

ACCCN 2026 POSITION STATEMENT

END-OF-LIFE CARE FOR CHILDREN AND YOUNG PEOPLE

AUTHORS

Position Statement development group

Melissa J. Bloomer RN, PhD^{a,b}

Ashleigh E. Butler RN, PhD^{a,b}

Laura A. Brooks RN, PhD^{a,b}

Alysia Coventry RN, MPhil^{a,b}

Stephen McKeever RN(Child), PhD^{b,c}

Kristen Ranse RN, PhD^{a,b}

Jessie Rowe RN, GD Nurs Pract (Paed Crit Care)^{ab}

Shontelle Thomas GC Nurs Pract (Paed ICU)^{a,b}

Rebecca Thornton RN, PhD^{a,b}

Vanessa Jean-Pierre^d

Hannah Reiman^d

Erin O'Connor^d

Clinical Expert contributors

Meagan Baldwin, Georgia Bennett^b, Jane Harnischfeger^b, Arielle Jolly^b and Melanie Tarantik^b

a. ACCCN End-of-Life Advisory Panel; b. ACCCN Member; c. ACCCN Paediatric Advisory Panel; d. Parent with lived experience.

ACKNOWLEDGEMENT

We acknowledge and remember Chevelle Ava Purdon, Cillian Donn O'Connor and Harriet May Reiman, whose lives and experiences are an important part of the perspectives brought to this work, and continue to shape our shared commitment to improving care for future children, their parents and families.

INTRODUCTION

The Australian College of Critical Care Nurses Limited (ACCCN) is the peak professional nursing association representing critical care nurses in Australia.¹ The purpose of this ACCCN Position Statement is to provide evidence-based practice recommendations to support nurses in providing consistent, patient- and family-centred end-of-life care to children, young people and their families in critical care.

BACKGROUND

End-of-life care is a core component of critical care nursing practice. For parents and family members, a child's admission to critical care is a stressful, traumatic and often unexpected event.²⁻⁴ The unfamiliar care environment,³ and uncertainty^{4,5} can contribute to feelings of disconnection from the child and typical familial roles.^{4,6} The experience can impact family members' physical and mental health,^{2,7,8} with long-lasting consequences.⁹

Thus, how critical care nurses provide end-of-life care to a child, and support families is important.¹⁰ High quality end-of-life care must include optimal communication and information sharing, facilitating family presence and participation, privacy and dignity, respecting personhood, cultural and spiritual needs, preparation for death, memory-making, care after death and bereavement support.¹¹⁻¹⁵ Whilst the Australian Commission on Safety and Quality in Health Care provides national guidance for safe and high-quality paediatric end-of-life care,¹⁶ it is not specific to critical care.

KEY TERMINOLOGY

For the purposes of this Position Statement, the following definitions are provided:

Critical care refers to all critical care or intensive care (ICU) environments in which critically ill children and young people receive care.¹⁷

Child/children and **young person/people** are used inclusively to refer to all children between 28 days and 18 years.^{18, 19}

End-of-life care refers to the physical, psychosocial, cultural and spiritual assessment, care and treatment provided when a child or young person is approaching death, including care associated with limitation or withdrawal of life-sustaining treatment, care during dying, care immediately after death, and support for parents and family.²⁰

Family encompasses those people identified as important to the child or young person and may include parents, carers, siblings, extended family and other significant people.²¹ Recognition of family structure, relationships, culture, beliefs and individual preferences is fundamental to family-centred end-of-life care.

Nurse is used to refer to all registered nurses working in critical care, with or without specialist critical care postgraduate education.

METHOD OF DEVELOPMENT

This position statement was developed using a three-stage process. A systematic review was undertaken to synthesise the research evidence about nurses' and parents' experiences of end-of-life care in critical care for children.¹² Forty-one evidence-based practice recommendations were developed, then assessed for consensus and face validity through a modified eDelphi process, by clinical experts. Parent researchers, with lived experience, evaluated the meaningfulness of the practice recommendations. A senior nurse leader provided feedback on the future implementation of the practice recommendations.

