Report of the Health Committee

Petition of Associated Myalgic Encephalomyelitis Society Incorporated: Reclassification of ME/CFS to disability

August 2023

Contents

Dr Tracey McLellan
Chairperson

Petition of Associated Myalgic Encephalomyelitis Society Incorporated

Recommendation

The Health Committee has considered the petition of Associated Myalgic Encephalomyelitis Society Incorporated—Reclassification of ME/CFS to disability—and recommends that the House take note of its report.

Request to reclassify ME/CFS as a disability

The petition was presented to the House on 2 September 2022. It requests:

> That the House of Representatives urge the Government to reclassify Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) from chronic illness to disability.

In the petitioner's view, people with ME/CFS face barriers to receiving support under the chronic illness classification, resulting in poor quality of life and health inequity. It believes reclassification will lead to real improvements for those in need by providing access to much needed home help, housing and financial support, and counselling.

Comments from the petitioner

The Associated New Zealand Myalgic Encephalomyelitis Society Incorporated (ANZMES) is the national body for ME/CFS in New Zealand. Since 1980, it has provided information, built awareness, funded research, and advocated for people with ME/CFS. ANZMES is a founding member of the World ME Alliance and represents the ME/CFS voice globally. It also uses advocacy and leadership to act as a voice for people living with ME/CFS in New Zealand.

About Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

The petitioner described ME/CFS as a severely debilitating, chronic neurological condition, which is often triggered by a viral illness. It involves overwhelming fatigue and other symptoms that range in severity because it affects multiple body systems, including the immune, neuroendocrine, and autonomic nervous systems. Post-exertional malaise is the main characteristic of ME/CFS. It presents 12 to 48 hours after exertion, and can result in days to weeks of exacerbated symptoms. For people with very severe ME/CFS, the exertion can be from simply trying to eat or speak. At present, there is no diagnostic test, recommended medication, or cure.

According to the petitioner, the precise disease burden in New Zealand is unknown because prevalence is estimated based on overseas data. It is estimated that there are at least 25,000 sufferers in New Zealand. This number is expected to increase to about 45,000 people because some people with Long COVID will also fit the diagnostic criteria for ME/CFS as a post-viral symptom.

The petitioner explained that ME/CFS lacks a universally accepted case definition, and symptoms vary. However, the condition can be characterised by chronic fatigue that is not alleviated by rest.

Current classification of ME/CFS

The New Zealand Government definition of disability is as follows:

> A disability is an impairment—physical, intellectual or sensory—that lasts for more than 6 months and limits your ability to carry out day-to-day activities. This can include psychiatric illness.[1]

The petitioner submits that, although ME/CFS meets this definition, it is not recognised as a disability for the purposes of health-related funding and support. Instead, it is classified as a chronic illness.

The petitioner's concerns about the current classification

Inequitable access to support

The petitioner believes the current system creates inequitable access to government funding and support. It points to a complicated assessment process, service disparities across regions, and a lack of dedicated funding for ME/CFS.

In 2010, the Ministry of Health transferred funding for Long Term Support-Chronic Health Conditions to individual district health boards (DHBs). According to the petitioner, this led to inconsistencies between regions and inequitable access because each DHB managed funding differently. The petitioner said that many of the support systems provided have policies that "bounce people around" to services that do not actually provide them with support.

Lack of knowledge about the condition

The petitioner stated that Māori and Pasifika are under-diagnosed with ME/CFS and are disproportionately affected by negative COVID-19 outcomes. We asked whether this disparity is because health professionals do not understand ME/CFS or are not diagnosing it appropriately. We heard from Dr Sarah Dalziel, ANZMES medical advisor, who is a GP in Rotorua. She told us that a lot of GPs are not familiar with how to diagnose ME/CFS. Patients then have to seek diagnosis from a practitioner who knows about ME/CFS, which may involve a private consultation. Dr Dalziel considers that one of the problems for Māori and Pasifika is accessing health care where GPs have that knowledge.

We also heard from Professor Warren Tate, a researcher at the University of Otago. He told us that the Ministry of Health had declined funding several years ago for a research project he had proposed on long-term conditions. As part of the programme, Professor Tate had organised an oral history with a rūnanga (Māori council) in Otago to visit Māori communities to learn how they were dealing with the illness.

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[1] New Zealand Government. Disability Allowance (2021). Retrieved from https://www.govt.nz/browse/health/financial-help/disability-allowance/.

The President of ANZMES, Fiona Charlton, said it has found that knowledge and expertise of ME/CFS is limited in the GP population. It has therefore produced its own education programme for health professionals to educate them about ME/CFS and Long COVID. The Royal New Zealand College of General Practitioners has accredited the programme.

