Health New Zealand
Te Whatu Ora

Palliative Care Survey

Initial findings from our national survey, May 2024

Jo Hathaway, Stephanie Read, and Caitlin Leslie, July 2024

Redesigning palliative care services

Our National Palliative Care Work Programme is redesigning palliative care services and systems to better meet the palliative and end-of-life care needs of patients, whānau and communities.

We developed a short survey to hear directly from:

- people who had used palliative care services for adults (aged over 24 years) in Aotearoa New Zealand (NZ), either for themselves or a loved one
- people working in the NZ health sector with an interest in palliative care.

We wanted to understand what's important to people as we work to identify core palliative care services and develop nationally consistent models of adult palliative and end-of-life care services.

The survey

We asked 11 questions. Seven were closed-ended, asking people to choose an option that best suited them. Four questions were open-ended so people could freely express their thoughts and feelings about palliative and end-of-life-care services.

We especially wanted to know:

- What's working well now
- What's not working
- What are the highest priorities for change

The survey closed on 31 May 2024.

1052 people completed the survey

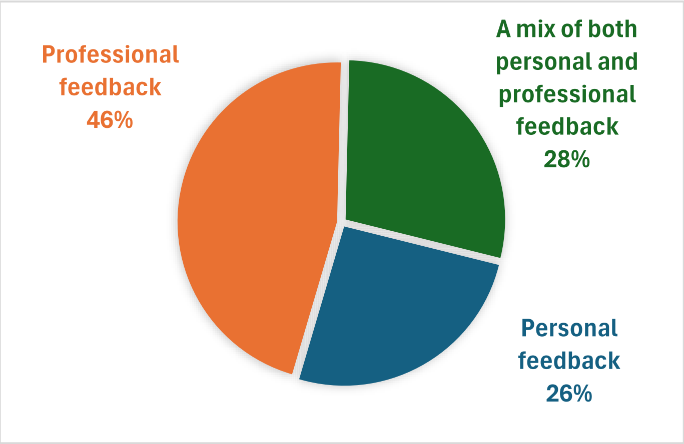
This is what people told us

Thank you to everyone who took the time to share your thoughts with us. After completing an initial review of the responses, we are excited to share the findings for each question with you.

We hope to complete a fuller analysis of the responses over the coming months.

Question 1:

What type of feedback would you like to provide?



Almost half (46%) of people who filled in the survey work in our NZ health system.

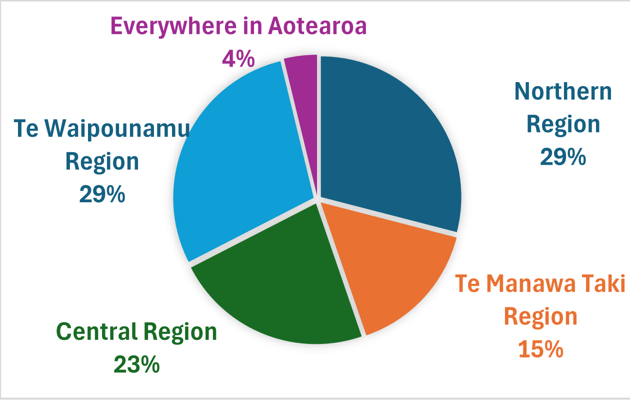
A quarter (26%) were members of the public who had used palliative care services in NZ, either for themselves or for a loved one.

Another 28% were people who work in our health system and had also used these services for themselves or a loved one.

The 4 health regions in Aotearoa New Zealand

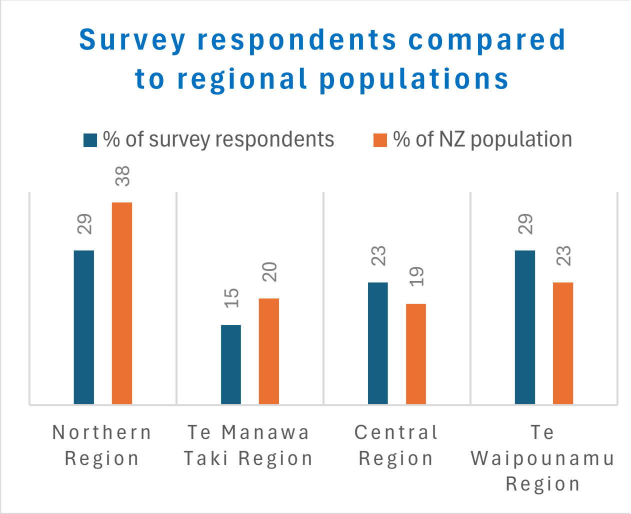
Question 2:

Where in Aotearoa New Zealand does your feedback relate to?



More people gave feedback about services in the Northern Region (29%) and the Te Waipounamu Region (29%) than the Central Region (23%) and the Te Manawa Taki Region (15%).

However, when we compare these percentages with regional populations, it shows that responses for the Northern Region and the Te Manawa Taki Region were lower than their percentage of the population.

