

Navigating decisions to provide, limit or withdraw treatment in children towards the end of life: A framework for clinical practice, 2026

Scope for update

1. Document title

Navigating decisions to provide, limit or withdraw treatment in children towards the end of life: A framework for clinical practice, 2026.

Short title: Navigating end of life decisions in children.

2. The remit

The Royal College of Paediatrics and Child Health (RCPCH) aims to update the framework for practice published in 2014.

The framework¹, originally developed by the Ethics and the Legal Advisory Committee (ELAC) at the RCPCH, aims to help clinicians considering or making decisions about life-sustaining treatment (LST) in children and young people.

3. Clinical need to update the framework

This is an update of a previous work, published in 2014 to include new evidence and changes to clinical practice. The update aims to condense and clarify the framework and include an accessible summary for parents.

4. Framework content

- a) This document is the scope of the update. It defines exactly what the framework will (and will not) cover, and what specific areas will be considered.
- b) The areas to be addressed by the framework are in the following sections.
- c) The framework will be updated based on key stages of the RCPCH Standards for guideline development² and ensure relevant expertise included in the working group and relevant stakeholders (Appendix 1).

4.1 Population

4.1.1. Groups that will be covered

Infants, children and young people (up to 18th birthday) with life-limiting and life-threatening conditions. The framework will include specific guidance for 16 and 17 years old.

4.1.2. Groups that will not be covered

Fetuses and embryos (outside of antenatal discussion).

4.2 Healthcare settings and services

All settings in UK where children receive health care. Includes children and young people being cared for outside children's hospitals – e.g., in the community, in primary care settings, hospices, in newborn units, or in adult hospitals. Both NHS and private healthcare facilities are included.

4.3 Key areas

4.3.1 Issues that will be covered

- Definitions and language:
 - Communication principles, including:
 - Timing of discussions (including discussions before birth)
 - Communication across different healthcare organisations and service interfaces
 - The voice of the child / young person
 - Advance care planning and relevant documents such as Wishes and RESPECT
- Legal framework and principles, including:
 - Roles within decision making, for parties such as clinicians and parents
 - Role of the young person in decisions (with/without parents)
- Ethical framework and principles, including:
 - Best interests of the child
 - Parental authority and discretion in decision-making
 - Deciding with children
 - When is it ethical to limit Life-Sustaining Treatment (LST)?
 - Situations when it is appropriate to limit treatment
 - Uncertainty and decision making
 - Including skills, processes and justification for revising decisions as circumstances evolve
 - Parallel planning and role of palliative care

- Clinical and practical considerations and specific ethical questions:
 - Role of clinical ethics services
 - How should decisions about LST be made?, including:
 - Provision of an accessible, supportive and inclusive environment for families and professionals
 - Individual preferences and wishes, e.g., preferred place of care and death
 - Working in partnership
 - Trust and relationship building
 - Setting and managing expectations
 - Involvement of services, such as palliative care
 - Impact of ethnicity, faith, disability, socioeconomic status and safeguarding issues
 - Special considerations for young people undergoing transition to adult care
 - Interpretation of certain symptoms, e.g., terminal gasping
 - Navigating disagreement, e.g.,
 - Guidance for professionals, CYP and families where there is disagreement, e.g.,
 - Where parents disagree with each other or where parents disagree that treatment should be offered
 - Where there is disagreement within the healthcare team
 - See RCPCH guidance on: Achieving consensus - on prevention, recognition and management of conflict in paediatric practice
 - Misinformation, internet, social media and public scrutiny
 - Seeking second opinions (see RCPCH guidance on seeking second opinions), mediation or dispute resolution.
 - Potential for transfer to other hospitals or jurisdictions
 - Going to court
 - What specific decisions may be made? e.g.,
 - Decisions to provide or withhold cardiopulmonary resuscitation
 - Including special circumstances such as the peri-operative period
 - Decisions on intensive care admission

- Decisions to withdraw mechanical ventilation in intensive care
- Decisions to withhold or withdraw clinically assisted nutrition, (including parenteral nutrition) and hydration
- Decisions about performing tests for death by neurological criteria
- Decisions about initiation or withdrawal of long-term ventilation
- Decisions about other forms of treatment, invasive procedures or organ support e.g., ventricular assist devices, extra-corporeal membrane oxygenation, permanent pacemakers
- Decisions about novel and experimental interventions

4.3.2 Issues that will not be covered in detail (instead the framework will signpost where appropriate to other resources)

- Assisted dying
- Wider aspects of end-of-life care including specific guidance on:
 - Bereavement care
 - Practical aspects of palliative care
 - Decisions and ethics of tissue and organ donation (other than language and communication around the topic).

