



“On Your Way” - Skill Building Worksheets for Families and Caregivers

Dear Mom and Dad (or Caregiver),

Congratulations on the birth of your baby! We know that being in the NICU may be scary and overwhelming. We are a Team and want you to know that your presence here will help your baby! Hearing your voice, smelling you, and touching you will make your baby feel safe and secure. We will work together so you understand medical procedures, equipment, and developmental information and feel comfortable being involved in the decision making process. We value your participation in helping your baby grow healthy.

The NICU can be a stressful place for families and there are many things to remember each day. As you go through the learning process, please ask us questions. We don't expect you to “get it” the first time. The more you are able to practice the strategies and skills taught to you, the more comfortable you will feel in managing your baby's daily care. Our goal is to provide the coaching you need to become confident in caring for your baby to get you...On Your Way!

The following worksheets explain how your baby senses and manages stimulation in the NICU and how you can learn specific strategies to help protect your baby from stress; give your baby comfort; and support your baby's development. In each section, your NICU Team will coach you in the techniques and strategies and give you opportunities to practice. When you feel comfortable doing them on your own, you will sign off with someone from your Team.

When your baby is ready to go home we will discuss a referral to Early Intervention. Early Intervention is a community resource available after discharge that will continue to coach and support you in helping your baby develop.

YOUR NICU TEAM

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RECOGNIZING STRESS: Look at my face, hands, posture, and movement to understand how I am feeling (READING MY CUES). **This is how I look when I am:**

Body Part	Feeling Calm and Relaxed	Feeling Stress
Face	Relaxed, calm	Frown or worry
Mouth	“O” shape, relaxed lips	Tight lips, clenched jaw
Hands	Gently fisted, close to chest/mouth	Clenched fists, splayed fingers, scratching face
Body	Arms & Legs bent towards the tummy/chest	Arched head/neck, arms & legs stretched out away from the body
Movement	Random, movement of arms/legs in and out	Jerky, shaky, or rigid movement of arms/legs away from the body
Eyes	Open or closed	Looking away, squinting
Actions	Sucking pacifier, sucking hands, quiet/calm stare, sleeping	Excessive yawns, sneezes, hiccups, high pitch cry, whimper

CALM



Relaxed face and mouth with hands towards face and tummy



Arms and hands close to chest and face with relaxed eyes and mouth

STRESS



Frown, arching my head, with arm and leg moving away from body



Frown with both arms away from the body and fingers open (splayed)

CALM



Quiet, alert face

STRESS



Frown with eyes and lips tightly closed



Sucking on hands with relaxed face



Frown with high pitch cry

I/We are able to recognize our baby's cues to understand how he/she feels _____(initial/date)

Comments:

How to help me calm:

- giving me a finger to hold
- swaddling or containing me
- holding me and talking to me softly
- changing my position
- giving me a pacifier



In a nest, on my side, with gentle hands to contain me



Offering me a pacifier helps me soothe myself



Sleeping swaddled on my side



Holding me and talking to me softly while swaddled

I/We know how to calm our baby and help him/her relax _____(initial/date)

Comments:

SLEEP: I love it when you visit! But if I am sleeping when you arrive, please let me stay asleep.
When I'm sleeping:

- My brain is working hard to make new cells and new connections
- I can manage stress, relax, and focus on growing

How to help me rest:

- Turn the lights and sounds down
- Offer me a pacifier – sucking is calming for me and helps me self-soothe
- Help me feel contained – nesting or swaddling
- Make sure I am warm



Swaddled, warm and cozy on my back



Sleeping on my tummy sometimes helps me rest more comfortably

While I am in the NICU on a monitor and under 24 hour medical care, I can sleep in different positions like on my side or on my tummy. But when I go home I should always sleep on my back. My NICU Team will explain why SAFE SLEEP is important for me.

