



Topic Expert Group: Ethical decision-making and palliative care

Decisions of withholding or withdrawing life support

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Target group

Infants, parents, and families

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of Standard

Decisions of withholding or withdrawing life support are based on shared decision-making between parents and healthcare team taking into account the best interest of the infant and family in the context of the clinical situation and legal frameworks.

Rationale

In many societies and cultures, active life support to infants has only become accepted standard practice years after this was routinely offered to children and adults. This may reflect different views on the value of newborn life, and the uncertainty about future health. (1,2) In most high-resource settings, newborn infants born alive have full legal status regardless of gestation or size at birth, and legally all actions should be motivated by the child's 'best interests'. In the judgement of this, due emphasis should be put on careful observation and interpretation of the child's own behaviour.

Deliberations about limiting life support should be taken in partnership with the parents, who should be a part of the shared decision-making process. Such decisions must be based on local data, international experience, national laws and yet be individualised as such decisions are of ultimate importance. (3–8) In all cases the values, experiences, conditions, and wishes of the family have to be taken into consideration recognising that the child is a child in a family and that the future of the life of the family is involved. (9,10) The responsible physician must be able to take full responsibility if the decision is questioned at a later stage.

Benefits

- Reduced suffering of the infant (3)
- Facilitated acceptance of the decision by involving families in the choices to be made (1,2)
- Better provision of care by healthcare professionals when the benefit to the child and the family is well defined (consensus)
- Reduced numbers of healthcare professionals suffering stress and 'burnout' when shared decision-making is used (11,12)



Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals about the decision-making process as far as they wish and within the national legal framework. (1–3)	A (Low quality) B (High quality)	Parent feedback, patient information sheet
2. Emotional, psychological, ethical, and religious/spiritual support is offered. (1,3,6,10)	A (Moderate quality) B (Moderate quality)	Parent feedback, patient information sheet
For healthcare professionals		
3. A unit guideline on withholding or withdrawing life is adhered to by all healthcare professionals.	B (High quality)	Guideline
4. Training on ethical decision-making processes is attended by all responsible healthcare professionals.	B (High quality)	Training documentation
5. The family is involved as much as they wish and the information given as well as the family's responses and choices are recorded. (2,4,5,8,9)	A (Moderate quality) B (Moderate quality)	Clinical records, healthcare professional feedback
6. A clinical basis for decisions is created at multi-professional conferences involving healthcare professionals with the relevant knowledge and skills as well as healthcare professionals with the most direct contact with the infant and family. (5,7)	A (Moderate quality)	Clinical records, healthcare professional feedback
For neonatal unit		
7. A unit guideline on withholding or withdrawing life support is available and regularly updated. (8)	B (High quality)	Guideline
8. Multi-professional case reviews of decision-making practice are organised where specific challenges are discussed. (7,8)	A (Low quality) B (Moderate quality)	Audit report



9. Multi-professional debriefing meetings are organised routinely or when relevant after the death of infants following a decision to withhold or withdraw treatment. (7,8) (see TEG Infant- and family-centred developmental care)	A (Low quality) B (Moderate quality)	Audit report
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For hospital

10. Training in ethical decision-making processes is ensured.	B (High quality)	Training documentation
11. A clinical ethics committee is available for advice.	B (Moderate quality)	Audit report

For health service

12. A national guideline or legislation on withholding or withdrawing life support is available and regularly updated. (12–14)	A (Moderate quality) B (High quality) C (Moderate quality)	Guideline
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Where to go – further development of care

Further development	Grading of evidence
For parents and family	
<ul style="list-style-type: none"> • The development of parental peer groups is supported. (1–3) • Methods of parental feedback on the decision-making process are developed. (15) 	A (Moderate quality) A (Low quality)
For healthcare professionals	
<ul style="list-style-type: none"> • Mentor junior healthcare professionals in ethical decision-making. 	B (Low quality)
For neonatal unit	
<ul style="list-style-type: none"> • Organise regular healthcare team meetings to remind healthcare professionals of the importance and relevance of family involvement in decisions of withholding or withdrawing life support. (8) 	B (Low quality)
For hospital	
N/A	
For health service	
<ul style="list-style-type: none"> • Develop training programmes in communication around decisions in limiting life support. 	B (Moderate quality)



Getting started

Initial steps

For parents and family

- Parents are verbally informed about and involved in ethical decision-making processes by healthcare professionals.

For healthcare professionals

- Attend training in ethical decision-making processes.
- Organise regular team meetings to discuss ethical issues.

For neonatal unit

- Develop and implement a unit guideline on withholding or withdrawing life support.
- Develop information material for parents to be involved in the decision-making process.
- Organise multi-professional meetings to discuss ethical issues.

For hospital

- Support healthcare professionals to participate in training in ethical decision-making processes.
- Initiate a clinical ethics committee.

For health service

- Develop and implement a national guideline on withholding or withdrawing life support.

Source

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Lifecycle

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