Lack of access to home help

The petitioner noted that ME/CFS is a fluctuating disease with cycles of remission and relapse of severe symptoms. It observed that the most defining feature of ME/CFS and Long COVID is post-exertional malaise, which exacerbates symptoms and necessitates long periods of rest. The petitioner said that this feature is often misunderstood and makes levels of disability difficult to assess without adequate knowledge and education about the condition.

The petitioner explained that post-exertional malaise means that people with ME/CFS have to choose between household tasks, such as taking a shower or doing laundry. The petitioner described the “constant battle” between doing a task and having the energy to function enough to carry out those tasks. In the petitioner’s view, ME/CFS is a disability because of this limited energy capacity. It added that ME/CFS is a condition that impairs the ability to function cognitively and physically on a regular basis. ME/CFS also frequently confines people to their home or bed, causing unemployment and an inability to perform basic tasks.

Needs Assessment Service Coordination (NASC) agencies assess whether a person is eligible for disability support services, including funded home help. The petitioner told us that NASC has confirmed that ME/CFS patients are not considered for assessment. We heard that people with ME/CFS are “theoretically” entitled to receive support under the Long Term Support-Chronic Health Conditions designation. However, the petitioner said that, in practice, the majority of people with ME/CFS do not fit the criteria for home help. Instead, the designation is targeted at those over the age of 65, with very high needs, or conditions like diabetes.

The petitioner maintains that the people with very high needs who meet the criteria receive insufficient care, leaving the care to fall to families. It provided an example of a 22-year-old woman with severe ME/CFS who is unable to speak, toilet, bathe, or feed herself. She is also bed-bound and unable to leave her darkened room due to extreme sensitivity to light and touch. Her mother, who was a nurse, has left her job to be her daughter’s full-time carer. The woman has been granted 22 hours of professional care but only 11 hours of this can be supplied because of staff shortages.

The petitioner observed that, of the estimated 25,000 people affected, the severity of their condition will be classed as mild to moderate, moderate to severe, and severe to very severe. It said that home help needs will vary across this spectrum. They range from several hours a week temporarily to ongoing daily support. In the petitioner’s view, people in the moderate to severe and severe to very severe categories should be eligible for a NASC assessment for support. This includes home help, meals, accommodation modification, and subsidised medication.

Effect of increasing prevalence of Long COVID

The petitioner said that the chronic illness classification of ME/CFS significantly affects the funding that people living with the condition can access. Consequently, support is primarily provided by non-profit organisations.

The petitioner explained that people who do not recover from Long COVID after six months may then be diagnosed with ME/CFS. It told us that the ME/CFS-related non-profit organisations have provided support to Long COVID clients as requested. The petitioner pointed out that, given the estimated prevalence of Long COVID, the burden on these organisations and the healthcare system will increase substantially. It considers that more government investment will be needed to accommodate the increase.

Financial effect of ME/CFS on patients and their families

In a survey conducted by ANZMES, only 8.5 percent of 585 respondents with diagnosed ME/CFS reported that they were able to work full time. We were told that families are also affected under the current classification. This is because family members often take on the role of carer because of what the petitioner described as the “unrealistic threshold” for funding eligibility. The petitioner noted that a 2017 study found that the estimated annual economic cost to each family with a ME/CFS sufferer was between $35,000 and $45,000.

Request to reclassify ME/CFS as a disability

The petitioner requests that ME/CFS be reclassified from chronic illness to a disability to enable ME/CFS patients to be supported under the existing framework for disability support services. It considers that classifying ME/CFS as a disability would demonstrate that the Government understands how disabling the condition is. Reclassification would also legitimise ME/CFS and provide the protection of rights as a disabled person. We heard that other potential benefits include enabling a person to fit the criteria for NASC assessment and home help. Access to these services may result in earlier intervention, which promotes recovery and improved outcomes, and may prevent further worsening of the condition. Access to home help may also allow a person with limited energy to take on a job working from home.

Request to improve services for people with ME/CFS

On 1 July 2022, Te Whatu Ora—Health New Zealand and Te Aka Whai Ora—the Māori Health Authority were established under the Pae Ora (Healthy Futures) Act 2022. The petitioner considers that the establishment provides an opportunity to create better pathways and funding to support people with ME/CFS. It submits that this could be achieved in the following ways:

- The petitioner understands that the Ministry of Social Development has a unique clinical code for ME/CFS but the healthcare system does not. It requests a unique code for ME/CFS to enable more accurate data to be recorded. This data could be used for funding purposes, to better understand the prevalence, and to monitor long-term health outcomes and equity of access.
- The petitioner would like a universal referral process with appropriate eligibility criteria to be developed. Te Whatu Ora and Te Aka Whai Ora would use this across all regions in New Zealand. The petitioner suggested that the FOCUS service used by the Wairarapa

DHB could be adopted as the nationwide model. This service offers a single point of entry for support referrals. Patients are paired with a community coordinator who assesses their needs and helps them access services.

