



Clinical rehabilitation guideline for people with long COVID (coronavirus disease) in Aotearoa New Zealand

2022

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Executive summary

Quantifying the impact of long COVID in Aotearoa New Zealand at this time is difficult, however this is not impacting on preparing guidance on the condition. Long COVID imposes impairment on the individuals affected and impacts those who live with or care for them.

Since the beginning of the Delta outbreak (17 August 2021) more than 138,000 Māori have contracted COVID-19, with 90 percent (125,000) cases occurring since 24 February 2022. Māori have been disproportionately affected through both the Delta and Omicron outbreaks. Since the beginning of the Delta outbreak in August 2021, Māori have been 75 percent more likely to contract COVID-19, and after accounting for age, Māori were 2.4 times more likely to contract COVID-19 compared with non-Maori non Pacific.

In addition, since the beginning of the Delta outbreak (17 August 2021) 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-Maori non Pacific.

Purpose

This guideline is intended to provide clinical guidance on long COVID conditions in both children and adults in Aotearoa New Zealand. The guideline is an evidence-based summary that covers the definition and diagnosis of long COVID. It seeks to provide the best evidence currently available to assist informed decision-making to improve the health, vocational and social outcomes for individuals with long COVID.

The guideline is intended for use by primary care practitioners, community and hospital clinicians, policy makers, funders, parents, carers, specialists, individuals with long COVID, whānau and any others who make provision for individuals with long COVID.

This document is not intended to address prevention of COVID-19 infection or reinfection but as a mitigation strategy to prevent/reduce the severity of long COVID.

The COVID-19 Māori Health Protection Plan (the Protection Plan) was published in December 2021 to respond to the pandemic evolving from the Delta variant to community-wide transmission of the Omicron variant. The Protection Plan helps guide health and disability system COVID-19 response actions for Māori through the next three to twelve months. The Ministry continues to monitor the impact of the COVID-19 pandemic on Māori as it is essential to ensure the ongoing response of the health and disability system gives effect to the principles of Te Tiriti o Waitangi.

The May 2022 Monitoring Report of the COVID-19 Māori Health Protection Plan: highlighted drivers of improving Māori vaccination uptake and growing 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 enabled a joined up approach for whānau isolating at home. Despite these improvements, persistent inequities remain in COVID-19 infection and hospitalisation rates, COVID-19 third (booster) dose, and child immunisation rates for Māori.

The Waitangi Tribunal's Haumarū COVID-19 Priority Report reaffirmed the Te Tiriti principles of tino rangatiratanga, partnership, equity, active protection, and options. The Tribunal was clear 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 Waitangi Tribunal's findings also included five recommendations and work is currently underway to address these across government.

The first iteration of the guideline has a clinical focus and future iterations will include more holistic models of wellbeing to prevent further failures to Māori, Pacific People, Disabled people and other priority populations.

Background

Within the guideline there is an expectation that communities acknowledge Te Tiriti O Waitangi obligations and develop a flexible, local response to support people with long COVID and whānau safely, effectively, and equitably in the community, leveraging existing district and local plans and processes. This document is intended to support management of individuals and whānau with long COVID, the Covid Clinical Care Module (CCCM) is a provider tool available to support individuals with acute COVID.

Since its first description just over two years ago, long COVID has been the subject of intense research, however a great deal is still to be studied to understand the condition. What is known, is that there are changes to individuals' wellbeing from when they have COVID-19 infection.

Symptoms of long COVID can be generalised to body systems, however, long COVID impacts the body and mind as a whole and symptoms need to be treated holistically and in person/whānau-centred ways. Long term consequences of COVID-19 infection can decrease quality of life, may cause emotional distress and have psychological implications to individuals, whānau.

Currently, there is no known 'cure'. This guideline addresses identification, assessment, diagnosis, interventions, supports and care pathways for rehabilitation of individuals with long COVID. These topics are covered in separate parts of the guideline.

In 2022, a programme of work was initiated in Manatū Hauora for long COVID. The programme included supporting development of this clinical guideline, review current and emerging research, identify gaps for future research and establish an expert advisory group to provide guidance and input into the long COVID rehabilitation guideline, with representation from Māori, Pacific peoples, researchers, disabled people

organisations, clinicians, service providers and individuals who have lived experience of long COVID.

In the following guidelines, recommendations have been graded according to the system below. The rate and volume of literature on the topic is still emerging, the guidelines will be updated as new evidence relevant to the Aotearoa New Zealand population and situation, becomes available.

| Recommendations: | 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, but there are some concerns about the volume, consistency, applicability and/or clinical relevance of the evidence that may cause some uncertainty but are not likely to be overturned by other evidence). | B |
| The recommendation is supported by EXPERT OPINION only (from external opinion, published or unpublished, e.g. consensus guidelines). | C |
| No recommendation can be made. The evidence is insufficient (either lacking, of poor quality or conflicting or if 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, it is referred to as a good practice point.

How to read this guideline:

Detailed information and background can be found in the following sections:

Section 1: Care pathways for long COVID

Section 2: Diagnosis, red and yellow flags

Section 3: Symptomology and Management

Section 3.6 Summary of common symptoms and management resources for individuals, whānau and carers.

Section 3.7 Summary of common symptoms and management resources for Clinicians.

Section 3.8 presents an Aotearoa New Zealand Long COVID Symptom Map.

