for people affected by long COVID and their whānau.

COVID-19 disproportionately affected Māori and Pacific people through both the Delta and Omicron outbreaks. Therefore, the likelihood these people will also be disproportionately affected by long COVID. This must be taken into account in the delivery of services and any future updates to guidance on rehabilitation for people living with long COVID.

Purpose

This guideline provides clinical guidance on diagnosing and treating long COVID conditions in children and adults in Aotearoa New Zealand. It is an evidence-based summary that sets out a definition and diagnosis of long COVID and then outlines the best evidence currently available to assist practitioners in their informed decision-making to improve the health, vocational and social outcomes for people with long COVID.

The guideline will assist primary care practitioners, community and hospital clinicians, policy-makers, funders, parents, carers, specialists, people with long COVID and whānau of affected people.

This document does not address prevention of COVID-19 infection or reinfection, but sets out a mitigation strategy to prevent/reduce the severity of long COVID.

The Ministry published the COVID-19 Māori Health Protection Plan (the Protection Plan) in December 2021 (Ministry of Health. 2022a.), in response to community-wide transmission of the Omicron variant. The Protection Plan helps guide response actions within the health and disability system for Māori through the next 3–12 months. The Ministry continues to monitor the impact of the COVID-19 pandemic on Māori, to ensure the health and disability system continues to give effect to the principles of Te Tiriti o Waitangi.

The May 2022 Monitoring Report of the Protection Plan highlighted the ongoing need to improve Māori vaccination uptake and improve Māori community resilience. It showed that, since December 2021, targeted communications had improved, funding to Māori providers to lead local responses had increased, Māori access to testing had improved and a joined-up approach for supporting whānau isolating at home had been enabled. Despite these improvements, persistent inequities remain, evident in COVID-19 infection and hospitalisation rates, COVID-19 third (booster) dose rates and child immunisation rates for Māori.

The Waitangi Tribunal's *Haumaru: The COVID-19 Priority Report* (Waitangi Tribunal, 2021) reaffirmed the need to adhere to the Te Tiriti principles of tino rangatiratanga, partnership, equity, active protection and options. The Tribunal stated that the Crown's response needed to work better for Māori, and provided a spotlight on systemic and structural issues that stand in the way of effective Māori–Crown partnership. The report included 5 recommendations; work is currently under way to address these across government.

The second iteration of this guideline has a clinical focus. Future iterations will include more holistic models of wellbeing to prevent further failures experienced by Māori, Pacific peoples, disabled people and other priority populations.

Background

Inherent in this guideline is an expectation that communities acknowledge their Te Tiriti obligations and develop a flexible, local response to support people with long COVID and their whānau safely, effectively and equitably in the community, making use of existing district and local plans and processes.

This document supports the management of people with long COVID and their whānau. The CCCM is a provider tool that assists providers to support people with acute COVID-19.

Since its first description just over 2 years ago, long COVID has been the subject of intense research. However, a great deal is still unknown.

Long COVID affects the body and mind as a whole. Practitioners need to treat symptoms holistically and in person-/whānau-centred ways. Long-term consequences of COVID-19 infection can decrease a person's quality of life, may cause emotional distress and may have psychological implications for people and their whānau.

Currently, there is no known 'cure' for long COVID. This guideline addresses identification, assessment, diagnosis, interventions, supports and care pathways for rehabilitation of people with long COVID. Separate parts of the guideline cover these topics respectively.

In 2022, Manatū Hauora initiated a programme of work for long COVID that included developing this clinical guideline, reviewing current and emerging research, identifying gaps in the research and establishing an expert advisory group to provide guidance on

the guideline, with representation from Māori, Pacific peoples, researchers, disabled people’s organisations, clinicians, service providers and people with lived experience of long COVID.

This guideline grades its recommendations according to the system below. We note that the literature on the topic is still emerging. We will update this guideline as new evidence relevant to the Aotearoa New Zealand situation becomes available.

Status of the recommendation	Grade
The recommendation is supported by good evidence (where there are a number of studies that are valid, applicable and clinically relevant)	A
The recommendation is supported by fair evidence (based on studies that are mostly valid and not likely to be overturned by other evidence), but there are some concerns about the volume, consistency, applicability and/or clinical relevance of the evidence that may cause some uncertainty	B
The recommendation is supported by expert opinion only (from external opinion, published or unpublished; eg, consensus guidelines).	C
No recommendation can be made. The evidence is insufficient (either it is lacking, it is of poor quality or conflicting or the balance of benefits and harms cannot be determined)	I

Where a recommendation is based on the clinical and lived experiences of members of the Expert Advisory Group, this guideline refers to it as a ‘good practice point’.

1 Care pathway for long COVID

1.1 Models of care

Internationally, models of care developed for people with long COVID include a care pathway integrating primary care, community rehabilitation services and specialised clinics for medical assessment. The entry into care pathway is through a centralised referral system. Care is multi-disciplinary, and delivered via clinic, community-based or telehealth methods tailored to the needs of individuals and their whānau. In the Aotearoa New Zealand context, Te Tiriti O Waitangi relationships and partnerships with local communities need to be paramount in models of care. In terms of equity, the availability of specialised and culturally safe services is particularly important. We also need to ensure that models of care follow universal design principles¹ complemented by specialised approaches for those who need assistance to equitably access the service (for example, some disabled people).

Models of care should be based on the following general pathway.

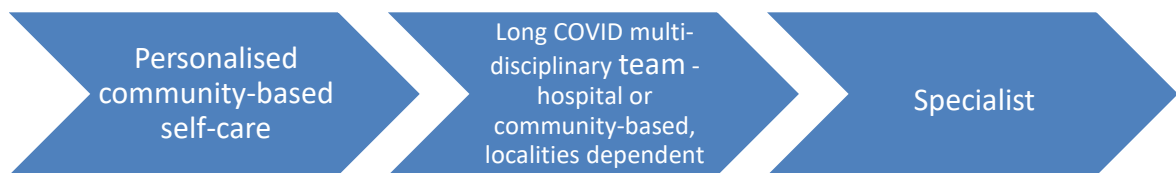


Figure 1: Long COVID Care pathway

Personalised community-based self-care	Long-COVID multi-disciplinary team – hospital or community-based, localities dependent	Specialist
<ul style="list-style-type: none"> Personalised management plan Access to resources that allow for people and whānau to learn to manage their symptoms with support and advice, eg, Health Navigator and Āwhina App 	<ul style="list-style-type: none"> Holistic assessment Personalised management plans Advice, rehabilitation and support for physical health, psychological health, mental wellbeing, and vocational improvement or recovery 	<ul style="list-style-type: none"> Referral for specific conditions according to health pathways A long-COVID multi-disciplinary team that continues while specialist care is undertaken Coordination between specialities

¹ Universal design is 'the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design' (Connell et al 1997; Story 2001).

Personalised community-based self-care	Long-COVID multi-disciplinary team – hospital or community-based, localities dependent	Specialist
<ul style="list-style-type: none"> Community-based face-to-face and non-face-to-face supports Virtual assistance, eg, apps Adaptation to peoples' impairments 	<ul style="list-style-type: none"> A nominated kaiārahi (guide) to support the management plan Adaptation to peoples' impairments 	<ul style="list-style-type: none"> Adaptation to peoples' impairments

Recommendations	Grade
Acknowledge key elements of the care continuum, including: <ul style="list-style-type: none"> the use of specific symptom screening and assessment tools to systematically identify long-COVID condition symptoms and functional impairments pathways to determine patients' rehabilitation trajectory and guide their transition between care settings customised, personalised, accessible management and education resources working with whānau and iwi to develop personalised management and education resources. 	B

1.2 Supports

Everyone has unique personal needs and a unique health status. An individualised approach to service delivery is therefore essential.

