



Family Education Notebook

This book belongs to:



Carolinas HealthCare System

Levine Children's Hospital



FAMILY EDUCATION NOTEBOOK

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Welcome to the World

Welcome to the World!

Born on:

at:

Gestational Age:

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**Congratulations from the staff of
Levine Children's Hospital**



Carolinus HealthCare System
Levine Children's Hospital

MESSAGE FROM OUR LEADER

Dear Parents,

As facility executive for Levine Children's Hospital, my highest priority is to ensure your infant and family receive excellent service throughout your stay. With more than 30 pediatric specialties, we will provide you with the best care possible, whatever your need. Our talented caregivers believe nothing is more important than the health of your child.

Parents are our partners. At Levine Children's Hospital, caring for your infant goes beyond medical procedures. On each step of your journey, we will take the time to talk through any questions you have and provide the information you need to understand your child's condition. We believe when families and medical staff work together, parents are better prepared to care for their child at home.

We hope you will find this Neonatal Family Education Guide helpful. It was designed to provide you with useful information about your baby's condition and plan of care. It is one of the many resources available to you while you are here. Please review the contents as your time permits.

We know you want nothing more than for your baby to be happy and healthy. Our job is to guide you through this experience, help you make informed decisions, and provide you with the information, advice and resources you need to get your baby home safely. In the difficult moments, when you feel alone and afraid, we are here to listen to your concerns and be a shoulder to cry on. We will celebrate the milestones and rejoice in the victories alongside you. But most of all, we will support you, and help you through this journey. Rest assured that the wellbeing of your baby is our first priority.

Again, if at any time we do not meet your expectations, do not hesitate to speak to the nurse manager on the unit or a member of our Levine Children's Hospital administrative team.

Sincerely,



Callie Dobbins
LEVINE CHILDREN'S HOSPITAL FACILITY EXECUTIVE





Dear Parents,

Congratulations on the birth of your baby! We understand that having your newborn in the neonatal nurseries can be a challenging and often frightening experience. Please know that our compassionate team of experts is here for you. We are committed to providing your baby and family with excellent care and support every step of the way.

With a focus on family-centered care, we believe that you and your family are the most important people in your baby's life. We encourage you to be with your baby as much as you can, not only to learn how to care for your newborn, but also to understand your baby's plan of care each day. Please do not hesitate to ask questions or share any concerns you may have.

You may call the neonatal nurseries at any time of the day or night (NICN: 704-381-7900, NPCN: 704-381-7100). Please understand that, for privacy reasons, we can only give information to parents or armband holders. Other concerned family members will need to contact you directly for updates.

Our goal is for your baby's discharge to be one of the happiest days of your life. We are here to provide help and support as you transition from the birth of your baby to a healthy and happy homecoming. We have provided this notebook for you and your family to use however works best for you. When your baby goes home, you will have a detailed guide to help you care for your infant as well as a record of your time with us.

Again, if you have any questions, please ask the dedicated staff working with you and your baby.

Thank you,

The Neonatal Staff
LEVINE CHILDREN'S HOSPITAL



VISITING THE NEONATAL NURSERIES

You are the most important person in your baby's life. We want you to be involved with your baby's care as much as you can. To provide a safe and healing setting for your baby and all other babies in our care, we have guidelines for visiting the NICU and NPCU.

The neonatal staff is here to help care for you and your baby. If you have questions or concerns, please ask to talk to the charge nurse, clinical supervisor or nurse manager.

VISITOR POLICY

Everyone:

- You must wear a Levine Children's Hospital visitor's badge.
- Everyone will be asked to leave when the nurseries are closed for:
 - Shift change (6:30 to 7:30, morning and evening).
 - Emergencies, critical admissions, surgeries or other procedures. You may wait in the family waiting area. We will tell you when the nursery is open again.
- To do what is best for babies, families, visitors and staff, we have the right to limit visits and visitors.

Parent/Armband Holder:

- You are welcome in the nursery anytime except during shift change.
- Wear your parent identification bracelet until your baby leaves the hospital. We will need to see the bracelet before you go into the nursery. We will also ask for the bracelet number before we give out any information over the phone.
- To protect your baby, we will only give information to you or someone you have picked to receive information.
- You choose who can visit your baby. You may pick up to four people, like grandparents or other special people, who may visit alone. We will need the names of these people in writing. These people may not bring visitors with them.
- All other visitors must be with a parent. Only two people can be at the bedside at a time.
- To respect everyone's privacy, please stay at your baby's bedside. We cannot answer questions about other babies.
- Up to four people may visit your baby without you. The names of these four people will be placed on a list at the front desk. They will not be allowed to bring in additional visitors.
- Please have your visitors ask you for news about the baby. We can only give visitors general information.

Other Visitors:

- Please ask the parents for news about the baby. We can only give you general information.

Siblings (brothers and sisters of the baby in the nursery):

- There will be times during the year when the nursery is closed to siblings. This is to help keep your baby safe from germs.
- Before bringing siblings for a visit, please call your baby's nurse to find out age limits and set up a time for the visit. The best time is between 10 a.m. and 4 p.m.
- Two adults and siblings may be at the bedside during a visit. One of the adults must be in charge of the siblings.
- At any time, if the siblings act in a way that bothers the baby, or poses a safety risk, an adult will need to take them out of the unit.
- No one under age 12 can be alone or put in charge of siblings in the family waiting areas.
- Other children (nieces, nephews, cousins and friends) must be at least 12 years old to visit.

INFECTION PREVENTION

We take proactive measures to keep your baby safe from infection. This includes protecting them from infections that visitors may carry into the nursery.

- If you are not feeling well, you cannot visit. With each visit to NICN or NPCN, all visitors are required to fill out a form answering questions about their health.
- Each week, we check your baby for a germ called Methicillin Resistant Staph Aureus (MRSA). MRSA is a germ that is found on the skin or in the nose of about one-third of people. This germ is usually not harmful, but it sometimes can cause infections. Weekly testing allows us to catch infections early and treat them before they become a problem.
- All visitors must wear a disposable gown to protect your baby from germs that may be brought in from the outside. At the end of your visit, throw your gown away in the trashcan in the nursery.
- All phones must be placed in a plastic bag. A new bag should be used for each trip to the nursery. Plastic bags are available at the check-in desk.

HAND HYGIENE

The best way to keep your baby safe from infection is with proper hand hygiene. Germs can spread from hands and surfaces to people and wounds. This can cause infections. Use both soap and water AND alcohol-based hand rub to kill all of the germs.

Soap and Water

1. Push the sleeves of your clothing up to your elbows.
2. Place one hand in each of the open cylinders. System will start automatically.
3. Leave hands in cylinder until water stops.
4. Use a clean paper towel to dry your hands.

Alcohol-Based Hand Rub:

1. Apply one squirt.
2. Rub hands together until dry.
3. Re-use alcohol-based hand rub each time you touch your baby or a personal item such as a camera or iPad.

MY BABY'S DOCTORS

Depending upon the particular needs of your baby, the following pediatric subspecialists may also be involved with the medical care of your child. Please feel free to write down the names of your baby's care providers.

Cardiac Surgery _____

Cardiology _____

Ear, Nose and Throat _____

Endocrinology _____

Gastroenterology _____

Genetics _____

Nephrology _____

Neurology _____

Neurosurgery _____

Ophthalmology _____

Orthopedics _____

Pulmonology _____

Surgery _____

Urology _____

Other team members I want to remember:

Caring for You tab



HOW DO I FEEL?

As parents, you feel love, hope, joy and happiness with the birth of your new baby. But, like many parents, the birth of your baby did not go as planned. You did not expect your baby to remain in the hospital and need the special care of the NICN. Your baby might be experiencing health challenges, and you are faced with decisions about his or her care. You may first feel shock, and then it is quite common to feel sad, angry, nervous and scared. You may blame yourself or feel helpless. Stress about the uncertainty of your baby's condition for the future may feel overwhelming. Know that it is okay to have these feelings. The more that you can think positively and be there for your baby, the better prepared you will be to take care of your baby.

The following tips may help:

- **Allow yourself to cry** – It is healthy to release your emotions.
- **Establish a routine** – Find a way to balance work, home life and visiting the hospital. While your baby is in the NICN, give yourself permission to leave your baby's side. Even though your baby needs you, it is important to take time for yourself and your family.
- **Connect with other parents with similar circumstances** – Find support groups and other parents you can talk to. Attend Family Focus, our support group offered in the hospital every Thursday evening. Connect with Family Support Network for a parent-to-parent match.
- **Keep a journal** – Sometimes writing your feelings down on paper can help you cope and move forward. A journal keeps track of how far you and your baby have come on your journey.
- **Vent your frustrations** – Tell others, including your partner, how you feel. If your baby has a setback, you may become scared and anxious. It's okay to talk about your feelings.
- **Celebrate when you can** – When your baby makes progress, share the joy with those you love.
- **Let others help** – Family and friends may be willing to help, but are not sure how to ask. Be specific about how other people can best help you.
- **Consider creating a Caringbridge website** – Caringbridge sites are simple to set up, and this will allow you to communicate updates about your baby to your family and friends (www.caringbridge.org)
- **Allow yourself to rest and sleep** – This allows you to recover from your delivery and be better prepared to take care of your baby.

Source: Excerpted from the March of Dimes booklet, *Parent: You and Your Baby in the NICU* written in collaboration with Deborah L. Davis PhD, and Mara Tesler Stein, PsyD, authors of *Parenting Your Premature Baby and Child: The Emotional Journey*.

HOW DOES MY PARTNER FEEL?

The birth of a baby is wonderful, but you and your partner were likely surprised about your baby's early arrival or need for a stay in the NICU. It is possible the stress of the experience will affect your relationship. There may be times when you feel differently about the ways to cope and how to care for your baby. Try to understand each other's point of view. Make time to listen, be respectful and provide support for each other. You will probably be focusing most of your energy on your baby, so remember that it is also important to make time to be together as a couple.