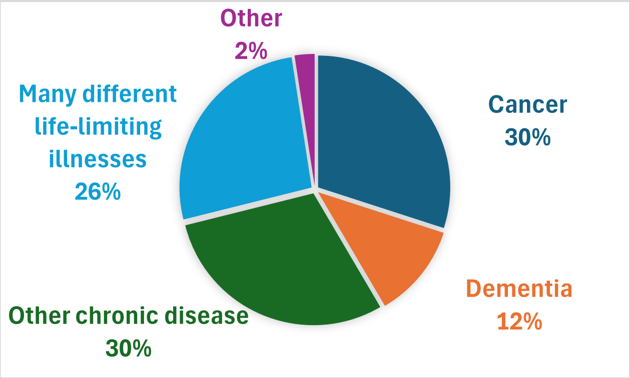

Survey respondents compared to regional populations

This means the Northern Region and Te Manawa Taki Region were underrepresented in this survey.

Knowing which region people have given feedback on will help us to consider the needs, opportunities and priorities for change at both regional and national levels.

Question 3:

What type(s) of illness does your feedback mainly relate to?



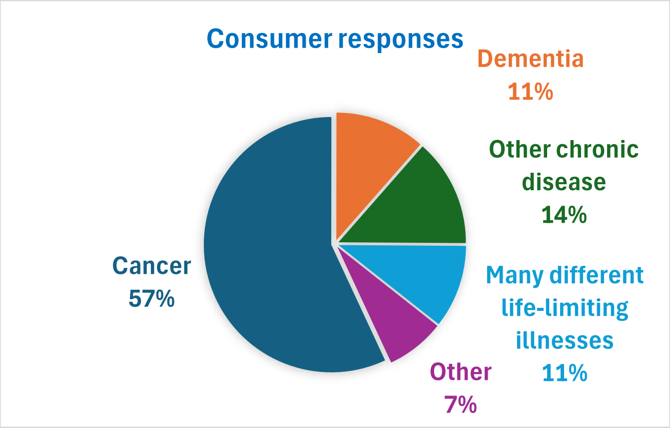
Note: people could tick multiple boxes.

People’s feedback related to a wide range of health conditions including cancer (30%), dementia (12%), and other chronic diseases (30%).

The 26% of people whose feedback related to many different illnesses, were all people who work in our health system.

The ‘Other’ conditions (2%) people identified included stroke, intellectual disability and a range of neurological conditions.

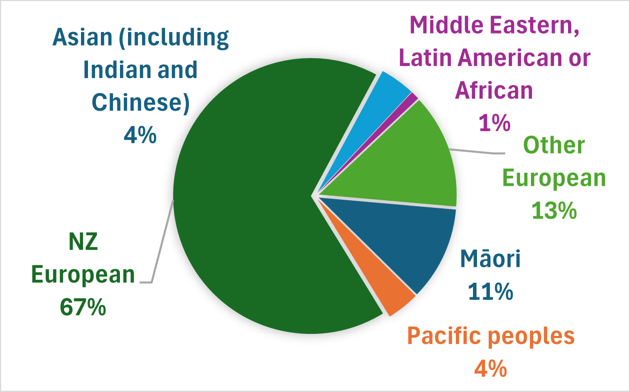
When we only look at the ‘personal feedback’ given by consumers (members of the public who have used palliative care services in NZ, either for themselves or for a loved one), most of their feedback related to cancer (57%).



Note: people could tick multiple boxes.

Question 4:

Which ethnic group(s) do you identify with?

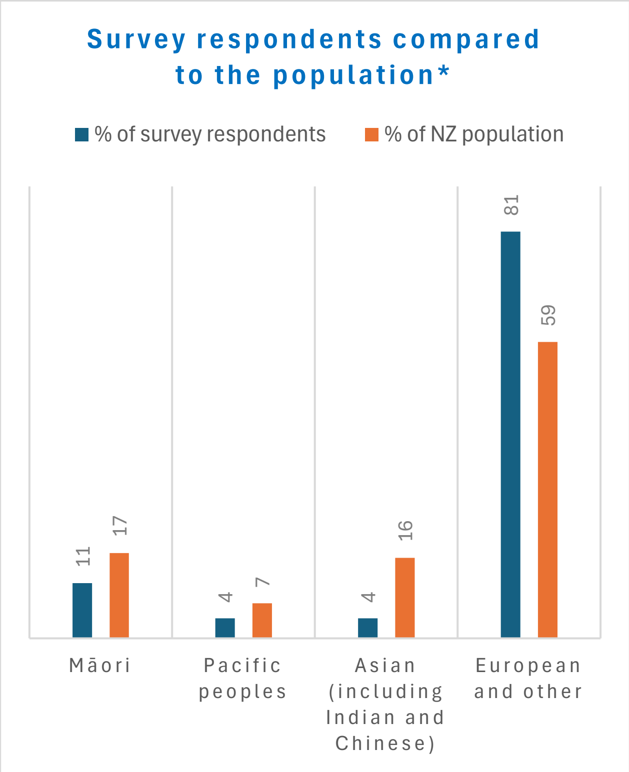


Note: people could tick multiple boxes.

People identified with a wide range of ethnicities. The majority (67%) identified with NZ European and another 13% identified with other European ethnicities.

11% of people identified with Māori, and 4% identified with Pacific peoples.

