

# Tips for Parents of Infants in the NICU

NICU=neonatal intensive care unit.

We acknowledge that some babies have a care village while residing in the NICU. Therefore, throughout this piece, we will use the term "*parent*" to refer to all parents, grandparents, guardians, and caregivers who care for the health and well-being of these infants.

## Your Role in the NICU



### How to care for your infant while in the NICU

Having an infant in the NICU may be one of the most stressful times in your life. But you are not alone: In fact, over the last 15 years, about 1 in 10 US births have been preterm births!<sup>1,2</sup> This short guide will give you quick pointers on connecting with your baby and navigating your NICU journey.

Although bonding with your baby in the NICU may not be what you had imagined, any time you spend with your infant will help your baby's growth and development. As you and your baby get to know each other, they will feel more relaxed with you around.<sup>3</sup>

Parents' active involvement may lead to shorter hospital stays, better development of the infant's brain, stronger parent-infant bonding, and decreased parental stress and anxiety.<sup>4</sup>

#### Participating in your baby's care

Parents like you can play a significant role in caring for your babies. Becoming more involved with your baby's care may help you adjust to the NICU environment.<sup>3</sup> Some parents may want to be present when the doctors examine their baby on rounds, and others may wish to participate in feedings. Tell your NICU care team you want to learn and participate, and ask them what is possible.

How you can participate in your baby's care:

- Ask questions of the NICU care team and the NICU support staff
- Talk with the NICU doctors about your baby's condition and treatments
- Establish how much or how little you want to participate, knowing you can change your mind at any time
- Ask for regular times to meet with the care team for updates
- Get to know your baby, what they like and what they don't like
- Perform any bonding activities that you wish, as long as they are medically appropriate for your baby
- Ask for any resources the NICU has to help you understand your baby's treatments
- Ask about what your baby's conditions or treatments mean for their future

Page 4 has a list of conversation starters to help you communicate with the NICU care team and support staff, and questions you can ask to continue building the bond with your baby.

### Bonding with your baby and strengthening connection

Talk with your care team to determine what activities are appropriate for your baby. Remember, your baby's health may change daily, so getting the newest information will help you to perform appropriate bonding activities.

- Performing kangaroo care, also known as skin-to-skin, may be a rewarding experience for you and your baby.<sup>5</sup> Parents can often kangaroo care while the feeding is infusing (via feeding tube) or after bottle feeding<sup>6,7</sup>
- Knowing the feeding schedule and being involved during feeding times help the nurse and are especially beneficial for the baby<sup>7</sup>
- Changing your baby's diaper can be a rewarding and bonding experience for you and them<sup>5,7</sup>
- Assisting with bathing the baby or changing the bed linens can also prepare you for life at home and help you connect with your baby<sup>5,7</sup>
- Communicate with your baby by touch; let them hold your finger or cradle them in your arms<sup>5,7</sup>
- Get your baby used to the sound of your voice by softly singing nursery rhymes or your favorite songs, reading your favorite book, and talking with them about your day<sup>5</sup>

### Advocating for Your Baby in the NICU

#### How can you advocate for your baby?

You know that the NICU staff is doing the best for your baby, and everyone is working toward the same goal: to help your baby be as healthy as possible. You are your baby's primary advocate, their number one supporter. You are the voice of your infant! You may feel overwhelmed and nervous talking with care providers, but this is the time to learn all you can to support your baby. In doing this, you will continue building your relationship with your baby.

Your baby is your primary focus, so trust your instincts! No question is too small, and your care team should encourage any and all questions. Speak up if you have a concern. Educate yourself and use that newfound knowledge to talk with the care team and support staff, while remembering that they are the experts and that you're all working toward the same goal. Approaching the care team with an open mind, and letting them know your concerns, will help establish a strong rapport.

#### How can you communicate with a busy care team?

Your NICU care team's primary goal is to care for your baby, and they are also an excellent resource to help you understand what is going on. Parent participation, shared decision making, and collaboration with the care team are all important goals in the NICU. Good communication between you and the nurses and doctors is key, but often it will be up to you to reach out. Remember to respect their time: They are busy caring for of all the NICU infants. By making it clear that you are interested in getting educated and becoming informed, you establish that you want to be a partner, not a nuisance.

- Sometimes, the care team is busy, and you may feel hesitant to interrupt their work
- Take a moment to think about when and how you can best approach them
- Find a time during the day when the care team doesn't seem rushed, and take that opportunity to talk with them
- Use an inquisitive, open tone to start conversations
- Let the team know your level of interest in medical updates on your infant
- Ask the care team or the NICU support staff about the NICU schedule. Knowing this allows you to plan a meeting when the care team may be more available to talk
- Let them know your schedule, so you can coordinate times to meet for updates on your baby

Knowing you are interested in your infant's treatments and status helps your care team become familiar with you, allowing communication to be open and easier.

