



Topic Expert Group: Ethical decision-making and palliative care

Palliative care

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Target group

Infants, parents, and families

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard

Interdisciplinary neonatal palliative care safeguards the quality of life of the infant and the family when a life limiting condition is diagnosed.

Rationale

The goal of this standard is to ensure that infants do not suffer unnecessary pain or discomfort in a setting in which parents receive support to enable them to be involved in the care based on their wishes.

Neonatal palliative care integrates clinical support of the infant and family support, starting from the diagnosis of a life-limiting condition and/or decision. Palliative care may commence before delivery and continue into bereavement care, so that a seamless clinical service is produced. (1–4)

Neonatal palliative care aims to optimise quality of life for the infant and family, and to create an environment that whilst death is likely, some infants may live for prolonged periods. There are wide variations in neonatal palliative care practices. (5–8) Family oriented, interdisciplinary, neonatal palliative care is essential in providing optimal care (9) and building trust between families and the healthcare team. (10) It is difficult to determine quality of life in an infant with a life-limiting condition. As an example, the balance between being awake and in contact with the parents, whilst still receiving adequate treatment for pain and discomfort can be difficult to assess. However, structured observations to assess pain and comfort are available and should be used. (11,12)

Parents must be allowed to stay with their infant at all times in an environment that meets their wishes and spiritual needs. (13) Healthcare professionals must support themselves - reflective practice groups and facilitated debriefs are helpful. (2) After the death of their child, families should be offered support by professionals trained in bereavement care.

Benefits

- Reduced suffering from pain and discomfort for infants (1,3,11,13)
- Improved support for parents during palliative care (1,3,4,10)
- Better informed healthcare professionals regarding care priorities and the wishes of parents (6–8,10,13)
- Better support for healthcare professionals in their role as palliative care providers (6,7,10)



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 life limiting conditions of their infant and family support options.	B (High quality)	Patient information sheet
2. Infants with life limiting conditions receive appropriate medication and care. (1,2,11,12)	A (Moderate quality) B (Moderate quality) C (Moderate quality)	Clinical records
3. Parents are supported in a way that meets their needs and respect their wishes. (1,3,4,10,8,13) (see TEG Infant- and family-centred developmental care)	A (Moderate quality) B (Moderate quality)	Parent feedback
4. Parents are supported in their grief rituals. (14,15)	A (Low quality) B (Moderate quality)	Parent feedback
For healthcare professionals		
5. A unit guideline on palliative care is adhered to by all healthcare professionals.	B (High quality)	Guideline
6. Training on palliative care is attended by all responsible healthcare professionals. (1,3)	A (Moderate quality) B (High quality)	Training documentation
For neonatal unit		
7. A unit guideline on palliative care is available and regularly updated.	B (High quality)	Guideline
8. Palliative care practice is integrated within direct care and with senior supervision. (3)	A (Low quality) B (Low quality)	Annual report
9. A specialist inter-disciplinary palliative care team is organised. (1,3,15)	A (Low quality) B (Moderate quality)	Guideline
10. Regular healthcare professionals debriefing sessions are	A (Moderate quality)	Minutes of debriefings



organised. (1,3)	B (Low quality)	
11. Collaboration with other palliative care professionals such as hospice care or community care is established. (7,10)	A (Low quality) B (Low quality)	Guideline
For hospital		
12. Training on palliative care is ensured.	B (High quality)	Training documentation
13. Specialists services are part of the neonatal palliative care team such as psychology, pastoral/spiritual and social care teams. (1,3,4)	A (Moderate quality) B (Moderate quality)	Annual report
For health service		
14. A national guideline on palliative care is available and regularly updated.	B (High quality)	Guideline
15. Smooth transition from hospital to home or hospice is provided by a good collaboration of healthcare services with palliative care services. (1,3–5)	A (Moderate quality) B (Moderate quality)	Annual report

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
<ul style="list-style-type: none"> Affected parents are supported with the help of parent peer groups. 	A (Low quality)
For healthcare professionals	
<ul style="list-style-type: none"> Make counselling support available for healthcare professionals. (7,8,13) 	A (Moderate quality)
For neonatal unit	
<ul style="list-style-type: none"> Establish a palliative care team at every neonatal unit. (7) 	A (Moderate quality)
For hospital	
N/A	
For health service	
N/A	



Getting started

Initial steps

For parents and family

- Parents are verbally informed by healthcare professionals about the life limiting conditions of their infant and family support options.
- The development of neonatal palliative care practice is encouraged by bereavement support organisations.

For healthcare professionals

- Attend training on palliative care.
- Provide comfort management to the infant.
- Provide privacy and dignity to parents.

For neonatal unit

- Develop and implement a unit guideline on palliative care.
- Develop information material on palliative care for parents.
- Explain to parents the transition to palliative care.
- Support parents throughout the palliative care process.

For hospital

- Support healthcare professionals to participate in training on palliative care.
- Provide access to psychological, emotional and spiritual support services.

For health service

- Develop and implement a national guideline on palliative care.

Source

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First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Latour JM, Greisen G et al., European Standards of Care for Newborn Health: Palliative care. 2018.