Health and Disability Commissioner Review:

Advocating for better health services for people with ME/CFS

Addressed to: The Health and Disability Commissioner

Compiled by Aotearoa Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Collective:

- ANZMES (Associated New Zealand Myalgic Encephalomyelitis Society) – National Advisory on ME
- Complex Chronic Illness Support
- M.E. Awareness NZ
- MECFS Canterbury
- MEISS Otago and Southland
- ME Support NZ
- Rest Assured Charitable Trust

Report

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The Purpose

This report advocates for better health services for people with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS) under the Health and Disability Commissioner (HDC) review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights. It examines the collective violations of rights experienced by patients and their carers (as health consumers) within the Aotearoa New Zealand healthcare system. Specifically, focusing on the infringement of;

- **Right to services of appropriate standard (Right 4)**: ME/CFS patients frequently encounter healthcare providers who lack the necessary knowledge and expertise, leading to substandard care. There are no senior specialists in ME/CFS, which further contributes to the inadequate dissemination of up-to-date clinical guidance.
- **Right to be fully informed (Right 6)**: Patients are often not informed about the lack of evidence for certain treatments and their potential risks, preventing them from making truly informed decisions about their healthcare.

Furthermore, the lack of appropriate funding and support services for ME/CFS patients underscores the need for the HDC to have stronger enforcement powers. This includes holding medical education institutions accountable for the quality of their training and ensuring that health services provide necessary information and practical supports to patients.

By shedding light on these issues, the report aims to advocate for necessary changes to ensure that the healthcare needs of ME/CFS patients are adequately met and their rights are upheld.

Compliance with HDC Review Criteria

This report adheres to the review criteria outlined in the consultation document by addressing the following objectives:

- Ensuring services meet professional and legal standards, and are provided with reasonable care and skill (Right 4).
- Upholding the right to be fully informed about treatment options (Right 6)."

The report ensures coherence and adherence to the intended review framework and each recommendation is designed to enhance the protection and promotion of health consumers' rights.[1]

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[1] Act and Code review summary doc (hdc.org.nz)

Background

The Situation

The Health and Disability Commissioner (HDC) is reviewing the Health and Disability Commissioner Act 1994 (the Act) and the Code of Health and Disability Services Consumers' Rights (the Code). The Act and the Code aim to promote and protect the rights of health consumers and disability services consumers, ensuring the fair, simple, speedy, and efficient resolution of complaints relating to the infringement of these rights.

The Code of Health and Disability Services Consumers' Rights

The Code of Health and Disability Services Consumers' Rights in Aotearoa New Zealand outlines the rights of individuals using health and disability services and the corresponding duties of service providers. It became law on July 1, 1996, under the Health and Disability Commissioner Act 1994.[2] The Code grants various rights, including:

- ➢ **The Right to be Treated with Respect (Right 1)**: Ensuring that all health and disability services users are treated with respect.
- ➢ **The Right to Fair Treatment (Right 2)**: Providing fair and non-discriminatory treatment.
- ➢ **The Right to Dignity and Independence (Right 3)**: Supporting the dignity and independence of service users.
- ➢ **The Right to Services of an Appropriate Standard (Right 4)**: Ensuring services meet professional and legal standards, and are provided with reasonable care and skill.
- ➢ **The Right to Effective Communication (Right 5)**: Ensuring clear, understandable, and effective communication between providers and service users.
- ➢ **The Right to be Fully Informed (Right 6)**: Providing all necessary information for informed decision-making.
- ➢ **The Right to Make an Informed Choice and Give Informed Consent (Right 7)**: Ensuring service users can make informed choices and consent to treatment.
- ➢ **The Right to Support (Right 8)**: Allowing the presence of a support person, where appropriate.
- ➢ **Rights in Respect of Teaching or Research (Right 9)**: Protecting the rights of individuals involved in teaching or research.
- ➢ **The Right to Complain (Right 10)**: Ensuring complaints are taken seriously and addressed promptly.