- The petitioner noted that current eligibility for NASC is for people over the age of 65 or those who require everyday care. It requests that the criteria be modified to include ME/CFS, and to grant appropriate access to support for those people with the condition who require care three to four days a week.
- The petitioner would like a subsidy for medication that has been shown to be beneficial. This includes low dose Naltrexone (an unfunded prescription drug), B12 injections, electrolytes, antivirals, and antihistamines.
- The petitioner requests dedicated funding for ME/CFS. This would consist of funding for a government contract with ANZMES to enable it to provide support services, education programmes, and information. It would also include funding for multidisciplinary and mentorship pilot programmes.

Comments from Whaikaha

Whaikaha—the Ministry of Disabled People was established on 1 July 2022. It incorporates the Office for Disability Issues and the former Disability Directorate of the Ministry of Health. Funding and responsibility for providing and transforming disability support services for eligible disabled people and their families was also transferred from the ministry to Whaikaha.

Recognition of ME/CFS as a disability

Whaikaha noted that ME/CFS is recognised as a disability under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It describes persons with disabilities as including:

> those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The New Zealand Disability Strategy also uses the UNCRPD definition of disability.

Access to services and support for people with ME/CFS

Whaikaha acknowledged that people with ME/CFS or Long COVID fall within the broader UNCRPD definition of disability. However, they do not fit within the current eligibility criteria for assessment to access most Whaikaha-funded disability support services.

People with ME/CFS who have certain impairments are eligible to be assessed for a range of disability support services that Whaikaha funds. The impairments are co-existing intellectual, sensory, or physical disability, or autism, and must be likely to continue for at least six months. They must also limit a person’s ability to the extent that ongoing support is required. Available support includes home and community support services or care support.

Whaikaha pointed out that no one agency in New Zealand is responsible for funding and providing services and support for all disabled people. Rather, responsibility is shared across several government agencies. The agencies responsible for funding or providing services and support for disabled people include: Whaikaha; Te Whatu Ora (previously DHBs); Te Aka Whai Ora; the Accident Compensation Corporation; the Ministry of Education; and the Ministry of Social Development. Each agency applies its own eligibility criteria to identify people who may need additional government-funded services and support.

Whaikaha explained that Te Whatu Ora is the main agency responsible for funding or providing services and support for people with chronic health conditions. This includes ME/CFS and Long COVID. Primary healthcare agencies also work with people with chronic health conditions to help them manage the health and wellbeing aspects of their lives.

Whaikaha recognises that there are inequities in the cross-government support services for many disabled people and their families, particularly for those with neurodevelopmental and neurological impairments. We heard that no decisions have been taken on changes to eligibility criteria because Whaikaha is still in its establishment phase. It has therefore not decided whether to reclassify ME/CFS as disability. As it moves out of its establishment phase, Whaikaha expects to have more opportunity to focus on the wider stewardship role for disabled people.

We are interested in the benefit that reclassifying ME/CFS to a disability would provide to people with ME/CFS. We asked whether they would have access to more services through Whaikaha. We were told that Whaikaha and Te Whatu Ora provide very similar services. However, the criteria may be different between the two.

Comments from the Ministry of Health

Access to publicly-funded health services

The Ministry of Health—Manatū Hauora explained that everyone who meets the eligibility criteria under the Health and Disability Services Eligibility Direction 2011 is eligible to access publicly funded health services. It pointed out that each health service has different clinical criteria for access. This reflects that the health system needs to ensure that people with the greatest need are prioritised. However, the ministry noted that the health system does not require conditions to be classified as a disability to enable access to services.

We asked whether the ministry believes that having ME/CFS classified as a disability would validate people’s experiences and make them feel heard. We heard that the reclassification would give affirmation for people that they are living with a disability. The ministry also said that reclassification would acknowledge the UNCRPD definition of disability, which it described as a “social construct” way of defining disability. It added that classifying ME/CFS as a disability would enable people to access some NASC services.

Work to address the effect of Long COVID

The ministry told us that it has led work in anticipation of the effect of Long COVID on individuals. An expert advisory group has been convened, including individuals with lived experience. The ministry has worked with the advisory group to develop clinical guidance for managing ongoing symptoms after an acute infection. The guidance contains information for clinicians and people living with ongoing symptoms. The ministry has monitored emerging evidence to inform the development of the clinical guidance, and published periodic reviews of evidence.

The ministry has developed and implemented specific clinical coding for Long COVID. This will enable data to be captured for people presenting with Long COVID symptoms to their GPs and hospitals. The ministry was also frequently communicating about this work with the sector. In its written submission dated January 2023, the ministry said it was transferring this work to Te Whatu Ora for ongoing update.

