



BRIEFING FOR THE INCOMING MINISTER OF HEALTH

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NEUROLOGICAL CONDITIONS – AT A GLANCE

- Are one of the biggest threats to our health
- Are the leading cause of disability and second cause of death worldwide
- Are responsible for 140,000 healthy life years lost every year in Aotearoa
- Impact 1 in 3 New Zealanders in their lifetime
- Are the cause of death for 1 in 5 New Zealanders
- Can affect people at any age
- Are rapidly increasing as our population grows and ages
- Are under-resourced with significant workforce shortages and underfunded community services
- A lack of resources means long wait times for specialists and delays in diagnosis and treatment
- Represented through the Neurological Alliance – a collaboration network ready to engage with Government.

Numbers affected

- ✓ 1.3 million New Zealanders suffer from tension-type headaches
 - ✓ 642,000 from Migraine
 - ✓ 300,000 from Rare Disorders
 - ✓ 83,000 from Dementia
- ✓ 70,000 from Myalgic Encephalomyelitis (ME) and Long Covid
 - ✓ 64,000 from Stroke
 - ✓ 50,000 from Epilepsy
- ✓ 37,100 from Traumatic Brain Injuries (TBIs)
 - ✓ 12,000 from Parkinsons
 - ✓ 4,100 from Multiple Sclerosis
- ✓ 4000 from Neuro-Muscular Conditions

OUR PURPOSE

The Neurological Alliance of New Zealand (the Alliance) was established in 1999 to provide a forum for organisations representing a neurological disease to:

1. **Advocate** for the best outcomes for those living with neurological conditions in New Zealand through Government and health service providers.
2. Provide an external **advisory** role to the Government and health service providers; supporting their development of strategic priorities, health policies, white papers, research programmes and funding models to address the needs of those living with neurological conditions.

Refer Appendix 1 – Neurological Alliance Mission and Membership.

WHY NEUROLOGICAL CONDITIONS ARE IMPORTANT

Neurological conditions place a significant burden on health and disability systems in Aotearoa and this is worsening. This includes pressure on social and health service providers in the non-governmental sector who are under-resourced and overstretched.

The social and economic cost of **not** responding is significant. Left unaddressed the number of people suffering and dying from neurological conditions will increase. Dementia alone is estimated to cost the country \$2.4b in 2020 increasing to \$6b by 2050, with the estimated cost of Stroke increasing from \$1.1b in 2020 to \$1.7b by 2038.

In addition to our ageing and growing population, Aotearoa is also in the unenviable position of having one of the highest and fastest increasing prevalence of obesity and diabetes in the world, which is contributing to the increase of some neurological conditions.¹

NEUROLOGICAL ALLIANCE PRIORITIES

The Alliance has pooled its collective knowledge to identify the four most important actions Government can take to optimise brain health, reduce inequities and better serve people in our communities with neurological conditions. Our priorities are based on feedback from our members and their experiences on-the-ground supporting people with neurological conditions, their carers and whānau.

OUR PRIORITIES

- 1) Address health workforce shortages to speed up diagnosis and treatment
- 2) Increase funding for pharmaceutical treatment to improve quality of life
- 3) Increase funding for community-based care and support services
- 4) Improve data collection on neurological conditions.

¹ Global Burden of Disease: expert Q and A, Professor Valery Feigin, Professor of Neurology and Epidemiology, Director of the National Institute for Stroke and Applied Neurosciences of Auckland University of Technology, 26 November 2018

MEETING GOVERNMENT'S INTERNATIONAL COMMITMENTS

By working with the Alliance to further our four priorities, the Government would be demonstrating its commitment to meeting its obligations as signatory to the UNCRPD and the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Conditions (2022-31).

United Nations Convention of the Rights of Persons with Disabilities (UNCRPD)

The purpose of the UNCRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Many people have neurological conditions that cause significant long-term disability. In its recent Observations Report (September 2022), the United Nations Committee responsible for monitoring our implementation of the UNCRPD made a number of recommendations² that would improve the quality of life of many New Zealanders with disabilities. We encourage you to work with Ministers across portfolios including Whaikaha, Social Development and ACC, to ensure each recommendation is enacted.

WHO Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Conditions (2022-31)

New Zealand is one of 194 member states that approved the IGAP ten year roadmap³ to reduce the stigma, impact and burden of neurological conditions in 2022. As a signatory the New Zealand Government has agreed to the 5 strategic objectives and 10 global targets within the IGAP.

By working with Alliance to advance our four priorities the Government will be contributing directly to at least two of the 5 strategic objectives, the most closely aligned being:

- Strategic Objective 2 - Provide effective, timely and responsive diagnosis, treatment, care; and
- Strategic Objective 4 – Foster research and innovation and strengthen information systems.

