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Meeting Briefing

Health New Zealand
Te Whatu Ora

Meeting with Dr Amanda Evans re: Paediatric palliative care

Due to MO:	26 March 2025	**Reference**	**HNZ00083314**
To:	Hon Simeon Brown, Minister of Health		
From:	Martin Hefford, Director Living Well		
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Consulted	n/a		

Contact for further discussion			
Name	**Position**	**Phone**	**1st contact**
Martin Hefford	Director, Living Well	s 9(2)(a)	x
Tim Wood	Group Manager Planned and Unplanned Care		

Attachments	
Appendix 1:	Bio of Dr Evans
Appendix 2:	Relevant recent media items

About the meeting

Purpose	To support you in your upcoming meeting with Dr Amanda Evans, an expert in paediatric palliative care.
Date	Thursday 27 March
Time	11.00 - 11.20am
Venue	EW 6.6, Parliament buildings
Attendees	Dr Amanda Evans, Paediatric Palliative Care Specialist, Founder of Rei Kōtuku Charitable Trust and a member of the paediatric palliative care clinical network for the Paediatric Society. A brief biography of Dr Evans is included as **Appendix 1**.
Health New Zealand | Te Whatu Ora officials	Tim Wood, Group Manager Planned & Unplanned Care
Media	No media are expected
Talking points	You may wish to: Thank Dr Evans for her work as part of Health NZ's Paediatric Models of Care Working Group. Indicate that Health NZ is preparing to release the Paediatric and Adolescent Young Adult Palliative Model of Care for public feedback, and encourage engagement on the topic. Discuss the avenues Dr Evans and Rei Kōtuku have explored to identify alternative funding sources, noting Health NZ is unable to address the funding shortfall for Rei Kōtuku.

Background and context

1. This meeting briefing provides you with information to support your meeting with Dr Amanda Evans. Dr Evans is a Paediatric Palliative Care Specialist, is the founder of the Rei Kōtuku Charitable Trust and is a member of the paediatric palliative care clinical network for the Paediatric Society. We anticipate that both the broader issue of paediatric palliative care and more specific issues regarding funding for both Rei Kōtuku Charitable Trust and the Paediatric Society may be raised.

2. The issue of paediatric palliative care (PPC) has been the focus of some attention recently (examples of relevant media coverage are included in **Appendix 2**).

3. This briefing provides information on:
   a) paediatric palliative care services nationally
   b) Health NZ's PPC work programme
   c) funding for the Paediatric Society
   d) the current statue of the services provided by Rei Kōtuku.

Paediatric palliative care services nationally

4. PPC services care for infants, children and young people with life-threatening conditions, life-limiting conditions and terminal illnesses.

5. Each year an estimated 274 to 328 children in New Zealand die from life-threatening or life-limiting conditions, including congenital anomalies, neurodisability, metabolic and cardiac conditions.

6. Most children with palliative care needs in Aotearoa are cared for by their local services including neonatologists, paediatricians, paediatric oncologists, hospital teams, general practitioners (GPs), and occasionally their local hospice.

7. Some children with complex needs require additional input from specialist PPC services.

8. There are currently three Crown-funded specialist services (Starship Hospital Auckland, Waikato Hospice Hamilton, and Nurse Maude Hospice Christchurch) with a total workforce of less than 10 FTE (approx.), including vacancies. In addition, True Colours (Hamilton) and Rei Kōtuku (Wellington) are non-Crown funded organisations that provide PPC in their regions.

9. Despite the excellent work of local services and specialist PPC teams, there is unmet palliative care need for children and their families/whānau in New Zealand.

10. The most significant factors in unmet need differ by region, but are largely due to an uneven distribution of specialist services across Aotearoa, as well as capacity and workforce sustainability constraints in these services.

Health NZ's Paediatric palliative care work programme

11. In 2023, Health NZ began a review of PPC services as part of the broader National Palliative Care Work Programme[1]. In December 2023, Health NZ established a Models of Care - Paediatric Working Group that was co-chaired by Dr Evans and Nicole Coupe.

12. This group of experts, whānau and sector representatives, have developed a proposed model of care and accompanying report (Paediatric and Adolescent Young Adult (AYA) Palliative Model of Care) that has been tabled with the National Palliative Care Steering Group.

13. The Steering Group has considered the report and has prepared a short summary with its recommendations, which will be shared with the wider sector and public for feedback, alongside the full Working Group report, by the end of March.

