

Submission to the Health New Zealand Paediatric, Adolescent and Young Adult Palliative  
Model of Care Summary Paper from the Child Cancer Foundation

May 2025

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## 1. Executive Summary

The recognition of paediatric palliative care (PPC) as a specialised discipline emerged in response to the growing number of children surviving with life-limiting or life-threatening conditions due to advancements in medical treatment. In New Zealand, the establishment of Starship's PPC service in 1999 marked a pioneering step, supported by a national committee and organisations like the Child Cancer Foundation (including the establishment by the Foundation of a Palliative Care Fund of \$119,479.94 in September 1998). This development included foundational training programs, clinical guidelines, and community education efforts. Influential global experts were brought to New Zealand to enhance understanding and capacity in paediatric palliative care, demonstrating a strong early commitment to integrated, compassionate care for seriously ill children.

Despite this promising start, challenges have persisted over the past 25 years. The PPC service remains vulnerable due to key staff departures and inadequate long-term funding. While clinical guidelines and an educational curriculum now exist—alongside some uptake of international training like EPEC—many children in New Zealand still lack access to the palliative care envisioned in the 1990s. Continued strategic investment, sustainable funding, and leadership are needed to ensure equitable access to high-quality paediatric palliative care across the country.

Over 30 years later, it is deeply concerning that many children in New Zealand who would benefit from paediatric palliative care (PPC) continue to lack access to the care originally envisioned. Although the PPC service at Starship has developed over time, it remains vulnerable due to the departure of key personnel and insufficient long-term resourcing and the Wellington service is funded by short-term philanthropic funding. In addition to these two services Te Whātu Ora Waitaha Canterbury funds a 0.2 FTE Paediatric Oncologist and 1.6 FTE Clinical Nurse Specialists (delivered by Nurse Maude in the community) to provide some palliative care services and Te Manawa Taki region of Health New Zealand/Te Whātu Ora funds seven FTE via Hospice Waikato/The Rainbow Place for paediatric palliative care with additional resources delivered by True Colours Children's Health Trust, which is fully funded via the community.

## 2. Background



- 2.1 The Child Cancer Foundation ('the Foundation') is a not-for-profit membership organisation which provides support to whānau and children experiencing a childhood cancer diagnosis. Our vision is to walk alongside and support all children and their whānau on their cancer journey and advocate improvements to child cancer care. In the 2023/2024-year CCF supported 309 whānau directly engaged in child cancer treatment services who are undertaking this journey, from Te Kao in the north to Invercargill in the south. More broadly we provided peer support services to 1,254 whānau. The Foundation was established by a group of clinicians and whānau nearly 50 years ago (1978) to improve cancer care and cancer survival rates in children. The Foundation receives no government funding.
- 2.2 The Foundation appreciates the opportunity to provide feedback on the Health New Zealand Paediatric, Adolescent and Young Adult Palliative Model of Care Summary Paper. We note the document provides an estimate of 274-328 children die from life-threatening or life-limiting conditions each year. On average between 28 to 32 children die of childhood cancer each year, meaning the Foundation provides services to around ten percent of children with a palliative diagnosis. In addition to those on active treatment, the Foundation provides services to the whānau of adolescents between the ages of 13 years and 20 years (noting that CanTeen provide support to the actual adolescents within this age cohort and beyond).
- 2.3 The Child Cancer Foundation is deeply concerned about the lack of a comprehensive national service for children and their whānau who require paediatric palliative care. Child Cancer Foundation while not a specialist palliative care provider perse, delivers a range of psycho-social care, financial support, counselling services (via funding third party providers including the Grief Centre and Skylight) peer to peer support, Nga Taonga e Huna Ana (Hidden Treasures) a highly successful programme for bereaved parents, and a sibling programme. We also provide funeral support and financial aid for bereaved parents.
- 2.4 Through this work, what we know is the lack of national paediatric palliative care service leaves many children with less-than-ideal living well and end of life outcomes, many parents with unresolved grief and a significant proportion of siblings with symptoms of PTSD<sup>i</sup>. Children undoubtedly want to die at home with their siblings, pets and wider family, and in familiar surroundings not in hospital
- 2.5 Like the Foundation, current services and other charity support providers and primary care teams involved in supporting whānau do their very best under very constrained circumstances. Compared to services for adult palliative patients, it is far more limited environment for children. For example, the only funded specialist service is available directly only to those who live in Auckland; this is currently



inadequate for even those who do live in Auckland due to lack of funded FTE of specialist paediatric palliative care clinicians; and for those who live further afield, palliative care is undertaken by GPs, pediatricians etc.

