



Ethical decision making & palliative care



european standards of
care for newborn health

EFGNI european foundation for
the care of newborn infants



Topic Expert Group
Ethical decision-making and palliative care

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Topic Expert Group: Ethical decision-making and palliative care

Overview

Neonatal care has advanced in the last decades resulting in survival of more preterm and ill babies. Still, not every baby can be saved and especially when the clinical team has identified a life limiting condition or a high risk of survival with significant long-term disability, communication is particularly challenging. (1) Parents often report that they do not feel that they participate meaningfully in important decisions for their infant's care (2). Therefore, open and honest information sharing is an important priority for parents (3,4). This increases parental trust and that decisions must be individualised based on clinical factors and in respect for family values. (1,2,5,6) In order to truly participate in decisions, parents need a trustful relationship with emotionally supporting healthcare professionals. (5,7)

When a life limiting condition is diagnosed, family oriented, interdisciplinary, neonatal palliative care is essential to safeguard the quality of life of the infant and the family. (8) Parents and healthcare professionals must share all relevant information such as the medical condition, the prognosis, and the choices for care of the infant, as well as the social situation, values, and preferences of parents. It has to be ensured, that decisions respect the rights of children, parents, and families as far as this is feasible. (9)

Effective communication skills and a suitable, unpressured environment are needed that can overcome language, educational, cultural, and socio-economic barriers. Healthcare professionals must seek to understand the social situation of the parents, their family values, and personal preferences, and must be able to explain the situation in plain language and a compassionate manner.

The Topic Expert Group on Ethical decision-making and palliative care has developed four standards. These are: (1) Decisions of withholding or withdrawing life support; (2) Communication in ethically complex decisions; (3) Palliative care; (4) Rights of infants, parents, and families in difficult decisions.

Sources:

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9. *UNICEF. The United Nations Convention on the Rights of the Child [Internet]. 1990. Available from: https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.163550268.1218459234.1527076484-403558301.1527076484*



Communication in ethically complex decisions

Latour JM, Greisen G, Verhaest Y, Alfonso E, Bucher HU, Caeymaex L, Cuttini M, Embleton N, Novak M, Nuzum D, Peters J, Rombo K, Wood D

Target group

Infants, parents, and families

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard

Parents and healthcare professionals share all relevant information such as the conditions, prognosis, and choices for care of the infant, as well as the social situation, values, and preferences of parents.

Rationale

The goal of this standard is to ensure that caregivers understand the conditions of the infant, values, and preferences of the parents and those parents understand the prognosis and choices for care for their infant and receive support in their role in decision-making.

Parents often report that they do not feel that they participate meaningfully in important decisions for their infant's care (1), especially when the clinical team has identified a life limiting condition or a high risk of survival with significant long-term disability (2), where communication is particularly challenging. Parents value shared decision-making (3) particularly where they are given choices for the direction of their infant's care. (4) In order to participate in the decisions they need a trustful relationship with emotionally supporting healthcare professionals. (5,6) Effective communication skills are needed regardless of language, educational, cultural or socio-economic barriers, and a suitable, unpressured environment.

Open and honest information sharing is an important priority for parents of ill infants. (7,8) Healthcare professionals must seek to understand the social situation of the parents, their family values, and personal preferences, and must be able to explain the situation in plain language and compassionate manner. They must make sure that parents understand the situation, and that arising questions are elicited. Transparency and continuity of communication with parents is vital (9) whilst acknowledging that spontaneous communication that responds to changing needs and priorities is also crucial. (10) Care should be taken to ensure consistency in communication when different healthcare professionals members are involved.

Benefits

- Increased trust of parents that decisions are individualised, based on clinical factors and respect for their family values (1,2,6,9)
- Improved understanding of healthcare planning in the short term, but also in the longer term when parents may reflect on the decisions that were made (2,3)
- Reassurance that the best decisions have been made by healthcare professionals in close dialogue with families (1,2,6,9,10)



