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Transforming ME/CFS Care: A Call to Action for Aotearoa New Zealand

Executive Summary

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) affects over 65,000 New Zealanders, severely impacting mobility, cognition, and quality of life. Despite meeting the government's definition of disability, ME/CFS is misclassified as a chronic illness, which excludes individuals from accessing essential disability support services. This systemic gap, compounded by stigma, fragmented care frameworks, and a lack of national guidelines, leaves many without adequate care or recognition.

The social and economic costs of inaction are staggering. Australia's annual economic burden from ME/CFS is estimated at $14.5 billion, primarily due to lost productivity and caregiver burdens—New Zealand faces similar challenges. With the intersection of ME/CFS and Long COVID, which meets diagnostic criteria for up to 50% of cases, the urgency for reform has never been greater.

ANZMES, as the National Advisory, is committed to leading change. We propose reclassification, national investment in research and care, and the creation of a National Centre of Excellence to address these systemic inequities. A cross-party parliamentary group partnering with ANZMES will enable appropriate reframing of policy and procedure that can be implemented nationally in all relevant areas. This report outlines the current challenges and the cost of doing nothing but provides evidence-based solutions to improve outcomes for individuals with ME/CFS, reduce healthcare strain, and align with international best practices.

The Cost of Inaction: Social, Economic, and Healthcare Impacts

Economic Costs

The financial burden of ME/CFS in New Zealand is profound, mirroring international patterns. For example:

- A Griffith University study estimated Australia's annual economic cost of ME/CFS at $14.5 billion, with 70% attributed to lost income.[1]
- Internationally, approximately 75% of ME/CFS patients are unable to work, leading to widespread financial hardship, reliance on government benefits, and reduced household income.[2] - Families of ME/CFS patients bear significant financial and emotional caregiving burdens, often compromising their own workforce participation and economic stability.

Healthcare Strain

- Increased Utilisation of Resources: The absence of early intervention often results in delayed diagnoses, worsening symptoms, and higher healthcare usage, including hospitalizations ($1,200 per day), specialist consultations, and emergency care.
- Diagnostic Costs: ME/CFS patients face higher annual out-of-pocket medical costs, with studies indicating over $1,000 annually spent on prescriptions alone.[3]
- Systemic Challenges: Long COVID, which overlaps significantly with ME/CFS, has been described as a "mass disabling event," further amplifying healthcare demands and costs in New Zealand.

Social Impacts

- Quality of Life: ME/CFS patients consistently report some of the lowest quality-of-life scores compared to individuals with other chronic conditions.

- Stigma and Disbelief: Persistent stigma within the medical and policy landscapes compounds the social and emotional toll on patients and caregivers, fostering isolation and exclusion.

- Equity Concerns: Māori, Pasifika, and other minority communities are disproportionately impacted, facing additional barriers to timely diagnosis and equitable care.

Systemic Gaps in Support and Classification

The challenges faced by individuals with ME/CFS in New Zealand are compounded by systemic barriers, including misclassification, inequities in access to services, and fragmented care frameworks.

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[1] https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2020.00420/full
[2] https://content.iospress.com/articles/work/wor203173
[3] https://pubmed.ncbi.nlm.nih.gov/18397528/

Misalignment with Disability Services Criteria

Despite meeting the government's definition of a disability, ME/CFS remains classified as a "chronic illness," excluding individuals from accessing essential disability support services under Whaikaha/MSD.

The designation of ME/CFS under Long-Term Support - Chronic Health Conditions (LTS-CHC) creates regional disparities, or a postcode lottery. Most regions have high thresholds for eligibility, leaving the majority of individuals with ME/CFS—particularly those with moderate symptoms—unsupported.

Fragmented Care Frameworks

Responsibility for chronic illness care and disability services is divided between Te Whatu Ora and Whaikaha, creating inconsistent policies and fragmented care pathways.

