



*Topic Expert Group: Infant- and family-centred developmental care*

**Parental involvement**

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*Target group*

Infants, parents of infants hospitalised in the neonatal intensive care units (NICUs) at all levels, and families

*User group*

Healthcare professionals, neonatal units, hospitals, health services, policy makers, and institutions involved in NICU care

*Statement of standard*

Parents are members of the caregiving team and, with individualised support, assume the primary role in the provision of care of their infant, and are active partners in decision-making processes.

*Rationale*

The goal is to ensure the parental involvement in the care of the infant. Most parents have a sensitive understanding of their newborn infant. Contingent with infant cues, parents *normally and intuitively* present well-timed interactions in multimodal forms involving the mediums of voice, proximity, touch and gestures to regulate infants' physiological, behavioural and emotional responses, and responding to their nutritional needs. (1) However, infants in neonatal intensive care units usually are physically and emotionally separated from their parents, making it difficult for the parents to assume this expected role of caregiver. (2)

Prematurity and illness implies infant fragility and behaviour quite different from that of healthy full term infants, but implementing parent involvement can significantly improve the well-being of both parent and infant.

Although the majority of units in eight European countries reported a policy of encouraging both parents to participate in the care of their infants, the intensity and ways of involvement as well as the role played by parents varied within and between countries. (3) Parents are willing to practice new skills through guided participation, even for more complex care. (4)

Parental integration enables their participation in the medical discussions and decision making about their infant. The full integration of families into the neonatal team to actively provide much of their infant's care is beneficial for both parents and the infants themselves. (3,5)

Educational programmes can be established to involve parents in the care of their infant. They can have a more theoretical (6–8) or more practical (9,10) foundation.

*Benefits*

*Short-term benefits*

- Reduced length of NICU stay (5,9,11)
- Increased breastfeeding rate (3)
- Improved weight gain (3)



- Reduced occurrence of moderate to severe bronchopulmonary dysplasia (5)
- Tendency toward a lower rate of nosocomial infection (10)
- Reduced stress for parents (3,12)
- Increased understanding of and involvement in infant pain management (13)
- Increased satisfaction regarding communication about their infant (14)

#### *Long-term benefits*

- Reduced rate of readmissions (15)
- Reduced risk of maternal depression (12,15)
- Improved child behaviour and long-term cognitive development (16–22)
- Improved quality of life for the child (16)
- Improved long-term outcomes from mother/father skin-to-skin contact (20)

#### *Components of the standard*

Component	Grading of evidence	Indicator of meeting the standard
<b>For parents and family</b>		
1. Parents and family are informed by healthcare professionals about the importance of their involvement in the provision of care for their infant during the stay on the neonatal unit.	B (High quality)	Patient information sheet
2. Parents are the primary caregivers for their infant. (1,2,23)	A (Moderate quality) B (Moderate quality) C (High quality)	Parent feedback
3. Parents participate in medical rounds. (3,5–7)	A (Moderate quality) B (Moderate quality)	Parent feedback
4. Parents are partners in decision-making processes. (3,5–7)	A (Moderate quality) B (Moderate quality)	Parent feedback
5. Parents have access to medical records. (3,5)	A (Moderate quality) B (Moderate quality)	Guideline, parent feedback
<b>For healthcare professionals</b>		
6. A unit guideline on parental involvement in terms of being the primary caregivers, participation in medical rounds, and partnering in decision-making is adhered to by all healthcare professionals. (3,5–7)	A (Moderate quality) B (High quality)	Guideline
7. Training on integrating parents into the neonatal unit is attended by all responsible healthcare professionals. (3,5,9,10)	A (Moderate quality) B (High quality)	Training documentation



8. The role as educator, coach, and facilitator of care and bonding is undertaken. (3,5,9,10)	A (Moderate quality) B (High quality)	Healthcare professional feedback
<b>For neonatal unit</b>		
9. A unit guideline on parental involvement in terms of being the primary caregivers, participation in medical rounds, and partnering in decision-making is available and regularly updated. (3,5–7)	B (High quality)	Guideline
10. A parent advisory panel is engaged in appropriate planning and decision-making processes. (3,5,9,10)	B (Moderate quality)	Parent feedback
<b>For hospital</b>		
11. Training on integrating parents into the neonatal unit and resources for the parents as primary caregivers is ensured. (3,5,9,10)	A (Moderate quality) B (High quality)	Training documentation
12. Appropriate resources are provided to support infant- and family-centred developmental care. (3,5,9,10)	A (Moderate quality) B (High quality)	Audit report
<b>For health service</b>		
13. A national guideline on the role of parents as primary caregivers of their infants and on the role of parents of advisory functions in hospitals is available and regularly updated.	B (High quality)	Guideline

