STROKE AOTEAROA NEW ZEALAND SUBMISSION FOR THE DRAFT CARERS' STRATEGY ACTION PLAN

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Tēnā Koe

In our capacity as the national charity dedicated to supporting people affected by stroke in Aotearoa thank you for the opportunity to provide a submission on the Draft Carers' Strategy Action Plan.

More than 9,000 strokes occur in Aotearoa each year. It is the second largest cause of death and the leading cause of adult disability. Stroke affects people of all ages, with nearly a third of these being under 65. Around 89,000 people live with the long-term effects of stroke, and when we include their whānau, carers and support networks, we estimate the number of people impacted reaches 350,000 New Zealanders. As strokes rates increase across vulnerable populations, this impact will continue to grow.

Our response draws on insights from our participation in the Mahi Aroha Advisory Group, and our engagement with carers through the many stroke groups we support, feedback from our Lived Experience Advisory Panel (LEAP), analysis of calls received on our 0800 Helpline, and Stroke Aotearoa's mahi in the community.

Stroke carers are diverse including parents, partners, young people, children, and older adults. All are balancing caregiving with other commitments, including employment, family life, schooling and study, their own health conditions, financial pressure, and more. Their caring responsibilities can significantly affect wellbeing, limit their ability to work, strain finances, impact mental health, limit social participation and contribute to isolation. There are limited opportunities for rest and self-care.

I received a letter from a carer last year, whose husband had a stroke in his late 50s. Her words were incredibly sobering. She was a nurse and described the change in her husband since his stroke, and the incredible toll this was having on her whanau. She finished her letter by telling me she lies in bed at night imagining how her life would be, if he were dead. Her story is not unique.

Carers are essential contributors to community resilience and wellbeing – and for them to do this government and society needs them to be resilient, well, and well-supported. Systems across health, disability, and social support must reflect the diversity of carers' experiences and address the barriers they face, including access to financial support, flexible work, respite services, and mental health and wellbeing support.

Stroke Aotearoa advocates for a carer support system which removes disadvantage, and responds to carers' needs in practical, equitable, and compassionate ways. Carers are an essential part of the New Zealand economy – without them this country could not meet its obligations to those in need of care and support. Supporting carers strengthens families and communities and enables everyone, regardless of background or circumstance, to live well.

Nāku noa, nā

Jo Lambert, Chief Executive Officer

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Stroke by numbers
In Aotearoa New Zealand

Stroke
Aotearoa NZ

A leading cause of adult disability

The second leading cause of death

9,000

Strokes happen every year, that's one every 55 minutes

89,000

People living with the effects of stroke

1 in 4

1 in 4 of us will be impacted by stroke in our lifetime

$1,100,000,000

Annual economic cost of stroke in 2020 increasing to:

$1,700,000,000

by 2038

90%

STROKES ARE PREVENTABLE

350,000

PEOPLE AFFECTED IN AOTEAROA

40%

INCREASE IN STROKES FORECAST 2018-2028

Māori and Pacific People experience strokes
10-15 years younger

60% of strokes for Māori and Pacific People occur at working age (15-64 years)

20% of strokes for other ethnicities occur at working age

1. What do you think about the change to a 'rolling' Action Plan to improve outcomes for carers over the short and long-term?

Stroke Aotearoa supports the shift to a rolling Action Plan. A rolling plan provides a flexible, long-term framework that can respond to changing carer needs, population and system pressures, and emerging evidence, while maintaining a sustained focus on outcomes. It also creates stronger conditions for ongoing relationships with carers, whānau, Māori, Pacific communities, disability organisations, NGOs, and enables more meaningful application of Te Tiriti principles of partnership, participation, and active protection.

However, flexibility must be balanced with accountability. Previous attempts to implement Mahi Aroha have failed, with very little progress made towards well-intentioned action plans. We know from experience that without clear milestones, accountability, transparent reporting, and strong governance, priorities and mahi will drift.

New Zealand's Carer workforce is at breaking point, and this cannot be allowed to happen again. We have concern that the short-term goals of the Action Plan are insufficiently specific, with a focus on thinking rather than action. Stroke Aotearoa recommends:

- Action focused 12 months goals within the plan, using existing data and analysis to introduce tangible programmes that directly improve financial wellbeing, respite care and support, and carer recognition. The Mahi Aroha Advisory Group working with agencies has already provided this information.
- Establishing a defined review cycle every 12 months with public progress reporting
- Setting medium-term milestones within the rolling plan for the 2-3 year horizon
- Embedding Māori and lived-experience carer representation in governance for each review cycle

A successful rolling plan should prioritise practical implementation, genuine partnership with carers and communities, and clear accountability so that it aspires to better outcomes and delivers these in ways that honour carers' vital contribution to Aotearoa.

