



Paediatric End-of-Life Care Toolkit

CHECKLIST

- Showing respect to each family, their choices, culture, spirituality, values, and beliefs, provides the cornerstone of good clinical practice at the end of life. Consider the practical ways in which you can respect, empower, and support families of children with a life-limiting illness. Some examples include:
 - Know what matter to each family member, don't assume
 - Ask, "What concerns you the most?"
 - Set up a [family meeting](#) as an opportunity to clarify goals of care.
- View end-of-life care decision-making as an ongoing process, rather than a single event. Ask, "If it looked like your child was approaching the end of their life, what would make this time the best it could possibly be?"
- When talking to a child with a life-limiting illness, actively listen to their questions and concerns. Observe their play and non-verbal behaviours for clues on how they may be feeling. Keep language simple and accurate.
- After a child dies, allow the family to express strong emotions. Give them the time and privacy they need, while also offering your support and reassurance. Remember, a wide range of grief reactions are normal. Be aware of local grief and bereavement supports and services available to families.

HELPFUL LINKS

- Paediatric Palliative Care Australia and New Zealand, Palliative Care Australia. Department of Health and Aged Care, Australian Government. 2023. [A Practical Guide to Palliative Care in Paediatrics - 4th Edition \(The Green Book\)](#)
- Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand. [Paediatric Palliative care website](#)
- [Quality of Care Collaborative Australia \(QuoCCA\) website](#): delivers education in paediatric palliative care to health professionals

VIDEOS, BLOGS, PODCASTS

- Blandford, M. Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand. 2024. ["When families have good care, they don't have regrets" – Jenny Hynson shares why paediatric palliative care is so important](#)
- Children's Health Queensland and Clinical Excellence Queensland. 2022. [Care Plan for the Dying Child: Discussing end-of-life care](#)
- Quality of Care Collaborative Australia (QuoCCA). 2024. [Conversations Matter – The Conversation](#)

FURTHER READING

- Donovan LA, Slater PJ, Delaney AM, Baggio SJ, Herbert AR. Building capability in paediatric palliative care and enhancing education through the voice of parents: the Quality of Care Collaborative Australia. *Palliative Care and Social Practice*. 2022;16. [doi:10.1177/26323524221128835](https://doi.org/10.1177/26323524221128835)
- Mack JW, Currie ER, Martello V, Gittus J, Isack A, Fisher L, Lindley LC, Gilbertson-White S, Roeland E, Bakitas M. Barriers to Optimal End-of-Life Care for Adolescents and Young Adults With Cancer: Bereaved Caregiver Perspectives. *J Natl Compr Canc Netw*. 2021 Feb 11;19(5):528-533. [doi:10.6004/jnccn.2020.7645](https://doi.org/10.6004/jnccn.2020.7645)