

the magic of everyday
moments[®]

Early

Finding the Magic of
Everyday Moments[®]
With Your Baby in the
Neonatal Intensive
Care Unit (NICU)



Arrival

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EARLY ARRIVAL:

Finding the Magic of Everyday Moments With Your Baby in the Neonatal Intensive Care Unit (NICU)

YOU are the most important person in the world to your baby. Even though your son or daughter arrived sooner than expected and is staying in the NICU, there are many ways for you to love, care for, and connect with your baby during the everyday moments you share. The very special relationship you have with your child provides her with the love and support she needs to grow stronger. Your nurturing attention also helps her benefit from the medical expertise in the NICU.

As parents, you are the most essential members of the NICU team. Before your baby was born, it was your voice and the voices of family members that your baby heard and recognized before all other sounds. Your body's warmth and your special smell and touch continue to be your child's anchor in the NICU.

Because preterm babies may be different from full-term babies—in the way they look, interact, and behave—it sometimes can be hard to know the “right” way to meet your baby's needs. This booklet describes some of the ways you can experience *the magic of everyday moments* with your baby, both while she is in the NICU and when she comes home.

Every baby is different, and so is every NICU. Some of the suggestions in this booklet may be useful to you and your baby right away. Others may not be useful for several weeks or months. Work with the medical team in the NICU to discuss your hopes and wishes for your baby and to plan for how you can help with your child's care.

WHAT IT'S LIKE FOR YOU

What it's like for you

Like most new parents, you are probably filled with joy and love for your child and hope for her future. But like many parents of a baby in the NICU, your baby's birth probably didn't go the way you planned. You were likely discharged from the hospital before your baby. Your child might be experiencing a range of health challenges and you may be facing important decisions about her care.

These can be stressful times. Some parents find themselves even questioning their role and importance in their baby's life. Rest assured, research has found that children who spend

time in the NICU are just as "bonded" or attached to their parents as children who had a more typical (non-NICU) start to family life.¹

It is also common for parents to feel some guilt or inadequacy after a preterm birth. Some wonder if the early delivery was their fault. They worry that something they did while pregnant caused their child's early arrival. Some parents also

struggle with feeling like their baby is a stranger. Although these feelings can be overwhelming and hard to deal with, they usually fade over time.

Your feelings matter

It is quite common to feel sad, angry, nervous and scared when your baby is in the NICU. During this time, pay attention to how you are feeling, and to talk to your partner



about how he or she is doing. Talking to friends and family can also be very helpful. If your feelings are interfering with taking care of yourself or sharing in the care of your baby, you may be experiencing depression. Research shows that many parents experience some degree of depression in the months following their preterm baby's birth and/or after their baby comes home.

Keep in mind that depression is common in fathers, too, though their feelings are often overlooked. Depression can range in intensity from mild to more serious.

Getting the help you need is important. It can take time for parents of a baby who started life in the NICU to feel like things are better, "normal," and safe. You are not alone.

To learn more, talk with a trusted health professional or visit www.marchofdimmes.com/pnhec/188_15755.asp for more information.

¹Goldberg, S., & DiVitto, B. (1995). Parenting children born preterm. In M. H. Bornstein (Ed.), *Handbook of parenting: Vol. 1: Children and parenting*, (pp. 209-231). Mahway, NJ: Erlbaum.

BEING THERE FOR YOUR BABY IN THE NICU

If your baby could talk:

Hearing your voice, feeling your touch, and having you by my side makes me feel loved and helps me get stronger. I know it seems as if I don't know you are there, but I do. I'm already familiar with your smell and your voice. As soon as I get bigger, I will start to open my eyes and look at you. For now, I am using all my strength to grow.

Being at your baby's side is the best thing that you can do for him. But it is also okay *not* to go to the NICU occasionally—to take “time off.” When you can't be at the NICU, leave a family photo in your baby's isolette or a tape recording of you speaking softly to him. Talk with NICU staff about these and other ideas for staying in touch with your baby.