Assessment and application processes are complex and often deter eligible individuals, particularly when compounded by regional variations in criteria.

Inequity and Stigma

Māori, Pasifika, tāngata whaikaha, and minority groups remain disproportionately underdiagnosed and underserved due to systemic inequities and lack of culturally tailored approaches.

Persistent stigma and misconceptions about ME/CFS as a psychosomatic condition undermine recognition and lead to disbelief and negative attitudes in both medical and policy frameworks.

Addressing these gaps requires:

- Reclassifying ME/CFS as a disability to ensure equitable access to essential services like home help, mobility aids, and financial support.
- Simplifying eligibility criteria and aligning with international best practices to eliminate inequities in service delivery.
- Developing partnerships with culturally tailored healthcare providers to improve access for underserved communities.

Data, Research, and Standardisation Challenges

Systematic gaps in tracking, reporting, and research funding, combined with inconsistent healthcare practices, leave individuals with ME/CFS underserved and policymakers without sufficient evidence to drive change.

Absence of Tracking and Reporting Mechanisms

ME/CFS cases remain untracked across primary and secondary care systems, leading to an inability to capture accurate prevalence data, service utilization, and patient outcomes.

Government agencies like Te Whatu Ora and Whaikaha currently lack the infrastructure for systematic coding and reporting of ME/CFS and associated conditions like Long COVID.

Although the code exists, government agencies are not utilising data through sensible reporting initiatives. Without this data, the scale of the problem remains invisible, hindering resource allocation and planning.

Insufficient Biomedical Research Funding

New Zealand lags behind comparable countries in its health research investment, with only 0.6%-0.8% of healthcare costs allocated to research—far below the recommended 2.4%.[4]

Dedicated funding for ME/CFS research is critical to advance understanding of the disease, develop diagnostic tools, and identify effective treatments.

Local researchers such as Emeritus Professor Warren Tate and Dr. Anna Brooks are globally recognized but face challenges maintaining their work due to limited funding.

Lack of Standardisation in Healthcare Practices

Inconsistent use of best-practice guidelines across New Zealand exacerbates disparities in diagnosis, care, and treatment. For example:

Some regions adhere to outdated UK guidelines that are no longer evidence-based.

NASC assessment thresholds vary widely, leaving even severely affected patients without adequate support.

This inconsistency prolongs delays in diagnosis, mismanagement, and inequitable access to care.

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[4] https://nz4healthresearch.org.nz/wp-content/uploads/2022/12/NZHR-Report-2022-Online-final.pdf

Proposed Solutions

Tracking and Reporting System: Implement systematic coding for ME/CFS and associated conditions, integrating indicators into Te Whatu Ora's healthcare data collection.

Research Investment: Allocate dedicated funding streams to support biomedical research, ensuring local researchers can contribute to global advancements.

National Guidelines Adoption: Mandate the use of unified, evidence-based healthcare guidelines to eliminate regional disparities and improve patient outcomes.

Evidence-Based Solutions

This section outlines the actionable steps to address the systemic gaps and challenges faced by individuals with ME/CFS, ensuring equitable care and support.

Reclassification of ME/CFS as a Disability

Align Eligibility Criteria: Ensure ME/CFS meets the Government's definition of disability, granting individuals access to critical services like home modifications, financial assistance, and mobility aids.

Implement Select Committee Recommendations: Action the 2023 Health Select Committee's recommendations to address flawed assessment processes, inequitable regional policies, and classification gaps.

Demonstrate Recognition: Reclassification is not just about access—it validates ME/CFS as a serious biological condition, affirming the rights and dignity of affected individuals.

Equitable Access to Healthcare Services

Address Inequities: Ensure Māori, Pasifika, tāngata whaikaha, and minority groups receive culturally tailored care to combat underdiagnosis and inequity.

Outreach and Partnerships: Collaborate with Māori and Pasifika health providers to create regionally and culturally relevant programs that improve access to healthcare for underserved communities.

