Supporting Your Infant After the Neonatal Intensive Care Nursery Experience

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Introduction:
A Developmental Guide for Parents of Medically Fragile Infants

Infants arrive home from the neonatal intensive care unit (NICU) with their unique hospital experience. These fragile infants are recovering from health and developmental challenges and they require interactive regulatory support that parents provide best. Of special concern is that medically fragile babies are very demanding from birth and can profoundly challenge their parents’ psychological resources.

The purpose of this book is to guide parents through the transition from hospital to home. It describes caregiver contributions to parent and infant interactions and specific strategies that support early infant behavior and development.
Chapter One:  
The Neonatal Intensive Care Nursery Experience  

The experience of having a baby who needs to be cared for in the neonatal intensive care nursery has been described by parents and caregivers as overwhelming, traumatic and life-altering. Some parents had very sudden rapidly progressing preterm labor, while other had a pregnancy that was early on diagnosed as “high risk”. These parents had time to discuss and plan for the experience, which may have even included a visit to the NICU before the actual delivery.

The intensity of a NICU experience may lead parents on a roller coaster ride of fear and vulnerability. Parents have deep concerns over survivability and outcome of their baby. Depression, fear and anxiety stay with parents throughout the hospitalization, as well as long after their infant’s discharge from the hospital. As one mother wrote “it was a shattered dream”.

“In reflecting upon the NICU experience, I realize that it has a lasting effect on my parenting. The experience had a way of lodging in my cells. When we left the hospital I asked the doctor what I could expect in the future. He smiled and put his head down. Then he said, “Well later on when she is 3 or 4 years old, she may have kidney or other problems. We will have to wait and see”. This information made me anxious and did not empower me as a parent. Even worse was waiting and fearing the kidney problem. It was similar to managing a ghost that hovered over my life.”
Parents deal with separation from the infant, loss of their decision making power as parents, and loss of the sense of the parent role. Parent confidence is shaken, as they find themselves behaving and thinking in ways they have never felt or thought before.

“There was a vigilance I had as a parent of a NICU graduate that is unique. There is a fear behind the vigilance that may or may not dissipate over time, depending on your infant’s particular needs. Every time there was a cold or a fever or any illness, my partner and I would document everything. We became nurses in the hospital. We were hypersensitive to anything out of the ordinary. That feeling seemed as if it would stay with us forever. Likewise, I met one parent at Special Start training who reported a similar feeling. She said, “She still worries more about her highly functional 26 year old son than her other children”. We agreed that there is a residual hyper-vigilance about health and safety that lingers.”
Chapter Two:
Claiming Your Baby

After taking a baby home from the NICU several changes may be occurring. The relationship between parents and their infant may seem very different than that for a full term infant. Responding to an infant that seems more irritable or less responsive and who does not appear to want to look at you or smile is very difficult. In addition some babies have difficulty sleeping, feeding and establishing routines.

Once the baby begins to have a consistent schedule their behavior may change. Emotionally, after recovering from the fear that your baby may not survive, acceptance and adjustment and believing that she now will grow and develop can be overwhelming.

“Suddenly we had to take care of a fragile sick baby at home without professional guidance. Like us, many parents are not ready to care for their baby at home. It can be terrifying, especially when your baby has medical issues that need ongoing attention. And, it is not unusual for parents to cope with numerous other responsibilities and issues at the same time. There can be the feeling of isolation and family and financial responsibilities. Sometimes you may not have the ability to take off of work because the NICU experience consumed much of your maternity leave.”

“I was still in shock the first week I brought my daughter home. Like many others, I had braced myself for her not to survive. Part of me still could not believe that
she had lived. At first I felt numb and overwhelmed. It was not until her first follow up visit with the pediatrician and the visiting nurse that I relaxed. The feeling of walking on eggshells started to disappear. I knew I was going to be okay. Soon after, we had a homecoming where I invited family and friends. At this time I was feeling myself claiming my baby as mine”.