HOW DO MY OTHER CHILDREN FEEL?

The early arrival of a baby, or a baby requiring neonatal intensive care, is difficult and emotional for all family members, including your other children. You may be worried about what they are feeling. Young children may feel upset or threatened by the changes in family routines or by being separated from you. Older ones may be worried about the baby's health. Be sure to spend special time with all of your children. Speak honestly and openly with information suited to your child's age. Make sure they know how their baby brother or sister is doing. Offer support, and include them in visits so that they can see the baby for themselves. The NICU Child Life Specialist can provide education and support for the older brother or sister. Ask your navigator or any NICU staff member to contact Child Life for you.

HOW DO I MANAGE MY STRESS?

It is normal to feel stress after the unexpected birth of a baby requiring neonatal intensive care. It is also important to keep your mind and body strong as you prepare to take care of your baby. Learning to manage stress will be important.

The following are tips and suggestions from the American Institute of Stress about how to manage stress in your life. This will help you have a positive outlook as you experience the NICU journey.

- Avoid alcohol, caffeine and tobacco. These substances add stress to your body and increase your heart rate.
- Surround yourself with people you love, and ask them for help.
- Seek spirituality, if you choose. Hospital chaplains are available if needed.
- Seek out the information you need as you face new situations. Be active in your baby's care. Ask questions.
- Keep a positive outlook and self-image.
- Keep your mind as active as your body. Find small bits of time for activities that you enjoy, such as exercise, lunch with friends or going to movies.
- Learn to remain calm. Try some simple relaxation techniques, like deep breathing, listening to your favorite music or imagining a dream getaway. Schedule a massage provided for our neonatal families. Ask your navigator for scheduling information.

DO I HAVE POSTPARTUM DEPRESSION?

If your feelings are interfering with taking care of yourself or your baby, you may be experiencing depression. Research shows many parents experience some degree of depression in the months following their baby's early arrival. Depression can range in intensity from mild to serious. Postpartum depression tends to linger much longer, sometimes weeks or months after the baby is born.

It is natural to feel many different emotions after your baby is born prematurely. However, if you experience any of the following feelings and cannot overcome them, talk to your healthcare provider or the hospital social worker. You may be experiencing postpartum depression.

Symptoms of postpartum depression include:

- Sadness
- Tiredness
- Anger
- Loss of hope
- Loss of interest in the things you like
- Inability to cope and feeling stuck
- Lack of feeling joy in other parts of your life
- Trouble with relationships with those closest to you
- A parent support group is not helping enough

Source: US Department of Health and Human Services Office on Women's Health

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. Talk to your healthcare provider immediately if you experience any of the following:

- Prolonged emotional numbness or detachment.
- Feeling detached from your baby.
- Difficulty getting out of bed and starting your day.
- Inability to manage your day-to-day activities.
- Thoughts of harming yourself or others.

Source US Department of Health and Human Services, Office of Women’s Health

You are the most important person in your baby’s life. Some parents find themselves questioning their role and importance in their baby’s life. Research has found that children who spend time in the NICU are just as attached to their parents as children who had a more typical (non-NICU) start to family life.

Being at your baby’s side is the best thing that you can do for your baby. But it is also okay to take “time off.” Hearing your voice and feeling your touch makes your baby feel loved and helps your baby get stronger. Your baby is already familiar with your smell and your voice. As soon as your baby gets bigger, he or she will open his or her eyes and look at you. For now, the baby is using all his strength to grow.

Your baby communicates with you through behavior. Watching your baby helps you understand what he or she is trying to tell you.

Once you are aware of your baby’s signals, you can respond in a sensitive way. For example, you may notice that your baby self-soothes by holding his or her fingers up to his or her face. You can then guide your baby’s fingers to his or her face to help self-soothe.

WHAT YOU CAN DO:

- Talk or sing to your baby in a very calm and quiet voice.
- Quietly read to your baby.
- Give your baby your finger to hold.
- Hold or provide kangaroo care for your baby if possible.
- Gently rest your hand on your baby’s arm, leg or body.
- Give your baby a cloth that you have worn to nuzzle and hold close.
- Support your baby’s efforts to self-soothe. Swaddle him or her. Try out different ways to hold him or her. Give your baby something to hold, suck or brace his or her feet against.
- Watch for signs of over-stimulation, such as turning away, changes in breathing, spitting up, arching his or her back, hiccupping or frowning.
- Share your observations with NICU staff. This is very important information for them to have. Ask about doing a developmental care plan that can be placed at your baby’s bedside.
- Talk with your baby’s caregivers to find out how he or she is doing.
- Ask questions.
- Speak up for your baby’s needs.
- Celebrate your baby’s firsts.
- Bring a camera to take pictures.
- Bring a picture of your family to place at your baby’s bedside.
- Participate in your baby’s daily care.

SMOKING CESSATION PROGRAM

Stop Tobacco Education Program (STEP)

As dedicated healthcare professionals, we encourage you to quit tobacco use. We want to support you in taking such an important step toward better health for you and your baby.

What are the dangers of using tobacco?

Tobacco use causes disease all over the body and shortens life on average by 14 years.

Tobacco use:

- Is the number one preventable cause of cardiovascular disease.
- Is a major cause of heart attack and stroke.
- Causes cancers of the lungs, mouth, lips, throat, larynx (“voice box”), esophagus, stomach, pancreas, kidneys, bladder, cervix and blood.
- Causes emphysema and bronchitis, and worsens asthma symptoms.
- When used during pregnancy, there is an increased risk for complications, miscarriage and premature delivery, as well as reduced fetal growth, leading to low birth weight.
- Causes complications from diabetes, particularly insulin-dependent diabetes.
- Interferes with healing and increases wound infections following surgery.
- There is growing evidence that exposure to secondhand smoke leads to disease.
- Increases the risk for pneumonia, cataracts, hip fractures, peptic ulcers, congestive heart failure and abdominal aortic aneurysm.

Are you ready to quit?

Quitting tobacco can be challenging, however, there are resources available to help. Most individuals will try several times to quit before breaking free of their tobacco addiction, and it is important not to be discouraged if you have tried and relapsed. Each quit attempt that you make puts you closer to better health. And, it is never too late to quit; even those individuals who quit after their 65th birthday will reduce their chance of dying from a tobacco-related illness by 50 percent.

You can request additional material on the most current and effective quit strategies. If interested, ask your baby’s nurse or call a free quit-line: the National Cancer Institute (877-448-7848) or the American Lung Association (866-784-8937). These quit-lines have trained staff that will provide one-to-one counseling to help you break free of tobacco.

The World Around You tab

GLOSSARY OF STAFF MEMBERS

Many people will help care for your child. We call this group of people your child's healthcare team. You are an important member of this team and should know the other members. All employees and volunteers wear name badges that show their name and department. If you do not see a name badge, please ask to see it or alert your baby's nurse. The people who care for your child are here to help answer your questions and concerns.

Levine Children's Hospital is an academic medical center engaged in teaching and research to provide the best care for your child. Doctors in various stages of training will assist in providing medical care for your child. These doctors are always led by a qualified attending physician who oversees the care of our patients. Under the leadership of the attending doctor, your child's healthcare team may include any combination of the following members:

- **Attending Doctor** (board-certified MD): is in charge of the healthcare team and directs your child's treatment.
- **Specialist** (board-certified MD): has advanced education about a certain health issue and may be asked to see your child by the attending doctor.
- **Resident** (MD): is a doctor in extended training who works under the supervision of your baby's attending doctor or specialist. A resident has graduated from medical school and is now completing a three or more years focused training program.
- **Physician Assistant** (PA): is a clinician licensed to practice medicine under the supervision of your child's attending doctor or specialist.
- **Nurse Practitioner** (NP): is a registered nurse who has additional graduate education to increase the ability to care for patients and works under the supervision of your child's attending doctor or specialist.
- **Registered Nurse** (RN): is a person who is educated and licensed as a nurse. A nurse will be assigned to your child for each shift.
- **Certified Child Life Specialist** (CCLS): is a person who is specially trained to help children and families cope with medical situations. The child life specialist can help support your baby's development while they are in the NICU or NICU and can provide toys and equipment and resources for parents. The child life specialist is also available to support and educate siblings about the new baby's special medical needs and equipment through age-appropriate therapeutic activities.
- **Clinical Social Worker** (CSW or MSW): is here to offer support, education, counseling and information about community resources while your child is in the hospital and getting you ready to care for your child at home.
- **Students**: may help care for your child. They are in school learning about their profession and are under the supervision of a member of your child's healthcare team. Students are integrated into many different areas including medicine, nursing, respiratory therapy and child life.
- **Chaplain**: helps care for your spiritual needs. This person has special training in supporting families and patients during their hospital stays and times of illness.
- **Clinical Care Coordinator or Discharge Planner**: is a nurse who communicates medical information to your insurance company about your child's hospital stay. They also help identify any needs your child may have after discharge.
- **Community Transition/Navigator Program Coordinator**: is a registered nurse responsible for coordination of the Neonatal Family Navigator Program. The Coordinator also ensures that all eligible children birth to five and their families are referred and connected to developmental follow up services upon discharge.
- **Neonatal Family Navigator**: is a consistent professional who partners with the family throughout their child's hospitalization to provide anticipatory guidance and support while assisting to meet each family's individual needs. The Navigator also provides education regarding community resources and transitions the family into community follow up resources.
- **Child Life Assistant**: works under the supervision of a child life specialist. They assist with play activities and help as needed.
- **Respiratory Care Practitioner** (RCP): specializes in the assessment and treatment of respiratory diseases. They manage the equipment and medications used to help patients breathe easier.
- **Licensed Practical Nurse** (LPN): is licensed by the state and works under the supervision of an RN.
- **Unit Secretary**: keeps each unit functioning by answering the phone, offering assistance with directions and monitoring the flow of people on each unit. They also process physician and nursing orders while assisting with other paperwork.