Emergency Crisis Support

Emergency Respite and Crisis Services: Establish government-funded emergency services to support individuals with severe or very severe ME/CFS and Long COVID, as well as their families. These services would include:

Respite Care: Temporary relief care for families, particularly for those supporting nonverbal or bed-bound individuals.

Temporary Housing: Crisis accommodations for those facing severe functional limitations or needing accessible housing due to the disabling nature of their condition.

Hospital Advocacy Services: Dedicated support professionals to act as advocates for nonverbal or severely ill patients during hospitalizations, ensuring their needs are met with dignity and precision.

Long-term residential care

Beyond emergency crisis support, there is an urgent need for long-term residential care tailored to individuals with severe to very severe ME/CFS and Long COVID, who usually also live with equally complex and misunderstood comorbidities such as Mast Cell Activation Syndrome (MCAS), histamine intolerance, hEDS, POTS, and other forms of dysautonomia. These patients require specialised environments with fully trained staff who understand the biomedical complexities, sensory sensitivities, and mobility limitations unique to these conditions. A government-funded residential care programme would provide stability, access to appropriate medical management, and relief for caregivers, ensuring these individuals can live safely, with dignity and proper medical oversight rather than being forced into unsuitable care settings or total isolation. ANZMES provides Care Plans and Resources and could be instrumental in training caregivers.

Streamlined Support Systems

Simplify Eligibility Processes: Advocate for simplified and transparent pathways to disability services and financial aid.

Energy-Based Assessments: Promote assessments focused on the fluctuating functional capacity of energy-limiting chronic conditions like ME/CFS, ensuring fair access to support.

Improved Data, Tracking, and Research Funding

National Tracking System: Introduce systematic coding, tracking, and reporting for ME/CFS and Long COVID across primary and secondary care. This enables accurate prevalence data and better resource allocation.

Dedicated Biomedical Research Funding: Mandate the inclusion of ME/CFS and Long COVID in national health research plans, ensuring consistent, long-term funding streams to drive advancements in diagnostics, treatments, and management strategies.

Research Prioritisation: Allocate at least $500,000 annually to support biomedical research, ensuring the sustainability of critical laboratories such as those led by Professor Tate and Dr. Brooks. This investment would cement New Zealand's place as a leader in post-viral research.

Collaboration for Global Progress: Strengthen partnerships between local and international research teams to contribute to and apply the latest findings in ME/CFS, creating pathways for innovative, globally recognized treatments.

Unified Best Practice Guidelines: Mandate the adoption of evidence-based healthcare guidelines nationally to standardize care delivery and eliminate disparities.

Flexible Work and Economic Policies

Support Employment: Advocate for flexible work initiatives, such as remote and part-time arrangements, to reduce benefit reliance while enabling individuals with ME/CFS to maintain economic participation.

Government Pilot Programme: Propose a government-subsidized trial encouraging employers to adopt workplace accommodations for individuals with chronic disabling conditions.

The Role of ANZMES and Centres of Excellence

Why ANZMES?

ANZMES stands as the trusted authority on ME/CFS in New Zealand, with over 40 years of experience advocating for research, education, and equitable care. Here's why ANZMES is uniquely positioned to lead transformative change:

1. Established Credibility and Expertise

ANZMES is internationally recognized, with leadership from MNZM recipients, academic researchers, and clinicians who are pioneers in the ME/CFS field. As a founding member of the World ME Alliance, ANZMES is globally networked and trusted.

2. Evidence-Based Approach

Known for high-quality resources like the "Know M.E." education series, ANZMES sets the standard for training healthcare professionals and policymakers. Its role as a Continuing Medical Education provider further highlights its commitment to evidence-based practices.

3. Proven Advocacy

ANZMES' strategic advocacy has been acknowledged by the Health Select Committee. From impactful petitions to policy recommendations, its collaborative efforts with advisory groups such as Whaikaha underscore its capacity to lead national reform.

