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David Cunliffe
Chair
Aged Care Ministerial Advisory Group

Tēnā koe, David

Thank you for the opportunity to provide information to the Ministerial Advisory Group on the changes that we consider are needed to the aged care system.

I am Deputy Chair of the Neurological Alliance of New Zealand, an umbrella organisation established 25 years ago which represents some of the largest NGOs in Aotearoa New Zealand representing the hundreds of thousands of New Zealanders living with neurological conditions. These NGOs include Alzheimers New Zealand, Dementia New Zealand, Stroke Aotearoa, Parkinsons New Zealand, Epilepsy New Zealand and more. A full list of our member organisations can be found on our website.

In August 2024 we made a submission to the Health Committee's *Inquiry into the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders.* We have provided a link[1] to our submission for your reference as this clearly outlines the Neurological Alliance's position. Some of the members of the Neurological Alliance also made their own submissions to the Health Committee Inquiry. As part of this process many of us also attended workshops convened by the Aging Well team at Te Whatu Ora, and our input will be included in these workshop write-ups.

The Neurological Alliance has four priorities which we believe have direct relevance to the Ministerial Advisory Group:

1) Address health workforce shortages to speed up diagnosis and treatment

   There is a chronic shortage of neurologists, specialist nurses, physiotherapists, occupational therapists, psychotherapists, speech language therapists and home-carers. This results in delayed diagnosis and treatment, poorer aging and age disability adjusted life years, and premature death. NGOs also face

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[1] Neurological Alliance submission to Aged Care Inquiry.pdf

challenges with recruitment and retention of specialist staff, as underfunding of the not-for-profit sector by Government undermines our ability to compete for staff in the wider health sector. Scarcity of services in the community means that people are less able to live independently in the community, relying more on scarce aged care service beds.

2) Increase funding for pharmaceutical treatment to improve quality of life

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 older people with neurological conditions. The Neurological Alliance is calling for full implementation of the recommendations from the Pharmac Review 2021.

3) Increase funding for community-based care and support services

Most people with neurological conditions live at home independently or are supported by family whānau carers. They rely on services and programmes delivered in their communities. Shortfalls in health and disability funding for community-based workers and historical underfunding of the sector means that our members can only reach a fraction of people who need support. Family whānau carers are also burnt out and struggling to access respite. As our population continues to grow and age, this burden of care will only increase. Without a well-functioning and resourced aged care sector, supported by sustainable funding, we already have a crisis in our communities.

4) Improve data collection on neurological conditions

There is no systematic collection of data on neurological conditions by the Te Whatu Ora, and given neurological conditions disproportionately affect our aging population, this data gap has reached critical impact. Without data, Te Whatu Ora, Pharmac, and NGOs cannot accurately plan services and workforce resource requirements, monitor the accessibility of services, or prioritise 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.

The Ministerial Advisory Group has requested that we focus on practical, innovative solutions to the challenges in the aged care system that would enable sustainable and high-quality service provision into the future. Given our priorities we have focused on the questions that relate to increasing community based funding to keep people living longer and better supported in the community. Workforce shortages also impact aged care services inhibiting people living with neurological conditions to receive timely diagnosis and treatment. Improvement in access to services will delay and/or reduce admissions to hospital and/or aged residential care.

Our answers are provided below. Please note that the aged care system is not relevant to some of our members for whom conditions affect younger people. Some of our members will also be making their own submissions related to their specific neurological condition – for example Alzheimer's New Zealand.

How could aged care settings better support care to be delivered in the "right care, at the right place, at the right time"?

There needs to be a scaling up of the quantum and diversity of services across all parts of the aged care continuum to match increasing demand. This includes workforce planning and investment for delivering more aged care services across the care continuum.

By 2028 over one million New Zealanders will be aged over 65. The number of people with neurological conditions in Aotearoa is increasing rapidly. For example, an estimated 83,000 New Zealanders are living with dementia and this is set to more than double by 2050[2] and strokes are forecast to increase 40% between 2018 and 2028.[3] An estimated 1 in 5 New Zealanders will be impacted by a neurological condition in their lifetime so it's essential that the health and disability systems are integrated and have the capacity to respond with flexibility to individual need.

