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RACP feedback: ACSQHC ‘Essential elements for safe and high-quality paediatric end-of-life care’

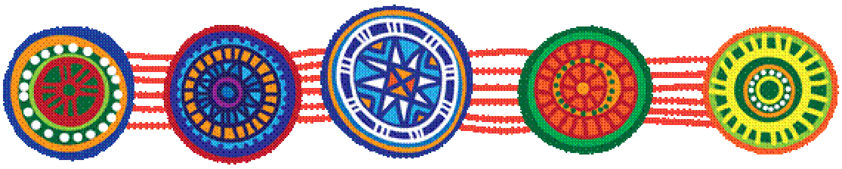
December 2025

About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 24,000 physicians and 9,300 trainee physicians, across Australia and Aotearoa New Zealand. The RACP represents a broad range of medical specialties, including paediatrics and child health, adolescent medicine and palliative medicine.

Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients, the medical profession and the community.

Contact – Amy Pond, Senior Policy and Advocacy Officer, via policy@racp.edu.au.



We acknowledge and pay respect to the Traditional Custodians and Elders – past, present and emerging – of the lands and waters on which RACP members and staff live, learn and work. The RACP acknowledges Māori as tangata whenua and Te Tiriti o Waitangi partners in Aotearoa New Zealand.

Role of the RACP

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to provide feedback on the Australian Commission on Safety and Quality in Health Care's 'Essential elements for safe and high-quality paediatric end-of-life care' National Consensus Statement. We recognise the importance of this work and are pleased to contribute to the review process.

Representing over 33,000 physicians and trainees across Australia and Aotearoa New Zealand, including over 7,100 paediatric and child health members and over 800 palliative medicine members, the RACP brings extensive expertise in paediatric and end-of-life care. **Our members are uniquely placed to inform the review of guidance materials on essential elements for safe and high-quality paediatric end-of-life care.**

Key comments about end-of-life care

The RACP agrees that end-of-life care is important and that improving end-of-life care through systems and cultural changes must be a priority for the entire population.

The RACP has identified five elements that are essential for the provision of good person-centred end-of-life care:

1. Diagnosing dying or the risk of dying.
2. Respecting patient autonomy and supported decision making and providing personalised care.
3. Ensuring that medical treatment decisions respect the patient's best interests.
4. Managing symptoms.
5. Supporting carers and family.

Comments on the National Consensus Statement

The following points represent a summary of positive feedback received from our RACP members on the draft National Consensus Statement:

- **Strong person and family-centred framing** consistently focuses on the child, young person, and their family as active participants in care, emphasising shared decision-making, respect for parental responsibility, and inclusion of the child's expressed wishes where developmentally appropriate.
- Clear articulation of **guiding principles** aligned with ethics and legislation ensures that avoiding harm, not offering unreasonable hope, respecting refusal of treatment, and avoiding burdensome interventions are ethically sound and clinically grounded.
- Strong focus on **cultural safety** and Indigenous perspectives is evident through dedicated sections on Aboriginal and Torres Strait Islander children and families. Emphasis on kinship, Country, Elders, and community involvement is integrated throughout multiple topics rather than isolated in one section.
- **Practical, actionable structure** is achieved through a breakdown into essential elements with clear actions, making the statement usable at the service level.
- Recognition of **workforce wellbeing** is demonstrated by the inclusion of moral distress, supervision, peer support, and burnout prevention, which is critical in paediatric end-of-life contexts.

- Attention to **communication complexity** acknowledges that communication around paediatric death requires advanced skill and provides guidance for preparing, conducting, and documenting these conversations.
- Commitment to **staff education and evaluation systems** is shown through the inclusion of education for staff members and emphasis on audit, feedback, and quality improvement.

Our RACP members also suggest potential improvements for consideration:

- **Clarify definitions and boundaries** between **palliative care** and **end-of-life care** because the document acknowledges end-of-life care as a phase of palliative care but at times uses the terms interchangeably.
- While the document acknowledges **variability to access of resources**, further guidance for what **regional, rural, remote**, and resource-constrained services can do in this situation would be valuable.
- Expand guidance regarding **adolescents** and **mature minors** because there is limited explicit reference to **Gillick competence**, **mature minor doctrine**, or **adolescent autonomy in decision-making**, which is particularly relevant for 14–17-year-olds.
- The draft currently allows the coordinating role of care to be undertaken by a broad range of people, including family members. While flexibility is helpful, this may place undue burden on families; it should be stressed that ultimate responsibility rests with a named clinician or service even if families assist.

In addition, the RACP notes other important topics that could inform the draft National Consensus Statement:

- The topic of ‘information’ is discussed in various contexts throughout the draft; however, **right to information and choice** is not a clear focus. In paediatric care, requiring an understanding of the child’s developmental stage is critical when considering right to information and choice. For a child to be considered autonomous, they must want to participate in decision-making and have the developmental capacity to think, decide, and act based on such thought, free from pressure or coercion. A child’s competence to participate and make an informed choice depends on their understanding of their illness and the risks and benefits of treatment and non-treatment. Older children, depending on maturity and family support, will often be able to influence or determine their treatment and should be actively encouraged to participate in decision-making.
- While the draft often highlights considerations for Indigenous babies, children and young people, the document lacks **the foundation that equitable care should be available to all**, regardless of ethnicity, religion, and/or social status. This requires an obligation to explore, respect, and adapt care and decision-making to the culture and beliefs of the family, and to develop sufficient understanding of the diverse cultural and religious belief systems surrounding death. The Western “nuclear family” model, in which decision-making power resides with parents, may not be universally applicable. Local policies should acknowledge the specific requirements of Indigenous peoples, including Aboriginal and Torres Strait Islander peoples, as well as multicultural populations.
- In addition to resuscitation plans discussed throughout the draft, it is useful to note **resuscitation orders can often be perceived negatively** by the family when framed as “Do Not Resuscitate,” as this wording tends to focus on what should not be done. To address this, other advance care/health directives such as Do Not Attempt Resuscitation (DNAR) or Allow Natural Death (AND) orders have been introduced,

which include measures that *should* be performed for the child. The AND discussion reframes care by emphasising the intensity of management from the perspective of the child's quality of life and best interests, concepts that parents often find easier to engage with.