When we compare these percentages with our national population estimates, it shows that the ‘European and other’ ethnicity group is over-represented in our survey responses. Māori, Pacific peoples and Asian ethnicity groups are under-represented.

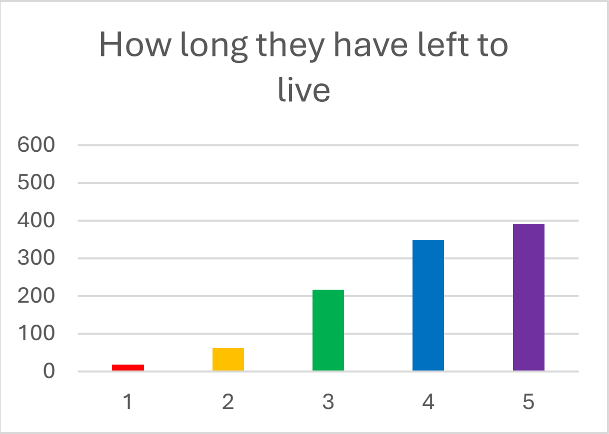


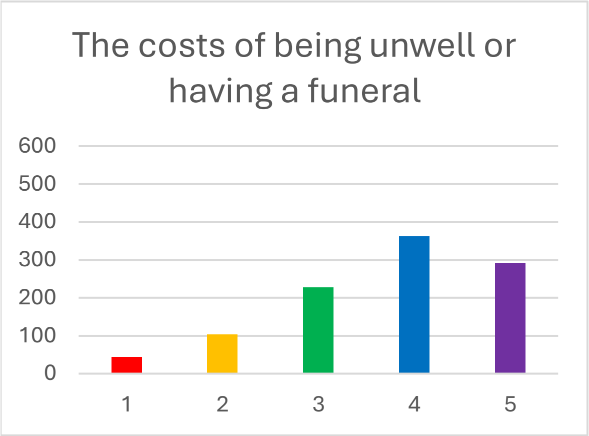
* Source of data: Statistics New Zealand

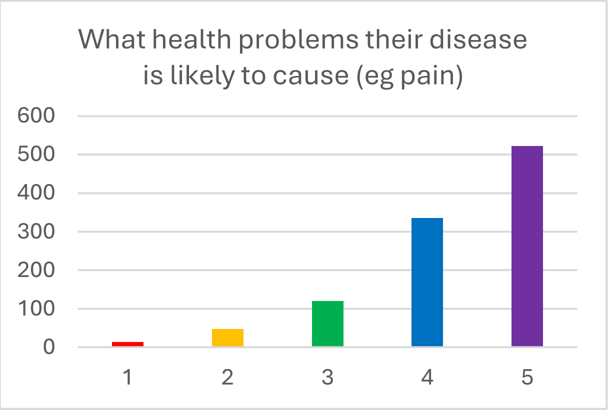
Question 5:

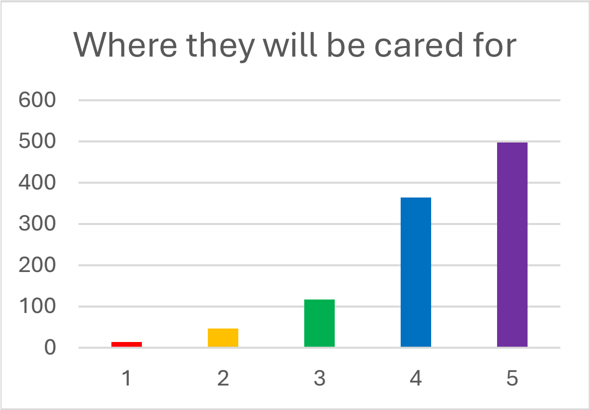
What do you think people receiving palliative care worry about?

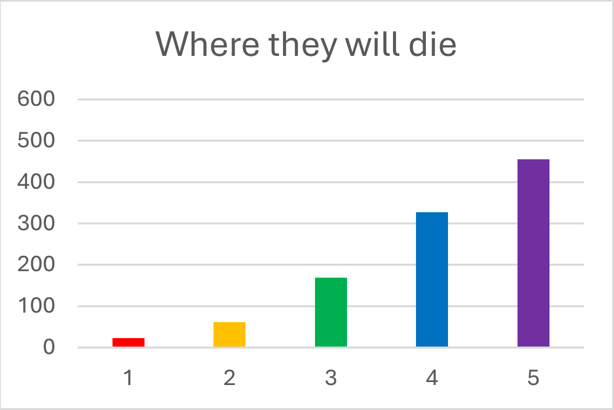
Key: 1 = not worried about this
5 = very worried about this