- **Imaging Technologist:** is someone who works in the radiology department and takes pictures of the body. This person will be specialized in one of several subsections of imaging such as ultrasound, x-ray, CT scan, MRI, nuclear medicine or interventional radiology.
- **Other team members:**
 - Speech Therapist
 - Support Services Staff
 - Medical Librarian
 - Clinical Nurse Specialist
 - Dietitian
 - Lactation Consultant
 - Occupational Therapist
 - Pharmacist
 - Physical Therapist

Volunteers

Levine Children’s Hospital volunteers are a valuable asset to our staff and family members. Each volunteer is screened and trained for their responsibilities. The volunteers are here to help with non-medical needs, and they want to help. Please do not hesitate to ask our volunteers questions or for their assistance. If you have any questions about our volunteers or our program, please feel free to call 704-355-2105.

CLINICAL CASE MANAGEMENT TEAM

Our clinical case management team is here to help you with any needs you have while your baby is in the hospital. They can assist from admission to discharge.

Clinical Care Coordinators/Discharge Planner can help by:

- Providing a list of area pediatricians, including those specially trained to care for premature babies.
- Providing a list of insurance-approved providers.
- Talking with doctors, nurses or other medical professionals.
- Scheduling classes or education.
- Answering insurance questions and problems.
- Sending updates to insurance companies.
- Scheduling home health nurse or therapist visits, if needed.
- Arranging for special equipment, if needed.
- Providing family support.

Clinical Social Workers can help by:

- Supporting you and your family during this stressful time.
- Providing education about our units.
- Providing information on follow-up resources, including early intervention and child service coordination.
- Applying for supplemental security income for premature infants.
- Counseling for depression, grief or adjustment issues.
- Referring to community agencies.
- Talking with doctors, nurses or other medical professionals.
- Providing written educational materials.
- Providing crisis assistance.
- Providing support group information.

A primary clinical care coordinator and social worker will be assigned to you and your family, but anyone can help you, if needed. Please call 704-355-3189 to schedule a time to meet.

RESPIRATORY CARE PRACTITIONER TEAM

The respiratory care practitioner (RCP) team at Levine Children's Hospital is a group of dedicated licensed practitioners trained specifically for the care of neonates and infants. Our respiratory practitioners are here to care for your child's respiratory needs 24 hours a day in the NICU and the NPCU.

The RCP is an active member of the multidisciplinary team developing and delivering your child's daily plan of care.

Common respiratory services your child may need:

- **Aerosolized medication delivery** – Medication, given in mist form, inhaled by your child to help him or her breathe better.
- **Blood gas collection and analysis** – A blood test that measures the PH, oxygen and carbon dioxide in your baby's lungs. This helps the healthcare team determine how well your baby is breathing and if he or she needs assistance.
- **Bronchoscopy assist** – A procedure performed by a board-certified physician. A tube with a camera is placed inside of the airways to look at the condition of the lungs and airways.
- **Continuous positive airway pressure** – Air or oxygen delivered under a small amount of pressure to help your baby breathe better.
- **Delivery room attendance** – Assist with the respiratory needs of newborns inside of the delivery room.
- **Ventilator management** – A machine used to assist your child's breathing. The RCP works in conjunction with the neonatal nurse practitioners and the neonatologist to manage your child's ventilatory status.
- **Neonatal resuscitation provider** – Trained in advanced life support measures for the neonatal population.
- **Oxygen therapy** – There are many devices that can deliver oxygen to your child. Your RCP will work with the medical team to decide what best fits your child's needs.
- **Special airway management** – Devices and procedures that can enhance your child's breathing. The respiratory practitioner will work with the care team to determine what best suits your child.
- **Surfactant administration** – A medication is delivered directly into the lungs to improve their function.

Feeding & Growing tab goes here

FEEDING AND NUTRITION

How will my preemie baby get nutrition when he or she is so small?

If your baby is sick or very tiny, he or she will receive nourishment by an IV. If it appears that your baby will not tolerate feedings within a few days, he or she may be started on total parenteral nutrition (TPN), nutrition that goes in the vein. Your baby can receive complete nutrition and grow on TPN alone. As your baby tolerates feedings, the TPN will be decreased. Your baby may be started on tube feedings. A tube is passed through the mouth or the nose into your baby's stomach. Milk is put through the tube. The amounts will be small at first and gradually increase. There is often a transition period between TPN and tube feedings where the amount of nutrition from TPN slowly decreases as the amount from tube feeding increases.

When will my baby gain weight?

Almost all babies lose weight before they begin to gain weight. This weight loss typically is 5 to 15 percent of the baby's birth weight. Much of the weight loss is loss of water because the baby is no longer surrounded by fluid. Sometimes very sick babies gain weight the first few days. This is not real weight gain, it is retention of water. As the baby's condition improves, the baby will lose weight. Usually, a baby does not regain his or her birth weight until two or more weeks of age.

Can I provide breast milk for my baby?

Yes. Just because your baby is premature or sick does not mean you must formula feed your baby. At first, a small or sick baby will not be able to suckle at the breast, but you can still provide breast milk for him or her. Additional nutrients may need to be added to the breast milk. Formula specially made for premature infants may be used to supplement your breast milk until your milk supply is large enough to ensure your baby's growth.

Excerpt from Jane E. Brazy, MD, University of Wisconsin and *The Center for Perinatal Care* at Meriter Hospital, Madison, Wisconsin



BREAST MILK

Breast milk is the best medicine for your baby. Every drop counts!

Lactation consultants are available to help with any breastfeeding questions or concerns that you have. They are specially trained to educate you about pumping and any challenges that you or your baby may face while pumping or breastfeeding. You can reach our lactation experts at 704-381-0315.

How will breast milk help my baby?

If your baby is premature or sick and is in the NICU, providing breast milk is one of the most important things you can do. Mothers who deliver early have more infection-fighting substances in their milk. Just as your body protected and nurtured your baby during pregnancy, your breast milk will continue to do so now that he or she is here.

Breast milk acts like a medicine that only you can provide. It has more than 200 special cells that cannot be found anywhere else. Some of these cells will build your baby's immune system, protecting your baby from many complications and infections during the hospital stay and long after. Other cells will help your baby's body grow and develop. Studies show that premature babies who received mother's milk have higher IQs and better development than formula-fed babies.

Breast milk:

- Digests easily.
- Can prevent colds, respiratory infections, RSV, ear infections, diarrhea and meningitis.
- Protects a baby from germs that his or her mother has been exposed to.
- "Paints" the intestines with protection against a very serious bowel complication called necrotizing enterocolitis.
- Helps a baby's vision.
- Helps a baby's brain grow.
- Decreases a baby's risk of diabetes, cancer, lung problems, allergies and being overweight.
- Lowers mom's risk of heavy bleeding after delivery and reduces the risk of cancers of the breast, uterus and ovaries.

It is important for babies in the NICU to get breast milk for their very first feeding and for as long as the mother can provide it. You can decide how long you want to pump or whether you want to feed your baby directly at the breast later, after you have learned more about lactation and breastfeeding.

Getting Started

- Start pumping your milk as soon as you can after delivery, within 3 to 6 hours.
- Pump 10 times per day, every 2 to 3 hours during the day with a 4-hour break at night.
- Use a hospital-grade pump. They are made to start help you establish a milk supply.
- Use a double kit and pump both breasts at the same time for 15 minutes until you are pumping 20ml total. Then pump for 2 minutes past the last drop, but no longer than 30 minutes.
- Wash your hands before you start.
- Center the flange over your nipple. Wipe a little olive oil onto the flange where it bends to make it slide easier against your skin and less likely to hurt.
- Hold with just enough pressure to keep an airtight seal on your skin.
- Turn the suction dial carefully so that it does not hurt, but is turned up to your maximum comfort level.
- The pump starts with fast "stimulation" pattern and then changes to a slower "milk removal" pattern.
- Massage your breasts partway through. Be gentle.
- You may not get anything at first. Even if you just get drops, save them.
- Start your pumping log.
- Place a label given to you by your nurse on collection container and date and time you pumped on all bottles.
- Colostrum will be the first milk you produce. It may be drops and a deeper yellow in color. It needs to go to the NICU right away.
- Ask a family member to help you with washing the pump parts and taking milk to your baby if you are unable to go.

COLOSTRUM COLLECTION AND FEEDINGS

Colostrum is the early milk that your body makes during the first few days after giving birth. It is different from the milk that is made later in lactation. Colostrum contains high amounts of antibodies and other substances that help to protect babies in the NICU from infection, bowel diseases and other complications. Colostrum is like a medicine for your baby; every drop should be collected and saved. Even if you do not plan to provide milk to your baby, we encourage you to remove the colostrum from your breasts so that it can be fed to your baby.

Colostrum does not suddenly stop being made. The breast changes gradually so the very first pumped milk is highest in protective substances, the second pumped milk is the next highest, and so on. For most mothers, small drops of colostrum during the first few days give way to larger amounts of transitional milk that is still very protective for babies. After several more days, mature milk replaces the transitional milk. Mothers who deliver preterm babies produce colostrum longer and their colostrum has higher amounts of protective substances than that of a mother with a full-term baby. Colostrum is very beneficial for your baby's first feedings.

The first two weeks are the most important for getting your body ready to make lots of milk. Please ask if you have any questions or concerns.

Before you are discharged from the hospital:

- Your nurse or lactation consultant will help you obtain a high-quality breast pump to use at home. You may either rent a pump or get one through WIC or your insurance.
- Store-bought pumps are not the best to use when baby is in NICU and not breastfeeding yet.
- Ask your baby's nurse for storage containers and labels.

