



Research Request – Central Sensitivity Syndromes and Functional Neurological Disorder

Brief	Information to assist Assessors from NAWM with their decisions for access requests relating to these specific conditions.
Date	Due 24 December 2019
Requester	s47F - personal privacy – Assistant Director TAT
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Please note:

The research and literature reviews collated by our TAT Research Team are not to be shared external to the Branch. These are for internal TAT use only and are intended to assist our advisors with their reasonable and necessary decision making.

Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters they are to call the TAPS line for advice.

There are already a significant number of resources, including commissioned expert reports and external specialist publications and clinical guidelines, which are available to NDIA staff to use in delegate decision making.

This paper aims to bring these resources together as a starting point and provide any additional information as required.

DRAFT

Scope of this document

The National Access and Workload Management Branch (NAWM) have requested assistance from TAT with assessing access for prospective participants with Chronic Regional Pain Syndrome, Functional Neurological Disorder aka Conversion Disorder, Chronic Fatigue Syndrome & Fibromyalgia.

- *Note: While the Disability Related Health Supports (DRHS) policy has not changed any of the established NDIS access criteria or legislation, the fact that 1) Participants can now receive DRHS through the NDIS and 2) A planner must now plan for the 'whole of person', means that the 'most appropriate funder/provider' proviso (under s34.1.f) no longer eliminates the typical types of supports that the NDIS could potentially fund for this cohort.*
- *This is causing an increase in access requests being made for these health conditions, based on their diagnosis and lived/reported significant functional impairment(s)*

The symptoms and experiences of people with these health conditions are individual and often complex, consequently it is often challenging for medical experts to determine a diagnoses.

Even once a diagnosis has been made, it remains difficult for NDIS access assessors to apply the Access - disability requirements criteria, particularly to determine permanency and the need for NDIS supports for life, compared to mainstream health treatment and supports.

Also, as the pathophysiology [*the disordered physiological processes associated with disease or injury*] of these conditions are still poorly understood, it is challenging for access assessors to determine whether these cohorts have exhausted all evidence-based, clinical, medical or other treatments.

- None of these conditions are included on the List A, B, C or D for common conditions that meet NDIS Access – disability requirements.
- While the outcomes of AAT hearings are not intended to set a precedent, the NDIA legal team's application of the access legislation against these health conditions in AAT cases is the only direction the NAWM have to guide their decision making.

Previous AAT Cases

The majority of these AAT cases were relating to access and were deemed 'access not met'. Generally, it was only in severe cases that access was met, where permanency and functional impairment were established through expert reports.

See APPENDIX A for full summary of AAT cases relating to these conditions to date.

Previous TAT advices

There are several previous TAT access advices relating to these health conditions. Most of these advices are from 2017 & 2018.

These TAT advices highlight that CRPS, CFS, FND, fibromyalgia, along with, Postural tachycardia syndrome (PoTS), depression, anxiety and other psychosocial disability, Lyme's disease & lupus often present as complex comorbidities.

See APPENDIX B for full summary of TAT advices relating to these conditions.

Chronic Fatigue Syndrome (CFS)

Expert report

In January 2018 the Technical Advisory Team commissioned a report on Chronic Fatigue Syndrome from an Australian expert in the field – Dr Andrew Lloyd, MD FRACP. The report was intended to assist with specific TAT AAT Chronic Fatigue access cases, but offers a holistic snapshot of the condition.

This report has all the information a NAWM team member would require to assess access and provides answers to the following questions:

Preamble

1. *What is the aetiology of this condition?*
2. *What is the impairment, if any?*
3. *What medical and allied health specialties are involved in: a) Diagnosis and b) Treatment of this condition?*
4. *What treatment options are clinically indicated for this condition? What are the indications and likelihood of success for each treatment? Please comment on details and dosage of any recommended treatments including frequency and duration as appropriate.*
5. *Is this condition results from an impairment, what is the likelihood that this impairment will be permanent?*
6. *Are individuals suffering this condition likely to require lifelong support? If so, what types of supports are likely to be required?*
7. *Would symptom management through interventions such as medication change, pain management, exercise programs etc. reduce the functional impact of the diagnosis and associated disability?*
8. *How prevalent is the incidence of Chronic Fatigue Syndrome being diagnosed as a stand-alone condition as opposed to being diagnosed as part of comorbidity?*
9. *Other comments:*

This full report is embedded in APPENDIX D for reference.

Information additional to the expert report are listed below.

Summary of CFS

CFS is often referred to as myalgic encephalomyelitis and sometimes it is abbreviated as ME/CFS.

In addition to fatigue for more than 6 months that is not relieved by sleep and interferes with activities of daily life, patients suffer other symptoms such as cognitive impairment, muscle and joint pains and sore throat.