Development of a Health of Disabled People Strategy

The Pae Ora Act 2022 requires the Minister of Health to develop a Health of Disabled People Strategy. The ministry is leading work on this strategy, and is engaging with a range of organisations across the disability sector. It said that the strategy will set out priorities for services and health sector improvements, and contain assessments of:

- the current state of health outcomes for disabled people
- the performance of the health sector in relation to disabled people
- the medium- and long-term trends that will affect the health of disabled people and health sector performance.

Comments from Te Whatu Ora

We received a written submission from Te Whatu Ora regarding the petitioner’s requests for a unique clinical code and a universal referral process for ME/CFS.

Unique clinical code for ME/CFS

In its written submission, the petitioner told us it understands that the healthcare system does not have a unique clinical code for ME/CFS. Te Whatu Ora explained that its National Collections and Reporting team collects, clinically codes, and ensures high-quality analysis of, national health data. It clinically codes data about diseases and other related health problems based on the International Statistical Classification of Diseases and Related Health Problems (ICD-10-AM). Te Whatu Ora uses the clinical code “G93.3” for Myalgic Encephalomyelitis and Chronic Fatigue Syndrome, in accordance with the international standard.

According to Te Whatu Ora, it should be possible to use this code to extract information from hospital settings related to a ME/CFS diagnosis. It said it would be happy to consider providing ANZMES with available data related to this code.

Universal referral process for ME/CFS

Te Whatu Ora observed that NASC agencies are funded to undertake assessments and allocate services primarily for people aged over 65 and those with a disability. Traditionally, they do not provide support to people who do not meet these criteria, such as people with a long-term condition. Te Whatu Ora told us that, as part of the health reforms, it will consider how it can work with regional NASC agencies to better support people with conditions outside aged care and disability. This includes people with long-term chronic conditions. The support may involve a case management function that helps people diagnosed with certain conditions to understand what support is available from the health system.

Our response to the petition

We commend the petitioner for highlighting this important matter. We thank ANZMES for its advocacy on behalf of people with ME/CFS and their families, and for its work to educate and inform others about the condition.

We note the petitioner’s request to reclassify ME/CFS from a chronic illness to a disability to enable ME/CFS patients to be supported under the existing framework for disability support services. We understand that ME/CFS meets the Government’s definition of a disability. The United Nations Convention on the Rights of Persons with Disabilities also recognises it as a disability. We acknowledge that the health system does not require conditions to be classified as a disability to enable access to services. However, we understand that the eligibility criteria differ between Whaikaha and Te Whatu Ora-funded services, resulting in inequitable access. We also acknowledge that recognising ME/CFS as a disability for the purposes of disability support services would legitimise the condition and provide for the protection of rights as a disabled person.

We note that Whaikaha has not yet made any decisions about eligibility criteria. We agree that having ME/CFS classified within Whaikaha’s definition of a disability would validate people’s experiences and make them feel heard. We therefore encourage Whaikaha to consider amending its eligibility criteria to enable people with ME/CFS to access Whaikaha-funded disability support services.

The petitioner requests that services be improved for people with ME/CFS and suggests a range of ways in which this could be achieved. We were pleased to hear that Te Whatu Ora already has a unique clinical code for ME/CFS and that it is working to improve support for people with long-term chronic conditions.

We acknowledge the petitioner’s request for certain medications to be subsidised, including an unfunded prescription drug. We respect PHARMAC’s independence and impartiality and do not believe it is Parliament’s role to influence which medicines should be funded. Although PHARMAC is ultimately accountable to the Minister of Health, making decisions independently from Government is important for the organisation to be able to function effectively.

Appendix

Committee procedure

The petition was referred to us on 25 October 2022. We met between 9 November 2022 and 16 August 2023 to consider it. We received written submissions from the petitioner, Whaikaha, the Ministry of Health, and Te Whatu Ora. We heard oral evidence from the petitioner, Whaikaha, and the Ministry of Health.

Committee members

Dr Tracey McLellan (Chairperson from 15 February 2023)
Tangi Utikere (Chairperson and member until 8 February 2023)
Matt Doocey
Dr Elizabeth Kerekere
Dr Anae Neru Leavasa
Marja Lubeck (from 8 February 2023)
Debbie Ngarewa-Packer
Sarah Pallett
Soraya Peke-Mason
Dr Shane Reti
Toni Severin
Lemauga Lydia Sosene (until 3 May 2023)

Evidence received

The documents we received as evidence in relation to this petition are available on the Parliament website.

Recording of our hearing

A recording of our hearing can be accessed online at the following link:

- Hearing of evidence with the petitioner, Whaikaha, and the Ministry of Health (3 May 2023).