I/We know how to control the lights and sounds around my baby's bedside _____ (initial/date)

I/We know ways to calm and comfort my baby so he/she can sleep _____ (initial/date)

Comments:

TOUCH: Nothing feels better than touching and feeling you! It helps me bond with you, relax, and know you are there to take care of me! Touching me too lightly (tickle or stroking) may startle me or feel unpleasant. I like gentle pressure better.

How to touch me so it feels good:

- Grasp your finger in my palm
- Skin to Skin (Kangaroo care) where I lie against your chest and feel your heart beat and your warmth and smell! Daddy can do this with me too!
- Before you move or unswaddle me, give me gentle pressure on the top of my head and bottom together for 20-30 sec. so I don't startle and talk to me quietly. This is called **containment** and helps me get ready for our time together!
- Massage (instructed by someone Certified in Neonatal Massage)

I/We know how to provide gentle pressure containment _____(initial/date)

I/We know how to do Skin to Skin _____(initial/date)



Skin to skin on Mom's chest



Gentle pressure on my head and bottom helps me feel contained and safe



Holding my Mom's hand helps me feel connected to you



Learning how to massage me using gentle pressure on my back

Comments:

POSITIONING: If I am in one position for too long my skin, neck, shoulders, and hips hurt! My head will get flat because my skull is soft. If I stretch my arms and legs out, I'm not strong enough to pull them back in. When my arms and legs are close to my body, I am more **organized** and happy!

How to help me change position and rest comfortably:

- Keep my arms and legs tucked towards the middle of my body with my hands together on my chest
- Build a nest so I feel contained using rolled blankets, bendy bumpers, or other devices my NICU team can provide ***Devices used in the NICU are not designed for home use.
- Swaddle me in a blanket or swaddler to help me feel contained
- Turn me onto my tummy or side every few hours so I'm not always on my back!
- Turn me **SLOWLY**, keeping my arms and legs tucked in a cradled position, and support my head

I/We know how to build a nest so our baby is contained _____ (initial/date)

I/We know how to swaddle our baby with arms and legs towards the tummy and chest _____ (initial/date)

I/We know how to roll our baby over so he/she doesn't startle _____ (initial/date)



Nested with blanket rolls so my arms and legs are bent towards the middle of my body



Rolling me to my side, keeping my hands towards my chest and my neck straight



Arms and legs tucked towards the middle of my body with my hands on my chest



On my tummy in a swaddler helps me relax and sleep

Comments:

SMELL: I can smell everything pretty well! Smells like heavy perfume or smoke will bother me and make it hard for me to breathe or make me sneeze. If you put a piece of cloth with your skin scent on it in my bed, I will remember how good it felt to have you close by.

I/We know how to make a scent cloth for our baby_____ (initial/date)



Smell cloth to put in my crib

Comments:

LISTENING: I know the sound of your voice and it makes me feel better! I can hear you much better than I can see you. My hearing is very sensitive and loud, sudden noises and voices can startle and upset me or make it hard for me to sleep.

How to help me manage sounds:

- Talk, hum, or sing to me softly (you can make a recording of your voice for the Nurses to play when you aren't able to be there)
- Read me a story (live or recorded)
- Play me soft music (such as lullabies and classical music)
- Sometimes I like background sounds (called white noise) like a fan humming; rain falling; heart beating; motor running; ocean sounds, etc.
- Do not talk on your phone or speak loudly with others in the room if I am taking a nap.

I/We played music for our baby today _____ (initial/date)

I/We read our baby a story _____ (initial/date)



Musical pacifier



Reading me a story. Photo by Robert Boston

Comments:

LOOKING: My eyes don't see very well so trying to focus is hard work and tires me out! The lights in the NICU are very bright and I have to shut my eyes when they are on. As I get older I will learn to find you with my eyes by hearing your voice. When I try to focus, my eyes might cross or I might have to look away quickly. This is hard work.