Diagnostic criteria for chronic fatigue syndrome:

- Unexplained, persistent fatigue that is not due to ongoing exertion; is not substantially relieved by rest; is of new onset (not lifelong); and results in a significant reduction in previous levels of activity.
- Four or more of the following symptoms are present for 6 months or more:

- impaired memory or concentration
- postexertional malaise (extreme, prolonged exhaustion and sickness following physical or mental activity)
- unrefreshing sleep
- muscle pain
- multijoint pain without swelling or redness
- headaches of a new type or severity
- sore throat that is frequent or recurring
- tender cervical or axillary lymph nodes¹⁶

RACGP Clinical Guidelines - CFS

In 2002, a Chronic Fatigue Syndrome Working Group, which convened under the auspices of the Royal Australasian College of Physicians (RACGP) published a comprehensive article Clinical Practice Guidelines on CFS. The publication was sponsored by the Commonwealth Department of Health and Ageing and was published in the Medical Journal of Australia. The article is comprehensive (40 pages) and addresses the following topics:

- What is chronic fatigue syndrome?
- Evaluating people with fatigue
- Managing patients with CFS
- CFS in children and adolescents
- Social and legal issues

The NDIA acknowledges that there is conflicting evidence regarding the permanency and best management of ME/CFS.

Currently, the NDIA continue to use these [RACGP Chronic Fatigue Syndrome Clinical Practice guidelines on diagnosis and management](#), as these are the accepted national guidelines.

It is understood that these guidelines are in the process of being updated but until this occurs, the current guidelines continue to be the accepted document of reference for the NDIA. It should be noted that NDIA does not have input into the guidelines as they are related to health practice.

It is recommended that all TAT advisors refer to this document in full.

The RACGP clinical guidelines state that:

- *“Fatigue can be defined as a pervasive sense of tiredness or lack of energy that is not related exclusively to exertion. It is a common complaint in the community and is usually transitory. If fatigue is prolonged beyond six months, is disabling, and is accompanied by other characteristic constitutional and neuropsychiatric symptoms, then a diagnosis of chronic fatigue syndrome (CFS) should be considered”.*
- *“CFS” is a descriptive term used to define a recognisable pattern of symptoms that cannot be attributed to any alternative condition. The symptoms are currently believed to be the result of disturbed brain function, but the underlying pathophysiology is not known. Therefore, CFS*

¹⁶ Krejnkamp-Kaspers, S, et al., ‘Treating Chronic Fatigue Syndrome: A study into the scientific evidence for pharmacological treatments, Australian Family Physician, vol.40, no.11, November 2011, <https://www.racgp.org.au/download/documents/AFP/2011/November/201111kkaspers.pdf>, accessed 10 December 2019.

cannot be defined as a specific “disease” entity at present. Indeed, there is growing evidence that the disorder is heterogeneous, and it will probably prove to have no single or simple aetiology. It is important for practitioners to appreciate the distinction between disease, illness and disability. Diseases are defined and categorised according to our contemporary understanding of causal mechanisms and pathophysiology. As new knowledge emerges, disease definitions and terminology change. Illness, by contrast, is the subjective experience of suffering and, as such, can only be defined by reference to the sick person. Disability is the functional impairment — physical, psychological and social — caused by disease and illness. Even though an underlying disease process cannot presently be defined in patients with CFS, the suffering and disability caused by the illness can be very considerable — in many cases comparable to that seen in multiple sclerosis and rheumatoid arthritis. It is therefore important that doctors acknowledge the reality and seriousness of the suffering and disability experienced by people with CFS. Our goal as physicians is not only to identify and treat disease, but also to help relieve suffering and disability, whatever the cause”¹⁷.

Section 24 Disability Requirement Considerations

What are the common evidence based clinical, medical and other treatments for CFS?

- See 5.4 of the NDIS (Becoming a Participant) Rules 2013.

The RACGP clinical guidelines state that:

- “No single pharmacological treatment has been shown to be effective for people with CFS.
- Cognitive–behaviour therapy may be effective for some people with CFS.
- Physical and intellectual activities should be “paced” according to the individual’s functional capacity.
- Graded exercise may be effective for some people with CFS.
- Antidepressant drugs may provide symptomatic relief of pain, sleep disturbance, and depressed mood in people with CFS”¹⁸.

See page 38-42 of clinical guidelines for more information.

The clinical guidelines emphasise a multidisciplinary approach.

- “People who are persistently housebound with severe disability arising from CFS may require the assessment and advice of a team, including specialists in rehabilitation medicine, pain management, physiotherapy, occupational therapy, and social work”¹⁹.

A wide variety of pharmacological treatments are used for chronic fatigue syndrome, however the evidence for effectiveness is very limited. A 2011 study published In the Australian Family Physician

¹⁷ Chronic Fatigue Syndrome Clinical practice Guidelines, Royal Australasian College of Physicians, Medical Journal Australia, vol.176, May 2002, p.23, https://www.mja.com.au/system/files/issues/cfs2_2.pdf, accessed 6 December 2019.