Section 4: Guideline feedback to maintain currency as evidence continues to emerge on the condition

Section 5: References for guideline content

1 Care pathway for long COVID

1.1 Models of Care

Internationally, models of care that have been developed for populations with long COVID includes 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. Delivery of care is multi-disciplinary, and delivered via clinic, community based or telehealth methods best suited to individual's, whānau and families' needs. Such models need to be adapted for the Aotearoa New Zealand context, with Te Tiriti O Waitangi relationships and partnerships with local communities paramount. The availability of specialised and culturally safe services is particularly important to manage and co-ordinate resources for equitable rehabilitation of long COVID. Consideration needs to be given to how the model of care follows universal design principles complemented by specialised approaches for those who may need accommodations to equitably access the service, for example some disabled people.



| Personalised community-based self-care | Post-COVID MDT – hospital or community-based, localities dependent | Specialist |
|--|---|--|
| <ul style="list-style-type: none"> • Personalised management plan • Access to resources for individuals and whānau to learn to manage their symptoms with support and advice e.g., Health Navigator and Awhina App • Community based face-to-face and non-face to face supports • Virtual assistance e.g., mobile app • Adapted to peoples' impairments | <ul style="list-style-type: none"> • Holistic assessment top to toe approach • Personalised management plan • Advice, rehabilitation and support for physical, psychological, mental wellbeing, and vocational improvement or recovery • Nominated kaiārahi (guide) to support management plan • Adapted to peoples' impairments | <ul style="list-style-type: none"> • Referral for specific conditions as per health pathways • Post-COVID MDT will continue in parallel whilst specialist care undertaken • Co-ordination between specialities • Adapted to peoples' impairments |

| Recommendations | Grade |
|--|-------|
| Key elements for the care continuum include: <ul style="list-style-type: none"> the use of specific symptom screening and assessment tools to systematically identify post-COVID condition symptoms and functional impairments pathways to determine patients' rehabilitation trajectory and to guide their transition between care settings Customised and tailored, personalised management and education resources which are accessible for all people, communities, and providers Working with whānau and iwi to develop personalised management and education resources | B |

1.2 Supports

Individuals have unique personal needs and health status. An individualised, tailored approach for individuals and their whānau, to service delivery is essential as long COVID impacts individuals differently and the need for service delivery is paramount. These challenges will need to be addressed.

| Key recommendations for support for individuals, families, whānau and carers | Grade |
|---|-------|
| The values, knowledge, preferences and cultural perspectives of the whānau and family should be integrated, respected and evident in services and resources. | B |
| Individuals, whānau and family members need to know how to find and access information and support. Health providers, support groups, whānau and iwi work together to develop appropriate support services for individuals, whānau and families to ensure sources of support and information are available. | B |
| A key service to support whānau and families is the provision of information about long COVID. Information needs to be accessible to all people, including translated material, easy-to-read versions and developmentally appropriate information. Support groups and government should work in close association to ensure all information is kept up to date. | B |
| Individualised support should be available to people with long COVID, their whānau and family who require assistance to manage their physical and mental wellbeing and health care needs. | B |
| Medical and health care practitioners should take into account the symptomatology of their long COVID clients/patients and adapt their practices and procedures accordingly. | B |
| Vaccination discussions with whānau with respect to starting or continuing childhood immunisation programmes 3 months following COVID-19 | A |
| Methodologically rigorous research is needed to examine the effectiveness of current evaluation methods and treatments used to address long COVID | B |
| A coordinated approach to planning and implementing services should be developed to meet the identified needs of an individual/whānau with long COVID, including linkage or integration and coordination of multiple services. | C |
| The use of specific outcomes measures should align with the recommendations from post-COVID core outcome set Consider paediatric specific core outcome if available set | C |

1.3 Māori population and communities

This section identifies limited research is available around the specific impacts of the COVID-19 pandemic in relation to outcomes for our New Zealand Māori population, 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. Initial thoughts considered Māori to be at increased risk of mortality from COVID-19, yet research found some Māori fared better from engaging more within their strong social connections and adapting their own cultural believes as means of protection (Sacha & Savage, 2020; Pihama, & Lipsham, 2020).

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

Modelling and data from COVID-19 hospitalisations suggests Māori are at higher risk of hospitalisation with adverse effects of COVID-19. This indicates they may also be at higher risk of developing long COVID symptoms. The Māori populations and communities have protected themselves from this risk by adapting language, mobilising Hapu and Iwi, changing traditional greeting of Hongi to “Kahungunu Wave” (Ngāti Kahungunu Iwi Inc, 2020), Tikanga has remained cohesive. Studies found during the initial pandemic outbreak regular whānau and family connection via virtual means, 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 during disjointed times (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.

| Key recommendations for service provision to Māori Whānau | Grade |
|---|-------|
| Support and funding for the community development of information packages in Te Reo Māori about long COVID using a range of media | B |
| Establishing a kaimanaaki who could work as a resource across sectors, to support individuals and whānau experiencing long COVID. A national network for the professional support for the kaimanaaki may be useful to encourage | B |
| Support for Māori led research and long COVID is put in place and institutionally developed. | B |
| Support a development strategy to facilitate increasing the capacity and capability of the Māori health workforce and disability workforce where there is ongoing collaboration and access to specialist training | B |
| Support for Rongoa and traditional Māori healthcare | C |

1.4 Pacific people populations and communities

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

| Key recommendations for Pacific Peoples and fanau | Grade |
|--|-------|
| Long COVID information packages in the widely spoken Pacific languages (Tongan, Samoan, Cook Island Māori, Niuean, Fijian, Tokelauan, Kiribati) using a range of media should be developed. This information could be distributed through Pacific people, mainstream and community providers of health, employment, education and disability services. | C |
| Systems responsibility to support fanau-based models of care with Pacific Peoples providers and community organisations eg. Churches with expertise, resources and training | B |
| A programme of research that would provide baseline information regarding long COVID and Pacific people should be developed. | C |
| A targeted recruitment and development strategy to support increasing the capacity and capability of the Pacific people health workforce and disability workforce should be developed. | C |
| A whole of system response should be developed aimed at improving the cultural safety of the mainstream workforce 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 the issues of concern for disabled people. Disabled people are more likely to have health conditions associated with their impairment that increases the level of risk for them if they have long COVID. Evidence tells us that many disabled people experience inequitable access to health services and that access is compromised by services not being designed to be accessible and information and communications not being available in alternative formats. Data should be collected on the number of disabled people accessing services because of long COVID as a means of understanding that services are being accessed as well as the service experience and outcomes.