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[2] The Code of Health and Disability Services Consumers Rights: https://www.hdc.org.nz/your-rights/the-code-and-your-rights/
Code of Health and Disability Services Consumers Rights: https://www.hdc.org.nz/.../code-of-health-and-disability.../

Obligations and Reviews:

Service providers must inform individuals of their rights and enable them to exercise these rights. They must take reasonable steps to give effect to these rights, and the burden of proof lies with the providers to show that they have taken reasonable actions.

The Code has undergone multiple reviews to ensure it remains relevant and effective, with the most recent review currently in progress.[3]

The Health and Disability Commissioner Act 1994

The Act establishes the role and powers of the Health and Disability Commissioner (HDC) to promote and protect the rights of health and disability service consumers, and to facilitate the resolution of complaints related to these rights. The HDC can investigate complaints, issue recommendations, and enforce compliance with the Code.[4]

What is Myalgic Encephalomyelitis (ME/CFS)

Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), is a complex, chronic illness which affects multiple body systems, including the neurological, immune, and endocrine systems. It manifests through a variety of symptoms such as profound exhaustion, cognitive dysfunction, muscles and joint pain, unrefreshing sleep, headaches, sensory issues, digestive issues and more. These symptoms are not alleviated by rest and are exacerbated by physical or mental activity. The hallmark symptom and cardinal feature of ME is 'post-exertional malaise' (PEM), which is a delayed (24-48 hrs) significant reduction in functioning and extreme worsening of all symptoms for days, weeks, months or even years after minimal physical or cognitive activity.

Prevalence in Aotearoa New Zealand is estimated due to insufficient coding and tracking in the health system. Prorated overseas data (pre-pandemic) suggests that there were at least 25,000 people living with ME/CFS, that's 1 in 250 adults and 1 in 134 youth. Based on US medical insurance claims, the NZ figure is more likely to be 45,000. With up to fifty percent of long COVID cases meeting the diagnostic criteria for ME/CFS these numbers will rise exponentially. ME/CFS is currently classified as a “chronic illness” rather than a disability in New Zealand, which poses significant challenges for policy recognition, support services, and funding. As a consequence, the lack of awareness and education among healthcare professionals leads to inaccurate patient diagnosis, and ineffective treatment and management plans.

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[3] The Code of Health and Disability Services Consumers Rights: https://www.hdc.org.nz/your-rights/the-code-and-your-rights/
Code of Health and Disability Services Consumers Rights: https://www.hdc.org.nz/.../code-of-health-and-disability.../

[4] The Health and Disability Commissioner Act 1994: https://www.legislation.govt.nz/.../latest/DLM333584.html

Current Challenges and Violations of Rights

Lack of Knowledge Among Health Practitioners

(Violation of Right 4)

Best practice guidelines highlight the importance of educating both patients and healthcare providers about ME/CFS to enhance understanding and facilitate a timely diagnosis.[5] Patients with ME/CFS face significant challenges in finding health practitioners who possess the necessary knowledge of the biomedical basis of their condition and the best practices for clinical assessment and management. This knowledge gap means that individuals often struggle to access accurate diagnoses and appropriate management for their symptoms. Additionally, the lack of informed healthcare professionals results in patients being deprived of essential financial and social support that could significantly improve their quality-of-life.[6]

Absence of Senior Specialists Focusing on ME/CFS in New Zealand

(Violation of Right 4)

New Zealand currently lacks senior specialists focusing on ME/CFS. The absence of these specialists means that there is inadequate dissemination of up-to-date, evidence-based clinical guidance to medical education institutions and practising healthcare professionals. As a result, the education provided by medical institutions and at conferences is often delivered by non-experts, leading to poor-quality or non-existent training on ME/CFS. Furthermore, the current health system in New Zealand for managing ME/CFS lacks consistency and continuity of care, with some medical professionals relying on outdated and harmful UK guidelines despite newer recommendations from the CDC, NICE, and Mayo Clinic. This deficiency in expert guidance further exacerbates the challenges patients face in receiving diagnosis, proper care and support.[7]

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[5] NICE 2021 guideline -https://www.nice.org.uk/guidance/ng206/

[6] This recommendation aligns with the review's goal of ensuring services meet professional and legal standards, and are provided with reasonable care and skill (Right 4).