2.6 Paediatric palliative care requires specialisation, and many health professionals, such as nurses, general practitioners, and local pediatricians across Aotearoa New Zealand—have stepped into this space to ensure children are well supported during this difficult time. Many do so without funding, at their own expense in both time and money. This is neither a long-term nor sustainable solution, and it means some children inevitably slip through the cracks.

2.7 The Foundation fully supports the description in the report that paediatric palliative care is provided within the context of a philosophy of whānau-centered, rather than person centered care. Using a service model that is informed by Trauma Informed Care (TIC), we also support the perspective that care is a partnership between parents who are experts in their child's health and health professionals who are experts in their fields.

2.8 Child Cancer Foundation acknowledges that the lack of a Specialist Paediatric Palliative Care Service (SPPC) is greater than paediatric oncology alone.

### 3. Recommendations

The Child Cancer Foundation makes the following recommendations to Te Whatu Ora/Health New Zealand which are discussed in greater detail in section three and four below.

- The Foundation supports investment in and establishment of four **fully funded** specialist integrated hubs which provide paediatric, and young adult palliative services but also provide bereavement support for whānau.
- The Foundation supports the establishment of a **fully funded** national Specialist Palliative Care clinical network that would include specialist PPC interdisciplinary teams working together as a national service network and shared care model.
- That psychosocial support (including bereavement care) is available for Tamariki and whanau where and when it is needed.
- The Foundation fully supports the description in the report that paediatric palliative care is provided within the context of a philosophy of **whānau-centered**, rather than person centered care and recommends developing a model that is informed by Trauma Informed Care (TIC).
- Agrees that Aotearoa/New Zealand **must achieve or exceed** the standards as set out in the International Standards of Paediatric Palliative Care.
- Any service design of a nationally delivered service needs to accommodate, via funding models, both those that wish to receive end of life treatment at home or in



their community through a fully funded national clinical network and those who choose to access clinical services via hubs/central hospital services.

- Te Whatu Ora/Health New Zealand establishes an expanded stakeholder transition group to work through the risks and look at how individual entities can support the new service model. We would encourage engagement with NCCN on the network coordination model.

#### **4. Feedback on the proposals.**

4.1 The Paediatric, Adolescent and Young Adult Palliative Model of Care Summary Paper proposes three 'options' to improve paediatric palliative care outcomes in Aotearoa/New Zealand. Option one is the establishment of a national specialist PPC clinical service network. The Foundation does not believe that this is an option, so much as a prerequisite prior to the establishment of SPPC services (hubs). The establishment of both the National Child Cancer Network (NCCN) and the AYA Cancer Network Aotearoa (AYACNA) while differently focused have been instrumental in providing data, coordination and research which have been fundamental to the improvement of outcomes for children and adolescents with cancers. We would see a nationally managed and fully funded specialist PPC clinical service network as being essential but just as NCCN and AYACNA play vital roles in the paediatric oncology sector they do not replace the two-specialist paediatric oncology treatment centers.

4.2 Given Aotearoa/New Zealand is a small country, the provision of integrated, high-quality care will be reliant on a nationally coordinated approach (Aburn G et al., 2024) which strengthen district level support, some education and training has been done but more is needed. Network relationship management will also be important as the district level key worker relationship is paramount for families as is the key workers relationship with the specialists.

4.3 And while these elements (outlined in 4.2) are important they alone are not sufficient to meet the needs of children requiring paediatric palliative care. Existing services, while doing their best within extremely limited resources, are unable to meet current needs. We believe without the establishment of expanded specialist clinical services, 'option one' is little more than a sticking plaster solution and will not in and of itself, support Aotearoa/New Zealand to achieve the standards set out in the International Standards of Paediatric Palliative Care. For example, Aburn et al. notes that every paediatric healthcare team in New Zealand should have 24/7 access to a specialist paediatric palliative care service, something the Foundations supports.<sup>ii</sup>

4.4 Options two and three of the document propose a two or four 'hub' solution with staffing provided by specialist PPC interdisciplinary teams. From a paediatric



oncology perspective, the Foundation believes that fully funded specialist treatment centers supported by fully funded networks have demonstrated their efficacy in the child cancer space. This has led to world class outcomes. These specialist treatment centers have led to improved outcomes and an 85.5% five-year survival rate in paediatric oncology (2010-2019 NCCN) from just 28% in 1970. This is something that compares favorably with similar countries such as Australia, Canada and the United Kingdom.