When you are with your baby, you can learn a lot about him just by watching and holding him, such as:

- how he shows he is alert and ready to interact
- what upsets or overwhelms him
- how to calm him
- when he is not feeling well or something is wrong
- when he needs a break from interaction
- how he likes to be held and fed, and how he likes to sleep

Your baby communicates with you through his behavior. Watching him helps you understand what he is trying to tell you.

Once you are aware of your baby's signals, the next step is to respond in a sensitive way. For example, you may notice that your baby calms himself by holding his fingers up to his face. You can then guide his fingers to his face to help soothe him when he gets upset. Figuring out the best response is often a process of trial-and-error. You may have to try a few approaches to find what works. Every baby is different and is soothed in different ways.

What You Can Do	What Your Baby Is Learning
<ul style="list-style-type: none"> • Talk and sing to your baby in a very calm and quiet voice. • Quietly read your baby a book or a letter you have written to him. 	<ul style="list-style-type: none"> • The sound of your voice. • That he is loved and special.
<ul style="list-style-type: none"> • Give your baby a finger to hold onto. • Hold your baby, if possible. • Gently rest your hand on your baby's arm, leg, or body. • Give your baby a scarf or cloth that you have worn (that has your smell) to nuzzle and hold close. 	<ul style="list-style-type: none"> • That loving touch can be pleasurable. • That he can depend on you. • Your familiar, distinct smell.
<ul style="list-style-type: none"> • Support your baby's efforts to calm himself. Swaddle him. Try out different ways to hold him. Give him something to hold on to, suck on, or to brace his feet against. • Watch for signs of over-stimulation, such as: turning away, changes in breathing, spitting up, arching his back, hiccupping, or frowning. • Share your observations about your baby with NICU staff. This is very important information for them to have. 	<ul style="list-style-type: none"> • That you will soothe him and help him learn to soothe himself. • That he can count on you to keep him safe and comfortable. • That you understand and respect his signals.



SLEEPING AND WAKING

If your baby could talk:

Sleeping helps me grow bigger and stronger. Even when my eyes are shut tight, there is so much going on inside me. My body is working hard to grow, stay at the right temperature, control my movements, and keep me calm. Sometimes I feel strong enough to open my eyes and look for you. I know I can depend on you to help me feel calm and safe again.



Babies cycle through five states of being asleep and awake:

- **Deep sleep:** Your child's eyes are closed and breathing is slow and regular.
- **Active sleep:** Your baby's eyes are mostly closed. If they are open, they are not focused on anything. Her breathing is irregular. There may be facial twitches, smiles, eye movements behind the eyelids, and body movements.
- **Drowsy:** This is a time when your baby is waking up or going back to sleep. Her eyes are mostly closed. If they are open, they are not focused on anything. Even if her eyes are open, this doesn't mean she is awake.
- **Fussy:** Your baby may make grunting noises or cry and move her arms, legs, head, or body to show distress or discomfort.
- **Quiet alert:** Breathing is regular and your baby's eyes will open and brighten. She is ready to interact with you.

Keep in mind that preterm babies may not have well-developed sleep-wake cycles. They may wake up unexpectedly. They may stay asleep when you think they should be awake. Or, they may move quickly between sleeping and waking.

Your child may only be alert for brief moments—as little as 3-5 seconds at a time. But her alertness will slowly increase as she grows.

What You Can Do

- Notice when your baby is becoming fussy and slow down your interaction with her.
- Wait for your baby to connect with you again. She may look or turn toward you, or open her eyes.

- Try to have the same small group of caregivers take care of your baby.
- If this is not possible, find ways for caregivers to share information and establish predictable routines. This makes your baby's care as consistent as possible.
- Be aware of your baby's sleep-wake cycles. Note any patterns. Are there times your baby enjoys activities (like baths) more than others?
- Ask your baby's medical team to adjust light and sound levels in the NICU to be in tune with sleep and awake times.
- Work with the NICU staff to "cluster" your baby's care—to do routine activities (diapering, vital checks, medication, etc.) at one time instead of disrupting your baby's sleep for each one.