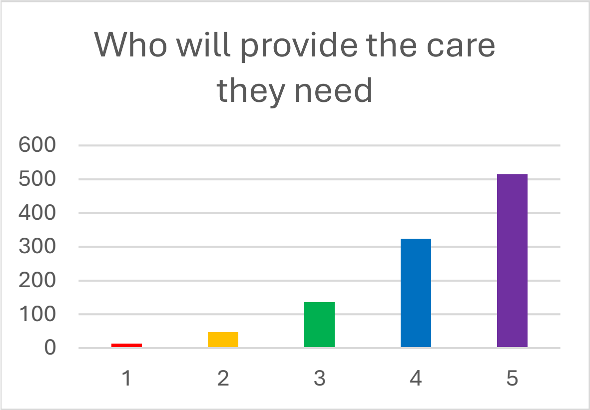


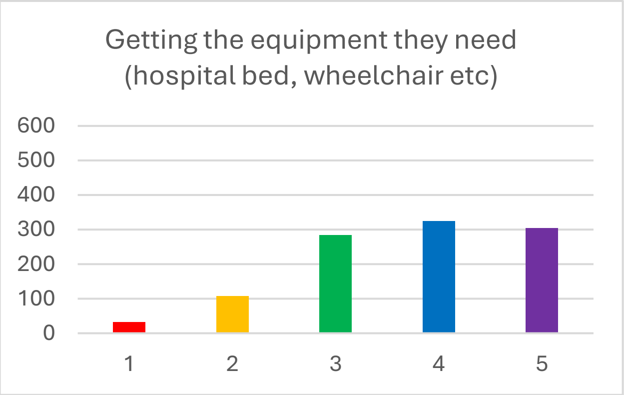








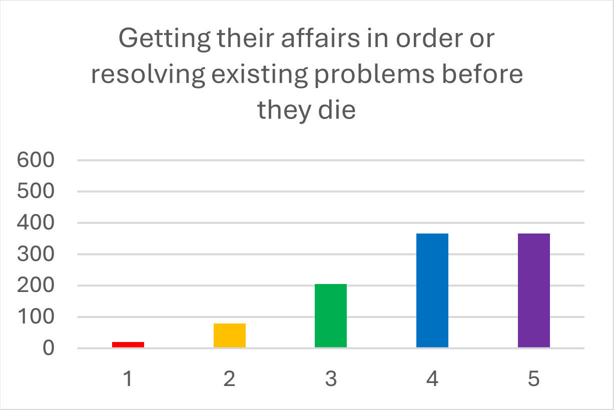


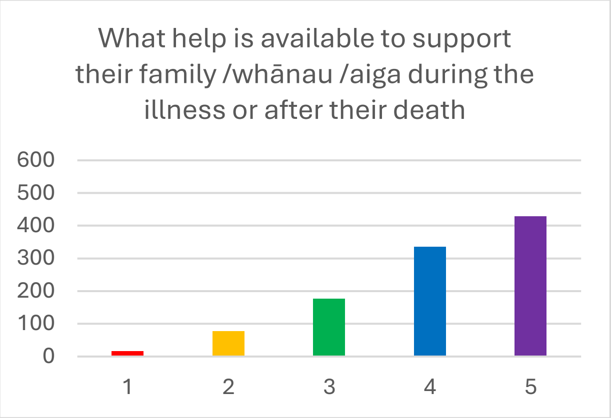


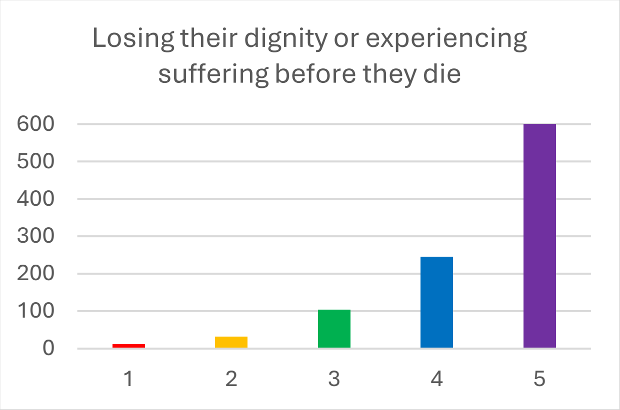
Question 5 *continued*:

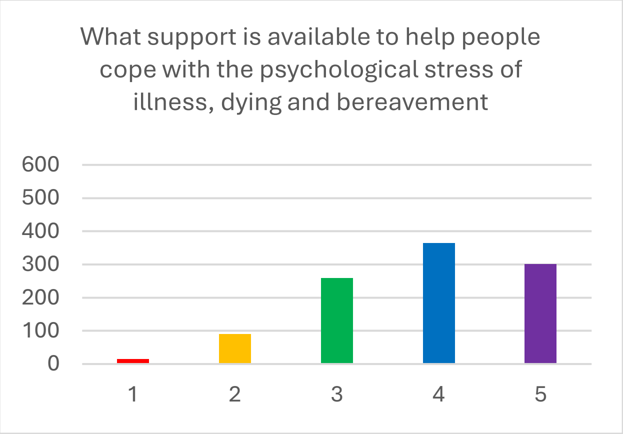
What do you think people receiving palliative care worry about?