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

The Human Rights Commission's Inquiry into the *Support of Disabled People and Whānau During Omicron report* identified considerable difficulties for disabled people and their whānau in accessing support through mainstream general practice services

despite reliance on these for essential COVID-19 information. In addition, access to mental health supports has been limited, concerns have been raised about accessing essential hospital-based services, and messaging and approaches between DHBs/Te Whatu Ora Districts throughout the country has varied.

The inquiry report recommended government further consider how to ensure people experiencing long term health and disability impacts of COVID-19, including long COVID and adverse events from vaccinations are responded to and supported appropriately by the whole health and disability system. People with physical disabilities, commonly encounter daily challenges such as barriers to community mobility, reduced access to healthcare services and higher risk of experiencing issues with mental health and wellbeing.

| Key recommendations for disabled people and their family/whānau | Grade |
|--|--------------|
| Reduce barriers for disabled people to access community mobility and health care services | C |
| Apply an Enabling Good Lives approach (EGL); family support, living environment and context of their life to be taken into account | C |
| Assess impacts to carers as well as the disabled person. Parents and Caregivers operate in environments that create additional risks | C |
| Existing peer support groups can be accessed for all individuals requiring informal supports | C |

| Good Practice Point | Grade |
|--|--------------|
| Individualised supports offered to each person need to be customised/tailored for disabled people, e.g., experts in disabled rehabilitation are involved and accessible for long COVID management. | C |
| Disabled people are prioritised for assessment and treatment. | C |
| Accessible communication, information and treatment options are planned for and available e.g., digital modifications, ramps, transport, Speech Language therapy interpreters, Braille, easy read etc. | C |

1.6 Rural and remote locations

Rural individuals, families and whānau experience significant challenges and disadvantages in accessing resources and services (eg, transportation, lack of local support, isolation, financial resources, lack of employment opportunities) compared with urban dwellers.

| Key recommendations for rural communities | Grade |
|---|--------------|
| Reduce access barriers for rural communities by providing services through the services that are established in those communities | C |
| Utilise 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 people who must access urban services | C |

| Key recommendations for rural communities | Grade |
|--|-------|
| Measure the impact of rural dwelling on access to services and where access is identified as significant use rural communities and providers to find “rural proof” solutions | C |

| Good Practice Point | Grade |
|--|-------|
| Mobile clinics make services more accessible. | C |
| Telehealth programmes make services more accessible | C |
| Use of Marae and non-health community services as a resource | C |

1.7 Older People and aged residential care perspectives

This section identified the issues of concerns for older people, many who are living with existing co-morbidities. Remaining in good health, ageing well and being able and supported to live well with long-term conditions, however complex, is critical to enable older people to continue participating and feeling valued (two important factors for health and wellbeing). Services recognise that older people have different needs at different times.

| Recommendations | Grade |
|---|-------|
| Older adults were more likely to report problems with mobility, choking and malnutrition, and performing daily physical, cognitive and social activities and be impacted by reduced cognitive functioning. | B |
| Those with a higher BMI (Body Mass Index) showed significantly more symptoms such as dyspnoea at rest and on exertion, feelings of chronic fatigue, problems with mobility, and in performing daily activities. | B |
| Studies show that those with Long COVID should receive multidisciplinary help including additional medical and psychological support | B |

| Good Practice Point | Grade |
|---|-------|
| Older adults presenting with mobility issues and long COVID symptoms are to be referred for a mobility assessment. | C |
| Older adults presenting with communication issues and long COVID symptoms are to be referred for a speech-language therapy assessment. | C |
| Older adults presenting with nutritional and swallowing issues and long COVID symptoms are to be referred for a speech-language therapy and/or dietitian assessment. | C |
| Older adults with a higher BMI presenting with symptoms of long COVID are to be assessed and referred for support with breathlessness, fatigue, mobility assessment and in performing daily activities. | C |
| Older adults with presentations of multiple symptoms will benefit from multidisciplinary help including additional medical and psychological support. | C |

1.8 Medication Management

If an individual takes medicines regularly for long term conditions, formal review of medicine therapy should be undertaken to ensure optimal medicines management and reduce potential for adverse outcomes from over or under treatment. An agreed time for follow up review should be noted as changes in symptoms may further affect management.

2 Clinical case definition, diagnosis, red and yellow flags

2.1 Presenting Issue

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

2.2 Acute COVID-19

The Covid Clinical Care Module (CCCM) is available to GP's to support individuals with acute COVID-19. The health response needs to be relevant to our health system and meet the needs of Aotearoa New Zealand population, including our commitment to Te Tiriti o Waitangi, Whakamaui: Māori Health Action Plan, The Haumaru 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-19 Clinical Case definitions

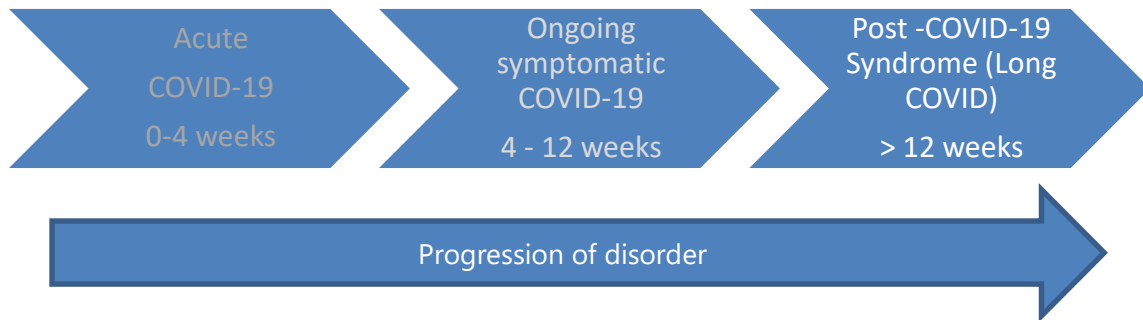
Long COVID-19 is also referred to in literature, as ongoing symptoms of COVID-19, post COVID-19 syndrome, post-COVID-19 conditions, post-acute sequelae of COVID-19, long-haul COVID, long-term effects of COVID, and chronic COVID. The term 'long COVID' is commonly used to describe signs and symptoms that 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, relapse and change over time and can affect any system in the body (NICE (National Institute for Health and Care Excellence), 2022).