Advancing the Alliance's four priorities also contributes to the Government's commitment to meet a number of global targets in the IGAP, including:

- 75% of countries have included neurological conditions in universal healthcare
- 80% of countries provide essential medicine/technologies for neurological conditions (this includes building an adequate neurological workforce)
- 80% of countries routinely collect indicators for neurological conditions.

Further information on the IGAP can be found at

<https://www.who.int/publications/i/item/9789240076624>

² For a list of Lead and Supporting Agencies responsible for implementing Concluding Observation Recommendations refer to [Appendix-One-Mapping-Concluding-Observation-recommendations-to-Lead-and-Supporting-agencies.pdf \(whaikaha.govt.nz\)](#)

³ https://www.ibe-epilepsy.org/wp-content/uploads/2023/01/IGAP-Unpacked_Guide_V2.pdf

PRIORITY 1: Address health workforce shortages to speed up diagnosis and treatment

*There are parts of New Zealand with no neurologist or consultant. (Parkinson's NZ)
In Auckland there is 1 FTE Specialist MS Nurse for approximately 1000 MS patients. Regular requests for more resourcing keep being declined. This is unsafe for staff and patients. (Multiple Sclerosis NZ)*

There has been a longstanding shortage of neurologists in Aotearoa which has created long waiting lists for many people with neurological conditions. In 2015 it was estimated in that Aotearoa needed 74 full-time equivalent neurologists (equivalent to 1 neurologist per 70,000 people) but had less than half this number (36).⁴ Information accessed via an Official Information Act⁵ request to Te Whatu Ora (TWO) reveals how critical neurological health workforce shortages are with only 47.8 (FTE) neurologists and 71.5 (FTE) neurology nurses across all our public hospitals as at November 2023. These shortages (and shortages in the broader health workforce) have a cascading impact on our other priorities.

The shortage in neurologists results in the rationing of resources – ranging from referrals being rejected to lengthy wait times to see a specialist, delays in diagnosis and delays in accessing treatment. Delays in diagnosing neurological conditions also compromises the ability to monitor and manage conditions effectively. This erodes the quality of life for people needing treatment and is particularly harmful for people with conditions that deteriorate quickly, such as Motor Neurone Disease, Multiple Sclerosis and Brain Cancers.

There are also more widespread health workforce shortages, including shortages in specialist nurses, physiotherapists, occupational therapists, psychotherapists, speech language therapists and home-carers. These shortages are more acute for people who live in rural areas.

Alliance member organisations face their own challenges with recruitment and retention of specialist staff, as underfunding of the not-for-profit sector by successive Governments, has undermined our ability to compete for staff within the health sector. Research by Martin Jenkin's in 2019 found that the Government funds community providers for less than two-thirds of the actual cost of delivering essential services, which has contributed to a growing wage differential between government and not-for-profit sector staff.⁶

Action Required

A Government commitment to address health workforce shortages⁷ so that people with neurological conditions can access specialist appointments, enabling more timely diagnosis, treatment, and ongoing support. This health workforce increase needs to meet the projected growth in the number of people with neurological conditions in future years.

⁴https://www.researchgate.net/publication/281780157_New_Zealand's_neurologist_workforce_A_pragmatic_analysis_of_demand_supply_and_future_projections

⁵ Information provided by Te Whatu Ora 30 November 2023 (OIA Reference HNZ00022531)

⁶ Social Service System: the funding gap and how to bridge it, Martin Jenkins, August 2019
<https://communityresearch.org.nz/research/social-service-system-the-funding-gap-and-how-to-bridge-it/>

⁷ This workforce includes (but is not limited to) homebased carers, GPs and nurses in primary care, occupational therapists and physiotherapists through to specialist nurses and neurologists.

PRIORITY 2: Increase funding for pharmaceutical treatment to improve quality of life

There are several brain tumour treatments approved overseas which are not Medsafe approved or PHARMAC funded in New Zealand. (Brain Tumour Support NZ)

We have a number of members over 18 years who have moved to Australia in order to access treatment. (Muscular Dystrophy Association of NZ)

Pharmac's complex decision-making processes, lengthy timeframes and strict rationing of pharmaceutical treatments is impacting the quality of life and, in some cases, the life expectancy of people with neurological conditions. Many treatments for neurological conditions available overseas are unavailable or unfunded in New Zealand.⁸ Approved and funded treatments by Pharmac can be inaccessible because of narrow eligibility criteria. This limits choice if the approved drug cannot be tolerated by an individual, no longer works, or someone does not meet the criteria.

