



Neurological Alliance – Briefing for Incoming Minister – Supplementary Details

On behalf of the [Neurological Alliance](#) (the Alliance) and all the New Zealanders living daily with a neurological disease or disorder, we would like to welcome you to your new Ministerial role and add our voice to the chorus of congratulations on your appointment to arguably the most significant portfolio in the government.

As reported in the [2018 Global Burden of Disease Report](#), neurological disorders are the leading cause of disability and second cause of death, representing a huge global health problem. One-in-three people now suffer from a neurological disorder worldwide. In the past 15 years, the proportion of people affected has increased from 20 percent to more than 30 percent.

We are writing on behalf of the Alliance to brief you on our collective priorities for neurological support, care and research for the 1 in 5 New Zealanders impacted by a neurological disease or disorder. The Alliance would also like to highlight the additional challenges faced by Kiwi's and their whānau when living with a rare neurological condition, where access to care and support can become even more challenging.

We have summarised the key issues for the Alliance members below, with more details for each of them in the supporting document. The members of the Alliance welcome an opportunity to meet with you to discuss the topics we have raised in more detail and to discuss how the Alliance and its members can support you, and collaborate with the government in providing the best outcomes for Kiwi's living with neurological conditions.

Summary of key issues

The key changes the Alliance would like to see for those living with neurological conditions in New Zealand, in order for them to live their best possible lives, are:

[NZ Burden from neurological conditions](#)

The Alliance would like to work with the Government to:

- Address the significant gap in the number of neurologists available to New Zealanders, providing ready access to specialist knowledge as the country forecasts a significant growth in the burden from neurological diseases
- Establish equitable access programmes to specialist neurological care throughout the country, to address the growing inequity for those living in rural areas that are unable to get the care needed
- Setup a national framework for managing rare disorders (including neurological disorders)
- Foster the growth of collaborative networks and platforms with countries around the globe, giving New Zealander's access to specialist knowledge and skills not physically available in the country

Review of Pharmac

The Alliance would like to work with the Government to:

- Lead a review of Pharmac and its processes and explore alternative funding options for those requiring specific medication for neurological conditions, including cost-sharing models
- Provide access to precision medicines and diagnostic tools available internationally for those living with neurological conditions

Support and care funding

The Alliance would like to work with the Government to:

- Introduce and fund support programmes for all New Zealander's diagnosed with a neurological condition, supporting them and their whānau during the many phases of living with a neurological condition
- Commit funding to providing specialist nurses, physiotherapists, occupational therapists and psychotherapists to provide community based primary health care for those living with a neurological condition, along with specialised neuro-physiotherapy programmes
- Partner with the Government on the best ways to deliver support and care services nationally
- Develop strategies and action plans for outreach to the Māori & Pasifika communities in developing culturally specific clinical and support services for those impacted by neurological conditions
- Adequately fund those providing 'in home care' supporting those living with neurological conditions throughout the sector, so that the Alliance members can deliver meaningful and consistent services
- Implement the Mahi Aroha action plan as part of the Carers Strategy for all New Zealanders

Neurological research

The Alliance would like to work with the Government to:

- Consider the development of a framework and plan for addressing the burden of neurological disease in New Zealand, which would include increasing the number of neurologists and research active clinicians working in a neurological discipline, and prioritising research funding according to the burden of neurological conditions

Conclusion

The impacts of neurological conditions are often hidden, and many have additional social stigma associated with them, though they affect a large number of New Zealanders. The 700 plus neurological conditions have a significant and growing impact on the health and wellbeing of New Zealanders, with social and economic impacts that touch all aspects of our health service and the fabric of our society.

The Alliance trusts that the summary above gives you an insight to the challenges and opportunities ahead for those living with neurological conditions in New Zealand. Each of the issues are expanded in a little more detail in the supporting document.

The members of the Neurological Alliance look forward to meeting you and discussing the opportunities and risks ahead for the 1 in 5 New Zealanders impacted by a neurological condition.

We look forward to hearing about the plans that you and the Government will lead in changing the future for everyone living with neurological conditions. And we look forward to collaborating with you and the government on these topics over the coming months and years.