- **Acute COVID-19** – Signs and symptoms of COVID-19 for up to 4 weeks
- **Ongoing symptomatic COVID-19** - Signs and symptoms of COVID-19 post the acute /infectious period of the illness from 4 weeks up to 12 weeks

- **Post-COVID-19 syndrome (long COVID)** - Signs and symptoms, consistent with COVID-19, that develop during or after an infection, continues 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 |
|--|-------|
| <p>GPs, primary care teams, all hospital and community-based clinicians, and private specialists to record details of COVID-19 in the affected patient's health record.</p> <ul style="list-style-type: none"> • Acute COVID-19, confirmed or probable • Ongoing symptomatic COVID-19 - Signs and symptoms of COVID-19 from four weeks up to 12 weeks • Post-COVID-19 syndrome (long COVID) - Signs and symptoms, consistent with COVID-19 that develop during or after an infection, continues for more than 12 weeks and are not explained by an alternative diagnosis | B |

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

2.4 Diagnosis, red and yellow flags

A Delphi¹ study was conducted in the UK (United Kingdom) with a panel of primary and secondary care medical practitioners. Recommendations were generated relating to the investigation and management of long COVID.

| Recommendations | Grade |
|---|-------|
| <p>All health clinicians should consider 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 in their differential diagnosis where appropriate</p> | B |
| <p>Indications for further investigation and specific therapies for:</p> <ul style="list-style-type: none"> • Myocarditis • Multi system Inflammatory Syndrome in children (MISC) or Paediatric Inflammatory Multisystem Syndrome temporally associated with Sars-Cov2 (PIMS - Ts). Further information can be found here | B |

¹ The Delphi technique is a well-established approach to answering a research question through the identification of a consensus view across subject experts.

| Recommendations | Grade |
|--|-------|
| <ul style="list-style-type: none"> • Postural Orthostatic Tachycardia Syndrome (PoTS) • Mast cell activation syndrome (blood disorder) • Hypoxia/desaturation • Chest pain • Palpitations • Histamine intolerance symptoms | |

| Good Practice Point | Grade |
|---|-------|
| <p>Consider the following red flags for patients presenting with ongoing symptoms from COVID-19, these should be managed when identified from clinical assessment:</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 • Postural Orthostatic Tachycardia Syndrome (PoTS) • Coagulation dysfunction • Functional Neurological disorder (FND) <p>Children and Young people</p> <ul style="list-style-type: none"> • Pulmonary embolism • Myocarditis • Cardiomyopathy • VTE • Renal failure • Type 1 Diabetes mellitus • Paediatric Inflammatory Multisystem Syndrome temporally associated with Sars-Cov2 (PIMS-Ts) • Multisystem Inflammatory Syndrome in Children (MIS-C) • Functional Neurological disorder (FND) • Paediatric Acute-onset Neuropsychiatric Syndrome (PANs) | 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 poor outcome <p>Children and Young People</p> <ul style="list-style-type: none"> • Absenteeism from school / education | |
|---|--|

Long COVID is a multifaceted condition, and its' resulting impact may include debilitating sequelae, impairments that impact on quality of life, capacity to return to work, and social and holistic effects on people. An impairment can be intellectual, psychiatric, physical, neurological, or sensory, and can be temporary, intermittent, or ongoing. Impairments are often considered to be disabilities.

Under the Social model, there is a distinction between the two concepts. 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.

Affected individuals and whānau often have complex care needs requiring holistic and multidisciplinary needs approach. Persistent symptoms have been reported in patients with both mild and acute COVID-19, therefore studies have been appraised which include non-hospitalised as well as hospitalised patients.

| Recommendations | Grade |
|---|-------|
| <p>Long COVID appears to be more common among people who have severe COVID-19 symptoms during acute illness, 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. The expected time to recovery from symptoms of COVID-19 are:</p> <ul style="list-style-type: none"> • Four weeks for muscle aches, chest pain, and sputum production. • Six weeks for cough and breathlessness to be significantly improved, if not fully resolved. • Three months for most other symptoms with residual fatigue. • Six months for all symptoms unless the patient had a complicated/prolonged admission to intensive care. | B |
| <p>There are many similarities between post-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.</p> | C |
| <p>Presentations in the post-acute COVID-19 scenario are likely to be for:</p> <ul style="list-style-type: none"> • nonspecific post viral symptoms, particularly fatigue, breathlessness chest pain and palpitations. • specific serious sequelae resulting from the acute infection, or 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 after infection on long COVID

It is widely recommended that after a COVID-19 infection, people should start or continue their vaccination schedule after three months from diagnosis with the acute illness, to allow for some time for recovery.

In studies reporting on symptom changes following vaccination of people with long COVID, there was a higher proportion of people with long COVID who reported unchanged symptoms following vaccination than people whose symptoms improved or worsened.

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

| Recommendations | Grade |
|--|-------|
| Vaccination should start or continue after three months following COVID-19 | B |

| Practice Point | Grade |
|---|-------|
| Clinicians should work with whānau to start or continue vaccination three months from diagnosis with the acute illness | C |
| 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 | |

2.6 Pharmacology

Clinical trials are currently underway with a range of therapeutics and future updates will provide further information.

| Recommendations | Grade |
|--|-------|
| Medications for long COVID are not yet validated | B |

| Practice Point | Grade |
|--|-------|
| Medications for specific symptom management may be of benefit for example 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 to the longer-term rehabilitation of people recovering from COVID 19. 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 while providing specialist care to New Zealanders.

Transdisciplinary team members value the specific knowledge and core skills of other team members whilst acknowledging the skills they share. These shared skills allow team members to collaborate across professionals’ boundaries. Transdisciplinary team working requires mutual understanding, trust and respect of all professionals to enable the team to function efficiently, enabling whānau-centred care.