POSITION STATEMENT

The ACCCN endorse the following 41 evidence-based practice recommendations, which represent the **minimum standards for paediatric end-of-life nursing care**. Importantly, the practice recommendations should be individualised to the dying child and family. Nurse leaders should use the recommendations to inform local policies, education and quality-improvement initiatives. Individual nurses can use them to reflect on practice, particularly communication and preparation of families for the dying process and end-of-life care. Implementation will require organisational commitment, policy alignment and consideration of local models of care and resources, alongside, access to education and opportunities for reflection and debriefing within the context of local resources, policies and models of care.

Practice recommendations

The practice recommendations below are grouped, reflecting the needs of children and young people, their parents and families, and the nurses providing care.

*To optimise **communication at the end of life**, critical care nurses should:*

1. Encourage and support family members to ask questions and share their views and needs as desired.
2. Work with the multidisciplinary team to promote regular, open communication with family members at the bedside, during ward rounds, and in formal family meetings.
3. Ensure written and verbal information is consistently presented in an accessible and understandable format using non-technical language.
4. Ensure communication is honest, unambiguous, sensitive and appropriately paced to optimise comprehension.

*To support **end-of-life decision making**, critical care nurses should:*

5. Prioritise the development of a trusting relationship with family members
6. Identify whether the dying child verbalised or documented their wishes or preferences
7. Identify and explore beliefs, ethical or legal concerns that may impact on decision making
8. Explore and document family member preferences for involvement in decision making
9. Explore and document family member preferences for involvement of extended family, faith or cultural leaders in decision making
10. Ensure family members have sufficient time and information to enable decision making, as desired
11. Offer support and reassurance and demonstrate respect for parent and family member wishes

*To **minimise suffering at the end of life**, critical care nurses should:*

12. Identify and address possible signs of physical, emotional, or psychological suffering in the dying child
13. Regularly assess and review actions that promote comfort and dignity for the dying child
14. Explore and respond to family member perceptions of suffering in the child

*To optimise **care at the end of life**, critical care nurses should:*

15. Explain the possible actions and care processes prior to death
16. Ensure care aligns with the agreed plan of care

Support the child's parents and family members to care for the child by:

17. Facilitating a private, quiet space for the dying child and family members, with nursing staff nearby as needed
18. Building rapport and connection with parents and family members
19. Facilitating opportunities for interaction and physical contact, and to provide care and comfort for the child

Honour the personhood of the child by:

20. Talking and engaging with the child
21. Acknowledging and caring for the child as a person, not a patient
22. Attending to the child's physical appearance
23. Minimising equipment and technology attached to the child, or in the bed area that may impact family engagement with the dying child
24. Support family members to remain present when their child is dying, including during CPR, according to their preferences

*To optimise **care after death**, critical care nurses should:**Offer practical support to family members by:*

25. Providing a private space for family members to spend time with their deceased child, in accordance with their wishes
26. Ensuring family members are supported in cases where the child's death necessitates involvement of police or other external agency
27. Facilitating involvement in post-mortem care (e.g. washing and dressing the child) as desired
28. Facilitating memory making or keepsake activities, for parents, siblings and family members as desired
29. Facilitating access to cultural or faith-based services or supports
30. Continuing care until they leave the hospital
31. Allocating a nurse known to family members, where possible
32. Acknowledging and responding to family members' expression of emotions, as appropriate
33. Demonstrating compassion, kindness and maintaining child's dignity

Support ongoing bereavement care, where possible, by:

34. Acknowledging that needs may vary between mothers, fathers and other family members
35. Offering written information about grief and bereavement resources and services.
36. Sending a condolence letter, following up by telephone and/or attending the child's funeral, if appropriate.
37. Offering a follow-up meeting with member/s of the treating team, to debrief, and respond to questions.

*To support **nurse wellbeing**, critical care nurses should:*

38. Acknowledge the range of impacts that a child's death may have on self and colleagues.
39. Respond to distress in self and colleagues.
40. Engage in education and training related to end-of-life care and staff wellbeing.
41. Engage in self-care activities and seek support from preferred sources as desired.