Recommendations	Grade
Ensure that the values, knowledge, preferences and cultural perspectives of the whānau are integrated, respected and evident in services and resources.	B
Ensure that people and their whānau know how to access information and support. Work with support groups, whānau and iwi to develop appropriate support services.	B
Ensure the provision of accessible information about long COVID. For example, ensure information is available in translated, easy-to-read and developmentally appropriate versions. Support groups and government should collaborate to ensure information is current.	B
Ensure individualised support is available to people with long COVID and their whānau, to help them manage their physical and mental wellbeing and health care needs.	B
Take into account the symptomatology of long COVID patients, and adapt practices and procedures accordingly.	B
Initiate vaccination discussions with whānau with respect to starting or continuing childhood immunisation programmes 3 months following COVID-19.	A
Pursue methodologically rigorous research to examine the effectiveness of current evaluation methods and treatments used to address long COVID.	B
Develop a coordinated approach to planning and implementing services to meet the identified needs of people with long COVID and their whānau, including linkage of multiple services.	C

Recommendations	Grade
<p>Ensure that the use of specific outcomes measures aligns with the recommendations from the post-COVID core outcome set.</p> <p>Consider using a paediatric-specific core outcome set, if available.</p>	C

1.3 Māori population and communities

Limited research is available on the specific impacts of the COVID-19 pandemic in relation to outcomes for Māori, including tāngata whaikaha Māori. Studies conducted following the first outbreak of COVID-19 in 2020 examined the response from different iwi around New Zealand and considered how Māori adapted their own cultural response in regard to the pandemic. Initially Māori were thought to be at increased risk of mortality from COVID-19, yet research found some Māori fared better from engaging within their strong social connections and adapting their own cultural beliefs as means of protection (Sacha and Savage 2020; Pihama and Lipsham 2020).

Preliminary results from the *Ngā Kawekawe o mate korona* study found that, of 65 Māori participants, 43% (28 participants) reported experiencing symptoms for more than one month, and of these, 75% (21 participants) reported experiencing long COVID symptoms for more than 3 months post-infection. The data for the survey included people aged 16 and over who had COVID-19, or were a probable case, before 1 December 2021.

Since the beginning of the Delta outbreak (17 August 2021), more than 138,000 Māori have contracted COVID-19; 90% (125,000) of cases have occurred since 24 February 2022. Since the beginning of the Delta outbreak in August 2021, Māori have been 75% more likely to contract COVID-19 than non-Māori, non-Pacific peoples, and after accounting for age, Māori were 2.4 times more likely to contract COVID-19 compared with non-Māori, non-Pacific peoples

Modelling and data from COVID-19 hospitalisations suggest Māori are at higher risk of hospitalisation with adverse effects from COVID-19. This indicates they may also be at higher risk of developing long COVID symptoms. Māori populations and communities have protected themselves from this risk by strategies such as adapting language, mobilising hapū and iwi and changing the traditional greeting of hongi to a 'Kahungunu Wave' (Ngāti Kahungunu Iwi Inc 2020). Studies found that, during the initial pandemic outbreak, regular whānau and family connection online, food parcels delivered by iwi or friendly faces and regular phone check-ins from health care professionals supported Māori to maintain a sense of wellbeing (McMeeking and Savage 2020).

Submissions to the Human Rights Commission's *Inquiry into the Support of Disabled People and Whānau During Omicron* report highlighted the positive contributions of Māori and Pacific providers to better wellbeing outcomes for tāngata whaikaha Māori.

Recommendations	Grade
Support and fund community development of information in te reo Māori about long COVID in a range of media.	B
Establish a kaimanaaki role who could work as a resource across sectors, to support people experiencing long COVID and their whānau. A national network offering professional support to kaimanaaki may be useful.	B
Support Māori-led research into long COVID and institutionally develop it.	B
Support a development strategy to facilitate increasing the capacity and capability of the Māori health and disability workforce involving ongoing collaboration and access to specialist training.	B
Ensure support rongoā and traditional Māori health care.	C

1.4 Pacific populations and communities

This section identifies issues of concern to Pacific peoples. This guideline takes a pan-Pacific approach to highlight broad principles, acknowledging the cultural diversity of Pacific cultures. Structural inequities and systemic racism in the health care system mean that Pacific communities face a much greater burden from COVID-19. Older Pacific people, disabled Pacific people and those with pre-existing health conditions are also at greater risk.

Since the beginning of the Delta outbreak, more than 148,000 Pacific people have contracted COVID-19. Pacific people were disproportionately represented in case numbers in the earlier stages of the pandemic, and have the highest COVID-19 hospitalisation and mortality rates. Pacific people are less likely to receive a clinical assessment within 24 hours when presenting with COVID-19 compared with non-Māori, non-Pacific peoples.

Recommendations	Grade
Develop long COVID information packages in the widely spoken Pacific languages (Tongan, Samoan, Cook Island Māori, Niuean, Fijian, Tokelauan, Kiribati) in a range of media. Distribute this information through mainstream and community providers of health, employment, education and disability services.	C
Work with providers and community organisations (eg, churches) to support fanau-based models of care by providing expertise, resources and training.	B
Develop a programme of research that would provide baseline information regarding long COVID and Pacific people.	C
Develop a targeted recruitment and development strategy to support increasing the capacity and capability of the Pacific health and disability workforce.	C
Develop a whole-of-system response aimed at improving the cultural safety of the mainstream workforce, helping health care workers to acquire knowledge and understanding of Pacific cultural values and world views and appropriately apply this to their work.	B

1.5 Disabled peoples' perspectives

This section identifies issues of concern for disabled people. Disabled people are more likely to have health conditions associated with their impairment, which increase the level of risk from long COVID. Evidence tells us that many disabled people experience inequitable access to health services and that access is compromised by inaccessible services and a lack of information and communications in alternative formats. Data should be collected on the number of disabled people accessing services because of long COVID.

COVID-19 has exposed the vulnerabilities and inequalities that disabled people already face in their everyday lives.

The Human Rights Commission's *Inquiry into the Support of Disabled People and Whānau During Omicron* report identified that disabled people and their whānau face considerable difficulties in accessing support and information on COVID-19 through mainstream general practice services. In addition, access to mental health supports has been limited, concerns have been raised about disabled people's ability to access essential hospital-based services, and messaging and approaches between Te Whatu Ora districts throughout the country have varied.

The Human Rights Commission's report recommended that government further consider how the whole health and disability system can respond to and support people experiencing long-term health and disability impacts from COVID-19, including long COVID and adverse events from vaccinations. People with physical disabilities commonly encounter daily challenges such as barriers to community mobility, reduced access to health care services and a higher risk of experiencing issues with their mental health and wellbeing.

Recommendations	Grade
Work to reduce the barriers disabled people experience in accessing community mobility and health care services.	C
Apply an Enabling Good Lives approach; consider family support, living environments and the context of disabled people's lives.	C
Assess the impacts of long COVID on carers, and be aware that parents and caregivers operate in environments that create additional risks.	C
Consider accessing existing peer support groups for people requiring informal supports.	C

Good practice points	Grade
Customise individualised supports for disabled people, eg, by involving experts in disabled rehabilitation.	C
Prioritise disabled people for assessment and treatment.	C
Plan accessible communication, information and treatment options and make them available, including digital modifications, ramps, transport options, speech language therapy interpreters, Braille and easy-read versions.	C

1.6 Rural and remote locations

Rural people and their whānau experience significant challenges and disadvantages (eg, less public transport, a lack of local support, isolation, lack of financial resources, lack of employment opportunities) compared with urban dwellers.

Recommendations	Grade
Reduce the access barriers rural communities experience by providing services through the services that are already established in those communities.	C
Make use of mobile, telehealth and 'pop-up' services in rural communities where people face significant problems with transportation.	C
Provide supported transport and, where appropriate, accommodation services for rural people who must access urban services.	C
Measure the impact of rural dwelling on people's access to services, and where access is identified as significant, use rural communities and providers to find 'rural proof' solutions.	C

Good practice points	Grade
Make use of mobile clinics to make services more accessible.	C
Make use of telehealth programmes to make services more accessible.	C
Make use of marae and non-health community services as a resource.	C

1.7 Older people and aged residential care perspectives

This section identifies issues of concern for older people, many who live with existing co-morbidities. Remaining in good health, ageing well and being supported to live well with long-term conditions is critical to older people's ability to continue participating and feel valued, which are important factors for health and wellbeing. Services need to recognise that older people have different needs at different times.