Parents may become aware of the process of beginning to “claim your baby.” Remember that this is YOUR baby and you know more about your baby than anyone else. This becomes a process of building up confidence and coming to the realization that you are the caregiver, the primary special one in your baby’s life.

Parents may feel this sense of claiming your baby coming very slowly. Some may feel afraid to connect and the distance may seem huge. Every situation is different and every parent is different. You may have a unique pace and feelings of identifying with your baby may come slowly and imperceptively. It may be helpful to know that studies have shown that parents and babies who have graduated from the intensive care nursery still have the ability to form the special parent-infant bond (Browne, 2003.)

Aware and sensitive caregivers will admit to the struggles in providing attuned care when overwhelmed by an agitated sick and/or fussy baby despite knowing what to do to support or care for their infant. It is essential to remind yourself that you are the most important person in your baby’s life. Remember your commitment to be an emotionally aware and responsive caregiver. There are special ways as you care for your baby that will build your connections. You can provide the foundation that your baby needs to build and nurture a healthy secure relationship between yourselves.

**Taking Your Baby Home: Guidance for Parents**

* Before you go home, sit down with the nurse or doctor who knows your baby best and talk through all of your questions and concerns.
* Make sure you get a list of what are the normal things to expect and what are the “red flags” or signs of distress to look for.

* Ask specifically about what might warrant a call to a nurse and what would warrant a visit to the emergency room.

* Plan nothing for the first week or two of your baby’s homecoming. No relatives or friends visiting unless they will be helpful.

* Remember that the NICU experience is traumatic for most families. You have been through an ordeal. An experience that was supposed to be a joyous celebration turned out really differently.

* You may feel shock, grief, anger, shame and generally a range of emotions the first months. Allow space for your emotions.

* Your coping mechanisms and your emotions may be different than your spouse or partner’s. This experience is hard on everyone but we all have different ways of coping. Respect others and ask that they respect you.

* Include your other children in discussions about the NICU experience. Ask them what it is like to have the baby come home and then listen.

* Your coping method may be to be on the internet getting more information and talking with other parents with preemies when your partner gets relief from crying every night before going to sleep. We all handle stress differently.

* It may be good to see a counselor if emotions are too strong and make relationships with the baby or other family members difficult.
* Don’t be afraid to ask for help. Figure out whether it is a friend or relative, clergy, medical provider, counselor or other that could help you get through the first months.

* If your child has disabilities early on, ask for helping deciding on what all of your options for help are in your community.

* Trust yourself and your gut. If something doesn’t feel right with your baby, act on your feelings. Initially they may just be your fears but over time you will build confidence and learn the difference between fear and the need for intervention.

* Don’t isolate yourself. Try to find a group of other families that you could talk to or meet with, in person or through the computer.
Chapter 3:  
The Caregiver-Infant Interaction

All children are born ready to form relationships. Parents and infants are programmed to establish a close nurturing bond, which becomes a fundamental base for the infant’s future development. The development of these strong relationships begins in pregnancy and continues throughout the child’s early years and later in his/her adult life.

Parents taking their baby home from the neonatal intensive care nursery wait patiently throughout the hospitalization to take their baby home and experience the intimate privacy to enjoy the relationship they both deserve. In the NICU parents may learn about the importance of their voice, touch and smell to their baby. They may also learn that their baby may respond to them differently than they expected and that their baby’s behavior is not the same as a full term infant. Parents also begin to see that their baby has unique ways that he/she communicates and that his/her behavior tells them about how he/she is feeling.

How an infant and parent interact and communicate together is an essential foundation component of infant development. A sick and recovering infant needs the establishment of this most important relationship, just as any newborn does, in order to
form the development of emotions, affection, self-esteem and the give and take of what it means to be human. This caregiver-infant relationship creates meaning between the two partners and satisfaction in sharing what is felt between two human beings.