Details of the issues raised

NZ burden from neurological conditions

Neurological disorders encompass all health conditions associated with the brain, spinal cord and nervous system. They are the leading cause of disability and the second leading cause of death in the world. The global burden of neurological disease is continuing to increase, bringing a call from the World Health Organization (WHO) for countries to take immediate action before this burden becomes increasingly serious and unmanageable.¹

The WHO uses the Global Burden of Disease (GBD) framework to assess disease burden. This is measured using disability-adjusted life years (DALYs), which represent lost years of healthy life as opposed to living to an old age free from disease and disability. Globally, in 2016 neurological disorders accounted for 11.6% of DALYs and 16.5% of deaths, making them the leading cause of DALYs and the second leading cause of deaths in the world. When standardised by age, in 2016 neurological conditions resulted in 2518 DALYs per 100,000 people in New Zealand.²

In New Zealand in 2016, there were 152,210 cases of stroke, dementias, refractory migraines, epilepsy, Parkinson's disease, multiple sclerosis, motor neuron and muscular dystrophy diseases, and rare brain disorders and other central nervous system cancers combined.

The total time required for first specialist assessments was 17,349 hours and the time required for neurology follow-ups was 169,559 hours. From this we can estimate that today New Zealand needs approximately 88 full-time neurologists (considerably more than are currently available).² This is exacerbated in rural areas where access to neurological services and specialists is particularly poor.

New Zealand has approximately 50% of the recommended neurologists, based on international studies, which creates extensive wait periods, delayed access to treatment and over-burden of health professionals.

Inequity of access to services is a significant concern. While in urban centres we see an escalating over burdening of the system, without increases in resourcing to match, those in rural areas experience minimal access, delaying diagnosis, access to treatments and worsening outcomes.

It is well accepted in many neurological conditions that timely access to diagnosis, services and treatments improves long term health outcomes and brain health.³

Whilst some neurological diseases and disorders have growing numbers living with the condition in the New Zealand population, such as stroke, migraine, dementia, epilepsy, there are others that touch only a very small number of New Zealanders. This makes support, care and research even more challenging for those struggling to cope with these rare, lived conditions. Rare Disorders NZ (RDNZ) represents 74 rare support groups with a neurological condition and RDNZ, along with the Alliance

¹ World Health Organization. (2006). Neurological disorders: Public health challenges. Geneva: World Health Organization.

² Feigin VL, Vos T, Nichols E, et al. The global burden of neurological disorders: translating evidence into policy. *Lancet Neurol.* 2020;19(3):255-265. doi:10.1016/S1474-4422(19)30411-9.

³ MS Brain Health (2015). Brain Health: Time matters in MS

members, feel it is vital these are included within broader health review and policy changes. As a collective people with rare disorders collectively represent 300,000 people in New Zealand.

There are opportunities to foster the growth of collaborative networks (such as World Health Organisation Collaborative [Global Network for Rare Disease](#)) and platforms with countries around the globe, giving New Zealander's access to specialist knowledge and skills not physically available in the country.

The Alliance would like to work with the government to:

- Address the significant gap in the number of neurologists available to New Zealanders, providing ready access to specialist knowledge as the country forecasts a significant growth in the burden from neurological diseases
- Establish equitable access programmes to specialist neurological care throughout the country, to address the growing inequity for those living in rural areas that are unable to get the care needed
- Setup a national framework for managing rare disorders (including rare neurological disorders)
- Foster the growth of collaborative networks and platforms with countries around the globe, giving New Zealander's access to specialist knowledge and skills not physically available in the country

Review of Pharmac

Access to treatments is a concern not only for those with neurological conditions, but all health conditions. Advances in research are developing treatments for many conditions at rates we haven't seen before. However New Zealanders are having to wait too long to access these treatments, even though they could be lifesaving or life-improving. The Alliance would like to see Pharmac's factors for consideration and funding models take into account the true cost that living with chronic neurological conditions has on individuals and their families.

Similarly, issues for people with rare disorders related to access to medicines leads to concerns over future funding models. Precision medicine and new diagnostic tools like genomics are peeling back layers to reveal unsuspected complexity and heterogeneity. Precision medicine is inexorably splitting what in the past was diligently lumped together, or worse, undiagnosed.

The Alliance would like to work with the Government to:

- Lead a review of Pharmac and its processes and explore alternative funding options for those requiring specific medication for neurological conditions, including cost-sharing models
- Provide access to precision medicines and diagnostic tools available internationally for those living with neurological conditions

Support and care funding

The recent release of the Dementia Action Plan, a collaborative effort between Dementia NZ, Alzheimers NZ, and The Dementia Cooperative (now known as the Dementia Foundation), included the recommendation that government should fund the first year post diagnosis of dementia. This would provide direct support to the person with dementia and the care partner / whānau.