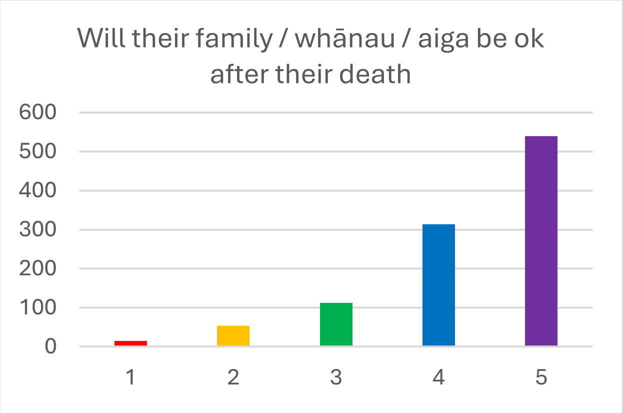
Key: 1 = not worried about this
5 = very worried about this


Getting their affairs in order or resolving existing problems before they die

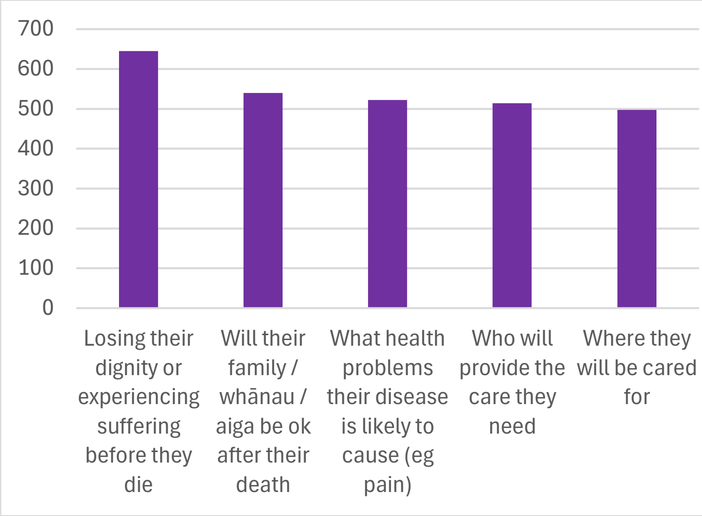

What help is available to support their family /whānau /aiga during the illness or after their death


Losing their dignity or experiencing suffering before they die

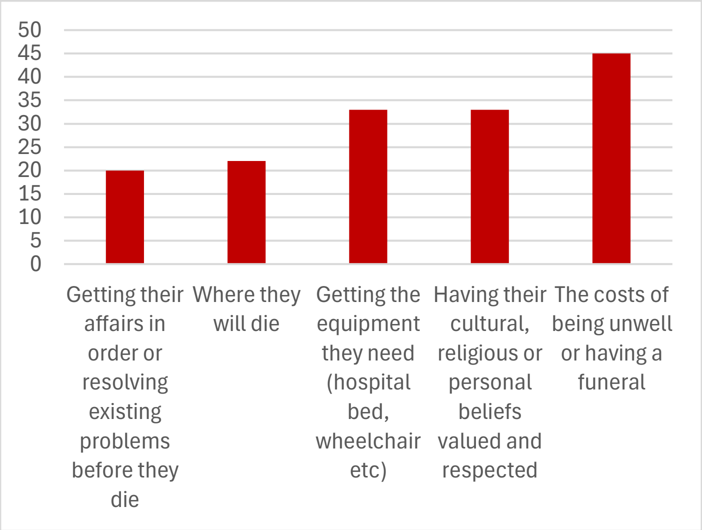

What support is available to help people cope with the psychological stress of illness, dying and bereavement


Will their family / whānau / aiga be ok after their death

Overall –
The 5 things people worry about the most were:



The 5 things people worry about the least were:



Question 6:

Can you tell us what aspects of palliative care services are working well at the moment?

We had 808 responses to this free-text question. The **key themes** were:

1. **Quality care** (symptom management, responsive/excellent staff, education/guidelines)
    a. “People are our biggest strength”
    b. “Hospice workers are outstanding”
    c. “Amazed to have such good care, even on a public holiday”
    d. “They were so efficient. The speed of response when we needed them was amazing”
    e. “Hospice definitely reduces unnecessary hospital admissions”.

2. **Holistic support** (whole person care, respect, cultural support, whānau support, psychosocial care)
    a. “Caring attitude is above and beyond”
    b. “Felt valued and cared for”
    c. “The holistic model adopted by Hospice (Te Whare Tapa Wha)”
    d. “…not restricted by where they are so moves between primary, community, hospital”.
    e. “…holding regular weekly support and activity groups. This gave me a break as a fulltime caregiver and an opportunity for my mum to connect and journey with other terminal patients”.

3. **Access to additional services** (e.g., counselling, equipment, complementary therapy, volunteers, telehealth)
    a. Many comments focused on the importance of Hospice services being free
    b. The importance of paediatric palliative care services was also mentioned.

4. **Preparation for death** (and after death care)
    a. “They allow people to die at home”
    b. ‘’Wonderful to be able to attend a memorial service”
    c. “They gave us a clear vision for care as the end of life was coming”
    d. “When she asked how long she could stay, the beautiful answer was - as long as you need to".