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

| Professionals | 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, 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. |

| Professionals | Unique skills for rehabilitation of people with long COVID |
|---------------------------|--|
| Social worker | Social workers assess and evaluate individual and whānau situations and needs, incorporating analysis of structural, cultural, social and economic issues to explore and identify 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, trauma and other major events and challenges. |
| 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 Symptoms can be generalised to the following body systems, however long COVID impacts the body and mind as a whole and these need to be treated holistically and in person/whānau centred ways.

Long term consequences of COVID-19 infection can strongly decrease quality of life and may cause emotional distress and have psychological implications.

- Respiratory
- Cardiovascular
- Musculoskeletal
- Neurological
- Gastrointestinal
- Endocrine
- Psychological and socio-emotional functioning

3.2 Symptomology and management

Long COVID usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. The exact symptomology of long COVID is unknown, with one systematic review identifying 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, not returning to usual level of exercise
- Post exercise malaise (PEM) - When symptoms can get worse, or individuals get very tired even after a small amount of activity
- Post exertional symptom exacerbation (PESE) - Tiredness that can last for more than 24 hours after physical or mental effort
- Post intensive care syndrome
- Orthostatic Intolerance, Dysautonomia and Postural orthostatic tachycardia syndrome (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

Key recommendations for symptom management

Rehabilitation should be tailored/appropriate for individuals and their whānau, with careful activity pacing, to avoid relapse, and with transdisciplinary support. A

3.2.1 Issues with Mental Health and wellbeing:

B

For individuals who are experiencing anxiety, or depression, by not acknowledging the condition can exacerbate the high level of distress some individuals are already experiencing. Anxious feelings, and stress are normal, reassurance of these normal emotions is important. Options for support include GP team and supportive friends.

Resources for patients can be found [here](#) and [here](#)

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

Individuals are likely to need support with BOTH the process (expectations, adjustment, navigating services) and the outcomes (managing symptoms of distress).

Individuals 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 help manage their symptoms.

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

'The process' may not be the same for all individuals. Particular consideration needs to be given to support Māori individuals and whānau, as well as disabled people.

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

Key recommendations for symptom management

Given the high number of individuals experiencing symptoms of trauma/PTSD, suicidal ideation, and cognitive difficulties, many may need to be supported to access more intensive (neurological) psychological interventions.

3.2.2 Fatigue:

Customised information and resources about fatigue management and **pacing activities** such as the use of the 'energy envelope' should be made available for individuals and their whānau. These strategies need to be tailored for the lifestyle, culture, environment, and social demands in the person's life and that of their whānau

Clinician resource can be found [here](#)

Referral to an occupational therapist for assessment and treatment may be of benefit for individuals who require additional support for management of this symptom. 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 private organisation directly. Link to find an Occupational Therapist [here](#)

Customised supports to meet needs of disabled people or those with existing health conditions to manage additional impacts on their health and wellbeing.

Equipment or adaptive aids can assist individuals who need these for rehabilitation or due to fatigue.

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

Individuals presenting with **breathing pattern disorder**, cough, reduced exercise tolerance that isn't improving or symptoms getting worse 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 with skills in managing breathing pattern disorder for assessment and treatment. Referrals can be made through to local Te Whatu Ora districts via local pathways or by contacting a physiotherapist or speech-language therapist directly. Link to find a physiotherapist [here](#). Link to find a speech-language therapist [here](#)

Reduced exercise tolerance, caused by altered ventilation and circulation and not deconditioning

Individuals who experience a worsening of symptoms following exercise should seek advice from their family doctor or a physiotherapist. Clinicians are to prescribe graded exercise therapy after a thorough assessment of the absence of PEM/PESE. It is essential to assess for the following:

- Cardiac symptoms; breathless on exertion, tachycardia, chest pain
- Post exertional symptom exacerbation DePaul Post-Exertional Malaise Questionnaire (DSQ-PEM link [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, feeling faint can contribute to exercise intolerance.
- Screen for orthostatic intolerance or PoTs – using NASA lean test or active stand. It is difficult to distinguish from cardiac conditions and therefore requires medical examination

Cough

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

Information for individuals and whānau can be found [here](#) and [here](#)

Key recommendations for symptom management

For clinicians the Leicester cough questionnaire can be found [here](#)

3.2.4 Thought processing, memory and 'brain fog'

Individuals presenting symptoms such as sustained and ongoing brain fog, headaches, memory impairment, or other new cognitive difficulties that are severely impacting on 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

Resource for clinicians can be found [here](#)

3.2.5 Sleep Issues:

The quality and quantity of sleep of people with long COVID may benefit from advice from health care professionals or traditional/cultural health practitioners who specialise in sleep problems as these can be addressed therapeutically. B/C

Rehabilitation specialists such as Occupational therapist, 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

Resources for patients including children and young people can be found below:

Resources from **Sleep Foundation**

Resource on sleep for children and teenagers can be found [here](#) and [here](#) and [here](#)

Information on how much sleep do children need can be found [here](#) and [here](#)

3.2.6 Post Exertional Malaise / Post Exertional Symptom Exacerbation

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

Individuals who experience a worsening of symptoms following exercise should seek advice from their family doctor a physiotherapist or Occupational therapist.

Information for Post exercise malaise (PEM), or post exertional symptom exacerbation (PESE) which is different from fatigue, information can be found [here](#).

Referral to physiotherapists or occupational therapists may be of benefit for individuals 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 contact with private organisations directly. Link to find an Occupational Therapist [here](#). Link to find a Physiotherapist [here](#)

Information for clinicians can be found [here](#)

Equipment or adaptive aids can assist individuals who need these 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 and suggest using if the individual has an understanding/interest. The energy envelope theory is an alternative which can be used.

