Meeting Briefing

Health New Zealand
Te Whatu Ora

Current state of paediatric palliative care – for visit with families

Due to MO:	14 July 2025	**Reference**	HNZ00087837
To:	Hon Simeon Brown, Minister of Health		
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Contact for further discussion (if required)			
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Attachments	
Appendix 1:	Biography of Dr Evans

About the meeting

Purpose	You are meeting with families who have had differing experiences with paediatric palliative care.
Date	17 July 2025
Time	[TBC]
Venue	Trentham, Upper Hutt
Attendees	Dr Amanda Evans, paediatrician and paediatric palliative care specialist [biography attached as Appendix 1]
Health New Zealand | Te Whatu Ora officials	n/a
Media	No media are expected

[redacted]

Purpose

1. This meeting briefing outlines the current state of paediatric palliative care services in Aotearoa, and any key issues you should be aware of, for your meeting with families who have had differing experiences of paediatric palliative care. Dr Amanda Evans will also be in attendance

[redacted]

About Dr Evans and Rei Kōtuku

8. You previously met with Dr Amanda Evans (see **Appendix 1** for a bio) and expressed interest in meeting families who have received, or are currently receiving, paediatric palliative care (PPC) services.

9. Rei Kōtuku is a specialist PPC service that was established by Dr Evans in early 2023 as a pilot in Wellington, servicing the Central Region. Rei Kōtuku provides free care for babies, children and teens in hospitals or in the community. Their clinical team includes a Paediatric Palliative Care Specialist (Dr Evans), two Clinical Nurse Specialists and an Educational Psychologist.

10. Rei Kōtuku was set up independently with philanthropic funds. Health NZ thus has no

contract with Rei Kōtuku. Rei Kōtuku have indicated their philanthropic funding will run out after 3 years (early 2026).

11. Without further funding, Rei Kōtuku would need to reduce, and then stop, providing services. Patients would need to be handed over to existing secondary and primary health care teams. This would likely cause significant distress to the children and whānau involved.

12. On completion of handover, specialist PPC services in the Central Region would be similar to that available outside of Auckland, Hamilton and Christchurch (see paras 24-26).

13. Health NZ national and regional leads have met with Rei Kōtuku on several occasions to discuss their services and funding. The Central Region have not committed funding for Rei Kōtuku to date.

14. Rei Kōtuku continues to actively engage with media, funders (Crown and philanthropic) and sector leaders regarding the sustainability of their services.

Need for paediatric palliative care in Aotearoa

15. Each year an estimated 274-328 children die in NZ however, the predicted prevalence of PPC need is between 2,000-3,000 a year as children usually require episodic care over many years due to the nature of their conditions.

16. They can be babies, young children, adolescents or young adults and may have a rare condition specific to childhood, a perinatal or congenital condition, a cancer or an acute illness.

17. Most are medically fragile and have high daily care needs, frequent outpatient visits and extended hospital / ICU stays.

18. They and their parents, siblings, whānau and community need support, including bereavement care.

Who provides paediatric palliative care

19. Most children are well cared for by their local services including neonatologists, paediatricians, paediatric oncologists, hospital teams, general practitioners (GPs), and occasionally their local hospice.

20. Some children with complex needs require additional input (either directly or indirectly) from specialist PPC services.

Current specialist paediatric palliative care services

21. Access to specialist PPC services varies significantly across Aotearoa. This means whānau with a child who requires input from specialist services have variable experiences, depending on where they live.

22. Note that the term ‘specialist paediatric palliative care’ can be used differently. Dr Evans takes the view that only services with a specialist doctor trained in paediatric palliative care can use this term (i.e. Auckland and Rei Kōtuku). However, other uses include

teams who provide specialist paediatric palliative care to children with complex needs, this can include teams with specialist nurses (who are trained in paediatric palliative care) who are supported by paediatricians or doctors trained in adult palliative care (i.e. Hamilton and Christchurch).

23. There are currently three Crown-funded specialist services located in Auckland, Hamilton and Christchurch, with a total workforce of less than 10 FTE (approx.) including vacancies. There are also non-Crown funded services for children with palliative care needs in Hamilton (True Colours) and Wellington (Rei Kōtuku).

24. The specialist team based at Starship Hospital (Auckland), provide inpatient services as well as national outreach to support local paediatric or general practice teams around Aotearoa. However, outreach support can be limited by workforce capacity constraints in this small team.

25. Children who live in Auckland, Hamilton and Christchurch have direct access to Crown funded specialist PPC services if required. Children in Wellington currently have access to these services from Rei Kōtuku (non-Crown funded). These teams also strive to support children throughout their regions, as capacity and resources allow.

26. Access to specialist PPC services outside of these four cities is usually indirect with the nearest specialist PPC team offering advice and support to the local paediatric or general practice team on how best to manage complex symptoms.

27. For example, a child who lives in Tauranga will be cared for by their usual health care team. If their symptoms become increasingly complex and difficult to manage (e.g. escalating pain due to nerve damage), the local team would contact a specialist PPC service for advice. The child and their whānau are unlikely to be seen in person by a specialist PPC service, unless they were admitted to Starship hospital (Auckland).

28. This means children with complex symptoms, their whānau, and the local team often feel poorly supported, especially after-hours, and children regularly need to travel long distances to secondary and tertiary hospital services.

Unmet specialist paediatric palliative care need

29. Despite the excellent work of local services and specialist teams, there is unmet specialist PPC need for children and their whānau in Aotearoa.

30. This is largely due to the uneven distribution of specialist services, as well as capacity and workforce sustainability constraints.

Health New Zealand's paediatric palliative care work

31. In 2023 Health NZ began a review of PPC services and established the Models of Care - Paediatric Working Group (2023 – 2024) as part of the broader National Palliative Care Work Programme.

32. The Working Group, co-chaired by Dr Amanda Evans and Dr Nicole Coupe, included experts, whānau and sector representatives and delivered a report (Paediatric and Adolescent Young Adult (AYA) Palliative Model of Care) to the Steering Group.

33. During April 2025, Health NZ released this as a paper outlining recommendations and

proposed service configuration options and sought public and professional feedback.

[redacted]

Appendix 1: Biography of Dr Evans

Dr Amanda Evans is a paediatrician and paediatric palliative care specialist.

She is one of two fully qualified paediatric palliative care specialists in New Zealand (the other specialist is based in Starship Hospital).

She is the current Chair of the Paediatric Palliative Care Network for the Paediatric Society, and co-founder of Rei Kōtuku Charitable Trust.

You previously met with the Paediatric Society in February 2025 and Rei Kōtuku in March 2025.

Dr Evans was also a Co-chair of Health NZ’s Models of Care – Paediatric Working Group (2023-2024) for the National Palliative Care Work Programme and the main writer of the Working Group’s paper (which was released for feedback in April).