When you visit baby:

- Bring your pumped milk to the hospital.
- Bring your pumping log.
- Use the hospital pump by your baby's bedside with a privacy curtain or in the pumping room.
- Leave fresh milk here, as it's best for your baby to have some fresh (not frozen) milk each day.
- Ask for more bottles and labels when needed.
- Ask if your baby is ready for kangaroo care (holding skin to skin) or breastfeeding.

Pumping at home:

- Have a meal or a drink and snack about 30 minutes before you pump.
- A warm shower or warm compresses to your breasts help you relax and help milk flow better.
- Relax. Think about your baby and look at photos or videos of your baby while you pump.
- Listen to relaxing music.
- Try to nap each day.
- Stay hydrated with plenty of water.

Breast milk storage is important:

- Always wash your hands before pumping.
- Do not touch the inside of bottles or lids.
- Do not add freshly pumped milk to milk that you pumped earlier.
- Freeze your milk at home.
- Bring milk in a cooler with ice packs, not ice cubes.

Nutrition for mom:

- Try to eat a well-balanced diet, but don't worry if it's not perfect. Your milk will still be great.
- Get plenty of protein and calcium.
- Take your prenatal vitamins.
- Drink at least eight ounces of water eight times a day. Drink enough to keep you from being thirsty.

Taking care of your pump parts:

- Take special care when handling your pump parts to keep germs from getting to your baby.
- Keep them in a clean area - not in the sink.
- Wash all parts that touch your breasts or breast milk with hot soapy water, rinse well and air dry after each pumping session.
- The tubing does not need to be washed. If condensation occurs, run the pump with only tubing attached for 2 minutes.
- Be careful when washing the white circle valves. If torn or bent in anyway, the suction will not work properly on the pump.

Sterilizing

All of the parts that you wash need to be sterilized once per day. You also may sterilize them in a dishwasher or boil the parts on the stove for 20 minutes, then let them air dry.

Using your breast milk

When your milk is thawed for your baby's feedings, any milk not used in 24 hours must be thrown away. We don't want to throw away any of your milk, so ask your baby's nurse how to divide your milk into very small amounts for freezing. He or she may want you to do this for several days, then you can start filling up the bottles.

Mom's medications

Most medications prescribed to moms are safe for babies. Talk to your lactation consultant, doctor or nurse about your medicines and any new prescriptions that you are taking.

Breastfeeding in the NICN

When baby is ready to start breastfeeding, the nurse or lactation consultant will help you.

- A good milk supply makes nursing easier.
- Breastfeeding takes practice. Don't expect it to be perfect at first.
- A nipple shield is a silicone nipple placed over mother's nipple and is sometimes used to help premature babies breastfeed better.
- A baby weigh scale is a scale that may be used to tell how much milk your baby is getting from you. We typically start use the scales once your baby is breastfeeding well.
- Supplementation (extra breast milk or formula) is given if baby needs it after breastfeeding.
- As premature babies get stronger, they breastfeed better. Supplementation can be decreased or stopped at this time.

Be sure to ask for help when you need it!

The nurses and lactation consultants want to help you be successful. Your baby's nurse can arrange for a lactation consultant to talk with you and help you:

- If you need help with your milk supply.
- If you are having pain associated with pumping or breastfeeding.
- If you don't think your milk has come in.
- When baby first starts breastfeeding.
- Anytime you need help breastfeeding.
- When you room-in with baby.
- Set up a plan for continuing to breastfeed at home.

We also offer a Lactation Class. Please ask your nurse to sign you up if you are interested.

The American Academy of Pediatrics recommends breastfeeding for a baby's first year. If you were not originally planning to breastfeed, but have decided to pump because your baby is in the NICN, you may want to consider pumping for as long as your baby is in the hospital. Your baby will benefit from any amount of milk you provide.

INCREASING YOUR MILK SUPPLY

Ensuring a great milk supply begins with immediately pumping after delivery. Beginning to pump within four to six hours after delivery will help encourage your body to make milk. Below are some ways to increase and maintain your milk supply.

Make time for pumping. Try not to skip pumping. In general, supply equals demand, so the more frequently and effectively that you pump, the more milk you will make. Keep a pumping log and ensure that you are pumping at least eight to 12 times in a 24-hour period. Use a hospital grade pump and pump both sides simultaneously, if possible. Use the preemie setting (or push the milk drop button) on the hospital pumps until you are pumping 20 to 30mls for three pumpings in a row. Increase pumping time to 20 to 30 minutes or two minutes past the last drop of milk.

Kangaroo Care is a special way to hold baby - skin to skin. While baby wears only a diaper and cap, the parent wears a front opening top and a blanket is placed over them both. There are benefits to the baby, mother and father. Your baby hears your familiar heartbeat and breathing, staying warm against your warm skin. This helps a baby have a regular heart rate and breathing and better weight gain. Kangaroo care helps parents bond with their baby, and mothers who “kangaroo” show improved milk supply and letdown - especially if they cannot breastfeed yet. Ask a doctor or nurse when you can kangaroo your baby.

You shouldn't feel any pain while pumping. Only use as much suction as necessary. Research has shown that the amount of suction has little to do with effective pumping. Gradually increase pump suction until it is slightly uncomfortable but not painful. By the third day most moms are able to have the suction to the half way mark on the display. If you are concerned about how much milk you are able to pump and/or if pumping is hurting, you might want to try a larger flange size. The kit given to you in the hospital has the standard size 24 and large size 27 flange inside. If you need a larger size, ask your lactation consultant. Also, apply olive oil to your nipples before and after pumping.

Pumping at your baby's bedside can be beneficial for your milk supply. By being close to your infant, you can trigger a greater hormone response that often increases milk production. Performing skin-to-skin care before pumping also often results in a larger amount of milk pumped. When pumping at home, think about your baby and/or have a picture of your baby to look at while pumping. Try using relaxation techniques, breast compression and massage during pumping, and warm compresses for a few minutes before pumping. Feel free to use one of our lactation rooms. They are set up for you to comfortably pump as often as you would like.

Breast Pump Rental is available at the Carolinas Medical Center gift shop, located at the main hospital entrance. The gift shop hours are from 8am -9pm Monday through Friday and 9 a.m. to 8 p.m. Saturday and Sunday. Pumps must be rented for a minimum of one month.

Breast Milk Pumping Log

This log helps you keep up with when you pump and how much milk you produce each time. Add the amounts every 24 hours. Bring your diary when you visit your baby. Do not concentrate on how much you are producing each time; concentrate on how often you are pumping. Pumping 10 times per day is the key to a good milk supply. A copy of the Breast Milk Pumping Log is located at the end of this section.

Day 1 (date:)											24 hour totals	24 hour goals
Time of pumping												every 2-3 hours
Minutes of pumping Left												10-15 mins per side
Minutes of pumping Right												
Amount of milk pumped												drops to 1 1/2 oz
Skin to Skin performed?											Yes or No	
Day 2 (date:)											24 hour totals	24 hour goals
Time of pumping												every 2-3 hours
Minutes of pumping Left												10-15 mins per side
Minutes of pumping Right												
Amount of milk pumped												more than day 1
Skin to Skin performed?											Yes or No	
Day 3 (date:)											24 hour totals	24 hour goals
Time of pumping												every 2-3 hours
Minutes of pumping Left												2 mins past last drop per side
Minutes of pumping Right												
Amount of milk pumped												more than day 2
Skin to Skin performed?											Yes or No	
Day 4 (date:)											24 hour totals	24 hour goals
Time of pumping												every 2-3 hours
Minutes of pumping Left												2 mins past last drop per side
Minutes of pumping Right												
Amount of milk pumped												350mL/day
Skin to Skin performed?											Yes or No	
Day 5 (date:)											24 hour totals	24 hour goals
Time of pumping												every 2-3 hours
Minutes of pumping Left												2 mins past last drop per side
Minutes of pumping Right												
Amount of milk pumped												more than day 4
Skin to Skin performed?											Yes or No	
Day 6 (date:)											24 hour totals	24 hour goals
Time of pumping												every 2-3 hours
Minutes of pumping Left												2 mins past last drop per side
Minutes of pumping Right												
Amount of milk pumped												more than day 4
Skin to Skin performed?											Yes or No	
Day 7 (date:)											24 hour totals	24 hour goals
Time of pumping												every 2-3 hours
Minutes of pumping Left												
Minutes of pumping Right												
Amount of milk pumped												more than day 4
Skin to Skin performed?											Yes or No	

Day 8 (date:)												24 hour totals	24 hour goals
Time of pumping													every 2-3 hours
Minutes of pumping Left													10-15 mins per side
Minutes of pumping Right													
Amount of milk pumped													drops to 1 1/2 oz
Skin to Skin performed?												Yes or No	
Day 9 (date:)												24 hour totals	24 hour goals
Time of pumping													every 2-3 hours
Minutes of pumping Left													10-15 mins per side
Minutes of pumping Right													
Amount of milk pumped													more than day 1
Skin to Skin performed?												Yes or No	
Day 10 (date:)												24 hour totals	24 hour goals
Time of pumping													every 2-3 hours
Minutes of pumping Left													2 mins past last drop per side
Minutes of pumping Right													
Amount of milk pumped													more than day 2
Skin to Skin performed?												Yes or No	
Day 11 (date:)												24 hour totals	24 hour goals
Time of pumping													every 2-3 hours
Minutes of pumping Left													2 mins past last drop per side
Minutes of pumping Right													
Amount of milk pumped													350mL/day
Skin to Skin performed?												Yes or No	
Day 12 (date:)												24 hour totals	24 hour goals
Time of pumping													every 2-3 hours
Minutes of pumping Left													2 mins past last drop per side
Minutes of pumping Right													
Amount of milk pumped													more than day 4
Skin to Skin performed?												Yes or No	
Day 13 (date:)												24 hour totals	24 hour goals
Time of pumping													every 2-3 hours
Minutes of pumping Left													2 mins past last drop per side
Minutes of pumping Right													
Amount of milk pumped													more than day 4
Skin to Skin performed?												Yes or No	
Day 14 (date:)												24 hour totals	24 hour goals
Time of pumping													every 2-3 hours
Minutes of pumping Left													
Minutes of pumping Right													
Amount of milk pumped													more than day 4
Skin to Skin performed?												Yes or No	