- Improved ability to cope with stress that comes with caring for ill infants (2,3,9)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals how ethical decisions are made in the neonatal unit. (9,10)	A (Low quality) B (High quality)	Patient information sheet
2. Parents are informed about the clinical situation. (1,2,11,12)	A (Low quality) B (High quality) C (Moderate quality)	Clinical records, parent feedback
3. Conditions and preferences of the family are actively explored. (3–5)	A (Low quality) B (Moderate quality)	Clinical records, parent feedback
4. Parents are offered assistance from an interpreter if necessary. (7,10)	B (Low quality)	Clinical records
5. Parents are given the right to bring family support or a spiritual adviser to meetings. (9,10)	B (Low quality)	Clinical records
6. For important decisions sufficient time to allow for appropriate reflection is given; multiple encounters may be required. (2,10)	A (Low quality) B (Moderate quality)	Clinical records, parent feedback
For healthcare professionals		
7. Training on communication of complex clinical issues is attended by all responsible healthcare professionals.(10)	A (Low quality) B (High quality)	Training documentation
8. Sufficient time for meetings with parents is provided. (10)	A (Low quality) B (Moderate quality)	Clinical records, parent feedback
For neonatal unit		
9. A private area for meetings between healthcare professionals and family is provided. (see TEG NICU design)	B (Moderate quality)	Audit report



10. Regular case reviews and training that includes discussing challenges in communication is conducted.	A (Low quality) B (Low quality)	Training documentation
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For hospital

11. Training on communication of complex clinical issues is ensured.	B (High quality)	Training documentation
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12. When designing neonatal units private rooms for parent meetings are included. (see TEG NICU design)	B (Low quality)	Audit report
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13. Healthcare professionals are adequately supported and appropriate facilities are ensured. (see TEG Infant- and family-centred developmental care, TEG Patient safety & hygiene practice, TEG NICU design)	C (Moderate quality)	Audit report
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For health service

14. In national curricula for healthcare professionals communication of complex clinical issues is included. (see TEG Education & training)	B (Moderate quality)	Training documentation
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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"> Organise parent support groups. (10) 	A (Low quality) B (Moderate quality)
For healthcare professionals	
<ul style="list-style-type: none"> Organise annual communication training for healthcare professionals. (9,10) 	A (Low quality) B (Moderate quality)
For neonatal unit	
N/A	
For hospital	
N/A	
For health service	
<ul style="list-style-type: none"> Develop resources for interpreters to work face-to-face, via telephone or internet. (13,14) 	A (Low quality)



Getting started

Initial steps

For parents and family

- Awareness is increased among parents of their right to be fully informed and involved in discussion of the clinical course of their infant by healthcare professionals.

For healthcare professionals

- Attend training on communication of complex clinical issues.
- Include parents in the discussion of the clinical course and prognosis of their infant from admission to the neonatal unit.

For neonatal unit

- Develop information material on the process of ethical decision-making in the neonatal unit for parents.

For hospital

- Support healthcare professionals to participate in training on communication of complex clinical issues.

For health service

N/A

Source

1. Staniszewska S, Brett J, Redshaw M, Hamilton K, Newburn M, Jones N, et al. The POPPY study: developing a model of family-centred care for neonatal units. *Worldviews Evid-Based Nurs Sigma Theta Tau Int Honor Soc Nurs*. 2012 Dec;9(4):243–55.
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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: Communication in ethically complex decisions. 2018.



Decisions of withholding or withdrawing life support

Greisen G, Latour JM, Verhaest Y, Alfonso E, Bucher HU, Caeymaex L, Cuttini M, Embleton N, Novak M, Nuzum D, Peters J, Rombo K, Wood D

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	
• The development of parental peer groups is supported. (1–3)	A (Moderate quality)
• Methods of parental feedback on the decision-making process are developed. (15)	A (Low quality)
For healthcare professionals	
• Mentor junior healthcare professionals in ethical decision-making.	B (Low quality)
For neonatal unit	
• 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	
• 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

1. Caeymaex L, Speranza M, Vasilescu C, Danan C, Bourrat M-M, Garel M, et al. Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in the NICU. *PLoS One*. 2011;6(12):e28633.
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First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Greisen G, Latour JM et al., European Standards of Care for Newborn Health: Decisions of withholding or withdrawing life support. 2018.



Palliative care

Latour JM, Greisen G, Verhaest Y, Alfonso E, Bucher HU, Caeymaex L, Cuttini M, Embleton N, Novak M, Nuzum D, Peters J, Rombo K, Wood D

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 organised. (1,3)	A (Moderate quality) B (Low quality)	Minutes of debriefings



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

1. National Institute for Health and Care Excellence (NICE). End of life care for infants, children and young people with life-limiting conditions: planning and management [Internet]. 2016. Available from: <https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-1837568722885>
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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.