- Notice when your baby is alert. Return her gaze and gently talk, sing, and/or touch her. See how your baby responds. Slow it down or stop if she shows you it is too much to handle.

What Your Baby Is Learning

- That you understand and respect her signals.
- That she can trust you.

- That her individual needs are important.
- That there is a time to rest and a time to interact with others and the world around her.
- That there is a predictable pattern to each day.



- The voice and touch of you and others who care for her.
- That she is loved.

CAREGIVING

If your baby could talk:

Being part of a family feels so good. When you watch me as I sleep, when you cradle me as I eat, when you give me your finger to hold onto—I know how precious I am to you. Even though we aren't home yet, I know that you are my special person, and I am yours. Your love keeps me strong.



When you were expecting your baby and thinking about his early days, you probably didn't picture the NICU. You might feel a sense of loss because you can't be your baby's only caregiver right now. But the love you show your baby in the moments you share is more important than all the diaper changing in the world. And remember—just by being with your baby you are doing something very important for him. As your baby gets stronger, there will be many more opportunities to take part in his everyday caregiving activities.

Until then, consider keeping a journal of your NICU experiences. Talk with the NICU team about their observations of your baby and share your own. Is he feisty? Easy going? Strong? Watchful? Jot down your thoughts to share with your baby later on when you tell him the story of "when he was born."

What You Can Do

What Your Baby Is Learning

- Talk with your baby's caregiver(s) to find out how he is doing and if there have been any changes since you saw him last.
- Ask as many questions as you need to in order to understand the procedures or health issues your child is facing.
- Speak up for your child's needs.
- Discuss with your child's medical team what you might be able to do or assist with when you are in the NICU.
- Let the nursing team know what you would like to be notified about when you are not at the NICU.

- That you are interested and involved in his life.
- That you will be his "voice" in the NICU.
- That you are thinking of him even when you can't be there.

- Celebrate your baby's firsts—first time you hold him, first time he wears clothes, first time he eats by mouth.
- Bring a camera to the NICU. Ask staff to take pictures of you and your baby. (Be careful not to flash light in his eyes.)

- That he is strong and growing stronger.
- That you take pleasure in his accomplishments and are proud of him.
- That you value and cherish him.
- That life can be joyful.

- Ask about kangaroo (skin-to-skin) care—when babies are held between their mother's breasts or on their father's chest.
- Participate in your baby's daily care, such as: temperature-taking, weighing-in, changing bedding, diapering, bathing, and more. You may also take on tasks like: placing a feeding tube, changing bags, or caring for wound sites.

- Your touch and smell.
- That spending time with you is enjoyable.
- To trust you.
- To depend on you to soothe him during difficult and, at times, painful procedures.
- That your touch is gentle and loving.

FEEDING YOUR BABY

If your baby could talk:

Eating makes me grow bigger and stronger. And it's a chance for me to spend special time with you. Sometimes eating can be really hard work! Even sucking for just a few minutes can tire me out. When you are patient with me and go slowly, I will start to feel more comfortable with sucking and swallowing. Over time, I'll get better at it, too—you'll see.



Feeding your baby is about much more than nourishment. It is an opportunity to connect with and nurture her. How a baby is fed in the NICU depends on her age and health. Your baby may be fed by an NG (nasogastric tube), OG (oral-gastric) or G (gastrostomy) tube. Or, your baby may receive nutrition by mouth—either by breast or bottle. Breastfeeding is a common challenge for preterm infants. But it is possible to breastfeed in the NICU, and breastmilk is the healthiest form of nutrition for babies. Ask to meet with your hospital's lactation consultant for information on and support with breastfeeding and pumping breast milk.