¹⁸ Ibid. p.38.

¹⁹ Ibid, p.37.

recruited ninety-four CFS patients and investigated the immunological biomarkers they filled out in a questionnaire assessing the medicines they were taking. Additionally, evidence from randomised clinical trials was sought in biomedical databases. The results found that “the 94 CFS patients used 474 different medicines and supplements. The most commonly used medicines were antidepressants, analgesics, sedatives, and B vitamins”. The study identified 20 randomised controlled trials studying these medicines in CFS patients as of 2011²⁰.

A systematic overview was conducted in 2015 with the purpose of answering ‘What are the effects of selected treatments for chronic fatigue syndrome?’ The researchers searched Medline, Embase, The Cochrane Library, and other important databases up to November 2013²¹.

This overview examined information relating to the effectiveness and safety of four specific interventions: antidepressants, cognitive behavioural therapy, corticosteroids, and graded exercise therapy. The overview found that graded exercise therapy has been shown to effectively improve measures of fatigue and physical functioning and cognitive behavioural therapy is effective in treating CFS in adults. It also concluded that it is still unknown how effective antidepressants and corticosteroids are in treating CFS, but Tricyclics in particular have potential therapeutic value because of analgesic properties²².

For children the recommended treatments/interventions are cognitive behavioural therapy and graded exercise therapy²³.

When is CFS permanent or likely to be permanent for the disability requirements? Does this condition ever improve?

- **See S24.1(b) of the NDIS Act 2013 & 5.3 of the NDIS (Becoming a Participant) Rules 2013.**

Diagnosis is established through the exclusion of other diseases causing fatigue. . . Currently, no curative treatment exists for patients with chronic fatigue syndrome. The therapeutic approach to this syndrome requires a combination of different therapeutic modalities²⁴.

Regarding prognosis, the same publication states that:

- “There is an average time of 5 years from the beginning of the symptoms to the diagnosis of the syndrome, with total recovery rates between 0% and 37%, and improvement between 6% and 63%. Younger patients and those without concomitant psychiatric diseases show the best prognosis, although other studies have estimated that the rates for both groups are similar”²⁵.

Regarding prognosis and permanency, the overview from 2015 (mentioned above) provides the following statistics:

²⁰ Kreijkamp-Kaspers, loc cit.

²¹ Cleare, AJ, et al., ‘Chronic fatigue syndrome’, BMJ Clinical Evidence, September 2015, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4585442/>, accessed 10 December 2019.

²² Ibid.

²³ Brigden, A et al., ‘Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood’, May 2018, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5947766/>, accessed 12 December 2019.

²⁴ Fernandez, AA, et al., ‘Chronic fatigue syndrome: aetiology, diagnosis and treatment’, BMC Psychiatry, vol. 9, October 2009, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2766938/>, accessed 6 November 2019.

²⁵ Ibid.

“Studies have focused on people attending specialist clinics. A systematic review of studies of prognosis (search date 1996) found that children with CFS had better outcomes than adults: 54% to 94% of children showed definite improvement in symptoms (after up to 6 years' follow-up), whereas 20% to 50% of adults showed some improvement in the medium term (12–39 months) and only 6% returned to premorbid levels of functioning. Nevertheless, one prospective follow-up study suggests that, even after long illness periods, around 50% of patients can return to part- or full-time work. Despite the considerable burden of morbidity associated with CFS, we found no evidence of increased mortality. The systematic review found that a longer duration of illness, fatigue severity, comorbid depression and anxiety, and a physical attribution for CFS are factors associated with a poorer prognosis. Another review found a median full recovery rate of 5% (range 0–31%), and the median proportion of patients who improved during follow-up to be 39.5% (range 8–63%). Good outcome was associated with less fatigue severity at baseline, a sense of control over symptoms, and not attributing the illness to a physical cause”²⁶.

The available research on ME/CFS indicates that, due to the natural progression of the condition, some individuals may recover without intervention over weeks to months. It cannot be considered that every person diagnosed with ME/CFS will go on to have a permanent and lifelong impairment.

Regarding children, a UK based review from 2017 found that:

“Reported outcomes vary, but the prognosis in children and young people is more optimistic than in adults. Four small studies (n=15–31) from the 1990s report that between 50% and 94% of children make a good or complete recovery at 13–72 month. The largest trial to date demonstrated that most children with CFS/ME will recover within 6 to 12 months if they receive internet-delivered CBT as treatment. For those who do not receive specialist care, recovery is much slower with less than 10% recovering at 6 months”²⁷.

What type of medical treatment and review is required to determine permanency?

Relating to 5.6 of the NDIS (Becoming a Participant) Rules 2013.