Recommendations	Grade
Be aware that older adults are more likely to report problems with mobility, choking and malnutrition and problems with performing daily physical, cognitive and social activities, and are also more likely to experience reduced cognitive functioning.	B
Be aware that older adults with a higher body mass index (BMI) show significantly more symptoms, such as dyspnoea at rest and on exertion, feelings of chronic fatigue, problems with mobility and problems in performing daily activities.	B
Studies show that older adults with long COVID should receive multi-disciplinary help, including additional medical and psychological support.	B

Good practice points	Grade
Refer older adults presenting with mobility issues and long COVID symptoms for a mobility assessment.	C

Good practice points	Grade
Refer older adults presenting with communication issues and long COVID symptoms for a speech-language therapy assessment.	C
Refer older adults presenting with nutritional and swallowing issues and long COVID symptoms for a speech-language therapy and/or dietitian assessment.	C
Assess and refer older adults with a higher BMI presenting with symptoms of long COVID for support with breathlessness, fatigue, mobility and need for assistance in performing daily activities.	C
Offer older adults with presentations of multiple symptoms multi-disciplinary help, including additional medical and psychological support.	C

1.8 Medication management

If a person regularly takes medicines for long-term conditions, practitioners should undertake a formal review of their medicine therapy to ensure it is optimal and reduce the potential for adverse outcomes from over or under treatment. They should also note an agreed time for follow-up review, as changes in symptoms may further affect management.

2 Clinical case definition, diagnosis, and red and yellow flags

2.1 Presenting issue

The COVID-19 pandemic has presented an emerging need to clinically rehabilitate people who meet the definition of long COVID while acknowledging that many people recover without any intervention.

2.2 Acute COVID-19

The Ministry of Health's COVID Clinical Care Module (CCCM) assists general practitioners to support people with acute COVID-19. The health response needs to be relevant to our health system and meet the needs of our population, including by reflecting our commitment to Te Tiriti o Waitangi. It needs to be consistent with *Whakamaua: Māori Health Action Plan*, *The Haumarū* report, findings from the Waitangi Tribunal, *Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025*, the United Nations Convention on the Rights of Persons with Disabilities, the New Zealand Disability Strategy (2016–2026) and Pae Ora (Healthy Futures) Bill.

2.3 Long COVID clinical case definitions

This document uses the term 'long COVID'. This is variously referred to as ongoing symptoms of COVID-19, post-COVID-19 syndrome, post-COVID-19 conditions, post-acute sequelae of COVID-19, long-haul COVID, long-term effects of COVID and chronic COVID. The term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. Symptoms may last for weeks or months after the acute illness. Clinical coding is available [here](#).

Long COVID usually presents with clusters of symptoms, often overlapping, which can fluctuate, return and change over time and can affect any system in the body (National Institute for Health and Care Excellence et al 2022). For the purposes of this guideline,

acute COVID-19, ongoing symptomatic COVID-19 and long COVID are defined as follows:

- **acute COVID-19** – signs and symptoms of COVID-19 for up to 4 weeks
- **ongoing symptomatic COVID-19** – signs and symptoms of COVID-19 after the acute/infectious period of the illness from 4 weeks up to 12 weeks
- **long COVID** – signs and symptoms, consistent with COVID-19, that develop during or after an infection, continue for more than 12 weeks and are not explained by an alternative diagnosis.

The clinical case is defined by the timeframes, irrespective of a confirmed diagnosis by testing.

Recommendations	Grade
General practitioners, primary care teams, hospital and community-based clinicians, and private specialists should record details of acute COVID-19, ongoing symptomatic COVID-19 or long COVID in people's health records.	

In this document we will use the term "long COVID" to refer to signs post-Covid-19 syndrome.

2.4 Diagnosis and red and yellow flags

A Delphi² 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: <ul style="list-style-type: none"> • myocarditis • multi-system inflammatory syndrome in children (MIS-C) or paediatric inflammatory multi-system syndrome temporally associated with Sars-Cov2 (PIMS-Ts) (find further information here) • postural orthostatic tachycardia syndrome (POTS) • mast cell activation syndrome (blood disorder) • hypoxia/desaturation • chest pain • palpitations • histamine intolerance symptoms. 	B

² The Delphi technique is a well-established approach to answering a research question through the identification of a consensus view across subject experts.

Good practice points	Grade
<p>Consider the following red flags for patients with ongoing symptoms from COVID-19, and manage the symptoms:</p> <ul style="list-style-type: none"> • heart failure • pulmonary embolism • acute coronary syndrome • post-exertional symptom exacerbation (PESE) • myocarditis • chest pain • tightness, worsening or increasing palpitations, dyspnoea, desaturation in exertion • POTS • coagulation dysfunction • neurological disorder . <p>In children and young people, consider:</p> <ul style="list-style-type: none"> • pulmonary embolism • myocarditis • cardiomyopathy • venous thromboembolism • renal failure • type 1 diabetes mellitus • PIMS-Ts • MIS-C • neurological disorder • paediatric acute-onset neuropsychiatric syndrome. 	C
<p>Consider the following yellow flags for patients with ongoing symptoms from COVID-19:</p> <ul style="list-style-type: none"> • elevated heart rate • increased oxygen demand • orthostatic hypotension • pre-existing conditions and/or psychological and or psychosocial factors that could predict a poor outcome. <p>In children and young people, consider:</p> <ul style="list-style-type: none"> • absenteeism from school/education. 	

Long COVID is a multi-faceted condition, and its impact may include debilitating sequelae, impairments that affect a person’s quality of life or capacity to return to work, and social and holistic effects. An impairment can be intellectual, psychiatric, physical, neurological or sensory, and can be temporary, intermittent or ongoing. Impairments are often considered to be disabilities.

The ‘social model’ of disability holds that people are disabled by barriers in society, not by their impairment or difference. The social model draws a distinction between the ‘impairment’ and ‘disability’, and holds that the experience of disability occurs when:

- people with impairments are excluded from places and activities most of us take for granted
- infrastructure and systems (the built environment) do not accommodate the diverse abilities and needs of all citizens

- people’s attitudes prevent people with impairments from being able to participate in society on an equal basis with non-disabled people.

People with long COVID often have complex care needs requiring a holistic and multi-disciplinary approach. Persistent symptoms have been reported in patients with both mild and acute COVID-19; therefore, we have considered studies that include non-hospitalised as well as hospitalised patients.

Long COVID appears to be more common among people who had severe symptoms during their acute COVID-19, but it can also affect those who initially had mild or moderate COVID-19. There appears to be no specific time course; symptoms may improve one week and relapse the next.

There are many similarities between long-COVID-19 conditions, other post-infectious fatigue syndromes and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). There is no current consensus as to whether ME/CFS can result from COVID-19.

Recommendations	Grade
Be aware that the expected time to recover from symptoms of COVID-19 are: <ul style="list-style-type: none"> • 4 weeks for muscle aches and chest pain and sputum production to cease • 6 weeks for cough and breathlessness to be significantly improved, if not fully resolved • 3 months for most other symptoms to cease, with residual fatigue • 6 months for all symptoms to cease, unless the patient had a complicated/prolonged admission to intensive care. 	B
Be aware that presentations by individuals with long-acute COVID-19 are likely to be for: <ul style="list-style-type: none"> • non-specific post-viral symptoms: particularly fatigue, breathlessness, chest pain and palpitations • specific serious sequelae resulting from the acute infection, or occurring as delayed complications • recovery after severe illness that required intensive care management • psychosocial effects of prolonged symptoms and functional impairment. 	C

2.5 The impact of vaccination

2.5.1 Hospitalisation rates

Over 20,000 people in Aotearoa New Zealand have been hospitalised with COVID-19 infections. Over half of these people are reported to be partially or fully vaccinated or to have received a booster. Over 11% had received no vaccination doses prior to being reported as a positive COVID 19 case.

2.5.2 After infection with COVID-19 and long COVID

The Ministry of Health recommends that after a COVID-19 infection, people should start or continue their vaccination schedule after 3 months from diagnosis with the acute illness, to allow for some time for recovery.

Some studies have suggested that vaccination after infection can significantly reduce the likelihood of long COVID; other studies suggest a more limited protective effect.