GESTATIONAL MILESTONES

GESTATIONAL AGES	FEEDING	BREATHING	MOVEMENT	TOLERANCE FOR INTERACTION
< 26 weeks	Immature GI system. No food into stomach. Nutritional supplement delivered intravenously.	On ventilator. Baby is unable to breathe independently (On "life support").	Jerky. Low muscle tone. Extended extremities.	None. Responds to advances (talk, touch, smell, etc.) with physiologic instability. (Apnea and Bradycardia, etc.) Self-soothing insufficient.
26-28 weeks	Immature GI system. May start to receive small tube feedings (A tube in the nose or mouth that empties into the stomach. Either breast milk or formula) in addition to IV nutrition.	Need for respiratory support may decrease to CPAP or nasal cannula.	Jerky. Low muscle tone. Extended extremities.	Minimal. Responds with physiologic instability. (Apnea and Bradycardia, etc.) Self-soothing insufficient. May begin to initiate kangaroo care.
28-30 weeks	GI system maturing. Baby beginning to practice suck reflex, although still unable to bottle feed. May receive all nutrition via tube.	Need for respiratory support may decrease to CPAP, nasal cannula or room air.	Mostly jerky. Smooth movements may begin to appear.	Minimal. Responds with physiological instability and behavioral cues. May tolerate one type of sensory stimulation at a time. Self-soothing insufficient.
30-33 weeks	GI system maturing. Suck becoming more rhythmic, may practice non-nutritive suck through pacifier. Bottle may be slowly introduced.	Need for respiratory support may decrease to nasal cannula or room air.	Movements more organized, purposeful. May see voluntary flexion of extremities.	Increasing. May respond with physiological instability and behavioral cues. May tolerate more than one type of sensory stimulation at a time (holding and talking). Self-soothing maturing.
33-36 weeks	GI system mature. Inconsistent suck/swallow/ breathe reflex. May be attempting to receive all nutrition by bottle.	Typically breathing room air or attempting to fully wean from nasal cannula.	Movements becoming smoother, more coordinated and purposeful. PT/ OT may be initiated at this time.	Increasing, may seek out social interaction when in a quiet alert state by pursuing eye contact, crying, etc. Still may demonstrate stress cues. Self-soothing maturing, hands to mouth and midline typical.
36-40 weeks (term)	GI system mature. Consistent suck/swallow/breathe reflex. Usually receiving all nutrition by mouth.	Typically breathing room air or receiving "chronic" oxygen through nasal cannula.	Wide variety of movements that is purposeful and coordinated. Head control emerging.	Participate and seek out social interaction. Explore environment, parent face, their own hands, etc. Self-soothing more mature, organized.

Caring for Your Baby Tab goes here



PHYSICAL ENVIRONMENT

Neonatal Webcam System

All our neonatal nurseries offer a secure, private webcam system, installed at each infant's bedside, to provide you with streaming video of your baby when you can't be at the hospital. We recognize that any time spent away from your new baby is difficult, and many of our parents make the trip to the hospital multiple times a day. But, at night, when you have to be at work, or at other times you can't be here in person, we hope our neonatal webcams will give you comfort and peace of mind while your baby gets well.

Our webcams stream live video, with no sound and no recording, from your baby's bedside to any phone or device that connects to the internet. The cameras will be turned on at specific times each day. During hands-on care, the camera is moved away from the bedside to allow staff to be close to your baby. If you log on during one of these times, the camera will be off, but will be turned back on when care is complete. For your security, the webcam system is protected with a username and password. Ask the secretary at the front desk for information and help with the setup process.

Equipment

In the NICU, there is a lot of equipment being used on and around your baby. There are a lot of people and machines that make noise. At times this can be overwhelming for you and your baby. Our staff work hard to make sure your baby is as comfortable as possible.

Your baby's physical environment can be changed to increase comfort by:

- Reducing the amount of sound.
- Reducing the amount of light.
- Providing some support for the baby's position.
- Making treatments less stressful.
- Reducing the number of times the baby is disturbed.

Sound

Why are loud sounds a concern?

- It may damage the baby's ears and lead to loss of hearing.
- It may be stressful for the baby.
- Loud or sharp sounds can cause physiological changes (high heart rate, fast breathing, apnea and a drop in blood oxygen levels). They also may startle the baby and disturb sleep.

How can the level of sound be reduced?

Sound levels can be reduced by talking quietly, closing doors and portholes gently, not dropping things on top of the isolette, turning down machine alarms and phone ring levels and turning off radios.

Are some sounds helpful?

The sound that seems to affect your baby the most is the sound of voice. Providing a tape recording of you talking and reading to your infant may be one way to provide sound to calm your baby. Keep in mind, however, that for the very small preemie or ill infant, extra sound when other things are going on may be disturbing. It is important to watch your baby when you turn on the tape to be sure that he or she responds favorably.

Light

Why is light a concern?

- Bright light may cause injury to the eye.
- Constant light may disturb body rhythm.
- Bright light may keep your baby from opening his or her eyes.

Infants are at risk for developing Retinopathy of Prematurity (ROP) changes in the eye that can lead to loss of vision. Although not yet proven, constant bright light may increase this risk by slowing the normal development of sleep-wake cycles. Infants that have been in nurseries where lighting is dimmed at night advance more quickly in their sleep-wake patterns. This means they develop healthy sleep patterns sooner than babies kept in constant light. Light can affect the level of alertness of your baby. In bright light the baby is less likely to open his or her eyes when awake, therefore missing chances to explore the world and to interact with you and others.

How can the amount of light be reduced for my baby?

Isolettes can be covered to block the amount of light reaching your baby. Laying a blanket over the top of the isolette is the easiest thing to do. With current monitors displaying heart rate, breathing, and oxygen levels, the staff knows how your baby is doing even with the isolette covered. When lights are dimmed, procedures requiring the use of extra light can be done with an additional light at your baby's bedside such as a lamp or ceiling spotlight. The staff also will try to be as quick as possible when the use of bright light is necessary.

Positioning

Why is positioning a concern?

- The small or sick infant cannot get into a comfortable position on his or her own.
- Over time, positioning affects your baby's motor development.

Guidelines for positioning while in the NICU include:

- Place baby on stomach or side when in the NICU and on monitors with arms and legs flexed.
- Cover, clothe, wrap or swaddle the baby to help keep the fixed position; this also gives him or her the feeling of being cuddled.
- Make a "nest" around the baby to hold him or her in a tucked position. Nurses use different ways to do this.
- To keep the baby in a tucked position, nurses often use special developmental aids.
- Leave the baby's hands free so he or she can get them to their face. Sucking fingers or hands and even just touching their own faces is one way babies calm themselves.
- Give the baby something to push against with his or her feet, allowing the baby to feel more stable.
- Encourage the baby to hold on to or grasp something like your finger, the edge of the blanket or a small rolled-up cloth. This helps the baby feel more stable.

Handling

Why is handling ill and premature infants a concern?

- It may lead to physiologic and behavioral stress.

When handled for medical care, ill and premature infants often show signs of stress by a rising heart rate or a dip in heart rate (bradycardia), rising respiration rates or periods of breath holding (apnea), falling levels of blood oxygen (desaturations), color changes to dusky or flushed, and other responses such as hiccups or yawning.





During daily care, such as diapering and feeding, ill and premature infants may react in the same ways. When handled, ill and premature infants also may show stress by more moving, jerks, startles, tremors and/or crying.

What is important to know about the effects of handling?

When a baby's blood oxygen level drops (desaturation) for a prolonged period of time, it could directly affect the brain. Therefore, it is important to prevent desaturation during activities that happen over and over again, such as taking temperature and blood pressure, diapering or feeding, as well as during treatments that are especially stressful or painful.

How can the baby be handled to make it less stressful?

Handling can be less stressful to ill and premature infants by using a developmental approach.

This means:

- Position the baby comfortably and securely and provide special supports to hold the baby in a tucked position during the handling. This includes containing or holding in the baby's arms and legs to keep him or her tucked and to prevent jerky movements.
- Pace the care according to how the baby reacts. For example, stop (give the baby a break) and gently contain the baby when he or she starts to get upset. Don't start again until the baby is calm.
- Give your baby ways to stay calm. This includes a pacifier, something to hold onto, something against which to brace his or her feet, and helping him or her to keep hands up near their face to allow sucking on fingers.
- Keep other stimulation at a minimum. This would include not talking or trying to make eye contact if the baby shows signs of stress, and keeping general noise levels low.
- Provide kangaroo care. This is when you hold your baby directly against your chest.
- Most of all, adjust to the infant's behavior as much as possible, letting him or her "tell you" what feels okay and what doesn't, when to keep going, when to stop and when to start again.

A sense of touch develops very early in fetal life. For very small infants, the skin is so fragile that touching has to be done with great care. For infants younger than about 30 week's gestational age, studies show touch may be more stressful than soothing. For older and sick infants, however, gentle touching can be helpful. Infants react in different ways to different kinds of touch. A light, feathery touch may be upsetting. A firm, steady touch is more likely to calm the baby. Giving the stable baby gentle human touch or massage for a short period every day has been shown to be helpful. It may help babies gain weight faster. As with everything, how and how often the baby is touched needs to be based on his or her responses.

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NICN CONDITIONS

You will get detailed information about your baby's condition from the doctors caring for him or her. These are brief reviews of problems that babies in the NICN may face.