4. Grassroots Connection

ANZMES bridges the gap between policymakers, healthcare providers, and the ME/CFS community. Initiatives like buddy programs and partnerships with regional organizations showcase its deep grassroots impact.

5. Alignment with Government Goals

ANZMES' objectives align with the UNCRPD and WHO's Intersectoral Global Action Plan (IGAP). Partnering with ANZMES enables the Government to meet its international commitments to reduce the stigma and burden of neurological conditions.

Building a Centre of Excellence (CoE) in New Zealand

ANZMES, as the National Advisory on ME/CFS, is uniquely positioned to lead the development of a Centre of Excellence (CoE) in partnership with the New Zealand Government. With its four decades of expertise and commitment to evidence-based practices, ANZMES ensures that all necessary and appropriate service provisions will be included in this gold-standard program. With adequate government support and funding, the CoE can establish a comprehensive framework that not only meets international best practices but sets New Zealand apart as a world leader in ME/CFS care.

The Centre of Excellence will deliver:

1. Integrated Medical Services: Providing nationwide access via telehealth for patient assessments and triage, ensuring timely and equitable care and accessibility.

2. Educational Initiatives: Offering evidence-based training for healthcare providers, benefit assessors, and employers to eliminate stigma and foster a compassionate, informed approach to care. Equipping healthcare professionals, government staff, employers, and educational institutions with evidence-based training to improve understanding and care.

3. Comprehensive Holistic Support Programs: Addressing financial, employment, and educational needs to improve quality of life and reduce economic strain on individuals and families.

4. Innovative Research: Supporting groundbreaking studies to advance diagnostics, treatments, and understanding of ME/CFS (and related conditions), while fostering collaboration with international leaders in the field.

5. Emergency and Crisis Support: Integrated critical emergency and crisis services which includes triaging the patient and carer's needs, providing representation and support for nonverbal bedbound patients during hospitalisations and care home transitions, emergency respite care for caregivers, and crisis housing assistance.

By empowering ANZMES to spearhead this initiative, the New Zealand Government has the opportunity to invest in a world-leading care model that aligns with global advancements, such as those in the UK, Australia, and the USA. This investment demonstrates a commitment to reducing healthcare burdens, addressing inequities, and advancing New Zealand as a pioneer in the treatment and management of ME/CFS and related conditions. A partnership with ANZMES to develop a Centre of Excellence will position New Zealand as a global leader in ME/CFS care and research.

Learning from International Successes

Australia: Emerge Australia

Emerge Australia has received government funding to integrate ME/CFS into chronic conditions care, focusing on research and education. This funding supports sustained advocacy efforts and elevates ME/CFS care into national health policy frameworks.

United States: Bateman Horne Center

The Bateman Horne Center serves as a gold-standard model of integrated care, combining medical services, education, and groundbreaking research to significantly improve patient outcomes.

United Kingdom: APPG on ME/CFS

The All-Party Parliamentary Group (APPG) has driven reforms in care pathways and funding allocations, enhancing access to resources and recognition of ME/CFS within the NHS.

New Zealand: Rare Disorders NZ

The Government's engagement with Rare Disorders NZ demonstrates a pathway for structured partnerships that could be emulated for ANZMES in addressing ME/CFS and Long COVID.

Call to Action

ANZMES calls on the Government to:

- Formally recognize ANZMES as the National Advisory on ME/CFS.

- Allocate funding equivalent to that received by international counterparts, enabling ANZMES to establish a CoE that leads ME/CFS research, education, and support services in New Zealand.

- Engage immediately with ANZMES through a Cross-Party Parliamentary Group to drive policy reform and invest in long-term solutions.

By partnering with ANZMES and funding a Centre of Excellence, the Government has the opportunity to make meaningful, lasting change for thousands of New Zealanders living with ME/CFS and related conditions.