The process for determining drug approval does not consider the broader health and wellbeing needs of people living with neurological conditions. There are equity issues for people with rare disorders trying to access medicines, half of whom are children with conditions that are usually life-long and debilitating.

The Pharmac Review 2021⁹ found that there are systemic deficiencies in the decision-making process and the quality of decisions from the Board down which has resulted in inequitable access to treatments for Māori, Pasifika, disabled people and people with rare disorders. There are issues with a lack of transparency with Pharmac processes and the lack of inclusion of societal costs to patients and their families in the factors for consideration.

The Pharmac Review 2021 also identified a need for greater diversity of voices in decision-making processes including its Consumer Advisory and Rare Disorders Committees. These findings reflect the experiences of our members.

Actions Required

Full implementation of the recommendations from the Pharmac Review 2021 alongside an increase in Pharmac's budget based on an evidence-based independent budget review to clear the Options for Investment List.

Development of a separate decision pathway for the allocation of funding for medicines for rare neurological conditions

⁸ Some examples from our members include Low Dose Naltrexone for ME/CFS, Bevacizumab for recurrent glioblastoma and Optune (Tumour Treating Fields, TTF) for newly diagnosed and recurrent glioblastoma, gepants and a ditans for acute migraine and monoclonal antibodies medications for migraine prevention, Cladribine for Relapsing MS and Siponomod for Secondary Progressive MS.

⁹ Final Report Summary May 2022 <https://www.health.govt.nz/system/files/documents/publications/pharmac-review-executive-summary.pdf>

PRIORITY 3: Increase funding for community-based care and support services

We are working off contracts which haven't been updated for more than ten years. They bear little resemblance to the complexity of, and services we provide, and do not come close to meeting demand and the actual cost of provision. (Stroke Foundation of New Zealand)

The majority of people with neurological conditions live at home independently, or are supported by family whānau carers, and rely on services and programmes delivered in their communities. Shortfalls in health funding for community-based workers, staffing shortages (exacerbated by a lack of pay parity), and historical underfunding of the sector means that our members can only reach a fraction of people who need support.

For our members this means not being able to deliver services equally throughout the country, having insufficient staff to meet demand, not being able to provide the right level of support and an inability to absorb cost pressures.

Overly prescriptive and out-dated contracts mean that services are often task-centred rather than person-centred and the criteria for accessing support often doesn't align with disability needs or Enabling Good Lives principles. There are very few services tailored to meet the needs of Aotearoa's culturally diverse populations.

Family carers are also burnt out and struggling to access respite. We are at crisis point.

The Carers Alliance commissioned two critical reports; *The State of Caring in Aotearoa Report* (2021) and an Infometrics report, exposing the vulnerable state of family carers nationwide. Using 2018 Census data, the Infometrics report calculated the economic value of carers' mostly unpaid work as being \$17.6 billion a year or 5.4% of GDP. The report recommendations include better financial recognition and support for carers, targeted wellbeing measures such as a responsive respite system so carers can have breaks, and partnerships with employers to help carers more flexibly work and earn.

The State of Caring Report, with input from 1,650 carers nationwide, shows they have much higher rates of anxiety, loneliness, and poor physical health than the general population, with 70% suffering from depression – largely due to financial stress. Half report having had to give up paid work due to family caring commitments. It also found many carers struggle to know what support is available and how to access it, with only 32% managing to access respite breaks a few times a year.¹⁰

Actions Required

Government to contract with the NGO sector in a fair and sustainable way that enables us to grow a resilient and well-trained workforce equipped to contribute to growing numbers of people with neurological conditions.

Renew a Carers' Strategy Action Plan from 2024 to protect the physical, financial and mental well-being of Aotearoa's one million plus family, whānau and carers to enable them to continue providing invaluable support in the community.¹¹

¹⁰ <https://cdn.alzheimers.org.nz/wp-content/uploads/2022/08/State-of-Caring-Report-Aug2022.pdf>

¹¹ <https://carers.net.nz/wp-content/uploads/2023/09/Carers-Election-Briefing-2023-Final.pdf>

PRIORITY 4: Improve data collection on neurological conditions

We have no epidemiology on Huntington's in New Zealand. There is no Multiple Sclerosis database or registry. There is no data collected about dyspraxia/DCD¹². There is no code for ME/CFS in primary care. The Government, Pharmac and hospitals often reach out to our organisations for our figures.

There is no systematic collection of data on neurological conditions by Government. In the absence of data, many Alliance members rely on data from the Global Burden of Disease Study to estimate prevalence of their neurological condition in Aotearoa.