NICN Breathing Problems

Respiratory Distress Syndrome (RDS)

RDS happens mostly in babies born early. RDS happens when there isn't enough of a lung fluid called surfactant. This fluid keeps tiny air sacs in the lungs open. Without enough of this fluid, air sacs collapse and may be hard to re-open. RDS makes it hard to get oxygen into the lungs, which makes it hard for the baby to breathe. Man-made surfactant and extra oxygen are used to help make breathing easier. Sometimes, breathing machines are needed to give the oxygen and help with breathing.

Transient Tachypnea of the Newborn (TTN)

Tachypnea is fast breathing. "Transient" means it comes and goes and doesn't last long. TTN usually happens shortly after birth and usually goes away in 2 to 3 days. Some babies just need to be watched while others may need some oxygen support until their breathing rate returns to normal.

Chronic Lung Disease (CLD)

CLD can happen to babies born early, have underdeveloped lungs, or spent a long time on oxygen or a breathing machine. CLD is sometimes called bronchopulmonary dysplasia. Certain drugs can help treat CLD. It may also get better as babies get older and grow bigger.

Meconium Aspiration Syndrome (MAS)

Meconium is the stool passed by babies in the first few days of life. If this stool is passed while the baby is still inside the mom, the baby can inhale the stool. A tube can be used to suck the stool out of the lungs. Some babies with MAS get very sick. Extra oxygen, a breathing machine and certain drugs can be used to treat MAS.

Persistent Pulmonary Hypertension (PPHN)

PPHN is high blood pressure in the lungs. At birth, blood flow and breathing changes as the baby has to do all the work without the placenta. In PPHN, some of the changes don't happen and it's hard to get oxygen out to the body. Babies with PPHN are very sick and may need special breathing machines and drugs to treat the PPHN.

Congenital Diaphragmatic Hernia (CDH)

The diaphragm is a muscle that separates the lungs and abdominal organs. In CDH, there is a hole in this muscle, and the abdominal organs can move up into the chest and block lung growth. If the hole is small, the baby may not have serious trouble breathing. Some babies may be very sick and need special breathing machines and drugs. When the baby is strong enough, surgery will be done to put the organs back in place and close the hole.

Surgical Diagnoses

Necrotizing Enterocolitis (NEC)

NEC is death of parts of the intestine. A full-term baby can get NEC, but a premature baby has a greater risk of developing it. Premature babies' intestines may not be developed enough to handle feedings. Damage to the intestines from infection and poor blood flow are also thought to be causes of NEC. An x-ray of the belly can confirm the diagnosis. Feedings are stopped to give the belly time to rest, and antibiotics are started. Surgery may be needed.

Gastroschisis

This is a birth defect in which a baby's belly doesn't close completely. This leaves a hole to the side of belly button. This hole allows some of the baby's organs, such as the stomach or intestines, to protrude. Babies with gastroschisis may only need one surgery to repair this defect.

Omphalocele

This is a birth defect in which there is an opening in a baby's belly button. Because of this opening, organs such as the intestines stick out. It is usually covered with a clear membrane. The defect is covered and kept moist until surgery can be done.

Non-Surgical NICN Diagnoses

Apnea of Prematurity

Apnea is when a baby doesn't take at least one breath in 20 seconds or more. Apnea is usually caused by immaturity in the area of the brain that tells the baby to breathe. Babies may need their back rubbed or feet tapped to remind them to start breathing again. A medication called caffeine may be needed if this happens often.

Jaundice

Jaundice occurs when a baby has a high amount of bilirubin in the blood. Bilirubin is the product of blood cell breakdown. The extra bilirubin gives the skin and the whites of the eyes a yellow color. A special blue-colored light is used to treat jaundice.

Sepsis

Sepsis is a serious infection. The infection can start in the lungs, intestines, urinary tract or skin. In newborns, infection can cause a number of symptoms. Preterm babies in the NICU have an increased risk of infection because of their immature immune systems, and they usually have more procedures done. Tests can be done to look for infection, and antibiotics will be started before we even know if there is an infection. Handwashing is a very important part of infection prevention.

Retinopathy of Prematurity (ROP)

ROP is an eye disease in premature babies. Causes include premature birth, low birth weight or the use of oxygen. The mild form of ROP may heal on its own but severe ROP may lead to the retina becoming detached (loose) and possible blindness. All infants at risk for ROP will be examined by an eye doctor and will be followed by the eye doctor after discharge.

Hypothermia Treatment (Cooling)

Hypothermia treatment is used for babies that went without oxygen at birth. It can be started within the first six hours of life. With body cooling, the baby is watched closely and placed on the cooling blanket for 72 hours, and then slowly rewarmed. This treatment has been shown to reduce damage to the brain and other organs of the body.

Interventricular Hemorrhage (IVH)

IVH is bleeding in the brain. It usually occurs in premature babies because the blood vessels in their brains are fragile and can bleed easily. An ultrasound of the head (called a cranial ultrasound or CUS) is done to look for blood in the brain.

Hydrocephalus

Hydrocephalus occurs when the flow of fluid is blocked in the brain. The buildup of fluid can create pressure that can damage the brain. This may cause the head to become large. A surgeon may need to place a tube in the brain (called a ventriculoperitoneal Shunt or VP Shunt) that drains the fluid in the brain into the belly.

Cardiac Defects

Patent Ductus Arteriosis (PDA)

A PDA is a “hole in the heart” between two large arteries. Normally, this hole closes within the first two days after birth. Sometimes, usually in babies born early, this hole does not close like it should. Thus, too much blood enters the lungs, which makes the heart work harder and increases blood pressure in the lungs. A PDA can be treated with medication or surgery, if needed.

Septal Defect

There are two types of septal defects, a ventricular septal defect (VSD) and an atrial septal defect (ASD), which are also sometimes referred to as “a hole in the heart.” In a VSD, there is a hole between the two major ventricles. An ASD is a hole between the upper filling chambers of the heart (the atria). These holes allow oxygen-rich blood and oxygen-poor blood to mix. Surgery may be needed to correct the defect.

More Complex Cardiac Diagnosis

Coarctation

The aorta is the major blood vessel that carries blood away from the heart to the body. With this condition, the aorta is narrowed at some point. The narrowing can affect the body’s blood flow because the left side of the heart has to work harder to get blood through the narrowed aorta. An ultrasound of the heart can diagnose this defect and it can be treated with surgery.

Tetralogy of Fallot (TOF)

TOF includes four birth defects that affect how blood flows through the heart.

- Ventricular septal defect.
- Narrowing of the outflow tract from the right ventricle into the pulmonary artery and/or pulmonary valve narrowing.
- Large and thickened right ventricle.
- Overriding aorta. Surgery is needed to repair this defect.

Transposition of the Great Vessels

Transposition is a rare heart defect where the two main arteries going away from the heart are reversed. This changes the way blood travels through the body, leaving a decrease of oxygen in blood flowing from the heart to the rest of the body. Without enough supply of oxygen-rich blood, the body can’t function right and your child faces serious problems or death without treatment. It is usually detected within the first hours to weeks of life. Surgery is needed to fix this defect.

AV Canal

This defect is made up of a few problems in the heart at birth. This defect happens when there’s a hole between the chambers of the heart and problems with the valves that regulate blood flow in the heart. This defect lets too much blood travel to the lungs, which puts too much work on the heart and causes it to get big. If not treated, it can cause heart failure and high blood pressure in the lungs. Surgery is needed to close the hole and fix the valves.

Hypoplastic Left Heart Syndrome (HLHS)

HLHS is a heart defect where the left side of the heart is not fully developed. The aorta and left ventricle are very small, and the aortic and mitral valves are either too small to allow enough blood flow or are closed. Surgery will be needed soon after birth.

Total Anomalous Pulmonary Venous Return (TAPVR)

TAPVR is a condition where the veins in the lungs do not connect normally to the left side of the heart. There are various forms of this defect, but all of them involve the oxygenated blood from the lungs going back to the right side of the heart rather than the left atrium. This defect requires surgery.

Tricuspid Atresia (TA)

TA is a type of defect where the tricuspid heart valve is missing or under-developed. The defect blocks blood flow from the right atrium to the right ventricle. A medicine is used to get oxygenated blood to the body. Infants with TA usually have a bluish skin color and become short of breath easily. These infants may need a ventilator until surgery can be scheduled.

NEONATAL EQUIPMENT



GIRAFFE INCUBATOR

Your premature baby will likely be admitted into this type of isolette



RADIANT WARMER

Typically used for late pre-term and term admissions



DRÄGER ISOLETTE

Used prior to transitioning to an open crib

RESPIRATORY EQUIPMENT



HIGH-FLOW NASAL CANNULA (HFNC)

How it works: High-flow uses air flow to help your baby remember to breathe.

Why we use it: High-flow can be used for two reasons. The first is to give a little bit of extra oxygen without any pressure support. The second is to help remind your baby to take deep breaths.

What to expect: High-flow looks like a little clear tube on your baby's face. You may be able to hear the "roar" of the flow but is a gentle therapy for the baby.

What about holding my baby? While on this kind of support, you can hold or kangaroo your baby as long as your baby is having a good day. Ask your nurse if it's okay!



BUBBLE CPAP OR "BUBBLE"

How it works: CPAP stands for continuous positive airway pressure and it works to keep the lungs and airway open. This allows the lungs to deflate and inflate as they would normally.

Why we use it: Bubble allows your baby to do all of the work of breathing, but helps babies keep his/her lungs from totally emptying.

What to expect: Bubble may make your baby's chest "wiggle." When you touch your baby, it may feel like a gentle vibration. Bubble may look funny at first, but it's great for the babies! A soft chin strap may be used to prevent air from escaping out of the mouth.

What about holding my baby? While on this kind of support, you can hold or kangaroo your baby as long as your baby is having a good day. Ask your nurse if it's okay!