- **Family involvement in decision making** is widely discussed in the draft. However, for some families there may be a history of **challenging relationships with authority figures and institutions**, and they may have become negatively stereotyped as a result. Management should aim to separate these issues and engage productively and openly with the family. In such situations, it is particularly important to simplify and clarify channels of communication and authority, and to empower the family to articulate their wishes and priorities for their child. In some cultures, the extended family may be central in determining decisions or providing a supportive context in which parents can explore and express their wishes. Sensitive engagement with this aspect of the extended family may facilitate progress.
- In addition to the comment on **dispute resolution processes** (line 529), **disagreement** within paediatric end-of-life care can arise among **healthcare teams, families, or between clinicians and families**. Within the healthcare team, disputes often centre on prognosis and management options and are usually resolved through further information, investigation, inclusive discussion, or a second opinion from a senior clinician outside the treating team. Family disagreements, whether between the child and parents or among adult family members, are not uncommon and may require repeated conversations to explore beliefs, fears, and conflicting goals, aiming for resolution or compromise. Between medical practitioners and families, the most frequent disagreement involves reluctance to accept withdrawal of intensive treatment, while less common is a request to cease treatment deemed appropriate by the healthcare team. Whenever disagreement occurs, a senior clinician should promptly identify its cause and engage in ongoing discussion, providing additional information to support resolution or compromise.
- The RACP also considers 'A Practical Guide to Palliative Care in Paediatrics' by Palliative Care Australia and Paediatric Palliative Care Australia and New Zealand, a valuable resource for paediatric end-of-life care.

In addition, please find a list of editing suggestions at Appendix A for consideration.

Next steps

The RACP greatly appreciates the opportunity to provide feedback on the Australian Commission on Safety and Quality in Health Care's 'Essential elements for safe and high-quality paediatric end-of-life care' National Consensus Statement. We trust our feedback has been helpful. For further queries or information, please contact Amy Pond, Senior Policy and Advocacy Officer, via policy@racp.edu.au.

Appendix A:

Overall Improvements

#	Issue / Area	Example	Suggested Action
Overall	Inconsistent use of hyphenation and compound words	end of life vs end-of-life, health care vs healthcare, non-verbal vs nonverbal	Select one consistent style and apply throughout
1	Example inconsistencies	Line 374: 'health care record'	Change to 'healthcare record'
		Page 26: 'non-verbal cues'; Page 20: 'nonverbal cues'	Use 'nonverbal' consistently
		Lines 461 & 463: 'after hours' vs 'after-hours'	Use one consistent form
2	Inclusion of babies, children, and young people	Lines 494, 505, 514	Change to 'end-of-life care for babies, children, and young people…'

Specific Improvements

#	Issue / Area	Example	Suggested Action
1	Repetitive paragraphs	Lines 55–59 and 60–65	Consolidate into one paragraph
2	Extra space	Page 17, paragraph 225: 'and/ or'	Remove extra space
3	Extra space	Line 260: '...care needs, and reduce...'	Remove extra space
4	Missing comma	Line 275	Add comma: '...in a safe, quiet and private environment'
5	Missing link	Lines 298 & 616	Add link to DonateLife
6	Missing link	Lines 299–300 & 616–617	Add link to Family Donation Conversation Workshop
7	Sentence clarity	Lines 304-306	Change to: 'care and prioritise the wishes of the child or young person and their parents.'
8	Avoid generalisation	Page 20, paragraph 3	Further context may be needed for clarity
9	Cultural terminology	Page 20, paragraph 4	Change to: 'Aboriginal and Torres Strait Islander health workers and liaison officers'
10	Missing comma	Page 20, paragraph 4	Add comma for clarity
11	Wrong word	Page 20, paragraph 7	Extend should be extended
12	Kinship terminology	Page 20, paragraph 7	Change to include Aboriginal and Torres Strait Islander
13	Terminology	Page 21, paragraph 1	Should 'maternal fetal teams' be 'maternal fetal medicine teams'?
14	Title case	Page 21	Remove title case for 'neonatal intensive care units'
15	Title case	Page 21	Remove title case for 'general practitioner'
16	Sentence clarity	Line 458	Update wording for clarity
17	Missing punctuation	Line 483	Add full stop
18	Missing word	Line 485	Add 'to' in sentence

19	Workforce wording	Line 548	Change to: 'An educated, suitably skilled and qualified workforce…'
20	Pain relief wording	Line 684	Change to: 'including the use **of** pain relief'
21	Repetition	Lines 735 & 738	Remove duplicate paragraph
22	Terminology	Lines 790 & 791	Change 'health care' to 'healthcare'
23	Extra space	Line 905	Remove extra space after '/'