The expert report from Dr Lloyd states that:

“Given that there is no evidence for any curative intervention (as above), the key issue regarding permanence of impairment due to chronic fatigue syndrome relates to the natural history of the condition. When followed prospectively from acute infections such as glandular fever, the great majority of individuals recover without intervention over weeks to months, but approximately 10% will meet diagnostic criteria for chronic fatigue syndrome at six months. When the chronic fatigue syndrome has been present in a stable, non-improving pattern, despite evidence-based management (as above) for 5 years, the Australian expert guidelines indicate that the condition should be regarded as permanent for medico-legal purposes. In this context, the only additional consideration relates to the severity of the impairment. As described above, chronic fatigue syndrome is an entirely subjective illness (that is there are no abnormal findings on history, examination or laboratory investigation), yet it is clear that the level of disability associated with chronic fatigue syndrome is

²⁶ Cleare, loc cit.

²⁷ A. Brigden et al., "Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood", *Arch Dis Child.*, Vol. 102, No 10, pp. 981-986, 2017, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5947766/>

commonly comparable to or greater than conditions such as rheumatoid arthritis. A small subset of all patients do suffer from both severely disabling and very prolonged (greater than 5 years) chronic fatigue syndrome – these patients may be housebound or even bed-bound as a result of the illness and despite best available evidence-based management” (see Appendix D).

What are the typical functional impairments associated with CFS?

The common functional impairments associated with CFS generally fall under the mobility, self-care, self-management and social interaction categories.

The expert report by Dr Lloyd highlights impairments to physical and cognitive functioning.

Is someone with CFS likely to require supports from the NDIS for their lifetime?

The key types of support the expert report highlight are assistance with daily living:

- “Patients typically require practical support to maintain independent living (assistance with shopping, cooking, cleaning) and travel (to/from medical appointments). This would rarely include the need for assistance with personal hygiene”.

Section 25 Early Intervention Considerations

How do early intervention access considerations apply to people with CFS?

Early intervention considerations do not apply to CFS. Any services that a person with CFS would receive before the condition is considered permanent would be considered time-limited health treatments.

Reference List

s22(1)(a)(ii) - irrelevant material

The Royal Australian College of Physicians, "Chronic fatigue syndrome: Clinical practice guidelines – 2002", MJA, Vol 176, 2002, https://www.mja.com.au/system/files/issues/cfs2_2.pdf

s22(1)(a)(ii) - irrelevant material

A. Brigden et al., "Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood", Arch Dis Child. , Vol. 102, No 10, pp. 981-986, 2017, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5947766/>

s22(1)(a)(ii) - irrelevant material

Appendix D - Report on Chronic Fatigue Syndrome

Double click on report front page to open the full PDF report.

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Report in response to a request for information and advice regarding chronic fatigue syndrome.

Preamble: The request (31.1.2018) sought information and advice regarding chronic fatigue syndrome, however it should be noted firstly that this diagnosis is syndromal - that is it is a syndrome recognized via a characteristic set of symptoms and careful exclusion of alternative medical and psychiatric explanations for those symptoms (individually or as a whole) via medical and psychiatric history, physical examination and laboratory investigation¹. This sort of assessment contrasts with diagnoses made on the basis of a test, such as pneumonia recognized by chest Xray. Secondly, as a consequence of this syndromal diagnosis the label of chronic fatigue syndrome is recognized to overlap with other syndromal diagnoses, such as fibromyalgia (in which pain rather than fatigue is the dominant feature).² In practice, this means that individual patients may be given both diagnoses in relation to the same set of symptoms. Thirdly, a diagnosis of chronic fatigue syndrome may be replaced in some circumstances with an alternative label (for the same condition) when the prolonged illness follows from a well-characterised initiating event. This includes post viral fatigue syndrome or post-infective fatigue syndrome when the triggering event was an acute infection (such as glandular fever)³. The label chronic fatigue syndrome is referred to in the UK as myalgic encephalomyelitis (ME). The symptom set and diagnostic approach for chronic fatigue syndrome is closely analogous to the diagnosis of post cancer fatigue, which is applied when survivors of cancer have completed surgery and adjunctive treatments such as chemotherapy and radiotherapy, are free of cancer recurrence, but have a disabling chronic fatigue state⁴. Finally, there are various diagnostic criteria that have been proposed for the chronic fatigue syndrome, placing emphasis on slightly different elements of the illness, but the most widely accepted and recommended criteria⁵, are those usually termed the 'international diagnostic criteria' which were formulated by an international expert group convened by the Centers for Disease Control in the USA⁴.

1. *What is the aetiology of this condition?*

Chronic fatigue syndrome is a condition characterised by prolonged (greater than 6 months), unexplained and disabling fatigue, which is accompanied by neurocognitive difficulties, like impairments in short-term memory and concentration, as well as the complaint of unrefreshing sleep. In addition, constitutional symptoms are typical including muscle pain (myalgia), joint pain (arthralgia), recurrent sore throat, headache, and tender lymph nodes in the neck (i.e. cervical lymph nodes)⁴. The fatigue state is characterised by a sustained worsening of symptoms after



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Long COVID-19

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Please note:

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Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters, they are to call the TAPS line for advice.