As a parent of a NICU graduate, you will begin to realize that your infant’s growing ability to socialize with you for longer periods each day will depend upon the amount of sensory input and stimulation you provide. In other words, how you respond and how much you respond will determine how your infant will respond back to you. Gradually, you may see that your baby can handle talking and looking for a specific amount of time, but then becomes tired and does not want to look any longer. Your baby’s looking away or dropping his eyes, or stopping may be a signal that he/she has reached his limit and may want to stop.

Being aware to what your infant is telling you in his movements, facial expressions and the sounds he/she makes, as well as the timing of his communications, will help you determine what your infant can tolerate. It also will help you respond in sensitive ways. Responding early to signs of distress will allow your baby to take a needed break from the interaction and develop a secure feeling that his or her needs are being met. As you continue to provide sensitive care that is timed to respond to your
infant’s cues, you will contribute the utmost support toward improving your infant’s recovery and early social-emotional communication that is the basis of your relationship.

As you learn your infant’s patterns of communication you can help your baby learn to calm him or herself, pace his/her responses to the environment and help him/her learn how to enjoy looking and listening. Some of this is a process of learning what works and what calms and what facilitates relaxation.

Some of the ways to build your relationship include the following:

* Holding your baby and giving yourself permission to make up the time you lost holding your baby in the NICU.

* Let your baby hold on to your finger, suck on his own fingers, brace his feet against you.

* Talk to your baby in a very quiet voice paying attention to if the level of your voice is comforting for your baby.
Chapter 4: Understanding Your Baby’s Communications

One of the main tasks for a newborn is that of organizing and integrating the input from the new environment after leaving the womb. This includes the sights, sounds, smell, sensations of touch and vibration, voices, faces, temperature changes. These sensory inputs are eventually integrated by the baby in such a way that they become understandable for the infant.

At the same time the infant is equipped with social capacities, which facilitate the ability to enter into relationships with their caregivers. The main requirement is that the caregiver be a consistent, available and responsive caregiver, who is able to facilitate the process of satisfying the infant’s needs. This caregiver must also be able to enter into a mutually satisfying relationship with the infant, which includes emotional communication and produces emotional experiences. Understanding each other is an essential way that we are “with” others. Tuning into feelings that are expressed along with other forms of communication, are essential to relationship building. Thus, as caregiver and infant interact, the caregiver strives to promote responsiveness in the infant and avoid “understimulating” the infant, as well as “overstimulating” the infant.

For the baby who is born at full term, these tasks include social abilities, which enable the infant to “read” and pay close attention to the caregiver’s emotional expressions, especially the caregiver’s eyes and voice. Recent studies have shown that infant’s are even able to tell the difference between happy, sad and surprised reactions in the caregiver. Each partner in the interaction becomes involved with the other and over time each develops empathy and an emotional understanding of the other.

For an infant who has been sick or born early, the first and foremost task is to stabilize breathing, control of their temperature, reducing startles and tremors and maintaining steady skin color throughout their face and over their limbs and body (Als, 1982). Along with establishing stable physiology, the sick newborn must also work on
controlling their movements, maintaining energy and relaxed flexed positions and developing balanced muscle tone. These tasks include learning to quiet random body movements and developing the ability to keep their arms, legs and trunk in a curled position. The tasks may be underway as the baby transitions home from the hospital and will take additional support from caregiver’s to continue their development.

An additional task for the sick or premature newborn is to develop the ability to regulate or manage their sleep and waking cycles. A specific job for the infant is to be able to screen out intrusive stimuli while asleep. This includes the development of a predictable sleep pattern and relaxed awake times. Infants who have spent many weeks in the intensive care nursery may have less quiet sleep than healthy newborns. Medical procedures and hospital routines may affect the pattern of an infant’s sleep. Less mature newborns may show variations in their sleep patterns. For example, quiet sleep may not
appear completely quiet, but may be accompanied by whimpers, irregular breathing and uttered sounds. Quiet sleep may also include some jerky movement, tremors and isolated startles. An infant may appear more active in sleep with random movements and facial grimaces. A premature newborn may even fuss in sleep (Als, 1999).