[7] This recommendation aligns with the review's goal of ensuring services meet professional and legal standards, and are provided with reasonable care and skill (Right 4).

Inadequate Funding for Services and Practical Supports

(Violation of Right 4)

ME/CFS meets the New Zealand government and United Nations (UN) definitions of 'disability',[8] yet the criteria for Disability Support Services (DSS) funding exclude ME/CFS. As a result, there is a significant shortfall in funding for ME/CFS services and practical supports in New Zealand. Furthermore, Health NZ does not allocate specific funding from the Long Term Support Chronic Health Conditions (LTS-CHC) budget for multidisciplinary health teams or domestic assistance. This leaves people with ME/CFS without the necessary supports to manage their daily lives effectively.

Quality-of-life for people with ME/CFS is significantly lower compared with conditions such as cancer, depression, heart disease, diabetes, and rheumatoid arthritis.[9] Many of these conditions have larger funding pools and patients can often more easily access home help. Post-Exertional Malaise (PEM) is a debilitating response to normal, every-day activities in people with ME/CFS, causing a severe increase in symptoms like brain fog, muscle pain, and extreme fatigue that can last for days, weeks or longer.[10] Additionally, recurring episodes of PEM can also impact ME/CFS overall, with the condition becoming increasingly severe in the longer term. The absence of home help and practical support forces patients to engage in activities that trigger PEM), severely impacting their functional capacity and overall wellbeing. Additionally, recurring episodes of PEM can also impact ME/CFS overall, increasingly severe longer term.

There is a significant cost to Aotearoa New Zealand for not supporting this condition. The CDC estimates up to 75% of ME/CFS patients are too ill to work, with rates of between 50 and 75% too ill to work worldwide.[11] ANZMES (Associated NZ Myalgic Encephalomyelitis Society) have stated that the economic cost, as at 2017, to each family with a sufferer has been estimated to be in the region of NZ$35-45,000 per year. It is crucial to understand the 'whole of life' benefit. Instead of focusing solely on the expense of providing accommodations and support services, the government should consider the broader implications and costs of inaction. This includes the importance of a social and wellbeing approach, with wraparound services to support individuals holistically.[12]

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[8] Definition of disability - Map (workandincome.govt.nz)

[9] Institute of Medicine report (2015) NAM-Annual-Report-2015.pdf

[10] ANZMES (2023). World ME Day asks you to learn about the broken energy system in ME/CFS – PRESS RELEASE. Retrieved from: World ME Day asks you to learn about the broken energy system in ME/CFS – PRESS RELEASE – ANZMES

[11] Vink, Mark; Vink-Niese, Alexandra (September 20, 2019). "Work Rehabilitation and Medical Retirement for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. A Review and Appraisal of Diagnostic Strategies". Diagnostics. 9 (4): 124. doi:10.3390/diagnostics9040124. ISSN 2075-4418.

[12] This recommendation aligns with the review's goal of ensuring services meet professional and legal standards, and are provided with reasonable care and skill (Right 4).

Recommendation of Inappropriate Treatments From Health Practitioners

(Violation of Right 6)

A troubling issue is that some health professionals recommend discredited treatments, such as Cognitive Behavioral Therapy (CBT), Graded Exercise Therapy (GET) and the Lightning Process, without informing patients about the lack of a quality evidence base for these treatments. These recommendations are made without disclosing the potential risks of harm, despite warnings from leading international health organisations like the CDC, NICE, and Mayo Clinic.