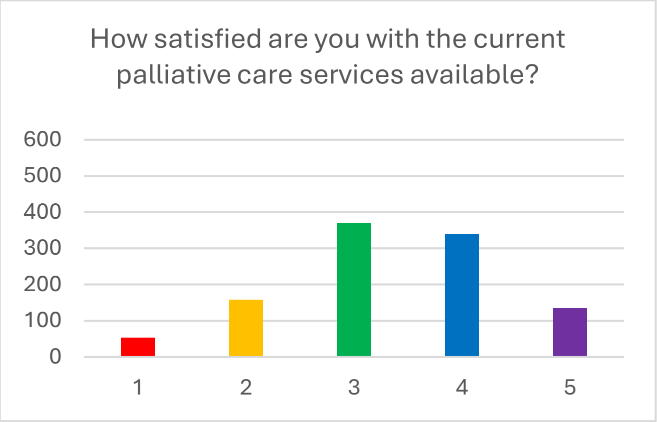
5. **Liaison with other services** (GPs, District Nurses, Rural, Aged Residential Care, Ambulance, Hospitals, and Paediatric services)
    a. “Dedicated team in all settings”
    b. “The network of support was amazing”
    c. “Interaction between inpatient unit and community was excellent”
    d. Many comments about support for GPs being vital
    e. Many comments about the need for Hospice support for those in Aged Residential Care (ARC)
    f. “Great support from our local hospice, we are lucky to have a dedicated ARC nurse who visits our facility twice a week”
    g. “I had a Navigator from the Alzheimer's Society…I felt supported knowing that she was just a phone call away”.

There were also many responses to this question that showed variable experiences such as:

- Some people felt they had good access to the services they needed, while others had difficulty accessing services
- Access to services during ‘office hours’ was much easier than ‘after-hours’
- People felt that their care improved if/when services worked well together, and with their whānau
- Some people had good experiences of the palliative care services provided by hospitals, aged residential care facilities (ARC), GPs and community nurses, while others did not
- Even if they had good experiences, people were concerned about the costs of getting the care they needed (eg., travel expenses and GP visit costs) as well as the government funding available for services in both hospital and community settings.

Question 7:

How satisfied are you with the current palliative care services available?



Key: 1 = Not satisfied 5 = Very satisfied

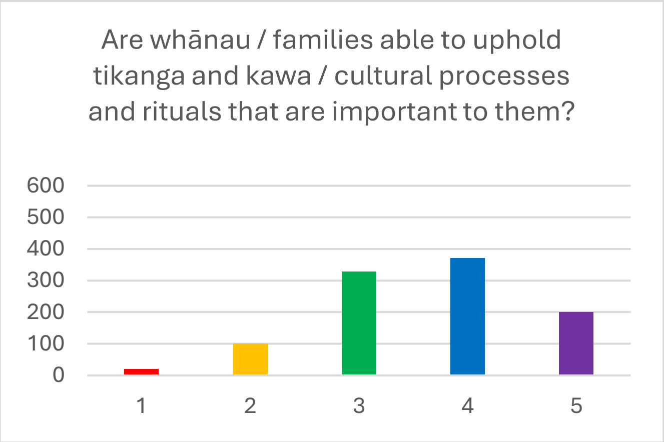
Only 13% of all people were very satisfied with the current palliative care services available.

Just under 1/3 (32%) were somewhat satisfied with services.

Another 35% were neutral, 15% were somewhat unsatisfied, and 5% were not satisfied.

Question 8:

Are whānau / families able to uphold tikanga and kawa / cultural processes and rituals that are important to them?



Key: 1 = No, not at all 5 = Yes, all the time

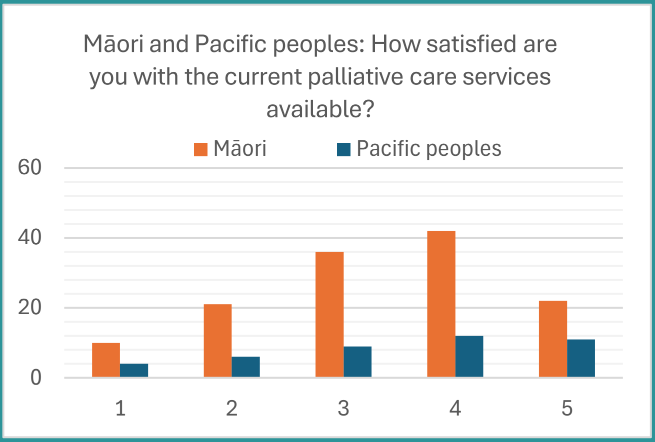
Only 20% of people thought families could uphold cultural practices that are important to them all the time. Just over 1/3 of all people (36%) thought families were able to do this most of the time.

Another 32% were neutral, 10% were sometimes able to, and 2% were not at all able to.

Responses for Māori and Pacific peoples:

When we just look at the responses for Māori and Pacific peoples for Questions 7 and 8, we can see there are some differences for these groups.

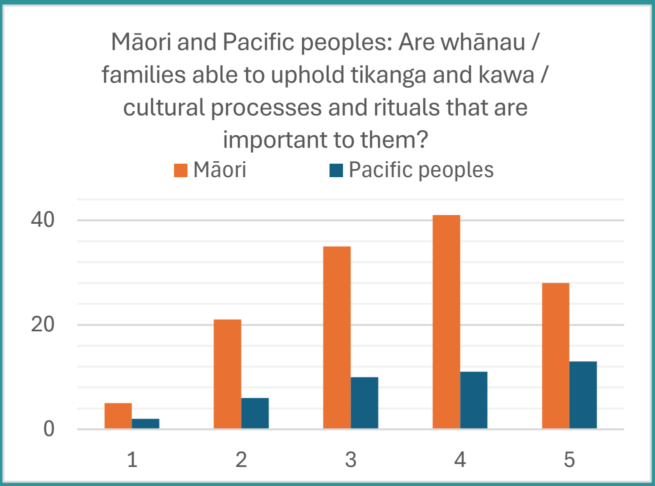
NOTE: Māori and Pacific peoples are under-represented in the survey results and overall response numbers were small.