Rights of infants, parents, and families in difficult decisions

Greisen G, Latour JM, Verhaest Y, Alfonso E, Bucher HU, Caeymaex L, Cuttini M, Embleton N, Novak M, Nuzum D, Peters J, Rombo K, Wood D

Target group

Infants, parents, and families

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard

The rights of infants, parents, and families in difficult decisions are respected by healthcare professionals. The values behind any decisions that may compromise those rights are transparent.

Rationale

The goal of this standard is to ensure that decisions respect the rights of children, parents, and families as far as this is feasible. For infants, the relevant rights related to treatment and care decisions are: The right to a human identity, care and nurture, association with parents, freedom from discrimination and from unnecessary pain. (1,2) The infant is an individual in its own right, but also a child in the custody of the parents and born into a wider family and into a society. (3) When infants are malformed, injured at birth, born preterm or ill and depend on special care for their comfort or survival, then the infant is particularly vulnerable and dependent on help. The family may be in acute psychological and social distress, increasing their vulnerability. This places an ethical duty on healthcare professionals to protect the integrity, dignity and comfort of the infants and their family, as well as supporting the autonomy of parents in their execution of parental custody. There is also a duty to protect privacy, promote equity and prevent discrimination, particularly when discussing ethical issues. (4)

Benefits

- Best possible care is provided to infants that is aligned with their clinical situation and therapeutic goals set for them (consensus)
- Increased trust of parents and families that their rights are respected (consensus)
- Increased transparency allows an open discussion of issues (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents and family are informed by healthcare professionals about the standards enshrined in the UN Convention on the Rights of the	B (High quality) C (High quality)	Patient information sheet



Child/the European Association for
Children in Hospital Charter or national
equivalents. (1)

For healthcare professionals

- | | | |
|--|--------------------------------------|------------------|
| 2. The standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter or national equivalents are adhered to by all healthcare professionals. (1) | B (High quality)
C (High quality) | Parent feedback |
| 3. The best interests of infants and wishes of parents are respected. There is no discrimination because of age, race, religion, beliefs, gender, or sexual orientation. (1) | B (High quality)
C (High quality) | Parent feedback |
| 4. When the best interests of infants or wishes of parents or families cannot be met the reasons are explicitly documented. | B (Low quality) | Clinical records |

For neonatal unit

- | | | |
|---|-----------------|--------------|
| 5. The adequacy of clinical services for infants is reviewed at regular intervals and any shortcoming declared. | B (Low quality) | Audit report |
|---|-----------------|--------------|

For hospital

- | | | |
|---|------------------|--------------|
| 6. The standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter or national equivalents are ensured. | B (High quality) | Audit report |
| 7. The distribution of resources among services for different groups of patients is reviewed at regular intervals to address questions of equity and to prevent discrimination. | B (Low quality) | Audit report |

For health service

- | | | |
|--|------------------|------------------------|
| 8. Rights of infants, parents, and families are included in the Curricula of the healthcare professional education. (see TEG Education & training) | B (High quality) | Training documentation |
|--|------------------|------------------------|



Where to go – further development of care

Further development	Grading of evidence
For parents and family	
N/A	
For healthcare professionals	
N/A	
For neonatal unit	
N/A	
For hospital	
N/A	
For health service	
N/A	

Getting started

Initial steps
For parents and family
<ul style="list-style-type: none">• Parents and family are verbally informed by healthcare professionals about the standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter or national equivalents. (1)• Encourage hospitals to adopt the UN Convention on the Rights of the Child. (1)
For healthcare professionals
<ul style="list-style-type: none">• Audit service against the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents.• Identify solutions where rights are compromised.
For neonatal unit
<ul style="list-style-type: none">• Develop information material about the standards enshrined in the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents for parents.• Audit service against the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents.• Identify solutions where rights are compromised.
For hospital
<ul style="list-style-type: none">• Audit service against the UN Convention on the Rights of the Child/the European Association for Children in Hospital Charter (1) or national equivalents.• Identify solutions where rights are compromised.
For health service
<ul style="list-style-type: none">• Incorporate the UN Convention on the Rights of the Child (1) in the Curricula of the healthcare professional education. (see TEG Education & training)

Source

1. UNICEF. The United Nations Convention on the Rights of the Child [Internet]. 1990. Available from: https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.163550268.1218459234.1527076484-403558301.1527076484



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First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Greisen G, Latour JM et al., European Standards of Care for Newborn Health: Rights of infants, parents, and families in difficult decisions. 2018.