This model easily scales to any New Zealander diagnosed with a neurological condition, beyond dementia to other conditions such as Huntington's, epilepsy, motor neuron disease, multiple sclerosis etc or has been impacted by a stroke.

Post diagnosis is a critical timeframe for people who are affected, they require information, advice, counselling, physiotherapy and advocacy to help them manage their journey and to build resilience. Conditions such as cancer, heart disease have recognised pathways and these are well resourced.

Beyond the initial post diagnosis support there are a number of other critical areas requiring funding for the frontline, primary healthcare services that some members of the Alliance provide around Aotearoa. These include:

- **Nursing and Allied Health Services** – Various Alliance members employ specialist nurses, physiotherapists, occupational therapists and psychotherapists to provide in-home primary health care services. Much of the funding for specialist care for those living with neurological conditions comes from fundraising carried out by support and care charities. It is the Alliances view that the provision of these services is a responsibility of the government.

Alliance members already provide these services in an extremely efficient and cost-effective way making the opportunity to partner with the Alliance an obvious first choice for the government.

- **Māori & Pasifika** – The reach into Māori and Pasifika communities needs to be developed urgently and many of the Alliance member organisations are reviewing this as a strategic priority. The ability to provide culturally specific nursing and support services is severely limited by our need to learn how and then to fund these services.
- **In-Home Support** - Right around Aotearoa, families are caring for people with a neurological disease or disorder in their homes. This takes a huge burden off the aged care services, other paediatric care services (etc) and saves the government significant amounts of funding. In addition, nurses and community support staff supported through some of the Alliance organisations do assessments of the home environment to identify risks, plus help to educate those with a lived condition and their carers on how to manage the wide range of complications associated with these neurological conditions.

Some Alliance members already provide support services for those impacted by the condition and their carers but much more can and should be done. Again, funding is a limiting factor. There is also a lack of appropriate available respite care facilities, particularly for those under 65.

The pandemic lockdown clearly demonstrated the vital role that community support staff provide, filling gaps in services not available elsewhere and keeping people in the community.

We are continuing to see the needs and numbers of those with neurological conditions rising, but no increases in funding or recognition to match.

- **Exercise** - Whilst there is still no known cause or cures for many of the 700 plus neurological diseases or disorders, we do know that exercise is one of the best ways to slow the progression of many neurological conditions. Specialised neuro-physiotherapy programmes have also been proven to repair and rehabilitate.

Exercise programmes and physiotherapy have a significant impact physically, mentally and psychologically. Exercise is also known to reduce pain. These programmes need to be provided by skilled professionals to have the greatest impact, particularly for those with greater disability, and therefore need to be subsidised to make them affordable for those living with the neurological condition, many of whom live on limited incomes.

- **Carers** – Carers make a significant contribution to the quality of the lives of the people they care for. Their work is not only of significant social value but also economic value to New Zealand - almost half a million carers support family members who are frail, unwell, or have a long-term health condition or disability.

While the interests of carers and the people they care for are closely related, support is usually focused on the person needing care. The demands of care often mean that carers have fewer opportunities to participate in education, in paid work, and in social and community activities. Over time this can have a negative impact on their wellbeing and ability to continue to provide care. It can also have wider impacts on the carer's (and their family's) finances and social connectedness.

New Zealand has had a Carers Strategy since 2008. The third Action Plan under this Strategy, [Mahi Aroha](#), was launched by the Minister for Social Development in December 2019. 11 other Ministers signed up to the Plan as part of its release. The Plan recognises that valuing and supporting carers is an investment in New Zealand's future. Specifically, the Plan focusses on the need for respite, support when things are not going well, assistance with the increasing financial pressures of caring, and a desire for greater carer choice and flexibility.

Unfortunately, the implementation of Mahi Aroha has been delayed by Covid-19. The Covid-19 lockdown demonstrated the critical role carers play - the pandemic disrupted access to home care, respite, day programmes and other services, and family carers stepped up, providing intensive support for weeks with little outside help. But a survey of almost 700 family carers, [Caring in Lockdown](#), shows how invisible and unsupported these New Zealanders were.