The Mayo Clinical Proceedings and updated guidelines from the Centers for Disease Control and Prevention (CDC) and the National Institute for Health and Care Excellence (NICE) have discredited CBT and GET as treatments for ME/CFS.[13],[14] The previous support for these therapies stemmed from outdated and flawed studies, including the 2011 PACE trial [15] and the 2007 NICE guidelines, which have been invalidated due to significant methodological limitations. The latest 2021 NICE guidelines, which reviewed a more extensive set of studies, no longer recommend CBT and GET, citing a lack of evidence for their safety and efficacy.[16],[17] Similarly, the Lightning Process (LP) is also not recommended due to insufficient quality evidence and potential harm, as highlighted by critical reviews of the single supporting study, the SMILE trial.[18]

This lack of transparency prevents patients from making informed choices about their treatment options, with many experiencing significantly worsened health status - sometimes permanently - due to following harmful treatment advice.[19]

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[13] Mayo Clinical Proceedings (2021). Consensus Recommendations for ME/CFS: Essentials of Diagnosis and Management https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext

[14] CDC Treating the Most Disruptive Symptoms First and Preventing Worsening of Symptoms, 2021. https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/treating-most-disruptive-symptoms.html

[15] Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. 2011. Lancet. https://pubmed.ncbi.nlm.nih.gov/21334061/

[16] National Institute for Health and Care Excellence (NICE). (2021). 'Overview | Myalgic Encephalomyelitis (or Encephalopathy)/Chronic Fatigue Syndrome: Diagnosis and Management | Guidance | NICE'. NICE. https://www.nice.org.uk/guidance/ng206

[17] Vink M, Vink-Niese A. The Updated NICE Guidance Exposed the Serious Flaws in CBT and Graded Exercise Therapy Trials for ME/CFS. Healthcare (Basel). 2022 May 12;10(5):898. doi: 10.3390/healthcare10050898. PMID: 35628033; PMCID: PMC9141828.

[18] Editor's note on correction to Crawley et al. (2018). http://dx.doi.org/10.1136/archdischild-2017-313375ednote

[19] This recommendation aligns with the review's goal of providing all necessary information for informed decision-making (Right 6).

Recommendations to Enforce Standards

Accountability in Medical Education

In alignment with the review's objective to ensure the fair, simple, speedy, and efficient resolution of complaints, medical education institutions must be held accountable for providing comprehensive education that ensures health professionals are well-informed about the biomedical basis of ME/CFS and evidence-based, best-practice clinical management. It is critical that all healthcare providers adopt the same evidence-based guidelines, as it's essential that GPs use recognised diagnostic criteria to ensure accurate diagnosis and management of ME/CFS. The Institute of Medicine Criteria (IoM 2015)[20] and the Canadian Consensus Criteria (CCC)/International Consensus Criteria (ICC)[21] are currently the preferred diagnostic criteria**.**

Currently, the lack of proper education on ME/CFS leads to delays in diagnosis and inadequate treatment for patients. For many patients, diagnostic delays and lack of good management advice can mean they progress to more severe illness and experience preventable reductions in quality of life and functioning. By enforcing standards that require thorough education on ME/CFS, we can significantly improve the quality of care and support provided to these patients. This step is crucial for bridging the knowledge gap among healthcare practitioners and ensuring that ME/CFS patients receive accurate, timely diagnoses and effective symptom management.

Adequate Support from Health NZ and The Ministry of Health

In alignment with the review's objective to ensure the fair, simple, speedy, and efficient resolution of complaints, Health NZ and the Ministry of Health must be held accountable for adequately supporting ME/CFS patients. This includes ensuring that health professionals and support services are sufficiently equipped to meet the specific needs of this patient group who meet the disability definition. Adequate funding and resources must be allocated to provide the necessary multidisciplinary care and practical supports, such as home help, that ME/CFS patients require for their health and wellbeing. By addressing these funding gaps, we can improve the functional capacity and overall quality-of-life for ME/CFS patients to prevent further disability and economic burden.