2. Do you think the set of immediate deliverables are an appropriate first step towards achieving the Action Plan outcomes? How could we make these more effective for you?

Overall, the immediate deliverables align with many of the challenges experienced by stroke carers. However, one of the most pressing issues we see through our work is carer distress, a significant and unmet need requiring urgent action. While the strategy acknowledges health, wellbeing, and financial security challenges, the current immediate actions are unlikely to alleviate these pressures in the short term.

There is a risk that the deliverables remain symbolic or analytical rather than producing timely, tangible improvements for carers under significant strain. Our feedback from carers indicates, for example, that a National Carers' Day will not meaningfully improve recognition or support.

There is also a risk that concepts such as "cultural safety" or "navigation" are interpreted too narrowly, resulting in training or resources that do not shift power or improve practical access for Māori, Pacific, rural or high-deprivation carers. To increase effectiveness, we recommend:

- Pairing recognition activities with real service or funding improvements
- Ensuring promotion of respite services is matched with actual investment in respite capacity, including kaupapa Māori and community-based respite
- Collaboratively developing navigation tools and services with carers, Māori, Pacific, disability and NGO partners
- Linking financial support to a time-bound programme of staged policy and service improvement

3. How can government work with communities to implement the Action Plan in the short, medium and long term?

Short term

Government must work with communities by collaborating with carers, Māori, Pacific, disability organisations, and NGOs on the development of immediate deliverables. Funding should support local providers to test and refine practical solutions such as respite models, navigation tools, and referral pathways. Establishing local and regional forums will ensure national actions are adapted to local contexts. Māori and Pacific partners should be resourced to lead engagement, using values-based models of care such as manaakitanga and whanaungatanga.

Medium and long term

Implementation should be supported by stable, inclusive governance that brings together agencies, carers, iwi, Māori providers, Pacific and disability organisations, and NGOs. Cross-party commitment is needed to avoid short-term political cycle decision making. Government can strengthen long-term progress by:

- Investing in capability (e.g., data, evaluation, and Te Tiriti-aligned practice)
- Supporting community-led and kaupapa Māori initiatives
- Feeding insights from local innovation back into updates of the rolling Action Plan

4. Is there anything else that agencies should consider when implementing current actions to ensure what is delivered meets the needs of family, whānau, aiga and individual carers?

Agencies must pay strong attention to equity and to the different, overlapping factors that shape each carer's experience. Carers are not a homogenous group. Māori carers, Pacific carers, young carers, older carers, disabled carers, rural carers, and those supporting people with complex needs face different barriers and opportunities, and for many caregivers, several of these factors apply at once.

Implementation should be grounded in mana-enhancing engagement and genuine collaboration, and in practical changes that reduce administrative burden, fragmentation, and the need to "knock on multiple doors" across services.

Applying a Te Tiriti lens is critical. Implementation should uphold tino rangatiratanga and active protection by:
- Enabling Māori governance roles
- Investing in kaupapa Māori and Māori-led services
- Ensuring measures of success reflect outcomes that matter to Māori, Pacific and priority communities

5. Many of these actions are intended to form the basis for future actions. What should we consider as we review and form future actions?

Future actions should be collaboratively shaped with carers', Māori, iwi, Pacific and disability partners, NGOs and carer groups, with a focus on what demonstrably improves outcomes for carers across groups and regions. Reviews should consider completed actions, as well as whether they:
- Reduced distress and disadvantage
- Improved access to effective supports, including kaupapa Māori and community-based options
- Strengthened financial security
- Enabled carers to sustain caring roles without compromising their own wellbeing or aspirations

To give effect to Te Tiriti over time, each review should assess how partnership, participation, and active protection are reflected in governance, funding, service models, and data practices. Future actions should be jointly shaped with Māori, iwi, Pacific and disability partners, NGOs, and carer groups, and supported by clear resourcing, accountability and evaluation plans.

Stroke Aotearoa New Zealand welcomes the opportunity to continue our contribution to the development of a Carers' Strategy Action Plan that truly reflects the needs, aspirations, and lived realities of carers across Aotearoa.

6. Thank you for the opportunity to provide a submission

We support the intent of the rolling Action Plan and are committed to working alongside government, Māori, Pacific partners, disability organisations, NGOs, and carers themselves to ensure its actions are meaningful, equitable, and grounded in practical change. By centering carers' wellbeing, strengthening systems of support, and upholding Te Tiriti o Waitangi, we can create a future where carers are recognised, valued, and empowered to thrive alongside those they care for.

We look forward to ongoing collaboration to turn this vision into sustained, measurable progress for carers, whānau, and communities in Aotearoa.