The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

Research question: Based on latest research, would long covid be considered permanent and what is the prognosis? What are the most effective treatments? What are the outcomes of these treatments? What are the more common longer lasting effects? What is the prevalence of long COVID-19?

Date: 15/07/22

Reviewed: 20/09/23

Requestor: s47F - personal privacy

Endorsed by (EL1 or above): s47F - personal privacy

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Next review date: 18/09/24

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2. Summary

Update (September, 2023): Heterogeneity of research data is still a significant barrier to determining the prevalence and incidence of long COVID, the persistence of disability associated with long COVID and any effective treatment and management techniques. Estimates of activity limitation for people with long COVID vary between 16% and 80%. Estimates of prevalence vary considerably, though studies coalesce around estimates in the range of either 10%-20% or 40%-55%. The evidence base for treatment and management techniques is growing with some evidence supporting physical therapy, multimodal and personalised approaches. No pharmacological or non-pharmacological technique has emerged as a preferred pathway.

Long COVID-19 is a collection of symptoms that persist after the initial acute phase of COVID-19 infection. While some consider 4 weeks the start of prolonged symptomology, 12 weeks is emerging as the point where long COVID-19 can be diagnosed. The prevalence of long COVID-19 is difficult to determine due to heterogeneity in the research data, however it is suggested to effect between 10-20% of people who survive a COVID-19 infection.

Management of long COVID-19 will likely follow the management protocols for other post-viral syndromes, such as myalgic encephalitis/chronic fatigue syndrome, or critical illness recovery paths, for example post-intensive care syndrome.

Permanence of long COVID-19 is difficult to determine at this point as the disease is in its infancy, however most people are expected to make a recovery over many months. Nonetheless, it is expected some people will continue to have physical and/or mental impairment that significantly impacts their functional capacity. As a consequence, the United States Department of Health and Human Services advises that long COVID-19 can be considered a disability after patients complete an individualised assessment that indicates they have severely impaired functional capacity.

3. Review, September 2023

3.1 Prolonged disability

Estimates of prevalence and incidence of long COVID, and estimates of the presence of impairment or activity limitation still vary widely. Centers for Disease Control and Prevention found approximately one quarter of adults with long COVID report significant activity limitations (Ford et al, 2023). Reviewing 35 studies, Oliveira-Almeida et al (2023) found activity limitations in between 16% and 80% of subjects.

The World Health Organisation still endorses a prevalence estimate of 10-20% (WHO, 2022). Woodrow et al (2023) reviewed 73 studies and found prevalence estimates between 0% and 93%. An international systematic review considered 194 studies including 735,006 participants and found 45% of COVID-19 survivors experience ongoing symptoms at 4 months (O'Mahoney et al, 2022). In a review involving 120,970 patients, Di Gennaro et al (2023) found an incidence of 56.9%. In contrast, 10 longitudinal studies from the UK found continuation of symptoms after 12 weeks in 8-17% of cases (Hallek et al, 2023). Hallek et al (2023) found 15% of unvaccinated adults infected with SARS-CoV-2 met criteria for post-COVID syndrome, with lower incidence among vaccinated COVID-19 survivors. Evidence from the US also supports the rate of around 15%. Between 14% and 16% of respondents to the Household Pulse Survey report experiencing long COVID (National Centre for Health Statistics, 2023).

Centers for Disease Control and Prevention found approximately 16% of adults with COVID-like symptoms reported ongoing symptoms after 12 months (Montoy et al, 2023). In contrast, Woodrow et al (2023) found prevalence estimate of 48.5% after 12 months. Woodrow et al conclude that the way in which long COVID is defined and measured affects prevalence estimates. Estimates are lower in studies using routine health records (13.6%) compared with self-report studies (43.9%). The highest estimates were found in studies systematically investigating pathology (51.7%).

3.2 Treatment and management

No pharmacological or non-pharmacological treatment or management strategy has emerged as the favoured method among researchers or clinicians (Chandon et al, 2023; Chee et al, 2023; Fawzy et al, 2023; Marshall-Andon et al, 2023; Hallek et al, 2023).

In their review of 37 practice guidelines, Marshall-Andon et al (2023) found some consensus around education, shared decision making and personalised care for patients with long COVID, including tailoring the modality and setting of treatment or management to the patient's situation.

A recent review of 12 studies found physical therapy (especially, moderate exercise and interventions related to respiratory muscles) was associated with a significant improvement in fatigue, dyspnea and quality of life in patients with long COVID (Sánchez-García et al, 2023).

