



# Alzheimers New Zealand

10 March 2026

Ministry of Social Development  
CAPSubmissions@msd.govt.nz

Tēnā koutou

Alzheimers New Zealand welcomes the opportunity to provide feedback on the Draft Carers' Strategy Action Plan.

## About Alzheimers New Zealand

Alzheimers NZ is a national organisation representing people with dementia and their family. We raise awareness of dementia, provide information and resources, advocate for high quality services, deliver dementia education, and promote research. We also support local Alzheimers organisations that provide community-based services across the country.

## Our feedback

We commend the Ministry of Social Development and government agencies with support from the NZ Carers Alliance, the Carers' Strategic Advisory Group, for developing the draft Carers' Strategy Action Plan. We support a national approach that recognises and supports family and whānau whose mahi makes a significant contribution to New Zealand's health and social care system.

Dementia is one of our fastest-growing health challenges, and carers play a critical role in helping people with dementia live well at home. Supporting carers' wellbeing, financial security, and ability to balance caring with daily life is important to sustainable dementia care.

Carers take on the role at great cost to their physical and mental health and financial wellbeing. It is imperative that all the parts of the care and disability system work together in a coordinated way if this Action Plan is to make a real difference to carers. Coordination and leadership are needed across government agencies but also needs to extend across all the bodies/organisations that shape the systems and policies that impact carers. A recognition of carers alone is insufficient if actions in the overall plan don't translate into practical supports.

## Dementia and the role of carers

Around [83,000 people](#) live with dementia in New Zealand in 2025 and it is projected to rise to an estimated 170,000 by 2050. In 2020, carers provided over [1 million hours](#) of unpaid dementia care each week, totalling around 53 million hours a year. If this care were paid, it would cost around \$1.19 billion annually. Carers are the backbone of dementia care, yet [many](#)

[experience burnout](#), declining mental health, social isolation and financial pressure. Without action, the rising number of people with dementia will place growing pressure on families and the wider health and social system.

### **Key issues for carers of people living with dementia**

1. Many carers experience anxiety, depression, loneliness, and feeling undervalued because caring for someone with dementia is long-term, intensive, and emotionally demanding.
2. Caring brings significant financial pressure, disproportionately affecting women.
3. Respite is important but [access is inconsistent](#), difficult to navigate and not always dementia-capable, age appropriate or culturally safe.
4. Māori, Pacific, and Asian carers often face cultural, language or access barriers and some may not identify with the term carer.

### **Responses to consultation questions**

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

Alzheimers NZ has reservations about having a rolling Action Plan. We acknowledge the importance of having some flexibility to respond to emerging changes however some safeguards are needed to ensure the plan is adequately resourced, delivered fully and on time. The Action Plan also needs to be supported by effective governance with measurable outcomes.

As a 'living' document, the Action Plan should continue to support carers' voices in shaping priorities and actions. This depends on regular engagement with carers, carer organisations, with clear reporting and ongoing evaluation. The expertise shared by carers and carer organisations should be resourced if it is to be sustained over time.

Our Lived Experienced Advisory Group has identified that not all carers are connected to a carer organisation and could therefore be quite isolated. We recommend looking at diverse ways to maximise the reach of the Action Plan.

#### **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?**

While we recognise the difficult environment within which this Action Plan is being developed, we are disappointed that the first deliverables are so modest and are not sufficient to achieve meaningful outcomes for carers of people living with dementia. There is a danger of tokenism if more substantive action such as greater access to respite and improving service navigation for carers does not become a priority from 2027.

## Recognition and appreciation

Public recognition is valuable, but carers also need practical support. The Plan should acknowledge the emotional and physical toll of long-term dementia care and strengthen access to dementia-capable respite, flexible work options and clear information.

Additional considerations for effectiveness:

- Recognition should be practical not just symbolic, including access to respite, flexible work, and clear information.
- Actions should address specific needs such as high-intensity, age appropriate and long-term care.
- Cultural safety should be included through co-design from Māori, Pacific, and other communities.
- Navigation support should help carers access the right services early and consistently.

## Health and Wellbeing - Respite support

Alzheimers New Zealand considers respite essential, not optional, for carers of people living with dementia. Dementia care is long-term and demanding. Respite protects carers' mental health, prevents burnout, and enables carers to provide safe care at home. Lack of respite contributes to crisis admissions and earlier entry into residential care.

We recommend that the final Action plan strengthens the future state wording, for example:

“Comprehensive and responsive respite and break options are available to carers, including in-home, out-of-home, emergency, informal, and planned short and long-term options for respite.