It is widely agreed that the best way to prevent long COVID is to prevent the initial infection. Studies reporting on symptom changes following vaccination of people with long COVID have reported a higher proportion of people who experienced unchanged symptoms following vaccination than people whose symptoms improved or worsened. Most studies comparing long COVID symptoms before and after vaccination report an improvement in symptoms after vaccination, either immediately or over several weeks.

Recommendations	Grade
Advise people that vaccination should start or continue after 3 months following COVID-19.	B

Good practice points	Grade
Work with whānau to start or continue vaccination 3 months from diagnosis with the acute illness. The following website allows health professionals to make enquiries about specific cases, to support complex clinical reasoning: https://www.immune.org.nz/contact-us .	C

2.6 Pharmacology

Medications for long COVID are not yet validated, but clinical trials are currently under way with a range of therapeutics. Future updates will provide further information.

Good practice point	Grade
Consider medications for specific symptom management (eg, sleep disturbance) or to support mental health and wellbeing.	C

3 Symptomology and management

Allied health, scientific and technical professionals are involved from the initial stages of recovery of people with COVID-19 to their longer-term rehabilitation. The allied health workforce entails approximately 60 qualified health professions, each with specialised expertise in preventing, diagnosing, treating or rehabilitating a range of conditions and illness. A broad scope of practice allows allied health professionals to work together in a transdisciplinary way.

Transdisciplinary team members value the specific knowledge and core skills of other team members while acknowledging the skills they share. These shared skills allow team members to collaborate across professional boundaries. Transdisciplinary team working requires mutual understanding, trust and respect. The efficient functioning of a transdisciplinary team enables whānau-centred care.

Table 1: Ways health professionals can rehabilitate people with long COVID

Professional	Unique skills for rehabilitation of people with long COVID
Clinical exercise physiologist	Clinical exercise physiologists use assessments to identify the causes of reduced functional capacity or exercise intolerance. They then develop individualised exercise-focused interventions based on their assessment to restore and mitigate loss of function.
Dietitian	Dietitians provide medical nutrition therapy, which involves assessing the nutritional needs of patients and together creating an individual nutritional plan to meet those needs as they recover, taking into account any other underlying conditions, swallowing difficulties, lifestyle and social and cultural factors.
Occupational therapist	Occupational therapists engage people and whānau in personally meaningful occupations (self-care, productivity, leisure) to empower them through rehabilitation that will optimise their recovery.
Physiotherapist	Physiotherapists are autonomous practitioners who work in partnership with the wider team to mitigate the physiological consequences of COVID-19. Physiotherapists may be involved in a person's rehabilitation from acute admission in an intensive care unit through to community, occupational and sporting environments. Physiotherapists interpret the findings of individualised assessments and prescribe a management plan supported by evidence to meet a person's needs and specific goals.
Psychologist	Psychologists are scientist practitioners who apply psychological knowledge, principles, methods and procedures to predict and influence behaviour and/or cognition to support people to achieve psychological and psychosocial wellbeing. Psychologists provide evidence-based psychological therapies to optimise wellbeing.

Professional	Unique skills for rehabilitation of people with long COVID
Social worker	Social workers assess and evaluate people's situations and needs alongside those of their whānau, incorporating analysis of structural, cultural, social and economic issues to explore and identify people's strengths, needs, context and support networks. Social workers view rehabilitation from the client's perspective, working in partnership to determine and prioritise goals that will enhance people's wellbeing, resilience and ability to cope with life stressors such as grief, loss and trauma.
Speech-language therapist	Speech-language therapists are autonomous practitioners who work in partnership with the wider team to provide specialist assessment and rehabilitation for people of all ages with acute and chronic communication and swallowing difficulties.

3.1 Body systems

Long COVID affects the body and mind as a whole and needs to be treated holistically and in person-/whānau-centred ways.

Long COVID can strongly decrease a person's quality of life and may cause emotional distress and have psychological implications. Generally, long COVID affects the following body systems:

- respiratory
- cardiovascular
- musculoskeletal
- neurological
- gastrointestinal
- endocrine
- psychological and socio-emotional.

3.2 Symptomology and management

Long COVID usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and affect any system in the body. The exact symptomology of long COVID is unknown: one systematic review identified 84 symptoms. Frequently reported symptoms include:

- anxiety
- depression
- fatigue
- breathlessness, cough and abnormal breathing patterns
- 'brain fog'

- cognitive changes, including memory impairment
- sleep disturbances
- exercise intolerance: an inability to return to a usual level of exercise
- post-exercise malaise (PEM): when symptoms get worse after exercise, or people get very tired even after a small amount of activity
- PESE: tiredness that can last for more than 24 hours after physical or mental effort
- post-intensive care syndrome: health problems that remain after critical illness. They are present when the patient is in the ICU and may persist after the patient returns home. These problems can involve the patient's body, thoughts, feelings, or mind and may affect the family.
- orthostatic intolerance, dysautonomia and POTS: POTS is due to an abnormal response by the autonomic (automatic) nervous system and is characterised by orthostatic intolerance (the development of symptoms when upright that are mostly relieved by lying down)
- communication, speech, voice and swallowing difficulties
- changes in eating patterns and appetite
- changes in bowel habits
- headache
- loss of taste and smell
- muscle weakness
- muscle/joint pain.

Recommendations

Tailor rehabilitation to people and their whānau, with careful activity pacing, to avoid relapse, and with transdisciplinary support. A

3.2.1 Mental health and wellbeing B

Not acknowledging a person's anxiety or depression can exacerbate already high levels of distress. Anxious feelings and stress are normal; reassurance of these normal emotions is important. Options for support include a general practice team and supportive friends.

Find resources for patients [here](#) and [here](#).

The following helpline numbers may be useful:

- Need to talk? 1737 (free call/text)
- Healthline: 0800 611 116
- COVID Healthline: 0800 358 5453
- Government helpline: 0800 779 997.

People are likely to need support with both the process of accessing help (expectations, adjustment, navigating services) and the outcomes (managing symptoms of distress).

People need access to timely, good quality information and well-informed multi-disciplinary team support to help them (and others) form realistic expectations of their recovery, as well as to manage their symptoms.

Experience suggests that positive contact with others who are experiencing similar issues is extremely helpful for that process – meaning coordinated group- and peer-based approaches will be of particular benefit.

Recommendations

The process may not be the same for everyone. Particular consideration needs to be given to supporting Māori and their whānau, as well as disabled people.

There is strong research evidence for the benefit of individual and group-based programmes to help people manage commonly reported issues.

Given the high number of people with long COVID experiencing symptoms of trauma/post-traumatic stress disorder, suicidal ideation and cognitive difficulties, many may need to be supported to access more intensive (neurological) psychological interventions.

3.2.2 Fatigue

Ensure people and their whānau have access to customised information and resources about fatigue management and **pacing activities** such as the use of the 'energy envelope'. These resources need to be tailored for person's particular lifestyle, culture, environment and social demands. The "energy envelope" theory suggests that by maintaining expended energy levels within the envelope of perceived available energy levels, people are able to better sustain physical and mental functioning while reducing symptom severity and frequency of relapses.

C

Find clinician resources [here](#).

C

Consider referral to an occupational therapist for assessment and treatment for people who require additional support for management of fatigue. Occupational therapists work in private and public health services and can be accessed by referring to local Te Whatu Ora districts via local pathways or making contact with a private organisation directly. Find an occupational therapist [here](#).

Consider customised supports to meet the needs of disabled people or those with existing health conditions.

Consider recommending equipment or adaptive aids can assist people who need them for rehabilitation or due to fatigue.

3.2.3 Breathing pattern disorder, cough, reduced exercise tolerance or muscle weakness

People who present with **breathing pattern disorder**, cough, reduced exercise tolerance that is not improving, symptoms that worsen after graded exercise or muscle weakness following COVID-19 infection are likely to benefit from a referral to a physiotherapist and/or speech-language therapist, who can assist with skills in managing breathing pattern disorder for assessment and treatment. Referrals can be made through local Te Whatu Ora districts via local pathways or by contacting a physiotherapist or speech-language therapist directly. Find a physiotherapist [here](#). Find a speech-language therapist [here](#).