4. What is long COVID-19?

There is no internationally agreed definition of long COVID-19, however signs and symptoms beyond 4 weeks is considered ongoing COVID-19 (Molhave et al, 2022). The World Health Organisation (WHO) recognised the existence of continuing symptoms and effects of COVID-19 after the initial infection period in September 2020, stating long COVID-19 is:

an illness that occurs in people who have a probable or confirmed SARS-CoV-2 infection; usually within 3 months of onset of the infection, with symptoms and effects that last for at least 3 months. These symptoms and effects cannot be explained by an alternative diagnosis (WHO, 2021a).

In the United States, Centers for Disease Control and Prevention (CDC) advise that post-COVID-19 conditions can be identified at least 4 weeks after the initial COVID-19 diagnosis (CDC, 2022). In the United Kingdom, the National Institute for Health Care and Excellence (NICE) proposes that 'acute COVID-19' is the period up to 4 weeks post infection diagnosis, 'COVID in progress' is the experience of signs and symptoms between 4-12 weeks post infection diagnosis, and post-COVID-19 syndrome are signs and symptoms that continue for more than 12 weeks after the initial infection and are not attributable to another diagnosis (NICE, 2022). A formal definition of long COVID-19 by the Australian Health Department could not be found.

The CDC suggests long COVID-19 is more common for people who had severe symptoms of COVID-19 during their initial infection (CDC, 2022), however the WHO advise there is no clear evidence of a relationship between initial severity of COVID-19 infection and the likelihood of developing long COVID-19 (WHO, 2021b). What is known, is people can suffer long COVID-19 regardless of whether they had mild or severe symptoms with the initial COVID-19 infection (Berger et al, 2021).

While research is continuing to try to identify those most at risk of long COVID-19, some risk factors may include (Berger et al, 2021; CDC, 2022):

- people who were in intensive care units during their initial COVID-19 infection
- people who have underlying health conditions prior to the infection including diabetes, heart failure, asthma, hypertension and epilepsy

- demographics with health inequities such as ethnic minority groups and people with disability
- people unvaccinated against COVID-19
- adults appear more vulnerable to long COVID-19 than children.

5. What is the prevalence of long COVID-19?

Despite the body of research emerging around long COVID-19, the prevalence is difficult to determine due to differences in study methodology, different outcome definitions and time frames, and different symptoms and levels of severity surveyed (Emecen et al, 2022). Additionally, prevalence is influenced by social determinants, such as poverty, racism and disability (Berger et al, 2021), therefore there is considerable inconsistency in the literature depending on participant demographics.

In one United Kingdom study, 18.2% of participants reported at least one symptom 6 months post initial COVID-19 infection (Emecen et al, 2022). This is in line with the WHO (2021b) estimate that around 10-20% of COVID-19 survivors experience mid- and long-term effects after the acute phase of illness has passed. However, a systematic review cited by Maglietta et al (2022), involving 57 studies and over 250,000 survivors of COVID-19, demonstrated more than half of these survivors experienced post-acute symptoms at 6 months post initial infection. I was unable to source clear data for the persistence of symptoms beyond this time point.

Further complicating prevalence data is the influence of different variants on recovery from COVID-19. Research from the United Kingdom comparing the Delta and Omicron variants suggests an increased risk of ongoing symptoms at 4 weeks post infection with Delta infection (10.8% participants) than an Omicron infection (4.5% participants) (Antonelli et al, 2022).

6. What are the most common symptoms of long COVID-19?

It has been noted that symptoms of long COVID-19 are similar to other post-viral fatigue syndromes such as myalgic encephalitis/chronic fatigue syndrome (Boaventrua et al, 2022; CDC, 2022), although the multisystem complications from long COVID-19 maybe broader and more intense than other post-viral syndromes (Boaventrua et al, 2022).