$(220 - \text{individual age}) \times 0.55 = \text{anaerobic threshold in beats per minute}$ – Stay below this heart rate

Or resting heart rate plus 15 beats per minute (more conservative)

Helpful poster can be found [here](#)

Resources specific to children can be found [here](#) (pacing penguins) and [here](#) (cautious tortoise)

Resources to share with teachers can be found [here](#)

3.2.7 Dysautonomia Orthostatic intolerance and PoTS

Symptoms which occur on sitting or standing can include feeling dizzy, faint, lightheaded, or nauseated B

Key recommendations for symptom management

Treatment

- Fluid intake
- Salt intake
- Contract relax muscle exercises
- Medical grade compression garments

Further information for clinicians can be found [here](#)

Resources for patients can be found [here](#)

3.2.8 Communication, voice or swallowing issues:

If a person takes medicines and swallowing affects ability to safely take medicines, a review should be undertaken and changes to medicine forms made as required. A review could be undertaken by a pharmacist and may require changes to medicine regimen by a prescriber. B

Individuals with increasing communication, voice or swallowing difficulties should be immediately referred 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 Therapists [here](#)

Resource from the New Zealand Speech Language therapists' association can be found [here](#)

3.2.9 Headache

Headaches are common during viral infections and usually disappear within a few weeks, however, some people continue to experience headaches many weeks or months after a COVID infection. The presence of a headache does not mean that the virus is still present. Many factors other than a viral infection such as diet, fatigue, lack of sleep and stress can contribute to headaches. Long COVID headaches may be more frequently experienced by those who have a history of migraines or headaches. Try some of the tips listed below to help manage headaches: B

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 individuals 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 healthcare provider if experiencing worsening headaches or dizziness.

3.2.10 Taste or smell issues:

For individuals with loss of taste and smell, provide reassurance that this is not an unusual post 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 two weeks but can sometimes take longer. Some people who lose their sense of smell can also lose their sense of taste. B

For individuals with loss of taste and smell who are at risk of malnutrition should be referred to a dietitian for assessment, treatment and prevention of malnutrition.

Referrals can be made through to Te Whatu Ora districts via local pathways or by contacting a dietitian directly [here](#)

Further information for patients can be found [here](#)

Key recommendations for symptom management

If there is a difference in an individual's weight and they are finding it hard to maintain weight, patients can follow the **healthy eating basics**. If weight loss continues, individuals should be referred to a dietitian for assessment, treatment, and prevention of malnutrition. Referrals can be made through Te Whatu Ora districts via local pathways or by contacting a dietitian directly [here](#)

For Smell re-training techniques for patients can be found [here](#)

3.2.11 Gastrointestinal changes

Individuals presenting with persistent gastrointestinal symptoms (nausea, bloating, pain, diarrhoea) should be referred 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](#)

3.2.12 Muscle/joint pain

For individuals with muscle and or joint pain, provide reassurance that this is not an unusual post-COVID-19 symptom. Encourage gentle, full range of movement exercises

Gentle exercise resources for patients can be found [here](#) and videos links below.

Exercise guidelines: it's important to keep moving and to keep moving with care

- Work at your own level: most videos 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 movements smaller, rest when you need.
- Make things harder: use your arms, lift your knees, do more repetitions, 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, please contact your doctor or the COVID Healthline 0800 358 5453 & for Emergencies 111.

| Time | Type of exercises | Link |
|--------|---|---|
| 18mins | Chair shaped: Seated & standing options for posture work | https://youtu.be/2r4cRTMYZUo |
| 12mins | Easy Sit & Fit 1: General fitness sit or stand | https://youtu.be/kko8fMZ212Y |
| 21mins | Easy Sit & Fit 2: General fitness sit or stand | https://youtu.be/qr_rDxkvLbo |
| 17mins | Crossing activities: 8mins seated, 8mins standing | https://youtu.be/gbb8Ldzsat4 |
| 20mins | Intro to strength & balance: warm up, 3 strength, 3 balance | https://youtu.be/xXrkmfyx4h0 |
| 35mins | Strong & Stable Class 2021, seated or standing | https://youtu.be/WlwHCbflaxY |
| 43mins | Strong & Stable Class 2020, seated or standing | https://youtu.be/wmWsa_TWVsU |
| 49mins | Strong & Stable Class 2021 #2, seated or standing | https://youtu.be/zWyeo6b_4qg |

Key recommendations for symptom management

| | | |
|--------|---|---|
| 60mins | Chair yoga including strength & balance, gentle | https://youtu.be/r3-S4lBuQ1A |
|--------|---|---|

3.3 Living with long COVID

Good Practice Point

Grade

It is essential that a coordinated approach to planning and implementing services is person and whānau-centred. Cultural and community providers who may be supporting the whānau already are key partners in integrating care of multiple services

C

A co-ordinated care or action plan for rehabilitation and management of long COVID should be developed with the individual and whānau by a member of the care team whom they trust and are able to have a long-term relationship with. Examples for patient use can be found [here](#)

C

3.4 Support and service needs

The complex range of emotional and practical difficulties that individuals with long COVID experience tend to change over time. Unmet needs can include:

- difficulties accessing health services due to issues such as cost, location i.e. rural location, culturally safe, lack of available services or accessibility 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
- difficulties finding and accessing services that are culturally safe or specialised for specific needs
- 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 access to transport with risk of discharge from out-patient services due to not attending
- disruptions in family routines and lifestyle limitations, including reduced access to opportunities for work, education, social interaction, recreation and leisure activities

| Good Practice Point | Grade |
|---|-------|
| Ensure options of treatment are available to access underserved communities | B |
| 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, Pacifica Peoples, rural and remote communities, disabled people, older people and those living in Aged residential care | B |

3.5 Children and Young People

Children, tamariki and whānau have specific needs due to the nature of the whānau unit. Tamariki illness affects parents/caregivers and other siblings. There is the need to be able to offer support to the wider whānau.