B

Reduced exercise tolerance may be caused by altered ventilation and circulation and not deconditioning.

Advise people who experience a worsening of symptoms following exercise to seek advice from their family doctor or a physiotherapist. Clinicians should prescribe graded exercise therapy after a thorough assessment of the absence of PEM/PESE. Assess for the following:

- cardiac symptoms: breathless on exertion, tachycardia, chest pain
- PESE: the DePaul PEM Questionnaire ([here](#)) is a useful outcome measure
- oxygen desaturation on exertion – desaturation of more than 3% needs investigation
- autonomic dysautonomia – breathlessness, palpitations, fatigue, chest pain, syncope and feeling faint can contribute to exercise intolerance
- orthostatic intolerance or POTS – using the **NASA lean test** or active stand. It is difficult to distinguish this from cardiac conditions, and therefore medical examination is essential.

Recommendations

Cough

Cough substitution techniques and reducing airway irritants can support re-education of chronic cough and abnormal breath patterns. People with an ongoing cough are likely to benefit from a referral to a physiotherapist and/or speech-language therapist, who can assist with skills in managing cough.

Find information for people and their whānau [here](#) and [here](#).

Clinicians can find the Leicester cough questionnaire [here](#).

3.2.4 Thought processing, memory and 'brain fog'

People presenting symptoms such as sustained and ongoing 'brain fog', headaches, memory impairment or other new cognitive difficulties that are severely affecting their day-to-day functioning may benefit from a referral to an occupational therapist, speech-language therapist, psychologist or other appropriately qualified cognitive rehabilitation specialist. B

Find resources for clinicians [here](#).

3.2.5 Sleep issues

People with long COVID experiencing sleep issues may benefit from advice from health care professionals or traditional/cultural health practitioners who specialise in sleep problems. B/C

Rehabilitation specialists such as occupational therapists, speech-language therapists, dietitians, physiotherapists or local sleep clinics may be appropriate for onward referral for serious issues with sleep. Sleep clinics can be accessed by referring to local Te Whatu Ora districts via local pathways. B

Find resources from the Sleep Foundation [here](#).

Find resources on sleep for children and teenagers [here](#), [here](#) and [here](#).

Find information on how much sleep children need [here](#) and [here](#).

3.2.6 Post-exertional malaise and post-exertional symptom exacerbation

Undertake a comprehensive assessment to establish if the problem identified is deconditioning or dysregulation (eg, PEM or PESE). B

With regards to management of adults with PEM or PESE, be aware that:

- long COVID is not a linear presentation
- symptoms that are made worse from physical or mental activities and onset can occur immediately or up to 72 hours from the exertion and affect people differently. Recovery can take days, weeks or months
- graded exercise therapy (GET: planned, regular exercise with incremental increases in frequency and/or intensity, duration and type with a goal to increase fitness) is not recommended for these people, because it can cause an exacerbation of symptoms.
- symptom led pacing is advocated for, this includes prioritising, planning, and use of an activity diary

Management of PEM/PESE can include breathing retraining, pacing and establishing a symptom-free baseline. Occupational therapists and physiotherapists can assess people to provide an individualised/personalised management plan.

The condition can be triggered by cognitive, physical, mental, or emotional reasons, with onset immediately or 24-72 hours post exertion.

People who experience a worsening of symptoms following exercise should seek advice from their family doctor, a physiotherapist or an occupational therapist.

Find information for PEM or PESE, which are different from fatigue, [here](#). Referral to physiotherapists or occupational therapists may be of benefit for people who require additional support for management of this symptom. Physiotherapists and occupational therapists work in private and public health services and can be accessed by referring to local Te Whatu Ora districts via local pathways or making

Recommendations

contact with private organisations directly. Find an occupational therapist [here](#). Find a physiotherapist [here](#).

Clinicians can find information [here](#).

Information on fatigue and PESE can be found [here](#)

Pacing information can be found [here](#)

How to conserve energy information can be found [here](#) and see [here](#) for a downloadable poster

How to manage post-viral fatigue after COVID-19 can be found [here](#)

Top ten energy saving tips can be found [here](#)

Additional information links are available on long COVID Physio website [here](#)

Equipment or adaptive aids can assist people who need them for rehabilitation.

Heart rate monitoring can be useful for both predicting a harder day and keeping activities below the ventilatory threshold. Heart rate monitoring can help management/pacing, although there are mixed opinions for its use and suggest using if the person has an understanding/interest. Estimated heart rate equation is: $(220 - \text{individual age}) \times 0.55 = \text{anaerobic threshold in beats per minute}$ – advise people to stay below this heart rate.

An alternative, more conservative theory is people should keep their heart rate at a rate that is their resting heart rate plus 15 beats per minute.

Find a helpful poster [here](#).

Find resources specific to children [here](#) (pacing penguins) and [here](#) (cautious tortoise).

Find resources to share with teachers [here](#).

3.2.7 Dysautonomia, orthostatic intolerance and POTS

Symptoms of long COVID that occur on sitting or standing can include feeling dizzy, B faint, light-headed or nauseated.

Treatment includes:

- fluid intake
- salt intake
- contract-relax muscle exercises
- medical-grade compression garments.

Clinicians can find further information [here](#).

Find resources for patients [here](#).

3.2.8 Communication, voice or swallowing issues

If a person takes medicines and swallowing issues affect their ability to safely take B them, consider a review and make changes to their medicine forms made as required. A review could be undertaken by a pharmacist and may require changes to a medicine regimen by a prescriber.

Immediately refer people with increasing communication, voice or swallowing difficulties to a speech-language therapist for an urgent assessment. This is particularly important if a person is prone to chest infections or has breathing difficulties already. Referrals can be made through to local Te Whatu Ora districts via local pathways or by contacting a speech-language therapist directly. Find a speech-language therapist [here](#).

Find resources from the New Zealand Speech-language Therapists' Association [here](#).

3.2.9 Headache

Headaches are common during viral infections and usually disappear within a few B weeks. However, some people continue to experience headaches many weeks or months after a COVID-19 infection. The presence of a headache does not mean that the virus is still present. Many other factors, such as diet, fatigue, lack of sleep and

Recommendations

stress, can contribute to headaches. Those who have a history of migraines or headaches may be more likely to experience headaches with long COVID. Advise people to try some of the following tips.

- Stress can be a common trigger for headaches. Practising **self-care** and relaxation techniques can be helpful to manage stress or changes in mood. Muscle relaxation techniques may be helpful to reduce stress and tension in the neck and shoulders.
- A regular **sleep schedule** is important for your recovery, and may help with pain, fatigue and headache symptoms.
- Identify triggers such as stress, alcohol or caffeine, and try to avoid them.
- Maintain a regular and nutritious diet and keep hydrated during the day.
- If you experience feelings of exhaustion along with headaches, try the **pacing** technique.
- Take medications or painkillers as prescribed. It is a good idea to speak to a health care provider if you experience worsening headaches or dizziness.

3.2.10 Taste or smell issues

Provide people with loss of taste and smell with reassurance that this is not an unusual long-COVID-19 symptom. There is not a lot of information about how long it takes for COVID-19 patients to get their sense of smell back. Research from other viruses that affect sense of smell shows us that smell usually returns within 2 weeks, but it can sometimes take longer. Some people who lose their sense of smell can also lose their sense of taste.

B

Refer people with loss of taste and smell who are at risk of malnutrition to a dietitian for assessment and treatment. Referrals can be made through Te Whatu Ora districts via local pathways or by contacting a dietitian directly [here](#).

Find further information for patients [here](#).

If a person with long COVID is finding it hard to maintain their weight, advise them to follow the **healthy eating basics**. If their weight loss continues, refer them to a dietitian for assessment and treatment. Referrals can be made through Te Whatu Ora districts via local pathways or by contacting a dietitian directly [here](#).

Find smell re-training techniques for patients [here](#).

3.2.11 Gastrointestinal changes

Refer people presenting with persistent gastrointestinal symptoms (such as nausea, bloating, pain or diarrhoea) to a dietitian for assessment and treatment. Referrals can be made through Te Whatu Ora districts via local pathways or by contacting a dietitian directly [here](#).

