



Getting Information from the Healthcare Team

Studies have shown that parents who are included in care giving and decision making are less likely to suffer from depression and anxiety, are less likely to experience a loss of trust in their healthcare providers, and are more likely to feel connected with their baby (Obeidat, Bond, & Callister, 2009). Multiple stakeholders have expressed the importance of family-centered care and the importance of family inclusion as partners in care (National Association of Neonatal Nurses, 2011; American Academy of Pediatrics, 2003; Maizes, 2009).

Each member of the NICU should consider the unit's physical layout and ability to maintain confidentiality when determining how best to include parents in rounds and exchange information about their infant. Parents should be presented not with a list of restrictions but instead with a list of options and opportunities to participate in both care and decision making. Parents should be recognized as both experts about and advocates for their child.

The following are suggestions for parental participation:

- Encourage parents to be consistent caregivers in any ways they can.
- Encourage parents to learn as much as possible about their child's health.

- Encourage parents to ask questions, include them in rounds when possible, and encourage them to participate.
- Encourage parents to keep a journal or write down their questions.
- Encourage parents to care for themselves, too (Gracey, 2002).

References

- American Academy of Pediatrics. (2003). Family-centered care and the pediatrician's role. Retrieved from <http://pediatrics.aappublications.org/content/112/3/691.full.pdf+html>
- Gracey, K. (2002). Family teaching toolbox: A parent's guide for advocacy and involvement. *Advances in Neonatal Care*, 2(3), 170–172.
- Maizes, V. R. (2009). Integrative medicine and patient-centered care. Retrieved from www.iom.edu/~media/Files/Activity%20Files/Quality/IntegrativeMed/Integrative%20Medicine%20and%20Patient%20Centered%20Care.pdf
- National Association of Neonatal Nurses. (2011). Age-appropriate care of the premature and critically ill hospitalized infant: Guideline for practice. Retrieved from www.nann.org/uploads/Age-Appropriate_Care-FINAL_11-01-11.pdf
- Obeidat, H. M., Bond, E., & Callister, L. (2009). The parental experience of having an infant in the newborn intensive care unit. *The Journal of Perinatal Education*, 18(3), 23–29.



Getting Information from the Healthcare Team: Information for Parents

You are the most important people in your baby's life and in their care. Your baby's healthcare team needs you to help us provide your baby's care. There are many ways that you can do this:

- Come to the NICU as soon as you can after your baby is born. Get to know your baby. Help us learn about his or her patterns, likes, dislikes, and communication. Let your baby hear your voice and feel your touch—they are comforting and familiar to your baby.
- Learn what care you can provide for your infant (for example, taking his or her temperature, diaper changes, bathing, feeding, and calming your baby).
- If we use words you don't understand, ask for a time out and ask us to explain what we mean.
- Talk with your baby's caregivers often. It helps to write down questions, anything that worries you, or things about your baby to share. Talk with your baby's bedside nurse and the doctor or nurse practitioner.
- Learn everything you can about your baby's strengths and differences.

In this unit, the best way/time to participate is _____. We ask that you respect the privacy of other babies and not ask questions about them or discuss them with others.

It's important to take care of yourself, because your baby needs you. Spend time talking with your family and friends each day. Discuss your feelings and concerns. Find friends or family who can help with other things to be done or offer support. It might help to talk to a social worker or chaplain. Tell the staff if you are having difficulty eating or sleeping.

Don't forget to ask your NICU team for information about support groups or websites that might be helpful.