ANTEPARTUM

• **Recognizing the Signs of Preterm Labor** In spite of our best efforts, preterm birth rates have not declined markedly. One in eight births will be preterm and many of those families will end up in the NICU. While there is still much to learn about preterm birth, we know that the sooner the mother seeks care the sooner we can put interventions in place. This tool describes what women should watch for, when they should get help, and what they can expect once they do.

• **When You're in Preterm Labor: What You Should Know** If a mother is in preterm labor the delivery of her baby may be imminent. This handout explains what the care team will look for when she comes to the hospital, when delivery needs to happen immediately, and when there are things we can do to hold off birth until the baby and mom are more stable.

• **Caring for Your Mental Health During a High-Risk Pregnancy and Bed Rest** When a pregnancy gets complicated, mothers may be prescribed bed rest either at home or in the hospital. Playing this high-risk waiting game can leave women feeling isolated, angry, scared and helpless. This article discusses ways mothers can empower themselves and gain both a sense of control and a measure of peace as they prepare for their baby's birth and possible NICU stay.

IN THE NICU

• **Bonding with Your Medically Fragile Baby in the NICU** More than one parent has described the NICU as an alien world full of scary machines and frightening procedures. This environment is intimidating to parents who may not be sure when or if they will be able to see or hold their baby. This article describes a variety of ways parents can begin to get to know their child and bond with them – even if they can’t hold them yet.

• **A Dad’s Guide to the NICU** Some fathers adapt to the NICU environment very quickly. Others find it incredibly threatening and intimidating. Care and attention is understandably focused on the mother and infant while the father struggles to find his role. This tool validates fathers’ feelings, acknowledges their important role, and gives them suggestions for navigating the NICU environment. It helps dads put the complex feelings they are experiencing – fear, anger, grief, guilt – into context and turns them into productive emotions.

NICU RESOURCE LIBRARY

The NICU Resource Library will serve to unify and inspire hospitals to extend and improve NICU parent education and support. Subscribers will have access to a private online resource library which features these comprehensive educational materials for NICU families. These resource tools validate family’s concerns, provide accurate and timely information, and support parents during and after their NICU stay.
What You Need to Know about Pumping and Breastfeeding  
Breastfeeding can be challenging under the best circumstances. Mothers in the NICU face additional struggles. This tool helps mothers understand their babies’ nutritional needs, gives them a better understanding of the physiological process of lactation, and offers reassuring support that will help them set their own breastfeeding goals, adjust their expectations, and adapt to the new reality of breast pumps, storing milk and round-the-clock pumping.

When Will We Go Home? A Guide to Understanding the Discharge Process  
Every parent anxiously awaits the answer to this question: When will we go home? Instead of focusing on a date or adjusted age, this handout talks about the things their baby will need to learn to do over the coming days to achieve physiological stability and learn how to feed, grow and prepare for life outside the NICU.

Finding a Balance between NICU and Home  
When parents are admitted to the NICU everything changes. Daily routines and obligations are replaced by the new demands of being a NICU parent. Parents would like nothing more than to be with their babies all the time. But they soon realize life outside the NICU is moving on without them and there are pressures to get back to “normal.” This handout gives advice on how to deal with these competing pressures while still taking care of yourself and your family.

What Does That Mean?: Reading Your Baby’s Cues  
NICU babies do not always act like typically developing babies. Even veteran parents can struggle to learn to communicate with their infants. This handout addresses neurological development and how babies in the NICU react to their environment— including their parents and caregivers.

A Guide to Your Baby’s Growing Brain  
Infants are born with fragile and immature nervous systems whether or not they have gone full term. When a baby is preterm they need to continue to grow and mature outside of the ideal environment of the womb. This resource teaches parents about developmental care and helps them understand their baby’s sensory world.

Caring for Your Late Preterm Baby  
Our understanding of the needs of Late Preterm Infants has improved dramatically, but there are still many parents who expect their late preterm babies to be more like full-term infants than premature infants. This handout explains the unique needs of late preterm infants and how they are like and unlike their full term or extremely premature peers. It offers timely information while in the NICU as well as things for follow-up after discharge.

Protecting Your Baby from Germs and Viruses  
The NICU is a safe place for babies to grow and develop, not only because of the care they receive but also because it is a clean and sterile environment. Parents learn the importance of hand washing early on, but protective measures don’t stop there. This resources discusses the importance of germ control and vaccination and educates parents about the risks their babies face from infections, bronchiolitis, and RSV. It also gives practical tips for what families can do to decrease their baby’s risks.

COMMUNICATION

How to Communicate with Your Baby’s Care Team  
Parents with a baby in the NICU can be overwhelmed by their child’s medical needs and may not understand what they can do to be an effective advocate for their baby. This article gives 10 tips for communicating well, stresses the importance of asking questions, and encourages parents to be actively involved in their baby’s care.

