



Ethical decision-making & palliative care

Decisions of withholding or withdrawing life support

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Statement of the 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.

Benefits

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



For parents and family

- Parents are informed by healthcare professionals about the decision-making process as far as they wish and within the national legal framework.
- Emotional, psychological, ethical, and religious/spiritual support is offered.



For healthcare professionals

- A unit guideline on withholding or withdrawing life is adhered to by all healthcare professionals.
- Training on ethical decision-making processes is attended by all responsible healthcare professionals.
- The family is involved as much as they wish and the information given as well as the family's responses and choices are recorded.
- 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.



For neonatal unit

- A unit guideline on withholding or withdrawing life support is available and regularly updated.
- Multi-professional case reviews of decision-making practice are organised where specific challenges are discussed.
- Multi-professional debriefing meetings are organised routinely or when relevant after the death of infants following a decision to withhold or withdraw treatment.



For hospital

- Training in ethical decision-making processes is ensured.
- A clinical ethics committee is available for advice.



For health service

- A national guideline or legislation on withholding or withdrawing life support is available and regularly updated.