AMBU BAG

A piece of respiratory equipment. It is used with a face mask and placed over baby's nose and mouth, or attached to ET tube or trach tube; it is then squeezed to give the baby oxygen and inflate the lungs.



CONVENTIONAL VENTILATOR

How it works: An endotracheal tube (ETT) or "breathing tube" is placed in your baby's trachea, and connected to the ventilator. Settings are changed based on your baby's blood gas results, and what your baby needs.

Why we use it: This type of ventilator helps your baby breathe.

What to expect: You will see the baby's chest rise and fall with the respiratory rate set on the ventilator, and he may breathe spontaneously over the ventilator as well.

What about holding my baby? It depends on what kind of day your baby is having. Ask your nurse if it's okay!





HIGH FREQUENCY OSCILLATING VENTILATOR OR "OSCILLATOR"

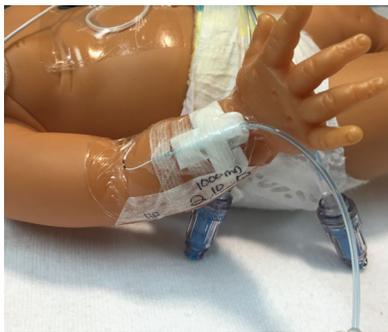
How it works: This method gives lots of very quick, small breaths each minute. This keeps the lungs from ever completely emptying.

Why we use it: The oscillator is used to help your baby breathe.

What to expect: While oscillating, your baby will "wiggle" in the chest. This looks much like how jell-o wiggles when you shake it. On this method, your baby will have a breathing tube. Your baby will not be doing any of the work of breathing on their own.

What about holding my baby? While on this kind of support, you will not be able to hold or kangaroo your baby.

TYPES OF INTRAVENOUS (IV) ACCESS



PERCUTANEOUS CENTRAL VENOUS CATHETER (PCVC)

A tiny catheter or tube placed into a large vein that is used to give fluids or nutrition to your baby for an extended period of time.



UMBILICAL ARTERIAL CATHETER/UMBILICAL VENOUS CATHETER "UAC/UVC"

A catheter that is inserted into an artery or vein in your baby's umbilical cord to provide fluids or nutrition. A UAC can also provide us with constant blood pressure monitoring.



IV TOTAL PARENTERAL NUTRITION (TPN)

IV Nutrition that contains essential nutrients to help your baby grow.



BILIRUBIN LIGHT/ PHOTOTHERAPY

This is a treatment for yellow jaundice or high bilirubin. The baby is placed under a bright light (bili light) or on a special blanket (bili blanket).

PAIN MANAGEMENT

Many parents worry their infant may be in pain. Most infants do not feel pain when we simply touch them. However, there are some things that we may have to do for your infant that can be painful.

The nurses who care for your infant know the signs of pain. For example, an infant in pain may cry, become restless or tighten face muscles. If your infant does show signs of pain, we will use comforting measures. Your nurses may swaddle, hold or rock your infant. They may also try using a soothing voice, soft music, pacifiers or dim lights to comfort your infant. They may ask you to give skin-to-skin contact with your infant. The nurses will teach you how to spot pain signs and how to comfort your infant.

If comforting measures do not lower the pain, medicine will be used. Medicines will also be given to your infant before a painful procedure is done. Your infant's doctor or the nurse practitioner will order the best treatment for your infant.

Please feel free to talk with the nurses, nurse practitioners or doctors about any questions or worries you have about your infant's care and pain treatment.

Almost Home cover tab goes here



START PLANNING TO BRING YOUR BABY HOME

What can you do?

Educational classes on important topics are offered throughout the month and last one hour each. They are free to parents and families with babies in the NICN or NPCN. Sign up for the following classes by asking your bedside nurse, unit secretary or calling the nurse's station in NPCN at 704-381-7100.

Neonatal Baby Care

Have questions about caring for your infant? Sign up for our Neonatal Baby Care class. This class will address your questions about caring for your baby at home.

Safe Sleep

Are you worried about sudden infant death syndrome (SIDS)? Hear the latest recommendations from the American Academy of Pediatrics and the North Carolina Healthy Start Foundation on how babies should sleep to prevent unsafe infant sleep death and decrease the risk of SIDS. This class is for all parents to learn how to create a safe sleeping environment for their baby.

CPR

All parents should know cardiopulmonary resuscitation (CPR) for emergency situations. If your child goes home on oxygen, monitors or both, two caregivers must be trained in CPR before your baby can be discharged.

Road to Home

Road to Home class helps inform parents on what their baby needs to do to go home, how they can get ready for their baby's discharge and what the day of discharge will be like.

How's Your Baby, North Carolina?

Discharging a happy and healthy baby is our top priority, but we need your help! We need to learn from you. We know that each baby is different and the needs of one family are not the same as the needs of another family. We are very lucky to give each family a chance to tell us exactly what they need for discharge. We do this by using a discharge planning tool called How's Your Baby, North Carolina. This online tool is simple and easy to use and each question you answer helps provide us with the special information you need for discharge. When you complete the survey, a sheet prints with your discharge teaching needs. Your nurse will go over these teaching needs with you and give you all the information you need for discharge.

Infant Car Seat Safety

Car Seat Safety class teaches families about car seat laws and guidelines. During the class, you will practice hand-on skills like how to place your infant in the car seat and how to lock the car seat base into your car. Bring in your baby's car seat (including the base) and attend our car seat safety class. (If you haven't gotten one yet, now is the time.) We will test your baby in the car seat prior to discharge to make sure your baby's first ride is a safe one.

CAR SEAT BASICS

- Always use a car seat, starting with your baby's first ride home from the hospital.
- Read the car seat manufacturer's instructions and keep them with the car seat.
- Read your vehicle owner's manual for more information on how to install the car seat correctly in your vehicle.
- Never place a child in a rear-facing car seat in the front seat of a vehicle that has a passenger airbag.
- The safest place for all children to ride is in the back seat.
- The harness system holds your child in the car seat, and the seat belt holds the seat in the car. Adjust both the harness system and the seat belt snugly to protect your child.
- Car seats expire. Check the manufacturer's label or the bottom of the car seat for an expiration date.

Which is the "best" car seat?

- The "best" car seat is one that fits your child's size and weight and can be installed correctly in your car.
- Price does not always make a difference. Higher prices usually means added features that may or may not make the seat easier to use.

Most new cars have air bags. When used with seat belts, air bags work very well to protect adults. However, air bags are very dangerous when used with rear-facing car seats. If your car has a passenger air bag, infants in rear-facing seats must ride in the back seat. Even in a low-speed crash, the air bag can inflate, strike the car seat and cause serious brain injury and death. Toddlers who ride in forward-facing car seats also are at risk from air bag injuries. All children, under 13 years of age, are safest in the back seat.

Has the car seat been recalled?

You can find out by calling the manufacturer or visiting the manufacturer's website. This information is also available online at the National Highway Traffic Safety Administration website. If the seat has been recalled, be sure to follow instructions to fix it.

Infant-only seats

- Can only be used rear-facing.
- For babies who weigh up to 20 pounds (or more, depending on model).
- Small and portable and fit newborns best.
- Have a five-point harness.

Infant-only seat features

- Car Seat Bases: Several infant seat models come with detachable bases. When using this type of seat, the base stays in the vehicle, allowing you to simply click the car seat into the base, instead of reinstalling the car seat before every ride. You can buy additional bases for other cars. Some bases are adjustable to make it easier to correctly recline newborns.
- Higher Weight Limits: Several infant-only seats are available for use up to 35 pounds. This may make it easier to keep your baby rear-facing for as long as possible. When your infant weighs more than the car seat manufacturer's limit, you must move your baby to a convertible seat.
- Harness Slots: Infant-only seats that come with more than one harness slot give more room for growing babies. On rear-facing seats, the harness slots should always be at or below your baby's shoulders. Check the car seat manufacturer's instructions to be sure.
- Handles: Carrying handles on car seats vary greatly in style and ease of use. Check the instructions for how to adjust the handle during travel. Angle indicators, built-in angle adjusters, harness adjusters and head support systems are required.

Convertible seats

- Bigger and heavier than infant-only seats, but can be used longer.
- Convertible seats do not fit newborns as well as infant seats. We do not recommend convertible seats for newborn babies. Make sure that your baby can recline comfortably in the seat.
- Check the car seat manufacturer's instructions to be sure that harnesses can be adjusted properly.
- Should be used rear-facing for infants until they have reached at least two years of age or weigh more than the manufacturer's limit. The American Academy of Pediatrics recommends that babies be kept in rear-facing seats for as long as possible.

Installing and using car seats correctly

Read the car seat manufacturer's instructions and the child restraint section of your vehicle owner's manual carefully to be sure you are installing and using the car seat correctly. When you install the seat in your car, check the following:

Is your child buckled into the car seat correctly?

- Be sure to use the correct harness slots for the child.
- Keep the harnesses snug. Place the plastic harness clip at armpit level to hold shoulder straps in place.
- Make sure the straps lie flat and are not twisted.
- Dress your baby in clothes that allow the straps to go between the legs. Adjust the straps to allow for the thickness of your child's clothes, making sure that the harness remains secure.
- In cold weather, tuck blankets around your baby after adjusting the harness straps snugly.
- To keep your newborn from slouching, pad the sides of the seat and between the crotch with rolled up diapers or receiving blankets.

Is the car seat buckled into your vehicle correctly?