Whichever way your baby is fed, talk with the medical staff about ways you can be involved. Participating in mealtimes helps you learn how to read and respond to your baby's hungry and full signals. This loving time together also offers your baby many positive experiences with taste, touch, smell, sight, and sound.

As you feed your baby, try looking slightly away and keeping still. This lets her focus on eating. Direct eye contact can feel intense and overwhelming to preterm infants. Talking or singing during feeding may also be too stimulating. When you respect your baby's signals, she will be more successful with feeding. Remember, sucking and swallowing is hard work for preterm babies and can use up much of their energy. Over time, your baby will be more ready to respond to you during feedings.

What You Can Do Through Feeding Routines

- Share your baby's feeding plan with all of her caregivers. This helps your baby have as much consistency as possible.
- Be the one to feed your baby whenever possible. Learn how to do tube feedings.
- Hold your baby during feedings, even tube feedings. Ask if there is a screen available for privacy.
- Set up a comfortable, quiet feeding environment. Sit in a cozy chair. Use pillows to support your arms.

If you are or plan to be breastfeeding:

- Pump and store breastmilk for your baby. Pumping at your baby's bedside helps you feel close to her and stimulates your milk supply.
- Encourage your baby to nuzzle your breast to prepare for breastfeeding.
- Let your baby smell and taste your milk. Drip some onto her lips. Let her lick a drop from your clean finger.

Follow your baby's lead. For example:

- Watch for your baby's hunger signals and feed her.
- Give her a break if she gets overwhelmed.
- Stop feeding her when she shows that she is full. She may turn away from or push out the nipple, gag, fuss, or fall asleep.

What Your Baby Is Learning

- That there is a regular pattern to each day, which includes particular times to eat.
- That feelings of hunger lead to being fed.
- That a sensation of being full is pleasant and relaxing.
- That she is loved and special.

- New tastes and smells.
- That sensations around the mouth can be pleasurable.
- That mealtime is a special time to share with you.



- That she is a good communicator.
- That she can trust herself to know when she is hungry and full.

GOING HOME



If your baby could talk:

Finally, I get to go home with you! I've worked so hard to grow and get healthy. And I've learned how to do lots of new things—to know and trust you; to eat; to fall asleep; and to calm myself. But there's so much more I want to learn and do. You are my first, best, and most trusted teacher.

As you begin to plan for your baby's homecoming, it is very normal for parents to feel a range of emotions. You may feel happy, excited, and hopeful. You may also feel some worry about the transition home: What if my baby gets sick? What if something goes wrong with his equipment? What if he doesn't grow well? And, after weeks or months in the NICU, you may miss having medical professionals nearby to answer questions about your baby.

What You Can Do to Support Your Baby's Development at Home

- Limit your baby's caregivers to a very few consistent people. Your baby will respond best to people who know him well, love him, and will take care of him as you do.
- Establish patterns throughout the day. Develop routines around eating, sleeping, bathing, and play each day. This helps your baby begin to learn how to eat and sleep in a more predictable pattern.

- Follow your baby's lead. When your baby looks into your eyes, look back at him. Try talking in a soft voice. When your baby looks away, goes limp, fusses, or arches his back, give him a break.
- Handle and position your baby carefully. Always move your baby gently and slowly. Hold him so that he stays tucked and so that he can get his hands to his face and mouth. Swaddle him, if he finds it comforting.

- Tune in to older siblings' feelings. Let them know you understand how they feel. Make special time for them and include them in the care of the new baby. This reduces feelings of being left out.
- Have fun as a family! Enjoy these first days at home, and know that there are many more to come!

What Your Baby Is Learning

- That you will "listen" and respond to his communications.
- That home is a safe, predictable, caring place.
- That he is part of a supportive and loving family and community.
- How to eat and sleep at regular times throughout the day.

- That he is loved and special.
- That you will help him calm down when he gets overwhelmed.
- That movement can feel safe.
- That he can trust you to always be there for him.

- That being in a family feels good.
- That life is joyful.