C

3.2.12 Muscle/joint pain

Provide people with muscle and or joint pain with reassurance that this is not an unusual post-COVID-19 symptom. Encourage a gentle full range of movement exercises.

C

Find gentle exercise resources for patients [here](#); see also the video links below.

Provide people with the following exercise guidelines.

- Keep moving, and keep moving with care.
 - Work at your own level: in most videos linked below, you can choose to sit or stand.
 - For balance exercises, have a chair, table, wall or something sturdy nearby for support.
 - Make sure you have a clear space to move in – no rugs or things to trip on.
 - Make things easier: take the arms out, lower your knees, make your movements smaller or rest when you need.
-

Recommendations

- Make things harder: use your arms, lift your knees, do more repetitions or add some oomph!
- Don't take risks: sit down, rest or stop when you need. Don't carry on if it causes you pain.
- If you feel unwell, contact your doctor or the COVID Healthline on 0800 358 5453. For emergencies, call 111.

Time in minutes	Name/type of exercises	Link
18	Chair shaped: seated and standing options for posture work	https://youtu.be/2r4cRTMYZUo
12	Easy sit and fit 1: general fitness sit or stand	https://youtu.be/kko8fMZ212Y
21	Easy sit and fit 2: general fitness sit or stand	https://youtu.be/qr_rDxkvLbo
17	Crossing activities: 8 minutes seated, 8 minutes standing	https://youtu.be/gbb8Ldzsat4
20	Introduction to strength and balance: warm-up, 3 strength, 3 balance	https://youtu.be/xXrkmfyx4h0
35	Strong and stable class 2021, seated or standing	https://youtu.be/WlwHCbfLaxY
43	Strong and stable class 2020, seated or standing	https://youtu.be/wmWsa_TWVsU
49	Strong and stable class 2021 number 2, seated or standing	https://youtu.be/zWyeo6b_4qg
60	Chair yoga, including strength and balance, gentle	https://youtu.be/r3-S4IBuQ1A

3.3 Living with long COVID

Good practice points	Grade
Ensure that a coordinated approach to planning and implementing services is person- and whānau-centred. Ensure that cultural and community providers who may be supporting the whānau already are key partners in integrating care.	C
Ensure that people with long COVID and their whānau work with a member of the care team they trust to develop a coordinated care or action plan for rehabilitation and management of long COVID. Find examples for patient use here .	C

3.4 Support and service needs

The complex range of emotional and practical difficulties that people with long COVID experience tend to change over time, and can include:

- difficulties accessing health services due to issues such as cost or location (especially for rural people), culturally safety, a lack of available services or a lack of accessibility (especially for people with mobility needs or communication barriers)
- anxiety and helplessness before diagnosis expectations of recovery from themselves and others at diagnosis and, for some, a sense of relief in finding a diagnosis
- lack of knowledge about long COVID among medical, employment, educational, social and community service agencies
- intolerance, misunderstanding and discrimination by the community
- management of co-existing conditions including but not limited to; COPD, individuals with renal conditions undergoing dialysis
- social supports or access to telephones to cancel appointments with Te Whatu Ora and or lack of access to transport, bringing a risk of discharge from out-patient services due to non-attendance
- disruptions in family routines and lifestyle limitations, including reduced access to opportunities for work, education, social interaction, recreation and leisure activities.

Good practice points	Grade
Ensure treatment options are available to underserved communities.	B
Offer education about long COVID to communities and providers to support acceptance and decrease discrimination.	C
Provide specialised options for cultural groups in the region and for priority populations such as Māori, Pacific peoples, rural and remote communities, disabled people, older people and people living in aged residential care.	B

3.5 Vocational rehabilitation

Long COVID presents people with unique challenges in terms of returning to workplaces or education settings. Some people may require vocational rehabilitation or support. A return to work or education plan should be individualised. Particularly at risk are:

- Women females of working age
- people who work in jobs entailing occupational risk, especially in health and education
- those with multi-morbidity
- those experiencing financial or other pressures to return to work
- those experiencing academic or social pressures to return to education.

Good practice points	Grade
Recognise the episodic and unpredictable nature of long COVID, acknowledging that treatment requires a phased approach that may involve remote work/study, flexible hours, a reduced physical and cognitive load, altered tasks or more time to complete tasks or more rest time.	B

3.6 Children and young people

Children and their whānau have specific needs. Childhood illness affects parents/caregivers and other siblings. Providers must be able to offer support to the wider whānau.

KidsHealth is an Aotearoa New Zealand site that provides information on recovering from COVID, including long COVID, for people and whānau; see helpful information [here](#) and [here](#).

As with all age groups, consider pre-existing chronic condition exacerbation in children and young people presenting with symptoms of long COVID.

The most common symptoms in children are:

- changes to sense of taste and smell
- unusual tiredness/fatigue
- headaches
- difficulty concentrating / 'brain fog'
- sleep disturbance.

Children can also have:

- muscle aches
- joint pain
- cough
- low mood
- dizziness
- POTS
- difficulty sleeping
- chest pain
- breathlessness
- a fast-beating or pounding heart
- new or worsening urinary symptoms.

The following table shows the most common symptoms for various age groups.

0–3-year-olds	<ul style="list-style-type: none"> • mood swings • rashes • stomach aches • cough • loss of appetite
4–11-year-olds	<ul style="list-style-type: none"> • mood swings • trouble remembering or concentrating • rashes
12–14-year-olds	<ul style="list-style-type: none"> • fatigue • mood swings • trouble remembering or concentrating
14–18-year-olds	<ul style="list-style-type: none"> • POTS

Good practice points	Grade
Support caregivers and monitor for caregiver fatigue.	B
Advise whānau to plan their children’s day and week, to balance activity and rest and maintain an energy envelope.	B
Screen for cardiac symptoms prior to sport, consider the risk of boom-and-bust behaviours and provide symptom-guided/paced return to sport.	B
Consider targeted psychological supports, particularly for those children who have experienced more boom and bust or frustrations, and find it harder to pace.	C
Advise whānau to ensure children can maintain their level of activity before progressing. Find resources specific to children here (pacing penguins) and here (cautious tortoise).	B
Advise whānau that education needs to be able to be delivered in flexible formats. Ideally, it should be home-based, online or hybrid and paced to allow a return to classroom attendance. Special education needs coordinators (SENCO) and Northern Health Schools can formulate a plan with the young person and their whānau that is individualised and symptom-led. Be mindful of the social, emotional, and sensory load of classroom/school attendance and factor this into the energy envelope. Also be mindful of the effect of decreased school attendance on working parents/caregivers.	B
Support from SENCO / Northern Health Schools may be available for young people for flexibility with NCEA credits	B
Acknowledge that schools need well-ventilated classrooms and that children may not tolerate mask use. Communicate with the Ministry of Education, teachers, and boards of trustees about continuous carbon dioxide monitoring and appropriate ventilation.	B
For children already known to an allied health profession, ensure adequate access to re-assessment, and where required ensure revised educational therapeutic programmes are available.	C

3.7 Summary of symptoms and management resources for people and whānau

This table provides a summary of common symptoms and resources to support people with long COVID, their whānau and carers. See section 3.2 above for detailed information regarding these symptoms.