The **Long COVID kids** resource is thorough and contains all of the symptoms. Kids Health is an Aotearoa New Zealand site which also has information on recovering from COVID including long COVID for individuals and whānau [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
- difficulty sleeping
- chest pain
- breathlessness
- fast-beating or pounding heart
- new or worsening urinary symptoms

| | |
|--|---|
| 0-3 age group symptoms | <ul style="list-style-type: none"> • mood swings • rashes • stomach aches • cough • loss of appetite |
| 4- 11 age group, the most common symptoms were: | <ul style="list-style-type: none"> • mood swings • trouble remembering or concentrating • rashes |
| 12-14 age group, the most common symptoms were: | <ul style="list-style-type: none"> • fatigue • mood swings • trouble remembering or concentrating |
| Teenagers 14-18 age group | <ul style="list-style-type: none"> • Postural Orthostatic tachycardia syndrome (PoTS) |

| Good Practice Point | Grade |
|--|--------------|
| Support Caregivers and monitor for caregiver fatigue | B |
| Plan the day and week to balance activity and rest and maintain energy envelope. | B |
| Clinicians to screen for cardiac symptoms prior to sport, risk of boom and bust behaviours, provide symptom guided/ paced return to sport | B |
| Consider targeted psychological supports particularly for those children who have experienced more boom bust, experience frustrations, and find it harder to pace | C |
| Maintain level of activity before progressing. See Pacing penguins and Cautious Tortoise from Long COVID kids | B |
| Education needs to be able to be delivered in flexible formats. Home based/ online/ hybrid and paced to progress to classroom attendance. Support from school SENCO, Northern Health Schools to formulate a plan with the whānau and tamariki /rangatahi that is individualised and symptom lead. The child can progress to education or other activities when they are able to participate in home activities. Be mindful of the social, emotional, and sensory overload of school classroom/ school attendance and factor into energy conservation/ energy envelope. Also be mindful of the effect of decreased school attendance on working parents/caregivers around ability to maintain current employment. | B |
| For rangatahi support from SENCO/ Northern Health Schools around flexibility with NCEA credits | B |
| Schools need well ventilated classrooms and children may not tolerate mask use. Communication with the Ministry Of Education, Teachers, Board of Trustees re: continuous Carbon dioxide (Co ²) monitoring and appropriate ventilation based on this | B |
| For tamariki already known to an allied health profession should ensure adequate access to re-assessment and where required revised educational therapeutic programmes are undertaken to account for each any long COVID symptoms, school absences and their impact on health and development in this population | C |

3.6 Summary of symptoms and management resources for individuals and whānau

This table provides a summary of common symptoms and resources to support individuals with long COVID, whānau and carers. Detailed information regarding these symptoms can be found in detail earlier in section 4.

| | |
|---|--|
| 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 management and pacing activities | <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/ 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 (PoTS) | <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> </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 |
| 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/qr_rDxkvLbo |
| 17mins | Crossing activities: 8mins seated, 8mins standing | https://youtu.be/gbb8Ldzsat4 |
| 20mins | Intro to strength & balance: warm up, 3 strength, 3 balance | https://youtu.be/xXrkmfyx4h0 |
| 35mins | Strong & Stable Class 2021, seated or standing | https://youtu.be/WlwHCbfLaxY |
| 43mins | Strong & Stable Class 2020, seated or standing | https://youtu.be/wmWsa_TWVsU |
| 49mins | Strong & Stable Class 2021 #2, seated or standing | https://youtu.be/zWyeo6b_4qg |
| 60mins | Chair yoga including strength & balance, gentle | https://youtu.be/r3-S4lBuQ1A |

Peer support Group links

- Balance Aotearoa provides peer support, advocacy, information and consultancy services for people affected by mental health & addiction distress <https://balance.org.nz/>
- <https://www.healthnavigator.org.nz/healthy-living/l/looking-after-yourself-with-long-term-conditions/>

Care plans and action plans

- Examples for patient use can be found [here](https://www.healthnavigator.org.nz/healthy-living/c/care-plans-and-action-plans/) <https://www.healthnavigator.org.nz/healthy-living/c/care-plans-and-action-plans/>

Children and young people

- The **Long COVID kids** resource is [here](https://www.longcovidkids.org/) <https://www.longcovidkids.org/>
- 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) <https://www.kidshealth.org.nz/recovering-covid-including-long-covid>

3.7 Summary of symptoms and management resources for clinicians

This table provides a summary of common symptoms and resources for clinicians supporting individuals with long COVID, whānau and carers found in detail earlier in section 4.

Vaccination

- 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

- The use of specific outcomes measures should align with the recommendations from post-COVID **core outcome set**
- Consider paediatric specific core outcome **set**

| | |
|---|--|
| Fatigue | <ul style="list-style-type: none"> • here The Why, When and How of Pacing Long Covid's Most Important Lesson 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 Post-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 • 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 / 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 • 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 |

| | |
|--|--|
| | <ul style="list-style-type: none"> 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 PoTS | <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"> The Long COVID kids resource is here https://www.longcovidkids.org/ 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 |