REFERENCES

1. Australian College of Critical Care Nurses. About Us: ACCCN; n.d. [Available from: <https://accn.com.au/about/>].
2. Abela KM, Wardell D, Rozmus C, LoBiondo-Wood G. Impact of pediatric critical illness and injury on families: An updated systematic review. *J Pediatr Nurs*. 2020;51:21-31.
3. Alzawad Z, Lewis FM, Kantrowitz-Gordon I, Howells AJ. A qualitative study of parents' experiences in the pediatric intensive care unit: Riding a roller coaster. *J Pediatr Nurs*. 2020;51:8-14.
4. Dahav P, Sjöström-Strand A. Parents' experiences of their child being admitted to a paediatric intensive care unit: a qualitative study—like being in another world. *Scand J Caring Sci*. 2018;32(1):363-70.
5. Gallegos C, Cacchillo N. Experiences of parents of children with medical complexity in the pediatric intensive care unit: A scoping review. *Crit Care Nurse*. 2023;43(4):20-8.
6. Broden EG, Deatrick J, Ulrich C, Curley MAQ. Defining a “good death” in the pediatric intensive care unit. *Am J Crit Care*. 2020;29(2):111-21.
7. Ko MSM, Lee WK, Sultana R, Murphy B, Heng KYC, Loh SW, Poh PF, Lee JH. Psychological outcomes in families of PICU survivors: A meta-analysis. *Pediatr*. 2024;154(1):e2023064210.
8. O'Meara A, Akande M, Yagiela L, Hummel K, Whyte-Nesfield M, Michelson KN, Radman M, Traube C, Manning JC, Hartman ME. Family outcomes after the pediatric intensive care unit: A scoping review. *J Intensive Care Med*. 2022;37(9):1179-98.
9. Butler AE, Pasek TA, Clark T-J, Broden EG. Supported privacy: An essential principle for end-of-life care for children and families in the PICU. *Pediatr Crit Care Med*. 2024;25(5):e258-e62.
10. Forster E, Hafiz A. Paediatric death and dying: exploring coping strategies of health professionals and perceptions of support provision. *Int J Palliat Nurs*. 2015;21(6):294-301.
11. Al Mutair A, Al Ammary M, Brooks LA, Bloomer MJ. Supporting Muslim families before and after a death in neonatal and paediatric intensive care units. *Nurs Crit Care*. 2019;24(4):192-200.
12. Bloomer MJ, Butler AE, Brooks LA, Coventry A, McKeever S, Ranse K, Rowe J, Thomas S, Thornton R. Parents' and nurses' experiences of end-of-life care in intensive care for children: A systematic review. *Aust Crit Care*. 2025;38(6).
13. Bloomer MJ, O'Connor M, Copnell B, Endacott R. Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: Nurses' emotional talk and sources of discomfort. A mixed methods study. *Aust Crit Care*. 2015;28(2):87-92.
14. Butler AE, Copnell B, Hall H. "Some were certainly better than others" - bereaved parents' judgements of healthcare providers in the paediatric intensive care unit: A grounded theory study. *Intensive Crit Care Nurs*. 2018;45:18-24.
15. Mu P-F, Tseng Y-M, Wang C-C, Chen Y-J, Huang S-H, Hsu T-F, Florczak KL. Nurses' experiences in end-of-life care in the PICU: A qualitative systematic review. *Nurs Sci Quart*. 2019;32(1):12-22.
16. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential elements for safe and high-quality paediatric end-of-life care. Sydney: ACSQHC; 2026.
17. Marshall JC, Bosco L, Adhikari NK, Connolly B, Diaz JV, Dorman T, Fowler RA, Meyfroidt G, Nakagawa S, Pelosi P. What is an intensive care unit? A report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine. *J Crit Care*. 2017;37:270-6.
18. World Health Organization. Newborn Health Western Pacific Region,. 2025.
19. Office of the High Commissioner. Convention on the rights of the child. Geneva: United Nations; 1989.
20. Australian Institute of Health and Welfare. 6.18 end-of-life. Canberra: Australian Institute of Health and Welfare; 2016.
21. Palliative Care Australia. The national palliative care standards. Sydney: Palliative Care Australia; 2022.