How to protect my eyes from the lights:

- Dimming the lights around my crib
- Covering my isolette with a blanket or specially designed isolette cover
- Shielding my eyes with your hand if you are holding me

I/We know how to manage the light around our baby's bedside _____ (initial/date)



Covering my isolette with a blanket protects my eyes from bright light



Dimming the lights and blanket covers help me rest

Comments:

Cluster Care: The Nurses take care of me by doing a bunch of tasks when I wake up. They will take my temperature and blood pressure; change my diaper; give me medicine; and change my position. This is called **Cluster Care**. If I can eat, this usually happens around a feeding time. Afterwards, I can rest for a longer period of time without being woken up. I like it when my Mom and Dad participate in my Cluster Care!

I/We know how to:

- Take our baby's temperature _____ (initial/date)
- Change our baby's diaper _____ (initial/date)
- Give our baby a bath _____ (initial/date)



Swaddled bathing helps me stay warm



Watching my Dad take my temperature



Changing my diaper



Comfort care is skin to skin time with my Dad

Comments:

Feeding: If I am too small or too young to eat, they will feed me using a tube going through my nose or mouth and down my throat (gavage feeding).

- Hold me and let me suck on a pacifier during my tube feedings so I can begin to bond with you and understand that sucking makes me feel full!



Pacifier sucking during a tube feeding

How do you know if I am hungry? When I am ready I will:

- Wake up and move my lips in a sucking motion
- Suck on my hands or pacifier
- Turn my mouth to the side to search for food (Rooting reflex)

When the Doctor says I can eat, I will need to go slow at first. It is a lot of work to coordinate sucking, swallowing and breathing all at the same time. I will need patience and practice!

I might need:

- A slower flow nipple
- A special bottle
- Fortified breast milk or donor milk
- A different type of formula
- A therapist to evaluate me and teach you special ways to help me coordinate my sucking and swallowing and pace myself so I don't tire out, choke or spit up.
- A Lactation Specialist to work with my Mommy on pumping so she can provide breastmilk, and possibly breastfeed.



Eating on left side with pillow support



Holding my hands towards my chest helps me coordinate suck, swallow and breathing



Learning to breastfeed may be something we can do when I get bigger



My NICU team will coach you on ways to help me eat. Photo by lehighvalleymagazine.com

I/We know how to feed and burp our baby using:

_____ nipple _____ bottle _____ formula/breast milk (initial/date)

I/We know how to help our baby eat more easily by: _____

_____ (initial/date)

Comments:

NEXT STEP..... ON YOUR WAY TO EARLY INTERVENTION!

What is Early Intervention? Early Intervention is a community-based program that provides services to infants and toddlers, birth to three years of age, who have developmental delays or disabilities. Some babies that have been in the NICU may need help learning the skills typically acquired in the first three years of life such as crawling, walking, communicating, playing, eating, and dressing. In Virginia, most programs are called the Infant-Toddler Connection, but they can also be called Parent-Infant Education (PIE) or Child Development Center (CDC). Early Intervention providers can be Physical Therapists, Occupational Therapists, Speech Therapists, Nurses, or Early Childhood Educators.

How do I get Early Intervention? Your NICU team will go over the Referral form with you and fax it to the local program where you live when your baby is discharged. Your baby may have a diagnosis that makes them automatically eligible. In other cases, an Early Intervention Team will evaluate your baby and talk with you to determine eligibility. You will be assigned a Service Coordinator to help you through the process below:



Where do I get Early Intervention? The Federal mandate for Part C of IDEA states that services will be provided in the baby's **natural environment**. Once your Plan is set up, the Provider will meet at your home, daycare, playground, or any place you and your baby spend time.

How much does it Cost? When your Doctor signs off on the Plan, the Early Intervention program will bill your Private Insurance or Medicaid for the billable services. You may have a co-pay if your Insurance Policy requires it. You will be assigned a monthly cap so, regardless of what your insurance pays, you will never be charged more than that amount. Based on the Federal mandate, children cannot be denied services based on a family's inability to pay.

Your Early Intervention Program is _____