Key: 1 = Not satisfied 5 = Very satisfied

For Māori, 17% were very satisfied with the current services available, 32% were somewhat satisfied, 27% were neutral, 16% were somewhat unsatisfied, and 8% were not satisfied.

For Pacific people, 26% were very satisfied with the current services available, 29% were somewhat satisfied, 21% were neutral, 14% were somewhat unsatisfied, and 10% were not satisfied.



Key: 1 = No, not at all 5 = Yes, all the time

For Māori, 22% thought whānau could uphold tikanga and kawa all the time, 31% could do this most of the time, 27% were neutral, 16% were sometimes able to, and 4% were not able to.

For Pacific peoples, 31% thought families could uphold cultural practices all the time, 26% could do this most of the time, 24% were neutral, 14% were sometimes able to, and 5% were not able to.

Question 9:

Can you tell us what aspects of palliative care services aren't working well at the moment, or what is missing?

We had 860 responses to this free-text question. The **key themes** were:

1. **Inadequate funding**
    a. Many people expressed views that the current government funding of palliative care services was inadequate and inconsistent
    b. People felt that the funding for services and workforce was not adequate to meet the increasing demands for palliative care being driven by our aging population.
2. **Service inequities**
    a. "We need palliative services that are not just western world viewed"
    b. People noted that we currently don't have enough Māori, Pacific or Asian clinicians and that staff need more education to ensure everyone feels their cultural and ritual needs are upheld
    c. Many services aren't providing information in multiple languages
    d. People felt that there are service gaps for those with dementia and non-malignant illnesses, and those that were referred to palliative care services were often referred too late
    e. Some also felt that palliative care was not available to everyone.
3. **Regional and geographical disparities**
    a. Many people expressed concern that those living rurally did not have the same access to services or resources that are available in urban centres
    b. Some communities have hospices with inpatient beds while others don't
    c. There isn't a standardized model of care in NZ so services differ across the country
    d. Services around NZ have different ways of collaborating – some are better at it than others.
4. **Poor access to, and resourcing of:**
    - General Practice (GP) teams
        a. Access to timely GP services that are responsive to palliative needs is often limited, especially after-hours, forcing other services to fill the gaps and deliver care
    - Specialist palliative care (eg., hospices and hospital palliative care teams)
        a. Only available to a few patients and don't have enough beds or staff to meet the demand
    - Palliative care support in aged residential care
        a. Access to hospital beds is becoming difficult in many places, some places only have 'Premium' rooms and facilities are becoming strained due to demand
        b. Some aged residential care staff don't have access to palliative care training or support
    - Wrap-around psychosocial care and support from multidisciplinary teams
        a. People wanted better whole-person support through counselling and allied health team input
        b. Access to Social Workers to help reduce costs and navigate subsidies
    - Education and information to empower patients and families
        a. People don't have enough information about what palliative care is and the services available
        b. Families aren't offered courses on how to care for their loved one until it's too late
        c. It can take years to understand how different services and agencies work together
    - Services to support those dying at home
        a. Many people didn't think the current services were adequate, including having staff available to help provide the physical care and access to the right equipment.
5. **Limited support 'after-hours'**
    a. This included both community and hospital settings
    b. Many people noted that few GPs are available after-hours now and most don't do home visits
    c. People wanted better access to support and practical advice outside of 'office hours', especially when patients rapidly deteriorated at home.

Question 10:

Can you tell us what you think needs changing or improving first (the most urgently)?

We had 835 responses to this free-text question.

Overall, there were many comments about hospices including praise for the services they provide and concern about their need to fundraise to provide these services. More funding for Primary Care services was also mentioned by many people.

Equity was discussed mostly in terms of the need to provide the same services around the country. Many respondents also mentioned the need for national guidance on palliative care services with a standardized assessment/template for patients that would enable all services to be evaluated nationally.

There was a strong recognition that with the increasing numbers of elderly in NZ, care for people in the last phase of their lives will need to be provided in the community and that whānau need to be better supported to provide this care.

People suggested that this started with additional support for patients to complete an Advance Care Plan so whānau had a clear outline of their wishes, and education for whānau on what services are available. But the main support required was for when things start getting tough at home. This included having staff who could go into people's home to help, equipment provided when required, good pain relief, and being admitted to aged residential care or hospice for respite or symptom management.

Having access to support 24 hours a day was another common theme and one suggestion was for this to be via video link so you could see another face in the middle to the night for extra reassurance.

Being able to share patient information easily between services was also mentioned regularly.

Delays and lack of information at all points on the patient journey were highlighted; from delays in diagnosis, to difficulty accessing services when they are needed, to finding someone to certify the person's death.

