

Making decisions to limit treatment in children with life limiting and life-threatening conditions: Framework for clinical practice - Update

Scope

1. Document title

Making decisions about treatment in children and young people with life-limiting and life-threatening conditions.

Short-title: Making decisions towards the end of life 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), 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/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

Unborn babies (e.g., when antenatal decisions are considered).

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 hospices, in newborn units, or in adult hospitals.

4.3 Key areas

4.3.1 Issues that will be covered

- Definitions and language. Communication principles
- Legal framework and principles
- Ethical framework and principles
- Clinical and practical considerations and specific ethical questions such as:
 - When is it ethical to limit Life-Sustaining Treatment (LST)?
 - Situations when it is appropriate to limit treatment
 - Dealing with uncertainty
 - How should decisions about LST be made?
 - The extent and limitation of parental authority in making decisions
 - Navigating disagreement, including faith-based concerns, potential for transfer to other hospitals or jurisdictions
 - What specific decisions may be made? For example,
 - Decisions to withhold cardiopulmonary resuscitation and/or intensive care admission
 - Decisions to withdraw mechanical ventilation in intensive care
 - Decisions to withhold or withdraw clinically assisted nutrition and hydration in children
 - Decisions about performing tests for Death by neurological criteria
 - Decisions about 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

4.3.2 Issues that will not be covered (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
 - Palliative care (beyond its important role in communication and decision-making about life sustaining treatment).
 - Decisions and ethics of 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>.

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>.
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 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.

They 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 Intensivist Paediatric Intensive Critical Care Medicine Adult intensivist Paediatric Intensive Care Nursing Paediatric Anaesthetists Paediatric Surgery General practitioner Paediatric Palliative Care Medicine Paediatric Palliative Nurse Legal expertise Trainee representative CYP representative Religious groups representative	Paediatric Critical Care Society (PCCS) British Association of Perinatal Medicine (BAPM) British Paediatric Neurology Association (BPNA) Royal College of Radiologists (RCR) UK Critical Care Nursing Alliance (UKCCNA) Neonatal Nurses' Association (NNA) Association of Palliative Care Faculty of Intensive Care Medicine (FICM) Faculty of Pharmaceutical Medicine (FPM) Royal College of Physicians (RCP) UK Clinical Ethics Network (UKCEN) Royal College of Anaesthetists (RCA) Royal College of General Practitioners (RCGP) Association of Paediatric Anaesthetists of Great Britain and Ireland (APAGBI) Royal College of Nursing (RCN) Royal College of General Paediatrics (RCGP) Together For Short Lives Sands—Still Birth and Neonatal Death Society BLISS Child Bereavement UK