Data collection is critical to identifying and responding to the level of unmet need in the community and spans prevention, research, diagnosis and treatment and the avoidance of mortality and morbidity.

Where data is available, for example hospital admissions, it is often insufficient to inform government decisions on health service provision because much care is provided outside of hospital settings.

It is not uncommon for Alliance members to provide data to the Government. Some of our members have developed their own databases. Others have paid third parties to carry out research/data analysis on social and economic costs to New Zealand of their neurological condition, which they use to inform their service planning. These initiatives come at significant expense to not-for-profit organisations, who must weigh up allocating critical funding to service delivery or data collection. This should be a Government responsibility.

Without data on prevalence and incidence of different neurological conditions the Government, Pharmac and Te Whatu Ora are not able to accurately plan service provision, plan workforce resource requirements, monitor the accessibility of services, or ensure equitable health outcomes.

Data gaps also make it difficult to model the social and economic costs of neurological conditions and creates challenges for neurological research in general:

There are significant gaps on prevalence across almost all types of neurological conditions in New Zealand making it challenging for scientists and clinicians to understand impacts when conducting research. There are also very few patient registries for those living with the various conditions...And the broader data on impact (financial / human) is missing for most areas, making it hard to link the benefits of investing in research to reduced burdens of disease, burdens of cost and burdens on impacted life years etc across our sector, both now and trends for the future.

(Neurological Foundation)

Action Required

Government to start collecting data on all neurological conditions across the life-course, for accurate health planning and service delivery and to inform neurological research.

¹² DCD – Developmental Co-ordination Disorder

Appendix 1: Neurological Alliance Mission and Membership

OUR MISSION

*Kia hautū, kia hapahāpai i te kōunga o te ora me te mahi haumi tika
mō ngā mate hinengaro i Aotearoa.*

To lead and advocate for quality lives and appropriate investment
for neurological conditions in Aotearoa.

ABOUT US

The Neurological Alliance of New Zealand (the Alliance) was established in 1999 to provide a forum for organisations representing a neurological disease to work together and make representations on matters of common interest.

The membership of the Alliance has grown over the last two decades, as has our expertise in a wide range of neurological conditions including Stroke, Alzheimers and other Dementia, Epilepsy, Parkinsons, Multiple Sclerosis, Motor Neurone Disease, Huntington's Disease, Migraine, Brain Tumour and others including a large group of Rare Disorders.

The Alliance's twenty member organisations represent neurological conditions across the life-course. This includes neurological conditions developed in-utero or at birth, during childhood and adolescence, conditions that can occur at any age and neuro-degenerative conditions commonly associated with ageing. The causes of neurological conditions are often unknown and many have no cure.

A few conditions such as Stroke and Alzheimers have known modifiable risk factors, lending themselves to preventive strategies. Modifiable risk factors are however unknown for most. In their absence the Alliance urges the Government to focus on improving early diagnosis and optimising treatment and rehabilitation.

ALLIANCE MEMBERS

1. Alzheimers New Zealand <https://alzheimers.org.nz/>
2. Associated New Zealand Myalgic Encephalomyelitis (ME) Society <https://anzmes.org.nz/>
3. Brain Injury New Zealand <https://www.brain-injury.nz/>
4. Brain Tumour Support New Zealand <https://www.braintumoursupport.org.nz/>
5. Cerebral Palsy Society <https://cerebralspalsy.org.nz/>
6. Dementia New Zealand <https://dementia.nz/>
7. Dyspraxia Support Group <https://dyspraxia.org.nz/>
8. Duncan Foundation <https://duncanfoundation.org/>
9. Epilepsy New Zealand <https://epilepsy.org.nz/>
10. Huntington's Disease Association of New Zealand <https://www.huntingtons.org.nz/>
11. Migraine Foundation Aotearoa New Zealand <https://www.migrainefoundation.org.nz/>
12. Motor Neurone Disease New Zealand <https://mnd.org.nz/>

13. Multiple Sclerosis New Zealand <https://www.msnz.org.nz/>
14. Muscular Dystrophy Association of New Zealand <https://www.mda.org.nz/>
15. Neurological Foundation of New Zealand <https://neurological.org.nz/>
16. NZ Dystonia Patient Network <https://www.dystonia.org.nz/>
17. Parkinson's New Zealand <https://www.parkinsons.org.nz/>
18. Rare Disorders New Zealand <https://www.raredisorders.org.nz/>
19. Stroke Foundation of New Zealand <https://www.stroke.org.nz/>
20. Tuberous Sclerosis Complex New Zealand <https://www.tsc.org.nz/>