Alzheimers New Zealand

9 October 2025

palliativecare@tewhatuora.govt.nz

Tēnā koutou

Alzheimers New Zealand welcomes the opportunity to provide feedback on the Proposed National Model for Integrated Adult Palliative Care in Aotearoa New Zealand.

About Alzheimers New Zealand
Alzheimers New Zealand is a national umbrella organisation representing people with dementia, their family and whānau. We raise awareness of dementia, provide information and resources, advocate for high quality services, deliver education to the dementia sector, and promote research. We also support local Alzheimers organisations that deliver support, education, information, and related services directly to those living with dementia in their communities.

Our feedback
Below we have provided our feedback, structured according to the consultation questions.

1. Primary palliative care
What is good about the core components?
We welcome the inclusion of primary palliative care as a core component. Highlighting early conversation is especially important for people with dementia. The focus on equity and compassionate communities is also very positive. Overall, the 11 core components are strong and reflect our view that most people can be supported in their communities with appropriate care. Embedding palliative care in primary care ensures timely and person-centred support, which is important for people with dementia.

What part(s) need improvement?
While the model references facilitation to personal care and respite, it does not address the current challenges many people face in accessing these services. Significant changes will be needed to ensure that supports are available to everyone who needs them. The model should also recognise the role of community-based organisations in supporting people at home and in the community. Additionally, primary care providers will also need more training, resources, and workforce support to meet the needs of people with dementia, including guidance on when and how to initiate palliative care conversations.

How satisfied are you with them?
The majority of people can be supported in their communities by primary care teams, which is likely the preference for many. However, we are cautious about whether it is achievable without significant investment in the primary sector, including additional resources, workforce development, and enhanced respite and community support options.

2. Specialist palliative care:
What is good about the core components?
We welcome all ten core components, particularly the focus on integration across all services and reducing inequities. It is very positive that specialist palliative care is driven by need rather than diagnosis or prognosis, as this approach benefits people with dementia who may not traditionally have accessed these services. We also support the flexibility for specialist palliative care to provide holistic, multi-disciplinary support, especially for people with advanced dementia who often have multiple health issues. The option for direct or indirect provision is also positive, extending the reach of services.

What part(s) need improvement?
While the 11 components acknowledge inequities and underserved communities, we are concerned that access remains a key issue, particularly in rural and underserved areas. Specialist teams need more training in dementia-specific palliative care to provide high-quality, tailored support. Coordination with primary and community services could be strengthened to improve continuity of care. The use of navigators and culturally appropriate support is welcome, but additional strategies, resources and investment will be needed to make specialist services truly equitable.

How satisfied are you with them?
We are pleased to see that specialist palliative care is guided by need rather than diagnosis or prognosis, which helps address historical inequities. The flexibility for direct or indirect provision is positive, as it will extend the reach of specialist services. Overall, we are supportive of the 11 core components but note that satisfaction depends on improving access, dementia-specific guidance and training, and resources for primary care providers to manage the needs of people with dementia, their family and whānau, and to know when and how to initiate palliative care discussions.

3. Overall model
What do you think is good about the proposed model as a whole?
We welcome the model's emphasis on integration, person- and family/whānau-centred care, and collaboration across services. This approach supports holistic care and recognises the roles of multiple providers in delivering comprehensive palliative care. The focus on coordination across services is particularly positive for people with dementia, ensuring that care is continuous and responsive to their complex needs.

What needs improvement?
The model should include dementia-specific pathways and address the unique needs of people with dementia. Key areas for improvement include early recognition of palliative care needs, guidance for advance care planning, and workforce development to build dementia-specific expertise across both primary and specialist services. It is also important to incorporate community services, which often provide specialist dementia support.

How satisfied are you with this as a future model?
We are generally supportive of the overall model but satisfaction is conditional upon the incorporation of dementia-specific considerations and resources to ensure equitable, high-quality care for people with dementia, their family and whānau.

4. Thought exchange question
What is the most important change you believe is needed to improve palliative care services for all adults in Aotearoa New Zealand?
From our perspective, the most important change is adequate resourcing across the full spectrum of palliative care services. Neither primary nor specialist services can deliver the comprehensive care outlined in the model without appropriate investment. This includes funding for workforce development, training in dementia-specific palliative care, home and community supports, respite services, and community involvement.

The other important change is the integration of dementia-specific pathways in palliative care. This should include guidance and support for advance care planning with people with dementia, their family and whānau and equitable access to services, including in rural and underserved communities. Implementing these changes will ensure people with dementia receive timely, compassionate, and appropriate care, with family and whānau fully supported.

Conclusion
The Proposed National Model for Integrated Adult Palliative Care is clear and well thought out. It focuses on person- and whānau-centred care, cultural safety, fairness, and working well across all services, with most care delivered by non-specialist services, with specialist teams supporting complex needs. The model could be strengthened with clear dementia pathways, practical guidance on workforce and resources, better coordination with primary and community services and improved access in rural and underserved areas. To be fully effective, the model will also need adequate funding, robust implementation plans, and ongoing review.

Ngā mihi

Catherine Hall
Chief Executive