Transparency and Informed Consent in Treatment

In alignment with the review's objective to ensure the fair, simple, speedy, and efficient resolution of complaints, medical institutions and professionals must be held accountable for informing

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[20] Institute of Medicine of the National Academies. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.2015. www.nap.edu/read/19012

[21] Carruthers BM, van de Sande MI, De Meirleir KL, Klimas NG, Broderick G, Mitchell, et al. Myalgic Encephalomyelitis: International Consensus Criteria. Journal of Internal Medicine. 2011 doi: 10.1111/j.1365-2796.2011.02428.x. (published online on 20 July 2011)

patients when recommending treatments that lack a quality evidence base, may be harmful, or are not recommended by leading international health organisations such as the CDC, NICE, Mayo Clinic, or expert ME/CFS clinicians. Patients have the right to be fully informed about the potential risks and benefits of any proposed treatments. Ensuring transparency and informed consent is essential to protect patients from harm and enable them to make well-informed decisions about their healthcare. This recommendation aims to safeguard ME/CFS patients from inappropriate, potentially harmful treatments and ensure they receive care that aligns with the best available evidence.

Conclusion

The Need for Change

As a collective, we have based this report on the general experiences of our members and patients, who face significant challenges in getting diagnosed and treated with ME/CFS. We have many individuals with ME/CFS taking years to find a general practitioner who understands ME/CFS, and even then, the available medical treatment and support is often inadequate.

"It took me 10 years to find a GP who had any understanding of ME/CFS, and even then he had no idea how to help me manage it." - ME/CFS patient/ME Awareness NZ member

This lack of understanding leads to delayed diagnosis and inappropriate management, such as the failure to advise patients on pacing their energy expenditure, which exacerbates the severity of their illness. This has meant that many individuals with ME/CFS have struggled to receive appropriate accommodations and practical supports; or even help from their workplace, their family, and social services like Work and Income.

This commonly experienced narrative highlights the critical need for systemic changes in how ME/CFS is understood and managed within the healthcare system. It underscores the importance of the recommendations outlined in this report, emphasising that without recognition, knowledgeable health professionals and adequate support systems, people with ME/CFS will continue to suffer unnecessarily, with compounding social and economic costs to New Zealand.

Medical education institutions and Health NZ need to have experts who understand ME/CFS, stay updated with current evidence-based research, and provide training and quality clinical advice aligned with best practice international guidance. **The Health and Disability Commissioner must have the powers to enforce these standards to ensure patients receive the care and support they need.**

Summary of Recommendations for HDC Review

Accountability in Medical Education

- Medical education institutions must be held accountable for providing comprehensive, up-to-date education on ME/CFS.
- Ensure health professionals are well-informed about the biomedical basis of ME/CFS and evidence-based, best-practice clinical management which are currently NICE [22], CDC[23], and Mayo Clinic guidance[24].
- Note, a national ME/CFS Health Pathways is being worked on but still, not all doctors refer to it.
- Bridge the knowledge gap among healthcare practitioners.
- Ensure timely and accurate diagnoses and effective symptom management for ME/CFS patients.

Transparency and Informed Consent in Treatment

- Medical institutions and professionals must be held accountable for informing patients when recommending treatments that lack a quality evidence base or may be harmful.
- Ensure treatments recommended by leading international health organisations such as the CDC, NICE, and Mayo Clinic are communicated to patients.
- Ensure transparency and informed consent to protect patients from harm.
- Enable patients to make well-informed healthcare decisions.

Adequate Support from Health NZ and the Ministry of Health

- Health NZ and the Ministry of Health must be held accountable for adequately supporting ME/CFS patients to improve their quality-of-life.
- Ensure health professionals and support services are sufficiently equipped to meet the specific needs of ME/CFS patients.
- Allocate adequate funding and resources for conditions such as ME/CFS that meet NZ government and UN ‘disability’ definitions so that multidisciplinary care and practical supports, such as home help, are accessible for patients.

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[22] Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management (nice.org.uk)

[23] Site Index | ME/CFS | CDC

[24] Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - Mayo Clinic Proceedings