The part of the aged care continuum of most relevance to members of the Neurological Alliance are the community-based services that enable people to live longer and more independently in their homes before requiring residential care. In addition, to alleviate pressure on community-based services, capacity is required in the aged care system for planned and unplanned residential respite in aged care facilities, to allow carers to regroup and during times when care in the community cannot be provided. Currently the availability of aged care respite beds is extremely limited.

What changes are needed to support people to live and age well for longer in their own residence or other non-residential settings?

People need to be able to easily access a range of tailored community-based support services and programmes close to home. For this to happen we need the Government to contract the NGO sector in a *fair and sustainable way* that enables us to grow a resilient and well-trained (primarily non-clinical) workforce equipped to contribute to growing numbers of people with neurological conditions.

Currently, most 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. We also have an aging unpaid whānau carer workforce, who have their own declining health to contend with. The lack of aged residential care beds has resulted in rationing of services through assessment processes, meaning that many whānau have no alternative than to care for their loved-one at home, even when it is beyond their personal capability, impacting on their health too.

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[2] Dementia Economic Impact Report, 2021 https://alzheimers.org.nz/podcasts/the-growing-impact-of-dementia-mate-wareware/?highlight=economic%20impact

[3] https://journal.nzma.org.nz/journal-articles/projected-stroke-volumes-to-provide-a-10-year-direction-for-new-zealand-stroke-services

Shortfalls in health funding for community-based workers, staffing shortages (exacerbated by a lack of pay parity) and historic underfunding of the sector means that only a fraction of people receive the community support they need. Family whānau carers are also burnt out and struggling to access respite, recognition, and financial support.

For our members, underfunding means not being able to deliver services equitably 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 annual 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. Annual contracting constrains community providers from taking a long-term, strategic, outcomes-based view. With grant funders being oversubscribed by over 50% year on year, every NGO in the Neurological Alliance is facing sustainability challenges.

Family, whānau, āiga carers are also burnt out and struggling to access respite. We recommended in our submission to the Carer's Strategy Action Plan that the Action Plan recognise that many carers of people with neurological conditions face long-term caring obligations, often lasting years or decades. This directly undermines their personal health, wellbeing and financial security, and that of their family. Moreover, an inflexible disability system means that many people with neurological conditions are ineligible for disability support services which places greater responsibility on carers. Greater access to respite care is urgently needed.

What changes are needed to the current aged care settings to support specific groups (e.g., Māori and Pacific communities, people with dementia, carers, rural communities, etc.)?

We have recently made a submission to the Carers' Strategy Action Plan and asked for greater access to respite care.

We also recommended that the Ministry of Social Development work across Government on policies and reviews likely to impact the wellbeing of people living at home who need support. This equally applies to the work of the Ministerial Advisory Group as it develops advice on aged care reform.

Agencies need to be better connected and workstreams align with each other. Please be cognisant of:

- the recommendations from the Disability Support Services Review
- priorities in the refreshed Disability Strategy
- the Better Later Life Strategy
- the Carers' Strategy Action Plan review

- the Dementia Mate Wareware Plan 2026-31 and
- submissions to, and the recommendation from, the Health Committee’s Enquiry into the Aged Care Sector's Current and Future Capacity to Provide Support Services for People Experiencing Neurological Cognitive Disorders.
- The Te Whatu Ora Aged Care Sector engagement workshops undertaken by the then Aging Well Director, Andy Inder, which gathered input across the motu from a broad cross section of the sector.

We appreciate the opportunity to share our thoughts on ways to improve aged care in Aotearoa New Zealand. Please contact me if you have any questions or would like the Neurological Alliance to meet with any of the Ministerial Advisory Group to explore solutions further.

Ngā mihi nui

Jo Lambert (Deputy Chair)
Neurological Alliance
CEO Stroke Aotearoa New Zealand