After the other areas of development (physiology and motor development) show some growth and the infant is beginning to recover, the development of the capacity to attend and interact with the external environment will emerge gradually. As their newborn begins to alert and awaken, parents are delighted finally seeing their infant interact and respond to them. Some newborns will at first avoid an approaching or close
caregiver, by looking away or turning away. This is common in early born infants. The looking away behavior is a signal from the infant, that the face or visual stimulus is either too close or has been in place too long. This may actually be a signal from the infant to slow down, take a break or time out. The infant may disengage. These reactions are temporary and eventually merge into longer periods of calm awake and eventual gazing at their caregiver’s faces. These moments can be ecstasy for parents.

Some infants who have been through extensive and lengthy hospitalization may need to recover completely from their breathing difficulties and stabilize their temperature and skin color, before they can interact for any length of time. Keep in mind that these infants have been through a great deal of treatment and care and required extensive support and facilitation to get well and grow. They may need more energy to signal their needs clearly; they may need more time to develop control over their breathing, and maintaining their body movements. They may need more time to learn to alert and respond to the sounds and sights in their environment. In fact, sometimes these infants come ready to disengage if necessary, in order to preserve their energy for continuing their recovery process. Learning to recognize and interpret the patterns of communication from the infant is important, because they could be clear messages from the infant that they need time out or a slowing of the activity. Prompt interpretation and acceptance of these patterns may prevent exhaustion and agitation in the infant.

When your baby is ready, it will be your face that your baby wants to look at and it is your voice that your baby wants to hear. The main element in your infant’s world is YOU. Your baby is telling you about himself through his behavior. Watching the patterns of breathing, skin color changes, movements, activity levels and sleep and waking patterns can tell you a many things about your infant’s comfort level and readiness to respond. (Als, 1999)

(See Getting To Know Your Baby available at http://specialstart.org for a complete range of NICU graduate infant behavioral patterns).
Chapter 5: 
The Caregiver’s Contributions

While parents are in the hospital with their newborn, they may have been frustrated that their baby seemed to not be able to respond to them. Very new, very young sick babies often are not ready to look at faces, or make sounds and respond to other people. Parents express concern over how their infant is feeling and reacting to medical care and to the intensive care nursery.

As recovering babies become bigger and change and grow, parents learn that they are telling them many new things about themselves through their behavior. By watching patterns of breathing, skin color changes, movements, activity levels and sleep and awake patterns, parents can tell whether their baby is becoming comfortable and relaxed.

Observing Your Baby’s Behavior

Babies who were born early or spent their first weeks in the newborn intensive care nursery may respond in very different ways than what a parent expects. The role of a parent includes in this situation learning to watch and take note and observe the ways that their baby may have patterns of movement, looking or breathing that tell them how their baby is feeling.
As parents observe their infant, they begin to see some patterns of behavior occur over and over, and see signs that tell them their infant is ready to interact. Paying attention to when certain behaviors occur may be clues. However, sometimes when a parent thinks a baby is ready, they may learn that the baby really wasn’t ready. For example, if an infant opens up his/her eyes and looks out, a parent might present their face and talk to their infant. In response, the baby could look away, turn away or look down, and appear uncomfortable or begin to breath faster or look pale.

This does not mean that the infant did not want to look at Mom or Dad. It means that the baby was not able to process all of the incoming stimuli, a sound from a voice, and a view of a face, all at the same time, or exactly at that moment. It also may mean that the baby may only be able to handle one thing at a time, the voice OR the face. It could mean that these things need to come to the baby very slowly and gradually, quietly and gently. It also could mean that the timing was not right for the baby.