5. Related guidance

- The 2025 Code of Practice for the determination of death by the Academy of Medical Royal Colleges ([AoMRC](#)).
- Treatment and care towards the end of life: good practice in decision making GMC <https://www.gmc-uk.org/professional-standards/the-professional-standards/treatment-and-care-towards-the-end-of-life>.
- [Nuffield Council on Bioethics report 'Disagreements in the care of critically ill children' \(2023\)](#).
<https://assets.publishing.service.gov.uk/media/651597336a423b000df4c579/NCOB-web-version-independent-review-disagreements-in-the-care-of-critically-ill-children-september-2023.pdf>.

6. References

1. Royal College of Paediatrics and Child Health. Setting standards for the development of clinical guidelines in paediatrics and child health,

2020. Accessed at [https://www.rcpch.ac.uk/sites/default/files/2024-12/Standards for paediatric guidelines 2020.pdf](https://www.rcpch.ac.uk/sites/default/files/2024-12/Standards%20for%20paediatric%20guidelines%202020.pdf).

2. Larcher V, Craig F, Bhogal K, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Archives of Disease in Childhood* 2015;100:s1-s23. Accessed at https://adc.bmj.com/content/100/Suppl_2/s1.

Appendix 1: Working Group Expertise and Stakeholders Organisations

The working group will consist of experts on the topic (multidisciplinary) and parent and CYP representation.

Stakeholders are organisations or relevant associations (i.e., specialty groups, speciality interest groups) that will be identified by the working group as having an interest in the topic, or who represent people whose practice or care may be affected directly. Stakeholders will be formally invited, informed at different stages of development and will be invited to provide their views during the scope and draft consultation.

Working group expertise	Stakeholder organisations
Neonatology	Paediatric Critical Care Society (PCCS)
Paediatric intensive care	British Association of Perinatal Medicine (BAPM)
Paediatric intensive critical care medicine	British Paediatric Neurology Association (BPNA)
Adult intensive care	British Paediatric Respiratory Society (BPRS) and National Long Term Ventilation
Paediatric intensive care nursing	Royal College of Radiologists (RCR)
Paediatric anaesthesia	UK Critical Care Nursing Alliance (UKCCNA)
Paediatric surgery	Neonatal Nurses' Association (NNA)
General practice	Association of Paediatric Palliative Medicine (APPM)
General paediatrics	British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGAHN)
Paediatric gastroenterology (co-opted)	Faculty of Intensive Care Medicine (FICM)
Paediatric respiratory medicine (co-opted)	UK Clinical Ethics Network (UKCEN)
Paediatric emergency medicine (co-opted)	Royal College of Anaesthetists (RCoA)
Paediatric neurology (co-opted)	Royal College of General Practitioners (RCGP)
Paediatric palliative care medicine	Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI)
Paediatric palliative nursing	
Legal expertise	

<p>Trainee representative Religious expert representative CYP/Parent representation</p>	<p>Royal College of Nursing (RCN) British Paediatric Respiratory Society (BPRS) and National Long term ventilation group British Academy of Children Disability (BACD) Association of Paediatric Emergency (APEM) British Association of Community Child Health (BACCH) Together For Short Lives Sands Bliss Carers UK Child Bereavement UK Contact a family Keech Hospice Well Child Smallest Things True Colours Nuffield Council on Bioethics Medical Mediation Health-Based Youth Worker's Network Child and Young Person's Advance Care Plan (CYACP) Collaborative All Wales Paediatric Palliative care (AWPPC) Welsh Government Scottish Government, Senior Medical Advisor (Paediatrics) Scottish Government Child Health & Wellbeing Team (Children and Families Directorate) Health Care improvement Scotland (Medical and Safety Directorate) Northern Ireland Child Services NHS Performance & Improvement National Palliative and End of Life Care Programme NHS England (NHSE) General Medical Council (GMC) Department of Health (DoH) Academy of Medical Royal Colleges (AoMRC)</p>
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