Advocating for Your Baby’s Needs  
When a baby is admitted to the NICU a family’s hopes and dreams for their child’s birth are interrupted. Parents find themselves in a medically complex environment where they are no longer the expert on their baby. This tool helps parents adapt to their new roles and responsibilities as NICU parents and gives them tips for working with NICU staff and other professionals in a reasonable, productive and mutually-respectful way.
• **Building Your Team** Babies in the NICU require complex care delivered by a team of specialists. Parents discover that they need to quickly identify who cares for their baby, what their roles are, and how to communicate with them. This resource guides parents through the process of building these relationships and gives them the information they need to find reliable care for their baby once they go home.

**FINANCES**

• **How to Pay for Your NICU Stay** Any NICU stay is expensive. For families with limited means and resources the cost can be overwhelming. This guide goes beyond just SSI and Medicaid. It talks about the Family Medical Leave Act, COBRA, CHIP, Medicaid Buy-In, WIC, Medicaid Waiver Programs and other resources to help families find help.

**FOR SIBLINGS**

• **Answering Your Children’s Questions about a Baby in the NICU** A NICU stay impacts the whole family. Siblings need information about their baby brother and sister in the NICU that is reliable and age-appropriate. This article shares how to answer difficult and complicated questions about the baby’s health so that siblings have the information they need to feel included, supported and less fearful.

• **I’m Special Too, Ways to Help Siblings Feel Important** When a baby is hospitalized, the whole family is affected including big sisters and brothers. Sometimes older siblings feel neglected as mom and dad make frequent visits to the hospital. Keeping the lines of communication open and letting them know what is going on – in a way that is appropriate for their age – helps siblings feel included and accept the situation. This article also gives practical tips for involving older siblings in the new baby’s care.

**DISCHARGE**

• **We’re Coming Home from the NICU** Discharge can be both exciting and tremendously stressful. Away from the NICU, families find themselves alone responsible for their baby’s care. It can be a difficult adjustment. Often, family and friends want to help but don’t understand how. This top 10 list helps parents educate their family and friends about what to expect by giving them the tools they need to have these conversations.

• **Your Baby’s First Month at Home** When a family is in the NICU, their goal is to go home with their baby as soon and as safely as possible… but then what? Their new at-home routine can be a daunting schedule of medications, therapies and follow-up appointments. This tool is a checklist for the first month at home, offering practical advice as well as reassurance from fellow families. It can be used as an introduction to the discharge process or as a way to begin a conversation with the baby’s caregivers about their child’s unique developmental needs.

• **Nutrition for Your NICU Graduate** Babies who are born preterm or who have special medical needs have unique nutritional needs. For many babies the need to fortify, supplement and monitor their feedings will continue beyond the NICU. How they are fed – whether they are breastfed, bottle fed or tube fed – is only one consideration. Each family needs information to find the feeding strategy that is right for their child. This handout talks about different types of nutrition, modes of feeding, and strategies to support the use of breast milk whether from the mother or a milk bank – as well as common feeding issues and where to turn for help.

• **Bringing Out the Best in Your Baby** Beginning your baby’s life with a medical crisis makes parents acutely aware of the curves life can throw you. While it’s true that babies who have had a NICU stay are more likely to experience developmental delays and disabilities, there are things parents can do to increase the odds in their favor. This article helps parents start looking at their baby’s developmental trajectory in new, more positive ways.
• **Understanding PTSD: When the Stress of the NICU Persists** What parents experience during their baby’s NICU stay can have a lasting, traumatic impact. It is natural for parents to experience heightened anxiety, intense fear and immobilizing depression during their child’s hospitalization. After the initial “roller coaster ride” has ended those emotions should diminish with time. Sometimes they don’t. This article describes the symptoms of PTSD to watch for so that parents can seek help for themselves. It also offers the reassuring message that these overwhelming feelings are both temporary and treatable.

**FOR NICU STAFF**

• **Equipping Families to Care for Their Babies** If babies are going to go home and thrive they, need smart, informed parents who understand their needs. NICU staff are in a unique position to help this happen. This handout shows staff how to identify and foster parent competency and gives practical tips for communicating with families during what may be the most stressful time of their lives.

• **When a Baby Dies** Most NICUs provide comprehensive bereavement training and support for their staff, but in that moment when you realize that death is a possibility it can be hard to remember what to do. Both parents and staff need support. This tool provides timely reminders that can make a difference in how staff handles a death and how parents feel about their child’s passing. Special attention is given to what words to use, what to avoid and how to care for the caregiver.

For more information check out www.handtohold.org