Other topics that were mentioned less frequently were assisted dying, palliative care for those with dementia, support for ambulance services, and access to psychological, spiritual, physiotherapy, grief counselling and secular care.

The **key themes** were:

1. Addressing resource and funding constraints in community services such as General Practice, hospices, and aged residential care – including pay equity for nurses.
2. Education for health professionals on holistic palliative care, emphasizing culturally safe and whānau centered care.
3. Development of a nationally standardized, auditable, palliative care model with standardized service components and specifications, at both generalist and specialist levels, including after-hours support.
4. Establishment of a nationally standardized referral pathway between generalist and specialist services, with clearly identifiable referral criteria.
5. Implementation of a coordinator/navigator/Kaiāwhina role to assist patients in navigating the healthcare system and accessing the necessary care.
6. Adoption of a shared patient record system to facilitate seamless care.
7. Streamlining the provision of end-of-life equipment in community settings.
8. Increasing the availability of respite beds with improved accessibility.

Question 11:

Is there anything else you would like the adult palliative care working group to consider as they look at developing nationally consistent models of palliative care?

We had 658 responses to this free-text question. The **key themes** were:

1. **More consistent services are required** (throughout NZ and across different age groups**)**
    - Services should be more consistent geographically, including for those who live rurally
    - Services should ensure they cater for young people and those with dementia
    - One size doesn't fit all though
    - Improved consistency would include; equal access to services, consistent referral and assessment criteria, after-hours support, funding, and hospice care.

2. **Training support for non-specialist services and primary care**
    - Many GP's don't have the time or skills to provide end-of-life care for patients at home. They need more training and support, and better funding to provide this care. There also needs to be better communication with GPs
    - There should be specialists available in rural areas and increased training for rural services
    - More palliative and end-of-life care training (including what palliative care is, communication skills, and the role of hospices) is needed for nurses, health care assistants and medical staff in emergency departments, aged residential care (ARC), hospitals and primary care/community services. It is also needed in undergrad programmes for all health professionals and those trained overseas. ARC should have mandatory online education on palliative care, dying and death
    - more funding is needed to increase the number of registrars hospices can train.

3. **Funding**
    - More government funding is needed for hospices, rural services, palliative care teams in hospitals, primary care and ARC, including funding for core specialist palliative care services for everyone
    - more consistent / equitable funding is needed across locations and services to ensure communities have access to similar resources and services eg hospice in-patient beds
    - specific funding is needed for end-of-life / last days of life care
    - We need to reallocate government funding from other health services into palliative care services
    - Funding should be ongoing (long term) with annual adjustments for demand and cost increases.

4. **Support for the patient and carer** (including whānau centred care, education for carers and bereavement care)

    - Services need to acknowledge the unrealistic expectations and burdens on family to do things like administer injectable medications
    - Carers need access to nationally consistent free training and easy guides explaining what palliative or hospice care is, how to support people at home and manage symptoms and medications, and the services available (including information about admission to aged residential care)
    - patients and their families need wrap around care including online support groups, support for children, services for people with intellectual disabilities and more consistent access to bereavement care
    - services need to listen to and work with whānau to make care decisions (whānau centred care)
    - Care Navigators or Case Managers are needed to guide families and ensure they make informed choices about care options. They also improve communication between services
    - More volunteers should be trained to support families
    - Whānau need financial support to provide full time care, as well as access to respite care
    - Patients and families need clear information from one source on:
        a) the patient's condition/prognosis (to make informed decisions, especially if they are dying)
        b) what services are available, when and how to access them
        c) the practicalities around the death process – what to look out for and how to manage this

Question 11 *continued*:

Is there anything else you would like the adult palliative care working group to consider as they look at developing nationally consistent models of palliative care?

  - d) the clinical care being provided eg., what medications they are on and why
  - e) contact information including when, how, and who to contact.

5. Attention to social care and holistic needs

- Treating people who are dying holistically and with dignity
- Applying the Te Whare Tapa Wha model of holistic care to the whole whānau
- Holistic care includes support with:
  - a) financial stressors including the need for carers to take time off work, health care costs and travel costs
  - b) psychological and spiritual care for the patient and family, especially at the end of life
  - c) acknowledging the importance of non-medical interventions / care
  - d) access to complementary therapies eg., music therapy, diversional therapy, aromatherapy, Rongoā Māori
  - e) helping the family to navigate the processes and legal matters after the person dies
- Including a multidisciplinary team assessment at the first visit
- Ensuring the appropriate equipment is available at home
- Increasing access to Social Workers and Occupational Therapists (beyond just equipment supply).

What happens next

Thank you again to everyone who filled in our survey. It has been very helpful to hear directly from people who have used palliative care services, as well as those who work in our health system.

Our Models of Care - Adult Working Group will use these results to identify core palliative care services and develop nationally consistent models of care.

For more information

If you would like more information about our work to redesign palliative care services for all New Zealanders, please visit our website:

https://www.tewhatuora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/palliative/national-palliative-care-work-programme/

Join our Stakeholder list

If you would like to join our stakeholder list and keep up to date with our National Palliative Care Work Programme (including opportunities to be involved), email us at:

palliativecare@tewhatuora.govt.nz