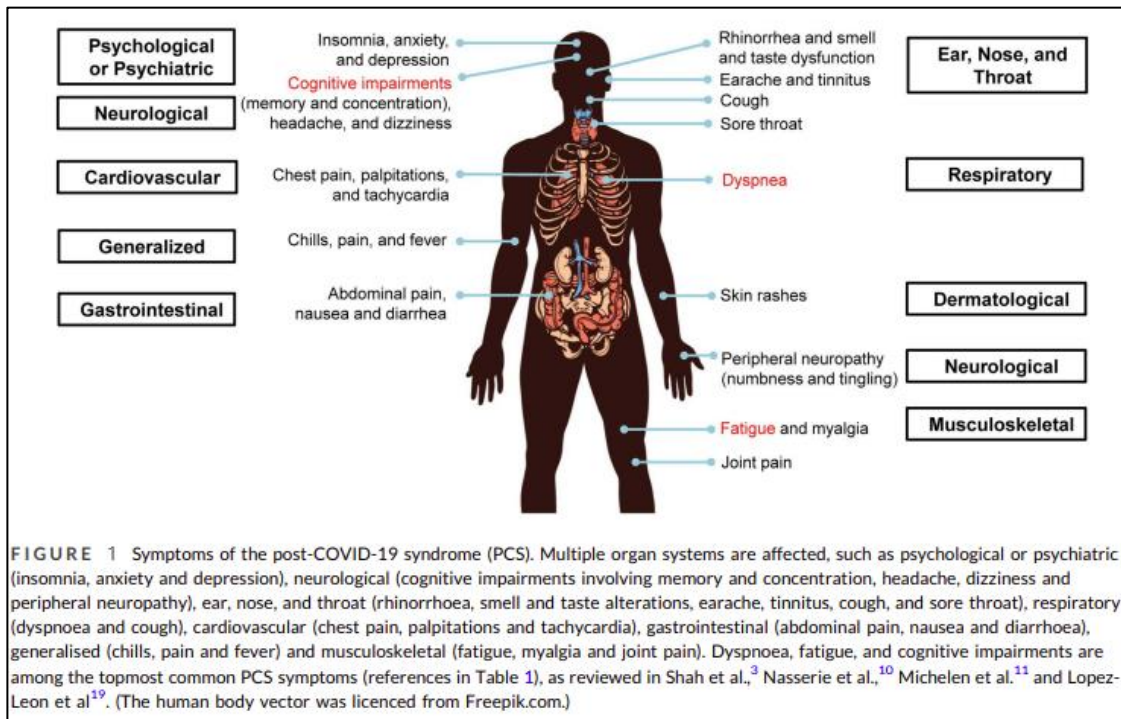
The most common symptoms of long COVID-19 reported in the literature include (Berger et al, 2021; CDC, 2022; Maglietta et al, 2022; Scordo et al, 2021; WHO, 2021b):

- Physical and mental fatigue that interferes with daily life
- Shortness of breath
- Memory and concentration problems ('brain fog')

- Headache
- Mental health impairment (e.g., anxiety, depression, mood swings)
- Abdominal pains
- Muscle weakness and joint pain
- Palpitations and chest pain
- Dizziness
- Gastrointestinal issues (e.g., diarrhea, stomach pain)
- Sleep problems
- Change in smell and/or taste
- Pins and needles feeling
- Skin lesions similar to chilblains

Long COVID-19 may affect people differently as different organ systems become involved, and an individual’s symptoms may fluctuate or relapse over time (Berger et al, 2021; WHO, 2021b).

Figure 1 below, an excerpt from research by Yong and Liu (2021), highlights the different organ systems that may be affected by long COVID-19:



7. What is the current management for long COVID-19?

There is no documented specific medication to treat long COVID-19 (Molhave et al, 2022) and much of the current literature describes medical management of long COVID-19. Effective management of long COVID-19 involves symptom relief and rehabilitation (Molhave et al, 2022; WHO, 2021b), and involvement of a multidisciplinary team for patients with multiple organ systems impacted may be required (Berger et al, 2021; Kokhan et al, 2022; Molhave et al, 2022; Scordo et al, 2021; Sundar Srethstha & Love, 2021).

Particular rehabilitation programs mentioned in the literature include physical rehabilitation to improve respiratory and cardiovascular function, which is best performed within 2 months of initial diagnosis of COVID-19 (Kokhan et al, 2022; Molhave et al, 2022). Also, cognitive therapy has been shown to be effective for patients with mental fatigue (Molhave et al, 2022).

As the existence of long COVID-19 is in its infancy, there is speculation, for example by Dr Anthony Fauci of the National Institute of Allergy and Infectious Diseases, that long COVID-19 may have a similar aetiology to other post-infectious conditions such as myalgic encephalomyelitis/chronic fatigue syndrome (Scordo et al, 2021; Sundar Shrestha & Love, 2021). Therefore, exploring the aetiology and management of myalgic encephalomyelitis/chronic fatigue syndrome may give some insight into long COVID-19 syndrome (Scordo et al, 2021). Current literature indicates cognitive behaviour therapy and graded exercise therapy are important in the management of myalgic encephalitis/chronic fatigue syndrome (Sharpe et al, 2021; Snook & Slowman, 2019). Cognitive behaviour therapy focusses on challenging fatigue related cognitions and planning social and occupational rehabilitation, while graded exercise therapy involves determining baseline ability and slowly increasing intensity and duration without exacerbating symptoms (Sharpe et al, 2021; Snook & Slowman, 2019).

Another significant medical condition that may be relevant to the understanding and management of long COVID-19 is post-intensive care syndrome (PICS) - the presence of health problems common to patients who have recovered from critical illness in intensive care units (Parker et al, 2021). Similar to long COVID-19, cognitive impairment ('brain fog'), extreme fatigue, muscle weakness, and shortness of breath are among the most common symptoms of PICS (Parker et al, 2021). Parker et al (2021) suggests applying the PICS post-acute phase framework to long COVID-19 patients could involve:

- Occupational therapy – provide energy conservation and work simplification strategies; address impact of cognitive impairments on work performance; monitor for residual impairment in gross and fine motor function, sensory integration or pain related to positioning (such as prolonged proning in ICU); strengthening and fine motor training using writing aids or assistive technology.
- Physical therapy – ICU acquired weakness can persist for years after the acute illness has resolved, therefore physical therapy can be beneficial to improve strength and physical function.

