**Webinar Q&A responses**

Webinar title: **Adult Models of Care (Palliative Care); National webinar for stakeholders**

When: Wednesday 23 October 2024, 3 - 4pm

Presenters: Louisa Ingham and Hinetewai (Co-chairs of the Models of Care – Adult Working Group)

Webinar: Teams Live event

The Co-chairs of the Models of Care – Adult Working Group presented an update to stakeholders of the Working Groups progress to date. The presentation included:

• An overview of the National Palliative Care Work Programme

• Providers of palliative care

• Current challenges

• Future population challenges

• Proposed guiding principles

• Proposed core components of palliative care

As well as an opportunity for attendees to ask questions (via the Q&A function)

The slides and recording of the presentation were made available on the Te Whatu Ora webpage from November 2024 [National Palliative Care Work Programme – Health New Zealand | Te Whatu Ora](https://www.tewhatuora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/palliative/national-palliative-care-work-programme).

Please email any questions about this webinar to: [**PalliativeCare@tewhatuora.govt.nz**](mailto:PalliativeCare@tewhatuora.govt.nz)

Thank you to everyone who attended the webinar, submitted questions or comments, or viewed the recording. Below are the Working Group’s responses to the questions and comments, grouped into 6 themes.

# **Navigation/Coordination:**

* It would be great to hear about the scope the group sees for 'cultural navigation' roles.

Our group has been considering what ‘navigator’ or ‘co-ordinator’ roles might look like. We see this type of role as important to support people to access the services they need and ensure service providers are working together.

* A strong service coordination approach and designated care coordination was mentioned. Do you see this occurring more at the primary palliative care level in the general practice or in the specialist palliative care space or both?

We think that ‘navigators’ or ‘co-ordinators’ could support people to access palliative care earlier, especially in our underserved communities. These roles could be based in either primary or specialist palliative care, or both. This would need to be considered further during implementation planning.

# **Aged residential care (ARC):**

* How do we improve the connect between Aged Residential Care facilities and Hospice? My recent experience this year was poor planning for managing pain and anxiety where hospice was unable to chart medications directly into Medimap and prolonged waits occurred, for the one Nurse Practitioner contracted by the facility, to have time to chart these. This often resulted in the pharmacy also being closed. My belief had been that these would be already charted in anticipation of the end-of-life process, to reduce suffering. The facility was reactive rather than responsive to planning for the person's needs.

Thank you for sharing your experience; this is a clear example of the issues we are striving to address by improving consistency of palliative care services across Aotearoa New Zealand. We agree that strong links between Specialist Palliative Care and facilities are essential, especially as the number of people living and dying in aged residential care (ARC) is increasing. These links could include providing ARC staff with education about palliative and end of life care, as well as face-to-face visits, phone advice when required, and better collaborative use of clinical tools such as Medimap.

* I'm wondering if the 'residential care' statistics related to place of death includes intellectual disability community residential services, or just aged-care residential services?

Yes, they do. These figures are based on the MORT study 2000-2018. The ‘Residential Care’ category includes drug, alcohol and IHC facilities (although the numbers in these places are small).

* I would like to know how much engagement there has been with ARC providers including those few medical practices that specialise in ARC. This seems important as 1/3 of deaths are within ARC.

Yes, engagement with the ARC sector is very important in this work. We have a nominated representative from the Aged Care Association’s Nursing Leadership Group in this Working Group (Anna Blackwell), as well as ARC sector representation in the Steering Group.

* In the aged care facility I work in, we are very fortunate to have regular input from Hospice and also the Hospice CNS participate in monthly MDT meetings which is very helpful.

That sounds like great collaborative working!

* Please note aged care statistics will likely be lower than actual as it may not include those that privately pay for ARC services.

Thank you. We checked the technical detail and the place of death data we shared is also based on the address on the death certificate, which picks up a wide range of residential care facilities.

# **Funding:**

* One of the challenges with a principle of "funding follows the patient" is creating sustainable services in small populations where the volume of funding is not sufficient to support the required infrastructure - how does the group propose to deal with this especially for our rural communities?

The funding challenges will be picked up by our next working group (Contracting and Funding) which will need to take things like rurality into consideration.

* What would the funding following the patient mean in an environment of TWO, NGO and private health services providing care to an individual and their whanau? Can you please give an example of how you see the funding following the patient?

The principle we are aiming for is that services providing palliative care should receive the funding to do so and that cost shouldn’t be a barrier to receiving services from the most appropriate provider. This would be especially important in rural communities with limited access to Specialist Palliative Care.