Coming home to support and services

Your child may be eligible for a number of support services after he is discharged. Take some time to talk to the NICU staff about what resources might be helpful, and what is available in the community. Try to organize a meeting of both the NICU staff and your community-based care coordinator. Together, you can create a plan for your baby's care during and after your transition home.

Connecting with other parents of premature infants for support and guidance can also be helpful. Ask about support groups and other ways to meet parents of NICU "graduates."

Helping your baby feel at home

After waiting so long to be completely in charge of your baby's care, you may find yourself really wanting to play, talk, and make up for what some parents think of as "lost time" with your child. But even after they come home, preterm babies still need lots of quiet and rest. One of the best ways to help your baby adjust is by keeping your home soothing, slow, and calm. Remind visitors of your baby's need to rest. Explain how he needs them to be quiet and gentle. Read your baby's signals. He will tell you when he's comfortable and rested. He will let you know when he has had too much and needs your help to calm down or fall asleep.

Take care of yourself

Remember that *one of the best ways to take care of your baby is by taking care of yourself*. Your baby needs you to be well-fed and well-rested. Don't hesitate to call friends or family for help with your baby or to assist around the house. It's also a good idea to find time to do some of the things that help you relax and feel good. Making time to connect with a partner is important, too. Get out of the house—even once in a while—and do something you enjoy together while a trusted friend or hired professional caregiver watches your baby. This will help keep you and your partner close and provide you both with needed support.

All in the family

While your baby's homecoming is a positive and joyful step forward, it is a big change for the family. Older brothers and sisters may want to touch and play with their new baby after waiting so long for him to come home. There may be some disappointment in not being able to interact with their





new sibling in this way. They may also be angry and jealous when they see that the baby takes up a lot of your time and attention. It is very important to find ways to be sensitive to your older child's feelings and to find some special one-on-one time for him each day. This can help reduce the normal sibling issues that arise when a new baby joins the family.

Final thoughts

You may find it hard to believe that your NICU days are now behind you. Although there will likely be some challenges ahead, it is time to celebrate how far you and your baby have already come together. Your family is strong, resilient, and a source of loving strength. Take a minute to appreciate the bond that you and your baby have created. This is just the beginning of your lives together as a family.

Reference

This brochure was based on the content found within the following professional curriculum:

Browne, J., MacLeod, A. M., Smith-Sharp, S., & Talmi, A. (1995; rev. 2006). *Family Infant Relationship Support Training (FIRST)*. Manual, National Workshop for Community Professionals. Denver, CO: The Children's Hospital

Resources for Parents

Books

- *Parenting Your Premature Baby and Child: The Emotional Journey* by Deborah Davis and Mara Tesler Stein
- *Your Premature Baby and Child* by Amy Tracy and Dianne Maroney
- *The Premature Baby Book* by William Sears, Robert Sears, James Sears, and Martha Sears

Web Links

- *Getting to Know Your Baby* by K. Vandenberg, J. Browne, L. Perez, and A. Newstetter. Available at: www.uchsc.edu/cfii/Documents/Getting%20to%20Know%20Your%20Baby.pdf
- March of Dimes—information for NICU families—www.marchofdimes.com/nicu
- March of Dimes—an online community of current and former NICU families—www.marchofdimes.com/share
- Postpartum Support International—information and support for mothers experiencing postpartum depression—www.postpartum.net
- National Early Childhood Technical Assistance Center—early intervention resources for parents of children with special needs—www.nectac.org

Children's Books About Preterm Babies to Share With Older Siblings

- *No Bigger Than My Teddy Bear* by Valerie Pankow
- *My Baby Sister is a Premie* by Diana M. Amadeo
- *Believe in Katie Lynn* by Bartholomew Resta
- *Evan Early* by Rebecca Hogue Wojahn
- *Waiting for Baby Joe* by Pat Lowery Collins

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This booklet and other ZERO TO THREE resources are available at www.zerotothree.org or by calling (800) 899-4301.