Issues with mental health and wellbeing	<ul style="list-style-type: none"> Resources for patients can be found here https://mentalhealth.org.nz/ and here https://www.healthnavigator.org.nz/healthy-living/m/mental-health/ Helpline numbers The team at 1737 are available to free call/text 24/7. Healthline 0800 611 116 COVID Healthline 0800 358 5453 Government helpline 0800 779 997
Fatigue	<ul style="list-style-type: none"> pacing activities https://longcovid.physio/fatigue
Link to find ...	<ul style="list-style-type: none"> Occupational Therapist here https://www.otnzwna.co.nz/find-an-occupational-therapist/ Physiotherapist here https://physio.org.nz/#find-a-physio Speech Language Therapists here https://speechtherapy.org.nz/find-a-therapist/ Dietitian here https://dietitians.org.nz/find-a-dietitian/
Breathing pattern disorder	<ul style="list-style-type: none"> https://longcovid.physio/breathing-pattern-disorders
Cough	<ul style="list-style-type: none"> Information for individuals and whānau can be found here https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-cough/ and here https://theconversation.com/still-coughing-after-covid-heres-why-it-happens-and-what-to-do-about-it-179471
Sleep issues	<ul style="list-style-type: none"> Resource on sleep for children and teenagers can be found here https://www.sleepfoundation.org/children-and-sleep <ul style="list-style-type: none"> and here https://www.health.govt.nz/your-health/healthy-living/food-activity-and-sleep/sleeping/helping-young-children-sleep-better#:~:text=Bedtime%20routine&text=Quiet%20activities%20are%20good%20before,it%20is%20time%20to%20sleep and here https://www.yourcovidrecovery.nhs.uk/children-and-young-people-with-covid/sleeping-well/ Information on how much sleep do children need can be found here https://www.sleepfoundation.org/children-and-sleep/how-much-sleep-do-kids-need <ul style="list-style-type: none"> and here https://www.healthnavigator.org.nz/healthy-living/s/sleep-and-children/#:~:text=Sleep%20is%20important%20for%20restoring,%2C%20health%2C%20wellbeing%20and%20weight

	<ul style="list-style-type: none"> Resources for patients including children and young people can be found below: Resources from Sleep Foundation https://www.sleepfoundation.org/
Post-exertional malaise / post-exertional symptom exacerbation	<p>Individuals who experience a worsening of symptoms following exercise should seek advice from their family doctor or a physiotherapist. Graded exercise therapy may not be an appropriate treatment option and can cause harm to some people with Long COVID</p> <ul style="list-style-type: none"> Post exercise malaise (PEM), information can be found here https://www.healthnavigator.org.nz/health-a-z/c/covid-19-positive-exercise/ Information on fatigue and PESE can be found here https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet3-Fatigue-and-PESE-Final-A4-v1.pdf Pacing information can be found here https://longcovid.physio/pacing How to conserve energy information can be found here https://www.rcot.co.uk/conserving-energy – see here for a downloadable poster (How to conserve energy guide link at bottom of the page in previous link) How to manage post-viral fatigue after COVID-19 can be found here https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0 Top ten energy saving tips can be found here https://workwellfoundation.org/wp-content/uploads/2020/09/Top-Energy-Saving-Tips.pdf Additional information links are available on long COVID Physio website here https://longcovid.physio/ Resources specific to children can be found here (pacing penguins) https://www.longcovidkids.org/_files/ugd/eabf28_ab86649a5dcf4f67bd07a7f4f953c08b.pdf and here (cautious tortoise) https://www.longcovidkids.org/_files/ugd/eabf28_b3a244eaf8a44278b746a1a260bc67a8.pdf Resources to share with teachers can be found here https://www.longcovidkids.org/post/long-covid-kids-back-to-school-tips-for-teachers
Dysautonomia, orthostatic intolerance and postural orthostatic tachycardia syndrome	<ul style="list-style-type: none"> Resources for patients can be found here https://www.potsuk.org/managingpots/
Communication or swallowing issues	<ul style="list-style-type: none"> Resource from the New Zealand Speech Language therapists' association can be found here https://speechtherapy.org.nz/find-a-therapist/resources-for-families/
Headache	<ul style="list-style-type: none"> Practising self-care https://www.waitematadhb.govt.nz/hospitals-clinics/north-shore-hospital/long-covid/managing-long-covid/#self-care sleep schedule https://www.waitematadhb.govt.nz/hospitals-clinics/north-shore-hospital/long-covid/managing-long-covid/#sleep pacing technique https://www.waitematadhb.govt.nz/hospitals-clinics/north-shore-hospital/long-covid/managing-long-covid/#fatigue

Taste or smell issues	<ul style="list-style-type: none"> information for patients can be found here https://www.yourcovidrecovery.nhs.uk/i-think-i-have-long-covid/effects-on-your-body/taste-and-smell/ 																														
Muscle and joint pain	<ul style="list-style-type: none"> Gentle exercise resources for patients can be found here https://www.waitematadhb.govt.nz/hospitals-clinics/north-shore-hospital/long-covid/managing-long-covid/#exercise and videos links below <table border="1"> <thead> <tr> <th>Time</th> <th>Type of exercises</th> <th>Link</th> </tr> </thead> <tbody> <tr> <td>18mins</td> <td>Chair shaped: Seated & standing options for posture work</td> <td>https://youtu.be/2r4ZUo</td> </tr> <tr> <td>12mins</td> <td>Easy Sit & Fit 1: General fitness sit or stand</td> <td>https://youtu.be/kZ212Y</td> </tr> <tr> <td>21mins</td> <td>Easy Sit & Fit 2: General fitness sit or stand</td> <td>https://youtu.be/qvLbo</td> </tr> <tr> <td>17mins</td> <td>Crossing activities: 8mins seated, 8mins standing</td> <td>https://youtu.be/gzsat4</td> </tr> <tr> <td>20mins</td> <td>Intro to strength & balance: warm up, 3 strength, 3 balance</td> <td>https://youtu.be/xyx4h0</td> </tr> <tr> <td>35mins</td> <td>Strong & Stable Class 2021, seated or standing</td> <td>https://youtu.be/VbfLaxY</td> </tr> <tr> <td>43mins</td> <td>Strong & Stable Class 2020, seated or standing</td> <td>https://youtu.be/vn_TWVsU</td> </tr> <tr> <td>49mins</td> <td>Strong & Stable Class 2021 #2, seated or standing</td> <td>https://youtu.be/zib_4qg</td> </tr> <tr> <td>60mins</td> <td>Chair yoga including strength & balance, gentle</td> <td>https://youtu.be/rS4lBuQ1A</td> </tr> </tbody> </table>	Time	Type of exercises	Link	18mins	Chair shaped: Seated & standing options for posture work	https://youtu.be/2r4ZUo	12mins	Easy Sit & Fit 1: General fitness sit or stand	https://youtu.be/kZ212Y	21mins	Easy Sit & Fit 2: General fitness sit or stand	https://youtu.be/qvLbo	17mins	Crossing activities: 8mins seated, 8mins standing	https://youtu.be/gzsat4	20mins	Intro to strength & balance: warm up, 3 strength, 3 balance	https://youtu.be/xyx4h0	35mins	Strong & Stable Class 2021, seated or standing	https://youtu.be/VbfLaxY	43mins	Strong & Stable Class 2020, seated or standing	https://youtu.be/vn_TWVsU	49mins	Strong & Stable Class 2021 #2, seated or standing	https://youtu.be/zib_4qg	60mins	Chair yoga including strength & balance, gentle	https://youtu.be/rS4lBuQ1A
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Peer support group links	<ul style="list-style-type: none"> Find peer support, advocacy, information and consultancy services for people affected by mental health and addiction distress here. https://balance.org.nz/ Find information and advice for people with long-term conditions here. https://www.healthnavigator.org.nz/healthy-living/l/looking-after-yourself-with-long-term-conditions/ 																														
Care plans and action plans	<ul style="list-style-type: none"> Find examples of care plans for patient use here. https://www.healthnavigator.org.nz/healthy-living/c/care-plans-and-action-plans/ 																														
Children and young people	<ul style="list-style-type: none"> Kids Health is an Aotearoa New Zealand site which also has information on recovering from COVID including long COVID for people and whānau here https://www.kidshealth.org.nz/recovering-covid-including-long-covid 																														

3.8 Summary of symptoms and management resources for clinicians

This table provides a summary of common symptoms and resources for clinicians supporting people with long COVID, their whānau and carers. See section 3.2 above for detailed information regarding these symptoms.