* Given the current context of healthcare change, interested to know that funding has been committed to implementing the steering group recommendations?

Additional funding for palliative care services has not been secured to date as the funding and implementation requirements for this work will not be known until the new models have been developed and finalised.

# **Community engagement:**

* Are you working with the people focusing on Advanced Care Planning - is it part of your work to help socialise communities to the concepts?

The Working Group believes that proactive care planning and collaborative decision making are important components of quality palliative care. Our Te Whatu Ora facilitators liaise with the Te Whatu Ora lead for ACP regularly.

* How do you engage with the community for whom the services are being developed?

In May this year, Te Whatu Ora held a public survey of palliative care services and gathered a wide range of views to inform this work. They received over 1000 responses. This has helped us to understand what is currently working well, not working well and the priorities for change. We also have community representatives on the Working Group, ensure updates (such as this webinar) are open to the public, and there will be an opportunity for public feedback on the model of care that our group develops.

* How do we help the community understand what is available - so at the end of your work will there be an education package?

We will need to think about this when we look at how the new model can be implemented.

* Would we agree it calls for a public health campaign?

Wouldn’t that be great!

# **Workforce:**

* As you've indicated, palliative care is about a lot more than end-of-life care. Palliative care services should ideally be initiated at diagnosis and are often essential years before expected death. Ideally, all care providers should be trained on basic palliative care competencies to ensure it is part of the standard of care.

We agree!

* Nurse-led services seem to be the way forward. Are enough palliative specialist nurses being trained? How do rest home nurses get supported into Palliative care – there’s a big workforce there.

Workforce capability and capacity is a big challenge for many sectors, including primary and specialist palliative care. The Workforce Woking Group (scheduled to start in mid-2025) will consider these challenges in more depth.

# **General:**

* What resources are available for palliative care patients in the Bay of Plenty?

We suggest people talk to their GP to find the right services for them locally. There is also a lot of information available online e.g. [Hospice New Zealand / Te Kahu Pairuri o Aotearoa](https://www.hospice.org.nz/)

* Will there be a paediatric palliative care webinar please?

Te Whatu Ora haven’t planned a webinar for the paediatric palliative care work however, public feedback on the proposed paediatric model of care will start early in 2025 so everyone has an opportunity to have their say. Keep an eye on their website and stakeholder email updates.

* How does the working group see the role of the Te Whatu Ora Assisted Dying team and service providers in relation to its work?

The Te Whatu Ora Assisted Dying team hold the remit for implementation of these services, which are governed by law. Our Te Whatu Ora facilitators liaise with this team regularly. Palliative care services focus on the experience of dying, rather than the mode of death. Our Working Group does not have the mandate to make any additional recommendations regarding Assisted Dying.

* When you say, a standardised bereavement structure, what detail do you have.

We know that at the moment, there is variable access to bereavement support across Aotearoa. We would like to see all people being able to access bereavement support from an appropriate service, as part of routine care.

* Thoughts re management with the expected increase of patients with cognitive decline and other neurological disorders?

We know that these patients have complex needs that often span long periods of time and can struggle to get the support they need. However, we haven’t looked at the needs of people with specific diseases or conditions as our focus is to design services for everyone.

* How has trauma informed care been considered in the model?

Thank you, this has come up in many discussions lately, especially after the release of [The-voices-of-underserved-communities-in-palliative-care.pdf](https://www.tewhatuora.govt.nz/assets/For-health-professionals/Clinical-guidance/Specific-life-stage/Palliative-care/The-voices-of-underserved-communities-in-palliative-care.pdf). We are starting to better understand how previous trauma experiences impact peoples’ choices and health outcomes, but there is more work to be done.

* We already have a post code lottery around the provision of such resources as equipment which is certainly a facilitator for people to remain at home. How will these inequities around equipment be addressed?

Access to equipment came up strongly in the palliative care survey responses with many people echoing your concerns. We would like to see more consistent and equitable access to equipment however, this can involve many different agencies (with their own access and exclusion criteria). This will not be a quick fix unfortunately.

Thank you again to everyone who joined us for the webinar and submitted questions. Please email any further thoughts or questions to:[**PalliativeCare@tewhatuora.govt.nz**](mailto:PalliativeCare@tewhatuora.govt.nz)

Please see the website for further information about the [National Palliative Care Work Programme – Health New Zealand | Te Whatu Ora](https://www.tewhatuora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/palliative/national-palliative-care-work-programme)