The important thing to remember is:

**Your Baby Wants You to Know**

And your baby is learning through your voice, and your touch, and even your familiar smell that he/she is loved and is very special.
Sometimes a baby may be very sensitive to light. For example, if when you turn a light on nearby and your baby blinks and pulls away looking uncomfortable, it is likely that your baby was overwhelmed by the light being so bright, and was a surprised with the brightness. This would be a clue to shield your baby’s eyes as you turn on lights, and keep bright lights away from shining on your baby’s face. This reduction in brightness and eliminating the surprise, could help your baby avoid becoming fussy and may help your baby relax.

The same principle applies to noise and activity. One infant we knew, cried when the TV was turned on. It was a loud abrupt sound that was too much for this baby to handle. The crying was a signal from the baby that she was unable to tolerate the sound. At the suggestion of a home visiting nurse, the baby was held in a corner of the room away from the TV, as it was turned on. The infant was able to avoid crying, and remain calm.

This does not mean that every baby reacts this way to light or noise. Every baby will be different and every baby will react differently at different times. As babies grow and develop, they will be able to tolerate such brightness or loudness more readily. Learning what your babies sensitivities are is part of building relationship between you and your baby.

**Comforting and Nurturing Your Baby**

Babies cry and fuss for many reasons. They may cry or fuss because they are tired or very exhausted. They may cry because they have had too much activity or the sounds and events in their outer world are overwhelming. This means that sometimes a baby can become overstimulated. The outer world activity level has exceeded their tolerance level.
When this happens, it helps to move your baby to a quieter calmer place, or just hold your baby close until he/she calms.

Some babies cry because they are really worn out and they may not be sure what they want. If your baby cries and cries, and you know he is not hungry or hurting anywhere, you may lay our baby down in a safe comfortable place for a few minutes. But do stay close by. You may want a helper to help you hold your baby. It is not a good practice to leave your baby to cry alone for a long time.
When your baby cries, you may try 2-3 things slowly and gradually to calm your baby. If you try too many things all at once and move from one activity to the next, it could increase your baby’s fussiness by overstimulating him/her. Decide on one activity at a time, such as holding your baby as he/she lies on the bed, or holding in your arms. You may also find that providing something to suck on helps. But keep in mind that when you try too many things in a row, or too many things all at once, your baby might become more fussy. The idea here is to REDUCE the activity level and help the input your baby is feeling be less and less. It is the lessening of the activity that will most likely help a recovering newborn.

By staying with your baby, and trying to comfort your baby, your baby is learning that you care about how she/he feels.

You also may help your baby throughout the day learn to calm or soothe him/herself. Babies have ways to calm themselves and each baby has preferences for how they like to use these strategies. A baby who spent weeks in the NICU may have forgotten how to use these strategies to calm themselves. Most babies enjoy sucking on Mom’s finger, or their own fingers or a pacifier. Other babies may prefer to grasp and hold on to the finger or to a blanket or a small toy. Babies also may like to brace their feet against the edge of the bed. Each baby will have their own preferences. It is helpful to know that these activities developed for your baby while he/she was growing in the womb. Even if they were born premature, your baby may have been sucking, bracing their feet, and grasping and holding on since the first 3 months of their fetal life.

**Interacting With Your Baby**

As you learn what your infant is sensitive to and what your infant’s preferences are, you are building your very special relationship. As your infant grows and begins to become more recovered, you will see many patterns of behavior that will be exciting for you.
The behaviors that tell you that your infant is a social partner are most exciting. Protecting and adjusting to your infant’s level of tolerance is a predominant focus in the early weeks and even months after taking your infant home from the hospital. As your baby shows small amounts of tolerance for the activity around him/her, you will begin to see gradually emerging the stability to begin to respond more to the environment around him/her.

At this point, your baby will slowly begin to look at your face for longer periods. Your baby will begin looking and following your face for short periods, but with some practice, when he/she is calm and awake, these episodes will lengthen. You will notice that you can talk face to face with your baby and have short conversations. Your sense of your baby’s ability to respond will grow. Trust your ability to help your baby learn how
to look, listen and respond to you and to his/her environment. You will develop your own ways of talking and looking and being together. These are golden moments for you, as well as your baby and become the basis for a life long relationship.
References