Carers and care recipients have meaningful breaks and better pathways to services and supports that are flexible, age-appropriate, culturally responsive, and reflect their choices and needs.”

The current draft Action Plan does not use strong enough language to reflect the critical importance of respite. Respite must be treated as a core part of carers' health, safety, and economic stability. The Action Plan should also clearly state that respite is central to sustainable caring. Mapping services, improving referrals, and promoting diverse respite models are important steps, but these actions must be prioritised, resourced and monitored.

Additional considerations for effectiveness:

- Respite should be flexible and accessible including in-home, day programmes and overnight stays.
- Respite should have options that are culturally appropriate and age appropriate. Approximately 8% of people with dementia have young onset (are aged under 65 years when diagnosed).
- Breaks should match care needs including during crisis and during periods of high stress.

- Services should have trained staff and safe environments for diverse families.
- Outcomes should be measured including equity, uptake, and impact on carers' wellbeing.

### **Financial security**

Alzheimers New Zealand recognises that caring for someone with dementia often brings significant financial pressure. Carers may reduce work hours, leave employment, or face additional care costs. The Action Plan should strengthen financial support. Financial security helps carers protect their own health and wellbeing and continue providing high-quality care.

We support initiatives that:

- Match financial support to the level and type of care.
- Provide short-term relief while longer-term reforms are developed.
- Support workforce participation through flexible work and employment protections.
- Monitor uptake, equity, and the impact on carers' wellbeing.

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

Alzheimers NZ believes that effective implementation of the Carers' Strategy Action Plan requires strong partnerships between government, carer organisations, community organisations, ethnic communities, and health providers. Strong partnerships with carers with lived experience are also essential in the short, medium, and long term. We recommend:

- Short term: Co-design with carers and community organisations, raise awareness of supports, expand flexible respite and peer support.
- Medium term: Expand successful initiatives, improve equity of access, and strengthen workforce capability.
- Long term: Support sustainably funded community-led care, integrate carer priorities into wider policies and monitor and evaluate outcomes.

### **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?**

When implementing the Action Plan, agencies should be flexible, practical and responsive to carers' real experiences. Support must be culturally safe, easy to access, appropriate to different age groups and able to adapt as needs change. Agencies should:

- Engage carers in monitoring, evaluation, and governance.
- Collect and use data.
- Prioritise improvements to respite, mental health, and navigation.
- Ensure cultural safety for Māori, Pacific, and diverse communities.
- Integrate implementation with health, social and dementia strategies including the Dementia Mate Wareware Action Plan.
- Maintain accountability and transparent reporting.

## 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?

Alzheimers NZ supports future actions that are carer-centred, evidence-based and financially sustainable. Future actions should:

- Prioritise carers' real experiences.
- Strengthen dementia-capable services
- Improve financial security including through paid leave, KiwiSaver contributions and flexible work or study options.
- Ensure timely access to respite and mental health support.
- Improve equity and cultural safety.
- Coordinate across services and align with health and social strategies.
- Use monitoring and evaluation to improve services over time.
- Fund sustainable, community-led, flexible care models.

### Recommendations

Alzheimers NZ recommends that the Ministry of Social Development:

- Recognise carers, including dementia carers as a priority group.
- Strengthen and expand dementia-capable respite services that are flexible, culturally and age appropriate and community-led.
- Invest in accessible and flexible mental health supports.
- Address financial inequities, particularly for women, through paid carer leave, KiwiSaver contributions and employment protections.
- Ensure equity and cultural responsiveness through co-design with Māori, Pacific, Asian and other underserved communities.
- Align the Carers' Strategy Action Plan with the Dementia Mate Wareware Action Plan and community dementia services.
- Strengthen accountability, monitoring, and evaluation.

### Conclusion

Alzheimers NZ supports the Draft Carers' Strategy Action Plan. Carers are essential partners in care and require strong, practical support that reflects their important role. By prioritising carers and investing in respite, mental health, financial security and culturally appropriate services, the Action Plan can better support carers' wellbeing. Strong accountability will help ensure the system is fair, sustainable and effective for carers and the people they support.

Our submission has been informed by our Lived Experienced Advisory Group. Some members of this group will be making their own submissions. Thank you again for the opportunity to provide feedback and we look forward to ongoing engagement as the Carers' Strategy Action Plan is finalised and implemented.

Ngā mihi

A handwritten signature in blue ink, appearing to read 'Catherine Hall', written in a cursive style.

**Catherine Hall**  
Chief Executive