4.5 While suggestions for a two-hub model may resonate for some, a sound public policy approach should not lead to worse outcomes or worse provision than already exists. This therefore means a four-hub model with services in Tamaki Makaurau, Te Manawa Taki, Te Whanganui-a-Tara and Te Wai Pounamu that are linked to Health New Zealand/Te Whatu Ora and delivering consistent models of care and enabling cross cover around the country. Working with current services is particularly important during any transition (which we see as taking years). Notwithstanding the many challenges, some of which we discuss below, Child Cancer Foundation supports the establishment of four fully funded specialist hubs which not only provide paediatric, adolescent and young adult palliative care services but also post bereavement support for parents and siblings.

4.6 We note however that we do not agree with some of the assumptions made in table one of the service configurations, for example the assumption that specialist PPC clinicians would be fewer under a two-hub model than a four-hub model which has not been tested. While it's true that co-location provides critical mass the need to ensure a twenty-four-hour, seven-day a week, three hundred and sixty-five day a year accessible service, it suggests more capacity needs to be built in rather than less. With one child dying every day and numbers requiring paediatric palliative care around the same (300+) as those accessing specialist paediatric oncology services on an annual basis modeling is required around the clinical workforce needed.

4.7 While the Foundation believes we are an important voice in the SPPC discussion we are not best placed to offer commentary on any specific service configuration or workforce composition in detail. However, we do note the following<sup>1</sup>:

- Services must be designed with whānau safety in mind. Safety within this context is the provision of 'planned', early and ongoing communication consistent treatment protocols and equitable partnerships between parents and clinicians.

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<sup>1</sup> The attached examples are based on Child Cancer Foundation system experiences, we acknowledge other providers such as Heart Kids, Cystic Fibrosis NZ etc. provide their own offerings based on the needs of the populations they serve.



- Services should be designed using a Trauma Informed Care model which supports the best quality of life and death outcomes for the child and minimises trauma to survivors.
- A national service with specialist medical staff operating as a single team in four locations providing planned comprehensive standard of care access across Aotearoa/New Zealand in collaboration with a child's wider medical team. This in our view requires close collaboration between hubs and shared coverage of out-of-hour service delivery.
- The provision and access to ongoing services that will enhance the life of a child enabling them to both live well and die well in the time they have available. This may include funding for physiotherapy, occupational therapy and other support services such as counselling, rather than funding for these services ending as soon as there is a palliative diagnosis, as appears to happen in many cases at present.
- A SPPC clinical service network needs to start with identifying, mobilizing and resourcing (both time and pūtea) existing shared care champions in each region or district to activate the network expeditiously.
- Quality palliative care starts with early and ongoing conversations between whānau, and clinicians, and is agile (in that it can adapt as circumstances change e.g. ensuring children live as well as they can once treatment fails). The Foundation often finds that it is our Family Support Staff who have non-clinical conversations about what it will be like when a child dies as this dialogue does not always occur at critical points during the illness journey.
- Support must also be provided (training, collateral) to secondary stakeholders, for example provision of support for school staff who support siblings, friends and the wider school community.
- One of the omissions from the definition of SPPC is post death support for parents and siblings such as grief counselling (which the Foundation currently funds via third party providers such as the Grief Centre or Skylight). We note the report mentions this and indicates many bereaved parents consulted for the report indicated bereavement services lack funding, cohesion, visibility and accessibility. While whānau supported by Child Cancer Foundation, who experience a bereavement, all receive support from our Family Support Team, with regular follow ups up to a minimum of eighteen months post bereavement, we are conscious that this does not occur for many non-child cancer bereavements who may not be connected to charity support organisations. This inadvertently creates and perpetuates inequalities. The Foundation also organises Remembrance Days and other opportunities for whānau to remember and help with the process of healing from the trauma of losing a child.
- While we acknowledge that New Zealand is a long thin country with a dispersed population and thus, this creates difficulties with standardised care, accommodation needs to be made for those whānau who currently struggle to access any kind of



specialist support, if they choose for end-of-life care to occur in their community or home. This is particularly the case if they live in remote or rural New Zealand.