- Speech therapy – intubation injuries can extend from the voice and airway to dysphagia; dysphagia can persist for months, but most patients will recover with support.
- Social workers – many patients report persistent symptoms that impact their ability to return to work. Social workers can connect patients with job resources, conduct screening for mental health impairments, and provide psychoeducation and referrals.
- Primary health care – primary health practitioners should provide aftercare and care coordination for long COVID-19 patients.

8. Permanence of long COVID-19

For most people, the natural history of long COVID-19 appears to be a gradual improvement of symptoms over many months (Berger et al, 2021; CDC, 2022; WHO, 2021b). However, the long-term prognosis for some people is unknown, as it is not known whether damaged organ systems will fully recover or if there will be lasting effects (Berger et al, 2021; Scordo et al, 2021). Unfortunately, it appears some people with long COVID-19 will continue to have long-term organ compromise, long-term complex immune and homeostatic dysfunction with disabling symptoms and impaired functional levels (Sundar Srethstha & Love, 2021).

In July 2021, long COVID-19 became a recognised disability under the Americans with Disabilities Act, Section 504 and Section 1557 (CDC, 2022; United States Department of Health and Human Services, 2021). In the United States, as long COVID-19 causes physical and/or mental impairment, it can be considered a disability if it substantially limits one or more major life activities such as caring for oneself, performing manual tasks, eating, walking or concentrating. Table 1 summarises further information from the [United States Department of Health and Human Services](#) (2021) regarding long COVID-19 as a disability.

However, whether long COVID-19 can be considered a permanent disability requires an individualised assessment to determine if the long COVID-19 symptoms and effects substantially impact the individual’s functional capacity (United States Department of Health and Human Services, 2021).

Table 1

Information regarding long COVID-19 as a disability (United States Department of Health and Human Services, 2021)

ADA, Section 504, and Section 1557 if it substantially limits one or more major life activities. These laws and their related rules define a person with a disability as an individual with a physical or mental impairment that substantially limits one or more of the major life activities of such individual (“actual disability”); a person with a record of such an impairment (“record of”); or a person who is regarded as having such an impairment (“regarded as”). A person

with long COVID has a disability if the person's condition or any of its symptoms is a "physical or mental" impairment that "substantially limits" one or more major life activities.

a. Long COVID is a physical or mental impairment.

A physical impairment includes any physiological disorder or condition affecting one or more body systems, including, among others, the neurological, respiratory, cardiovascular, and circulatory systems. A mental impairment includes any mental or psychological disorder, such as an emotional or mental illness.

Long COVID is a physiological condition affecting one or more body systems. For example, some people with long COVID experience:

- Lung damage
- Heart damage, including inflammation of the heart muscle
- Kidney damage
- Neurological damage
- Damage to the circulatory system resulting in poor blood flow
- Lingering emotional illness and other mental health conditions

Accordingly, long COVID is a physical or mental impairment under the ADA, Section 504, and Section 1557.

b. Long COVID can substantially limit one or more major life activities

"Major life activities" include a wide range of activities, such as caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, sitting, reaching, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, writing, communicating, interacting with others, and working. The term also includes the operation of a major bodily function, such as the functions of the immune system, cardiovascular system, neurological system, circulatory system, or the operation of an organ.

The term "substantially limits" is construed broadly under these laws and should not demand extensive analysis. The impairment does not need to prevent or significantly restrict an individual from performing a major life activity, and the limitations do not need to be severe, permanent, or long-term. Whether an individual with long COVID is substantially limited in a major bodily function or other major life activity is determined without the benefit of any medication, treatment, or other measures used by the individual to lessen or compensate for symptoms. Even if the impairment comes and goes, it is considered a disability if it would substantially limit a major life activity when the impairment is active.

Long COVID can substantially limit a major life activity. The situations in which an individual with long COVID might be substantially limited in a major life activity are diverse. Among possible examples, some include:

- A person with long COVID who has lung damage that causes shortness of breath, fatigue, and related effects is substantially limited in respiratory function, among other major life activities
- A person with long COVID who has symptoms of intestinal pain, vomiting, and nausea that have lingered for months is substantially limited in gastrointestinal function, among other major life activities
- A person with long COVID who experiences memory lapses and “brain fog” is substantially limited in brain function, concentrating, and/or thinking.

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10. Version control

Version	Amended by	Brief Description of Change	Status	Date
1.0	SJP131	Document creation	Cleared	15/07/22
2.0	AHR908	Review	Cleared	20/09/23