#### How to ask medical questions without a medical background

The NICU is intimidating in so many ways; one way is all the medical jargon casually used by your care team. To be the best advocate for your baby, you need to know what is going on and what these terms mean. In fact, as the primary advocate for your baby, you deserve to be informed about their condition in ways that you can understand. Here are some tips for learning these new terms to communicate effectively:

- During early discussions with your care team, be upfront with how much or how little you know about medical issues
- As appropriate, ask the care team to define words and devices, or jot the terms down and look them up later. A good
  resource is the <u>NICU Connections.com</u> site
- Take notes as the care team gives you updates. This allows you to go back and ask questions at a later time

The following page has a suggested list of questions to help you start learning about the NICU and having optimal conversations with your baby's care team and support staff.

### NICU Parent and Caregiver FAQs

#### Questions to empower you in your baby's care

You may be nervous about touching your baby or disturbing the NICU staff. Remember, as a parent, you can be involved as much or as little as you need. This section provides conversation starters to help you understand the NICU environment and determine your role in your baby's care.

The NICU is an overwhelming, highly active space with many people involved. Here are some questions you can ask to understand the flow of the NICU and your role in it:

- Who is on my baby's care team?
- What are their roles in my baby's care?
- What is the NICU schedule? Does it change from day to night? From day to day?
- When do the doctors examine my baby?
- Is it possible for me to participate in my baby's examination?
- How can I follow up with the doctor after they examine my baby?
- Do you have more information on the [device/medication]?
- How can I track my baby's progress?

Bonding with your baby may be difficult at first, but there are ways you can interact with them. To explore how to form connections with your baby, here are some questions you can ask:

- When is there a quiet time in the NICU to visit my baby?
- Can I change my baby's diaper?
- How long/how often can I do kangaroo care?
- Can I let them hold my finger?
- Can I pump next to them?
- Who should I give the pumped milk to?
- How else can I help care for my baby?

Having a baby in the NICU is stressful. You won't be surprised to learn that a study found that 40% to 50% of NICU parents are depressed, anxious, or experience post-traumatic stress during their infant's hospitalization.<sup>8</sup>

Many hospitals have facilities and professionals who can help you from mental health to financial support to NICU parent support groups.

Here are some questions to discover the services at your NICU:

- Who can I talk to about problems pumping/breastfeeding?
- Is there someone I can talk with about the stress I am feeling?
- Do you have any financial aid for gas, transportation, hotel bills, or food?
- Are there other parents I can talk to who have gone through the NICU experience?



#### **Suggested Resources**

The following websites provide more information about having an infant in the NICU:

- NICUConnections.com
- MarchofDimes.org
- HandtoHold.org

#### References

- 1. CDC. Preterm Birth. Accessed May 2023. https://www.cdc.gov/reproductivehealth/maternalinfantheal<u>th/pretermbirth.htm</u>
- 2. Births: final data for 2021. National Vital Statistics Reports. Volume 72(1). 2023;72(1). Accessed June 2023. https://www.cdc.gov/nchs/products/index.htm
- 3. Pineda R, Bender J, Hall B, Shabosky L, Annecca A, Smith J. Parent participation in the neonatal intensive care unit: predictors and relationships to neurobehavior and developmental outcomes. *Early Hum Dev.* 2018;117:32-38.
- 4. Toivonen M, Lehtonen L, Löyttyniemi E, Ahlqvist-Björkroth S, Axelin A. Close collaboration with parents intervention improves family-centered care in different neonatal unit contexts; a pre-post study. *Pediatr Res.* 2020;88:421-428.
- 5. Schrauwen L, Kommers DR, Oetomo SD. Viewpoints of parents and nurses on how to enhance parent-infant bonding at neonatal intensive care units: a qualitative study based on existing designs. *HERD*. 2008;1(3):61-125.
- 6. El Farrash RA, Shinkar DM, et al. Longer duration of kangaroo care improves neurobehavioral performance and feeding in preterm infants: a randomized controlled trial. *Pediatr Res.* 2020;87(4)683-688.
- 7. Craig JW, Glick C, Phillips R, Hall SL, Smith J, Browne J. Recommendations for involving the family in developmental care of the NICU baby. *J Perinatol.* 2015;35(suppl 1)S5-S8.
- 8. Grunberg VA, Vranceau AM, Lerou PH. Caring for our caretakers: building resiliency in NICU parents and staff. *Eur J Pediatr*. 2022;181:3545–3548.