14. The Steering Group's recommendations include increasing the specialist PPC workforce within hospital services and establishing a national managed clinical network to coordinate these services. It is considering options to achieve this.

15. The final funding and implementation requirements for this work will be known once the feedback process has been completed and the model of care has been finalised.

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[1] The review of PPC services is part of a broader National Palliative Care Work Programme in 2023. The purpose of the National Palliative Care Work Programme is to address many of the known pressures by developing a nationally consistent approach to palliative and end-of-life care planning, funding, service delivery and outcomes.

[redacted] Additional funding for specialist PPC services has not been secured to date.

Funding for the Paediatric Society

17. Dr Evans is a member of the paediatric palliative care clinical network for the Paediatric Society of New Zealand (Paediatric Society). The Paediatric Society is a not-for-profit, interprofessional organisation open to persons working or training within child health and wellbeing, including in child health policy. It aims to improve the delivery of high-quality and equitable information and care.

18. The Paediatric Society is largely dependent on funding from the Health NZ. It is estimated that over three quarters of its annual income is currently through two main Health NZ contracts (for New Zealand Child and Youth Clinical Networks, and Kidshealth).

19. The Paediatric Society runs several topic specific networks under the umbrella of the Child and Youth Clinical Networks including one for Palliative Care.

20. The main activities of the Palliative Care network in recent times include a formalised partnership with Palliative Care Australia to update the New Zealand PPC guidelines and contributing to the Models of Care - Paediatric Working Group (as set out previously).

21. Funding for the clinical networks contract in 2024/25 is over s 9(2)(b)(ii) (GST exclusive). Funding for the Kidshealth website contract in 2024/25 is around s 9(2)(b)(ii) per annum (GST exclusive).

22. s 9(2)(b)(ii)

23.

The current status of the services provided by Rei Kōtuku

24. Rei Kōtuku Charitable Trust is a specialist PPC service that was established by Dr Evans in early 2023 as a pilot in Wellington, servicing the Central Region.

25. Rei Kōtuku was set up independently and outside of Health NZ services with philanthropic funds. Health NZ has no contract with Rei Kōtuku.

26. Rei Kōtuku has advised that if it cannot attract further funding (likely either philanthropic funding or Health NZ funding) it will need to start 'winding down' its service from July 2025. For Rei Kōtuku, this likely means not taking on further referrals from 1 July 2025 and starting to hand over its current patients to appropriate secondary or primary health care teams.

27. Health NZ has had a number of engagements with Dr Evans and Rei Kōtuku about their financial situation. Our consistent message to this point has been that Health NZ is not able to provide the funding necessary to support Rei Kōtuku's ongoing operation.

28. If Rei Kōtuku ceases operation, Wellington will be without a local Specialist PPC service, and secondary or primary health care teams in the region providing PPC will need to access specialist PPC support remotely from the Christchurch or Starship services.

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Longer-term, once the paediatric palliative model of care has been finalised, Health NZ will consider the services required in each region and how they will be delivered.

30. In the interim, we will continue to work closely with Dr Evans and a range of other stakeholders to improve equitable palliative care access for children and their whānau across New Zealand.

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Appendix 1: About Dr Amanda Evans

	Paediatric Palliative Care Specialist; Co-Founder of the Rei Kōtuku Charitable Trust; Member of the paediatric palliative care clinical network for the Paediatric Society Dr Evans studied medicine at the University of Auckland, undertaking her paediatric training at KidsFirst, Waitakere Hospital, and Starship Children’s Health. She has worked at Melbourne Royal Children’s Hospital, John Hunter Children’s in Newcastle, NSW, and Mary Potter Hospice in Wellington. She set up Rei Kōtuku in 2023.

Appendix 2: Relevant media

RNZ Nine to Noon (25 Nov 2024)

https://www.rnz.co.nz/national/programmes/ninetonoon/audio/2018965638/the-desperate-need-for-a-child-palliative-care-service

Paddy Gower, Stuff (Feb 2025)

https://www.stuff.co.nz/nz-news/360578800/angels-world-despair-specialist-service-helping-terminally-ill-kids-die-dignity-set-shut-without

Anusha Bradley, RNZ (24 March 2025)

https://www.rnz.co.nz/news/in-depth/545754/new-zealand-facing-crisis-in-paediatric-palliative-care-as-sole-specialist-on-leave

Anusha Bradley, RNZ (26 March 2025)

https://www.rnz.co.nz/news/in-depth/547508/health-new-zealand-under-fire-for-inaccurate-palliative-care-recruitment-claims