The issues included poor access to information to keep themselves and vulnerable family members safe; no information or access to Personal Protective Equipment until risk Level 2; sudden changes to key respite and funding supports that confused carers at a critical time; and poor information and coordination so carers could access breaks after weeks of caring as New Zealand emerged from Covid-19 lockdown.

Both this survey and the consultation on the Carers Strategy Action Plan show that New Zealand is not doing enough to provide the support carers need, including around respite care. We must do more and better. We urge the incoming Government to implement the Action Plan as a matter of priority.

The Alliance would like to work with the Government to:

- Introduce and fund support programmes for all New Zealander's diagnosed with a neurological condition, supporting them and their whānau during the many phases of living with a neurological condition
- Commit funding to providing specialist nurses, physiotherapists, occupational therapists and psychotherapists to provide community based primary health care for those living with a neurological condition, along with specialised neuro-physiotherapy programmes
- Partner with the Government on the best ways to deliver support and care services nationally
- Develop strategies and action plans for outreach to the Māori & Pasifika communities in developing culturally specific clinical and support services for those impacted by neurological conditions
- Adequately fund those providing 'in home care' supporting those living with neurological conditions throughout the sector, so that the Alliance members can deliver meaningful and consistent services
- Implement the Mahi Aroha action plan as part of the Carers Strategy for all New Zealanders

Neurological Research

The Alliance would like to work with the government to consider, as a priority, the development of a framework and plan for addressing the burden of neurological disease in New Zealand. This includes increasing the number of neurologists, increasing the number of research active clinicians working in a neurological discipline, and prioritising research funding according to the burden of neurological conditions.

This would be aligned to the New Zealand Health Research Prioritisation Framework, developed to support the implementation of the New Zealand Health Research Strategy (NZHRS). The NZHRS calls for funding agencies to provide strategic leadership. Although the government has plans and frameworks for some neurological conditions, such as dementia, there is no overall strategy for reducing the burden of neurological disease in New Zealand.

There are more than 700 neurological conditions and research into the brain, spinal cord, and nervous system provides a lot of crossover in the understanding, prevention, and treatment of these conditions. New Zealand currently spends less than 1% of its total health budget on research, below the international recognised benchmark of 2.4%.

The recent decision not to continue the funding of Brain Research New Zealand, one of the Centres of Research Excellence (CoRE), will have an impact on the funding available to New Zealand's world leading neurological researcher community, based in academic institutions and DHB's throughout Aotearoa. There is significant risk that New Zealand will lose vital skills from the neurological research community as the competition for scarce funding intensifies.

Opportunities for research is one of the biggest draw cards for attracting and retaining highly skilled health professionals into employment. Reducing these opportunities even further will have a drastic impact on our already under resources neurology numbers.

The Neurological Alliance is keen to explore a collaborative working party with the Government, the Health Research Council, philanthropic funders and research institutions to develop the framework and plan needed to meet the ever-growing burden for New Zealanders. The Neurological Alliance encourages the new Government and its appropriate Ministers to seize on this opportunity and provide a clear pathway for the future.

The Alliance would like to work with the Government to:

- Consider the development of a framework and plan for addressing the burden of neurological disease in New Zealand, which would include increasing the number of neurologists and research active clinicians working in a neurological discipline, and prioritising research funding according to the burden of neurological conditions

About the Neurological Alliance

The Neurological 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. All members have a common desire to promote community awareness of neurological diseases and to see that the needs of people with neurological conditions are met.

More information and the Terms of Reference can be found at the Alliance's website:

<http://www.neurologicalalliance.org.nz/>

The Neurological Alliance is made up of the following organisations (listed alphabetically) along with their current representative:

Catherine Hall
Alzheimers NZ

Claire Williams
Cerebral Palsy Society

Scott Arrol
Dementia NZ

Ross Smith
Epilepsy NZ

Jo Dysart
Huntington's Disease Association NZ

Carl Sunderland
Motor Neuron Disease NZ

Amanda Rose
Multiple Sclerosis NZ

Dr Tristram Ingham
Muscular Dystrophy NZ

Rich Easton
Neurological Foundation of NZ

Dave Mitchell
NZ Dystonia Patient Network

Andrew Bell
Parkinson's NZ

Lisa Foster
Rare Disorders NZ

Mark Vivian
Stroke Foundation NZ

Helen Willacy
Tuberous Sclerosis Complex NZ