MANA MOKOPUNA
Children & Young People's Commission

Paediatric palliative care

> *"Our family is eternally grateful to [the nurses] for the opportunity to keep RJ at home with us right up until his final moments. It saddens me that there isn't a nationwide, publicly funded service providing specialist paediatric palliative care."*
>
> Jodie, sister of RJ, who died age 15 years[1]

Aotearoa New Zealand urgently needs a nationwide, paediatric palliative care service to provide specialist palliative care to all children who need it.

This is essential so that all mokopuna (children and young people) requiring specialist palliative care throughout the country can receive it, ensuring they experience their full potential in life, as well as a safe and dignified death. It is also crucial to provide support for whānau (families) to reduce trauma during the distress of the death of a child.

Each year in Aotearoa New Zealand, around 3000 mokopuna require paediatric palliative care due to life-threatening health conditions and terminal illnesses.[2]

Specialist paediatric palliative care[3] is available, but availability of this differs from region to region, and the majority of mokopuna who need this specialist care are unable to equitably access it.[4] There is currently only one permanent, publicly funded specialist children's palliative care service, located in Tāmaki Makaurau (Auckland). Unlike most similar countries around the world, there is currently no national paediatric palliative care service in Aotearoa New Zealand.

This means that not all mokopuna who need to access paediatric palliative care are able to, or they are unable to access it when they need it, and close to home or in their homes.

Available data shows that mokopuna Māori, as well as Pacific mokopuna, are impacted the most by the current gaps in paediatric palliative care. There is also a higher likelihood of these population groups, alongside mokopuna whaikaha (disabled children), experiencing health conditions requiring palliative care.[5]

The United Nations Convention on the Rights of the Child asserts the right of all children to the highest attainable standard of health,[6] requiring States parties to ensure no child is deprived of their right to access health care services, including children with terminal conditions. They should have access to health support and pain management during their lives, and a pain-free death that is dignified and alongside their parents, whānau and other special people.

Mokopuna with terminal conditions need different medical care from adults because they may live several years while they are still growing and developing, sometimes with an uncertain expected lifespan. They need specialists to prescribe paediatric medicines for pain, in ways that recognise their ongoing growth and enable them to live their lives to their full extent. They need physical attendance by specialists, including in all rural areas, to give their caregivers at home support and information about how to look after them.

Currently, the availability of paediatric palliative care in most of Aotearoa New Zealand is inconsistent with the basic rights of children under the UN Convention on the Rights of the Child. It infringes children's right to life, survival and development, their right to health, and their right to learn and play, among others.[7] All mokopuna have the right to medical assistance and health care, including appropriate pain and symptom management when terminally ill.

Better paediatric palliative care would reduce pressure on the wider health system. Effective, nationally available paediatric palliative care is projected to save millions of dollars. Non-expert care, and lack of access to round-the-clock support leads to frequent avoidable hospitalisations, including in intensive care. In contrast, specialist paediatric palliative care allows mokopuna to be cared for at home, attending hospital only when necessary.[8]

Making real its promises to children under the UN Children's Convention is a State duty and an obligation across government in Aotearoa New Zealand, as well as being the ethical and compassionate thing to do for children dying of terminal illnesses. It is also consistent with Crown obligations under Te Tiriti o Waitangi.

We note that as of mid-2025, this issue is under active consideration by the Government, following a public consultation process.[9] Mana Mokopuna provided a submission to Health New Zealand Te Whatu Ora as part of this process, which is available on our website.[10]

Our calls to action

Urgent action is required so that all mokopuna who need paediatric palliative care can access it. We call on the Government to:

- **Establish and fund a national paediatric palliative care service**, so that all mokopuna throughout Aotearoa New Zealand who need palliative care now and into the future are able to access this equitably, close to home, and in ways that uphold their full range of rights, including their cultural rights.
    - **Fund – without delay – the model of care 'Option Three'** proposed in the Health New Zealand Te Whatu Ora 2025 paediatric palliative care consultation document,[11] which includes specialist care, four hubs and a clinical network.
    - **Fund an interim service** if Option Three is not able to be funded in full until Budget 2026. This would retain the capabilities of the existing network of expertise required for a future, nationwide, all-hours specialist paediatric palliative care service.
- **Take a children's rights approach when making decisions relating to establishing a national paediatric palliative care service, informed by a children's rights impact assessment**, to ensure children's rights are holistically considered and met, and the rights of those most in need are considered and met.
- **Direct Health New Zealand Te Whatu Ora to listen to the voices of families and whānau whose children have required paediatric palliative care, as well as specialist paediatric palliative care professionals,** to ensure the service design and implementation of a national paediatric palliative care service is directly informed by them.

What whānau say

Many whānau of mokopuna who have died without access to the specialist paediatric palliative care they needed have shared their voices about this issue, including the following:

> *"Why is it that, as adults, our human right to die with dignity and without unnecessary suffering is acknowledged and funded but it is not if you are a child? Why is, it in this country, where you live is the difference between a death that is peaceful and managed, or horrendously traumatic?"*
>
> Lisa, Mum of Meg, who died age 14 years[12]

> *"So much stress and trauma that could have been avoided if we had support from people with training and experience. James deserved to be supported by a proper paediatric palliative team, just as much as my husband and I did, and our older two children. No family should have to take this journey alone."*
>
> Nicola, Mum of James, who died age 6 years[13]

Whānau of mokopuna who died with access to the specialist paediatric palliative care they required, have highlighted the difference it made.

> *"RJ was determined to keep his independence and would try his very best to do everything himself despite all the help we offered him. Our family is eternally grateful to Amanda and Mary [Rei Kōtuku's nurse] for the opportunity to keep RJ at home with us right up until his final moments. […] It saddens me that there isn't a nationwide, publicly funded service providing specialist paediatric palliative care. I strongly feel the service Amanda and Mary provide is essential for any family who has a child with a terminal illness and are wanting their child at home. The option should be non-negotiable."*
>
> Jodie, sister of RJ, who died age 15 years[14]

Endnotes

[1] Ibid, at p.18.

[2] Unheard Cries New Zealand's neglect of palliative children - Rei Kōtuku 2024

[3] A specialist doctor-led team, with nursing, allied health, pharmacist and bereavement support – as per National Institute for Health and Care Excellence guidelines: *End of life care for infants, children and young people with life-limiting conditions: planning and management,* Last updated 2019, Overview | End of life care for infants, children and young people with life-limiting conditions: planning and management | Guidance | NICE

[4] Gemma E Aburn, Merryn Gott, Tess Moeke-Maxwell, Ross Drake, Paediatric palliative care in Aotearoa New Zealand - current state and future direction, *New Zealand Medical Journal Te ara tika o te hauora hapori,* November 2024, Vol. 137.

[5] Unheard Cries New Zealand's neglect of palliative children - Rei Kōtuku 2024 p16 and 22.

[6] Article 24, the UN Convention on the Rights of the Child

[7] UN Convention on the Rights of the Child asserts a child's inherent right to life - Article 6; rights to education - Articles 28 and 29; and rights to play and recreation - Article 31.

[8] Reikōtuku Submission for the Paediatric Model of Care, Paediatric Palliative care network, indicated a national service would cost about $8 million and that "the government is currently spending ~$22 million per year on avoidable hospitalisations for palliative children." (at page 14).

[9] Health NZ wants your feedback on a Paediatric Adolescent and Young Adult Palliative Model of Care – Health New Zealand | Te Whatu Ora

[10] Mana Mokopuna 2025 Submission to Health New Zealand Te Whatu Ora on a model for Paediatric Palliative Care

[11] Paediatric, Adolescent and Young Adult Palliative Model of Care – Te Whatu Ora Summary Paper for feedback 2025

[12] Unheard Cries New Zealand's neglect of palliative children - Rei Kōtuku 2024 at p.15.

[13] Ibid, at p.8.

[14] Ibid, at p.18.