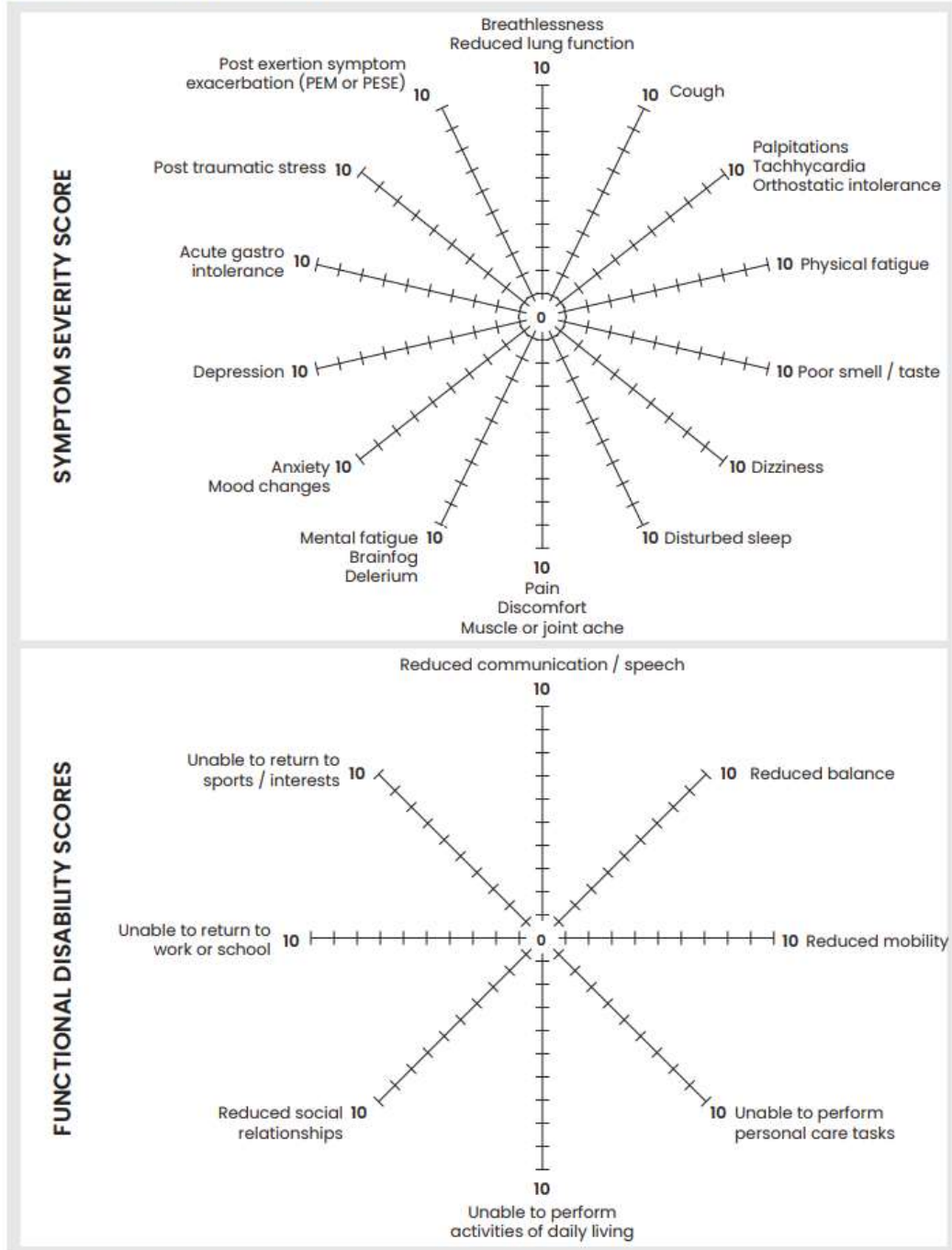
3.8 Long COVID symptom map

This clinical tool has been developed for use by clinicians with patients to track and monitor symptoms. This was developed by Fy Dunford, Physiotherapist and kindly shared from Te Whatu Ora Taranaki.

ATTACH PATIENT LABEL

Long Covid Symptom Map

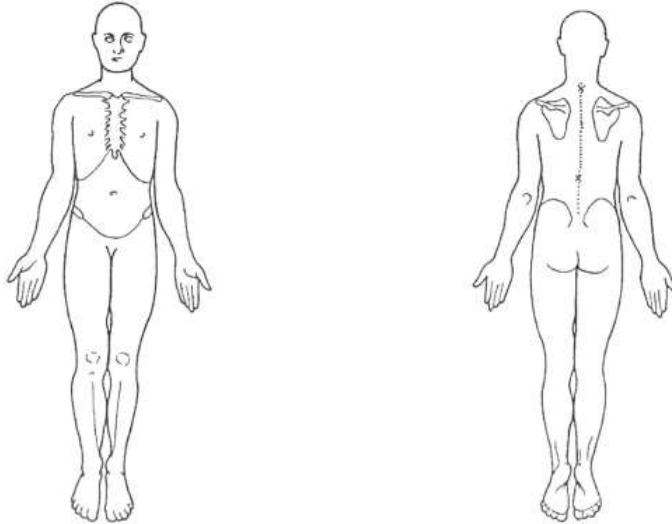
COVID-19 can cause many symptoms. Mark on the charts below to show us your symptoms today. Zero means nil or nothing and 10 is the highest level. It is ok to have help to complete this form from family/whānau or staff. If you do not have a symptom please leave the line blank.



ATTACH PATIENT LABEL

Long Covid Symptom Map

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

| | | |
|---|---|--------------------------|
| Long Covid Symptom Map DRAFT | | |
| Department: Allied Health | Responsibility: Fy Dunford Physiotherapist & Allied Health Prof Leads | Review By Date: 21/10/22 |
| 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 science and literature continues to evolve our understanding on long COVID conditions feedback is welcomed and updates to the information contained in the guideline.

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

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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5.17 Attention deficit

occupational therapist <https://www.rcot.co.uk/post-covid-syndrome-long-covid>

5.18 Taste or smell issues

here <https://www.yourcovidrecovery.nhs.uk/i-think-i-have-long-covid/effects-on-your-body/taste-and-smell/>

healthy eating basics. <https://www.healthnavigator.org.nz/healthy-living/h/healthy-eating-basics/>

here <https://abscent.org/learn-us/smell-training/how-smell-train>

5.19 Muscle/joint pain

Midland Community Pharmacy Group – Strong and stable

5.20 Living with Long COVID

here <https://www.healthnavigator.org.nz/healthy-living/c/care-plans-and-action-plans/>

5.21 Complementary medicines section

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5.22 Psychological wellbeing

Long COVID: Journeying Together through the Fog, Symposium slides Dr Paul Skirrow & Dr Lucy Morris "Thoughts that count." Psychological processes and outcomes in recovery from COVID-19 <https://az659834.vo.msecnd.net/eventsairaueprod/production-otago-public/bfb8d575b3b342c7b72be4c5fb221c0c>

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5.23 Children and Young People

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Postural orthostatic tachycardia syndrome (POTS)

<https://www.healthnavigator.org.nz/health-a-z/p/postural-orthostatic-tachycardia-syndrome-pots/>

Recovering From COVID - Including Long COVID <https://kidshealth.org.nz/recovering-covid-including-long-covid>

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