- Conversely for those who choose to engage with centralised specialist services or hubs, accommodations should be made to provide adequate funding and support to enable whānau to be present at bedside during the end-of-life experience. At present meeting the cost of this for whānau with a childhood cancer patient is provided by the Foundation.

## **5. Next Steps**

5.1 We note that Health New Zealand has indicated that it remains committed to ensuring palliative and end-of-life care that meets the needs of all New Zealanders. We remain concerned however that the consultation document does not commit to a specialist model of care for tamariki and their whānau and does not provide indicative funding to support such a model nor modeling of what this may look like. To a certain extent the funding envelope will dictate the composition of the service as much as workforce. Any new model will require a clear transition plan with funding plans and milestones. While we believe that SPPC is needed urgently we also acknowledge that a new model cannot be immediately implemented and will need time to evolve (see 4.3).

5.2 As the community organisation that supports the single largest group of children requiring palliative care (34 of the 300+ [2023]) we look forward to ongoing consultation. We believe we have expertise across a broad range of touchpoints within the paediatric palliative care space including post death bereavement services, where we almost exclusively provide support to whānau who have lost a tamariki to cancer.

5.3 Notwithstanding the above, the Foundation also remains concerned that there is no discussion in the document around transitioning from the current state to the new state given the workforce challenges outlined in the discussion document, without service disruption between what we have now (albeit limited) and what the future state may look like. While we acknowledge that there is a requirement to have a strategic direction of travel, there appears to be a limited appreciation within the document of the risks associated with the current provision of services transitioning to a new model. We would be in favour of an expanded stakeholder transition group being established, or series of meetings to work through the risks, looking at how individual entities can support any transition to the service model.

5.4 As a general principle while we believe psycho-social support, social work, counselling services, Māori liaison services can all be delivered via the not-for-profit sector, and indeed this may be the most cost effective and efficient way to deliver





these services, specialist clinical provision is best delivered via specialist clinical or hospice services.

## **6. Conclusion**

6.1 The Adolescent and Young Adult Palliative Model of Care – Working Group Report notes “that if New Zealand were reviewed today, we would be considered as having the same provision [of care] as a developing nation”. This powerful comment reflects the lived reality of many whānau in Aotearoa. Despite the sustained efforts of many over nearly four decades, the persistent failure of health authorities to address the specialised needs of children requiring palliative care stands as a stark indictment of the systems responsible for the care and protection of our youngest citizens.

6.2 While we fully support the conclusion of the report, and the options suggested in part this is because it is a right that children receive the same level of care as adults to both live well and die well. We have seen what can be achieved via nationally coordinated specialist treatment centers and shared care network model, in the case of paediatric oncology service provision.

6.3 While acknowledging the early stage of proposal development, we remain concerned that the options themselves have little detail and there has been limited (apparent) consideration of transitional arrangements. Given the current state of workforce capacity, available funding and the need to undertake education and training and expand service provision into, not only, the palliative space but also the bereavement space, transitional arrangements and significant startup funding and support of existing services will be required. This is to say the journey is just as important as the destination! We also believe that we need action now, not more reports and inaction.

6.4 As outlined, we note that several key groups engaged in the sector at present, do not appear have not been consulted prior to this report. This includes the Foundation who currently provide non-clinical palliative and bereavement care including financial hardship mitigation and funeral expense funding. Additionally, we believe St John/other Ambulance services should also be consulted as a provider of some out of hours care in some regions.

6.5 Notwithstanding the above comments we are fully supportive of the overarching principles and the intent behind the report, which is a fully funded, nationally provided SPPC network and service. As such we look forward to continued engagement in service design and encourage Health New Zealand/Te Whatu Ora to continue to engage with the sector to develop the best outcome possible for New Zealand children with life limiting or life ending illness and conditions.





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<sup>i</sup> International studies suggest up to 30% of siblings experience PTSD like that of the child with the life-threatening or life-limiting illness (Blamires, et al., 2024, Hovland, et al., 2020).

<sup>ii</sup> Paediatric palliative care in Aotearoa New Zealand – current state and future direction. Aburn G, Gott M, Moeke-Maxwell T, Drake R, 2024, New Zealand Medical Journal.