*Where to go – further development of care*

Further development	Grading of evidence
<b>For parents and family</b>	
<ul style="list-style-type: none"> <li>Parents give input to both written and electronic medical records. (3,5)</li> </ul>	A (Moderate quality) B (Moderate quality)
<b>For healthcare professionals</b>	
<ul style="list-style-type: none"> <li>Support parental presence throughout the 24 hours. (3,5–7)</li> </ul>	A (Moderate quality) B (Moderate quality)
<b>For neonatal unit</b>	
<ul style="list-style-type: none"> <li>Conduct ongoing quality assurance of parent participation. (3,5–7)</li> <li>Provide a unit guideline for parental and family presence throughout the 24 hours. (3,5–7)</li> </ul>	A (Moderate quality) B (Moderate quality) A (Moderate quality) B (Moderate quality)



• Provide unit guideline on full parental access and input to both written and electronic medical records by the parents. (3,5–7)	A (Moderate quality) B (Moderate quality)
<b>For hospital</b>	
• Include parents in hospital patient advisory committee. (3,5–7)	A (Moderate quality) B (Moderate quality)
• Provide facilities for parents to reside in the neonatal unit. (3,5) (see TEG NICU design)	A (Moderate quality) B (Moderate quality)
<b>For health service</b>	
N/A	

### *Getting started*

#### **Initial steps**

##### **For parents and family**

- Parents are verbally informed by healthcare professionals about the importance of their involvement in the provision of care for their infant. (3,5–7)
- Parents are involved in daily care procedures, e.g. changing nappies, measuring temperature, hygiene of the mouth, bathing etc. (3,5–7)

##### **For healthcare professionals**

- Attend training on infant- and family-centred developmental care. (3,5–7)
- Welcome parents as active participants in the care. (3,5–7)

##### **For neonatal unit**

- Develop and implement a unit guideline on parental involvement in terms of being the primary caregivers, participation in medical rounds, and partnering in decision-making. (3,5–7)
- Develop information material on care and treatment of infants for parents.

##### **For hospital**

- Support healthcare professionals to participate in training on infant- and family-centred developmental care. (3,5–7)

##### **For health service**

- Develop and implement a national guideline on family involvement in the care of their infant. (3,5–7)

### *Description*

According to natural order, parents expect to be the primary caregiver of their newborn infant. Although the medical professionals in most neonatal units attempt to involve parents in the care of their infant it is generally accepted that the type of care required in the neonatal unit is highly complex and should therefore be a responsibility of experienced professionals. Inadvertently, this approach makes the parents feel like passive spectators regarding the care of their infant and tend to make them feel insecure, more stressed, anxious and less competent when they later take the infant home at discharge from the hospital. (24)

Despite the challenging circumstances, under the guidance and supervision of the healthcare professionals, the parents can gradually learn how to adjust the normal parent behaviour and carryout even the more complex tasks of caring for their infant.



Subsequently – according to the individual competencies of the parents – the professionals will progressively be able to delegate most, if not all, nursing tasks to the parents.

#### *Challenges associated with the involvement of the parents*

It is possible that the parents may not detect changes that require prompt medical attention in their infant's condition. However, healthcare professionals retain primary responsibility for the infant and supervise parents closely, which should ensure that appropriate care is given. Another concern is that parents may become overly anxious about providing care for their sick infant. However, the provision of care procedures by parents is introduced gradually and individualised according both to the situation of the infant and the parents. Most parents involved in these programmes report decreased anxiety and stress because they feel in control and well informed when given a purposeful role in the care of their infant. (10)

#### *The barriers to implementing the involvement of parents*

For extremely ill infants who require mechanical ventilation or other complex treatments and where parents are not able to room-in, parental involvement in care giving is more challenging. Having parents as the primary caregivers in an intensive care setting represents a substantial shift in the current model of neonatal care in most countries. There are numerous barriers to widespread implementation of this model of care. Parents can feel stressed, over-whelmed and over-burdened when providing newborn infant care. (25) Thus, it is really important to give them continuous support and on an individual level, gradually introduce parents as the primary caregivers. On the other hand, healthcare professionals may feel uncomfortable about reducing their control of the infant's care. (26) Thus, also healthcare professionals could benefit from support and training concerning parental involvement. (3,5–7)

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