Vaccination	<ul style="list-style-type: none"> The following website has an option for health professionals to make enquiries about specific cases to support complex clinical reasoning. https://www.immune.org.nz/contact-us
Outcome measures	<ul style="list-style-type: none"> The use of specific outcomes measures should align with the recommendations from long-COVID core outcome set Consider paediatric specific core outcome set
Fatigue	<ul style="list-style-type: none"> The Why, When and How of Pacing Long Covid's Most Important Lesson here https://www.youtube.com/watch?app=desktop&v=gUPvNwvkOIA
Breathing pattern disorder	<ul style="list-style-type: none"> https://longcovid.physio/breathing-pattern-disorders
Cough	<ul style="list-style-type: none"> the Leicester cough questionnaire can be found here http://centerforcough.com/wp-content/uploads/2015/01/leicester-cough-quest.pdf Information for individuals and whānau can be found here https://www.nhsinform.scot/long-term-effects-of-covid-19-long-covid/signs-and-symptoms/long-covid-cough/ and here https://theconversation.com/still-coughing-after-covid-heres-why-it-happens-and-what-to-do-about-it-179471
Thought processing, memory and 'brain fog'	<ul style="list-style-type: none"> A range of resources for occupational therapy practitioners supporting people to manage Long-COVID syndrome, and those who are experiencing Long Covid themselves. https://www.rcot.co.uk/post-covid-syndrome-long-covid
Sleep issues	<p>Resources for patients including children and young people can be found below:</p> <ul style="list-style-type: none"> Resources from Sleep Foundation https://www.sleepfoundation.org/ Resource on sleep for children and teenagers can be found here https://www.sleepfoundation.org/children-and-sleep <ul style="list-style-type: none"> and here https://www.health.govt.nz/your-health/healthy-living/food-activity-and-sleep/sleeping/helping-young-children-sleep-better#:~:text=Bedtime%20routine&text=Quiet%20activities%20are%20good%20before,it%20is%20time%20to%20sleep. and here https://www.yourcovidrecovery.nhs.uk/children-and-young-people-with-covid/sleeping-well/ Information on how much sleep do children need can be found here https://www.sleepfoundation.org/children-and-sleep/how-much-sleep-do-kids-need

	<ul style="list-style-type: none"> • and here https://www.healthnavigator.org.nz/healthy-living/s/sleep-and-children/#:~:text=Sleep%20is%20important%20for%20restoring,%2C%20health%2C%20wellbeing%20and%20weight
Post-exertional malaise and post-exertional symptom exacerbation	<ul style="list-style-type: none"> • Information for clinicians can be found here https://www.jospt.org/doi/10.2519/jospt.blog.20220202 • Helpful poster can be found here https://workwellfoundation.org/wp-content/uploads/2021/03/HRM-Factsheet.pdf • Information on fatigue and PESE can be found here https://world.physio/sites/default/files/2021-06/WPTD2021-InfoSheet3-Fatigue-and-PESE-Final-A4-v1.pdf • Pacing information can be found here https://longcovid.physio/pacing • How to conserve energy information can be found here https://www.rcot.co.uk/conserving-energy – see here for a downloadable poster (How to conserve energy guide link at bottom of the page in previous link) • How to manage post-viral fatigue after COVID-19 can be found here https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0 • Top ten energy saving tips can be found here https://workwellfoundation.org/wp-content/uploads/2020/09/Top-Energy-Saving-Tips.pdf • Additional information links are available on long COVID Physio website here https://longcovid.physio/ • Resources specific to children can be found here (pacing penguins) https://www.longcovidkids.org/_files/ugd/eabf28_ab86649a5dcf4f67bd07a7f4f953c08b.pdf • and here (cautious tortoise) https://www.longcovidkids.org/_files/ugd/eabf28_b3a244eaf8a44278b746a1a260bc67a8.pdf • Resources to share with teachers can be found here https://www.longcovidkids.org/post/long-covid-kids-back-to-school-tips-for-teachers
Dysautonomia, orthostatic intolerance and postural orthostatic tachycardia syndrome	<ul style="list-style-type: none"> • Further information for clinicians can be found here https://www.potsuk.org/pots-for-medics/gp-guide/
Communication or swallowing issues	<ul style="list-style-type: none"> • Resource from the New Zealand Speech Language therapists' association can be found here https://speechtherapy.org.nz/find-a-therapist/resources-for-families/
Care plans and action plans	<ul style="list-style-type: none"> • Examples for patient use can be found here https://www.healthnavigator.org.nz/healthy-living/c/care-plans-and-action-plans/
Children and young people	<ul style="list-style-type: none"> • Kids Health is an Aotearoa New Zealand site which also has information on recovering from COVID including long COVID for individuals and whānau here https://www.kidshealth.org.nz/recovering-covid-including-long-covid

3.9 Long COVID symptom map

Fy Dunford, physiotherapist, of Te Whatu Ora Taranaki, developed this clinical tool for use by clinicians, to help them track and monitor patients' symptoms.

Ideally, the initial assessment should take a full hour. However, clinicians should be aware that cognitive fatigue may limit a person's ability to participate. Some people prefer to complete the form via email prior to attending the initial assessment. If so, clinicians should take appropriate steps to ensure the person understands how to use the form and has the ability (with whānau support if necessary) to complete it.

The assessment map lists the most common symptoms reported in long COVID presentations. A person may not have all of these symptoms; conversely, not all of their symptoms may be listed.

The body chart and narrative space allows a person to record their symptoms. Recording of symptoms must be consumer-led. The tool aims to capture patient symptoms as they present at the time of the assessment; it can also be used as a post-treatment measure to record progress in the symptoms of most concern to the person.

Using the symptom map guides assessment and navigates the assessor to the most appropriate starting point for symptom management. The aim is to save time in assessing, and to provide direction to relevant allied health professionals when a person presents with a cluster of symptoms.

Long Covid Symptom Map

DATE:

ATTACH PATIENT LABEL

COVID-19 can cause many symptoms. Mark on the charts below to show us your symptoms today. Zero means nil or nothing and 10 is the highest level. It is ok to have help to complete this form from family/whānau or staff. If you do not have a symptom please leave the line blank.

SYMPTOM SEVERITY SCORE

FUNCTIONAL DISABILITY SCORES

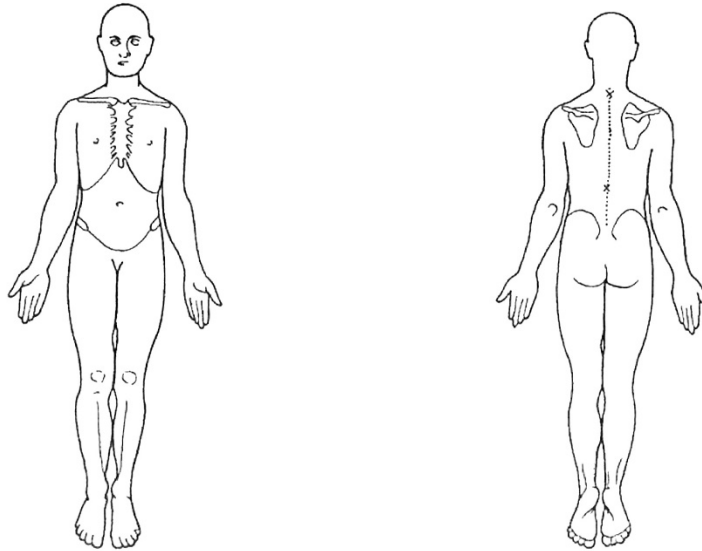
SIGNATURE

Long Covid Symptom Map

DATE:

ATTACH PATIENT LABEL

Mark on the body diagram where you experience symptoms and describe what they are.



OTHER

Please note below any symptoms that you feel have not been mentioned:

Form completed by _____ (Patient/family/staff) _____
PRINT NAME PRINT NAME

 SIGNATURE

Long Covid Symptom Map V2		Developed By Fy Dunford.
Department: Expert Advisory Group/ Ministry of Health	Responsibility: Physiotherapy New Zealand, Cardio Respiratory Special Interest Group.	Review By Date: 01/11/23
Caveat: The electronic version is the Master copy and in the case of conflict, the electronic version prevails over any printed version		

4 Guideline feedback

As the research continues, our understanding on long COVID develops. We welcome feedback and updates to the information contained in this guideline.

Please email your feedback and or new information to: Office of the Chief Clinical Officers: **occo@health.govt.nz**.

You can use the following form to provide feedback.

Which section of the guideline does your feedback relate to?

Free text box

New information to be added in the guideline:

Free text box

Outdated information to be removed:

Free text box

If you have articles or links, please attach or provide these:

Free text box

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