- Place the seat facing the correct direction for the size and age of your child. Route the seat belt through the correct path on the car seat (check your instructions to make sure) and pull it tight. Before each trip, check to make sure the car seat is installed tightly enough by pushing on the car seat where the seat belt passes through. It should not move more than one inch side-to-side or toward the front of the car.
- If your infant's head flops forward, the seat may not be reclined enough. Tilt the seat back until it is reclined according to manufacturer's instructions. Your seat may have a built-in recline adjuster for this purpose.
- Check the seat belt buckle. Make sure it does not lie just at the point where the belt bends around the car seat. If it does, you will not be able to get the belt tight enough. If you cannot get the belt tight, move the car seat to a different seat in the back seat of the car.
- Many lap/shoulder belts allow passengers to move freely even when they are buckled. Read your car owner's manual to see if your seat belts can be locked into position or if you will need to use a locking clip. Locking clips come with all new car seats (some have them built in). Read your instructions for information on how to use the locking clip.
- Some lap belts need a special, heavy-duty locking clip, available from the vehicle manufacturer. Check your owner's manual for more information.

What is LATCH?

If you choose to use the latch system to secure the car seat into the car, you should not also use the seat belt to secure the car seat. Most new car seats that can be used facing forward are required to be equipped with top tethers. A tether is a strap that hooks the top of the car seat to a special permanent anchor in the vehicle. Most anchors are located on the rear window ledge, the back of the vehicle seat, or the floor or ceiling of the vehicle. Tethers give extra protection by keeping the car seat from being thrown forward in a crash. Check with the manufacturer to find out how to get a top tether for your seat. Be sure to install it according to instructions. The tether strap may help make some seats that are difficult to install fit more tightly.

Starting in model year 2002, all new vehicles and new child seats are equipped with these lower anchors and attachments. Unless both the vehicle and the car seat have this new anchor system, seat belts will still be needed to secure the car seats.

If you have questions or need help installing your car safety seat, lists of certified child passenger safety technicians and child seat fitting stations are available on the NHTSA website at www.nhtsa.gov or at www.seatcheck.org. You can also get this information by calling 866-SEATCHECK (866-732-8243) or the NHTSA Vehicle Safety Hotline at 888-327-4236.

Information taken from the 2010 Family Shopping Guide to Car Seats—Safety and Product Information from the American Academy of Pediatrics

Welcome Home tab

FEEDING YOUR BABY

Your baby will receive a specialized recipe card for home use. Please follow the instructions on the card exactly. Consult your pediatrician before changing formulas.

Feeding your baby

Feeding a baby who has been in a neonatal intensive care nursery may be different from feeding a healthy, full-term baby. This infant may behave in one of several ways. He or she may wake up hungry and want to eat every two to three hours. He or she may be sleepy and not wake for feedings in four hours – and fall asleep during the feeding. Your baby may set his or her own schedule, waking 30 minutes to an hour before feeding.

If your baby is not awake when a feeding is due, wake him or her up by changing his or her position, talking or removing the blanket or sleep sack. This will bring your baby to a more alert state and make for a better feeding.

What to feed baby

Babies need breast milk or infant formula with iron for the first year of life. Most formula-fed babies go home on a formula based on cow's milk that has lactose (a form of sugar). A few babies need a non-lactose formula. This formula is often a soybean-based formula. It is used temporarily if your baby has intolerance to the regular infant formula (rare) or following an illness with diarrhea. Soy formula should be used only when suggested by your doctor. If your baby is on any other special formula, we will help you make arrangements for obtaining the formula.

Babies should remain on breast milk or an infant formula through the first year of life. Babies do not need cereal, juice or other baby foods until their pediatrician recommends this. All of their nutritional needs are met in the infant formula or breast milk. No other type of milk is recommended for infants under 12 months old.

Never add more water to make the formula last longer or less water to make the formula stronger. This could be very dangerous to your baby's health.

Exceptions:

- Some infants are placed on feedings thickened with cereal by their doctor because of problems associated with reflux (spitting up when feedings come up from the stomach into the esophagus—the tube connecting the throat to the stomach). Reflux also may cause your baby to feed poorly because the esophagus (throat) becomes irritated.
- Some babies may take the largest amount of formula they should have and still be hungry. Wait until your pediatrician recommends rice cereal before adding it to your baby's feedings.

With refrigeration, an opened can of liquid formula or a prepared bottle can be stored for 24 hours. Wash the top of the can with hot soapy water, rinse and air-dry before opening. If your baby drinks part of a bottle, you can leave it out at room temperature and offer the remainder up to one hour after your baby started eating. Then throw out the remaining formula because bacteria can begin to grow after one hour. DO NOT add formula to a partially finished bottle. Give your baby a fresh bottle each feeding. DO NOT use prepared formula that has been out of the refrigerator longer than the manufacturer recommends.

Special formula

Babies may go home on higher calorie formula (22 to 24 calories per ounce). It may be available to be purchased, like regular baby formula, in a grocery or drug store in your community, or it may be available through the WIC program.

How much to feed

The amount of formula your infant takes will vary. While in the hospital your baby was probably fed very specific amounts of formula and increases were made in small amounts. Start with the amount your baby was fed in the hospital (or a little more) when you fill your bottles at home.

Your baby is ready to feed on demand. This means he or she can have as much as he or she wants as often as he or she wants (unless your baby's doctor tells you otherwise). Babies tend to eat what they want and need, then stop sucking. They fall asleep, thrust the nipple from their mouth and stop sucking when finished. Sometimes your baby will eat more than other times. Do not be concerned about small variations in amounts. Most babies feed for about 20 minutes. Feedings should not last longer than 30 minutes. Many infants go home on a three- to four-hour feeding schedule and change back to a two- to three-hour schedule during a rapid period of catch-up growth. If your baby is taking more than 32-ounces of formula in a 24-hour period, ask your pediatrician if supplements like cereal should be started.

Sleeping through feedings

It often takes several months after going home before your baby sleeps through the night. After several months if he or she sleeps through the night, enjoy your rest and do not wake him or her unless your baby's doctor tells you to wake your infant to feed during the night. During the daytime you should not let him or her go longer than four to five hours without feeding. Your baby's discharge instructions will include specific information about how often your baby should eat when he or she is at home.

When to feed baby

We favor a demand feeding schedule of frequent, small feedings. Feed baby when he or she is hungry (he or she will cry, open his or her mouth and turn his or her head toward you, wiggle, lay quietly awake and then become vigorously active or fussy or suck on his or her hand when he or she is hungry). Babies do not usually go more than five hours between feedings and some eat as often as every two hours. Most babies eat six to eight times a day for several months after going home.

Feed your baby the amount he or she wants. They stop sucking when they have had enough. If your baby cries and changing diapers and holding your baby does not calm him or her, feeding may.

Offering the baby water

Follow the advice of your baby's doctor about offering water to your baby.

Increasing the feedings

As your baby grows and gains weight, he or she will need more breast milk or formula. When he or she takes an entire bottle regularly and sometimes cries for more or continues to suck strongly, it may be time to increase his or her feeding. Place an extra half-ounce of breast milk or formula in the bottles if you are concerned. If your baby begins to spit, he or she may be overfed. Decrease the amount of the feeding.

Warming the feeding

If the breast milk or formula needs to be warmed, put the bottle in a cup of warm water for 10 to 15 minutes. You may use a bottle warmer per the manufacturer's instructions. Do not use a microwave to warm breast milk or formula. This can create hot spots in the breast milk or formula and breaks down the nutrients.

Using tap water

Always mix formula as directed by the label on the container. If you make one bottle at a time, you can use warm tap water from the faucet. City water supplies are safe. If you have a question about your water, call the health department.

If you have well water, bring it to a very bubbly boil, keep it boiling for one to two minutes, and then let it cool or use bottled water. If your water comes from a well, it needs to be tested by the health department for bacteria and contaminants. Do not use it for drinking unless it is safe.

Sterilizing bottles and nipples

Sterilization of bottles and nipples is not routinely recommended if you:

- Have reliable city water.
- Wash the bottles and nipples in hot soapy water, rinse in hot water and air dry.
- Prepare one bottle at a time.
- Refrigerate opened formula no longer than recommended by the manufacturer.
- Clean bottles in the dishwasher.

Holding baby for feeding

Hold your baby using one of your hands to support your baby's head, neck and upper back. Never prop the bottle, and do not leave baby alone to drink it. Your baby could choke. Always hold your baby during feedings.

Pacifiers

Babies have a strong need and desire to suck. Some babies are satisfied by the amount of sucking done at feeding time, while others require more. Most infants enjoy sucking on pacifiers. Pacifiers may be used to help calm your baby as well as for your baby's own pleasure. Pacifiers should never be tied around your baby's neck because it could choke him or her. Pacifiers should not be dipped in honey. Cases of infant botulism, a serious type of poisoning, have happened in babies because of honey infected with the "bug." Only use a commercial pacifier – do not use a homemade pacifier. Homemade pacifiers are dangerous. Never make a pacifier from a nipple and plastic collar or ring. Some babies can separate the nipple from the collar and choke on it. A pacifier should fit your baby's mouth. If it is too long it might gag your baby. It should be flat enough to fit the palate and mouth comfortably. Small pacifiers are available in stores. Using a pacifier is not bad. Babies enjoy the sucking activity and outgrow the need for it later.

Solids

For the first 12 months of life the best diet is breast milk or infant formula. Solid foods do not help your baby sleep through the night. Your infant's pediatrician will talk with you about when and how to start feeding solid foods to your baby.

Weight gain and growth

Generally, babies gain approximately a half to one ounce of weight daily. There may be some days when your baby does not gain weight at all, but will gain more the next day. Normal size for age is usually reached at about 10 months after the time your baby should have been born.

Feeding problems

Spitting

Premature infants tend to spit more than full-term newborns. The "valve" or opening between the esophagus (tube that connects the mouth and the stomach) and the stomach is not tight, so he or she tends to spit up small amounts with feeding and burping. If spitting becomes a serious problem, your baby may be tested for gastro-esophageal reflux (called G-E reflux or reflux).

Reflux (gastro-esophageal reflux or G-E reflux)

Reflux means formula comes up from the stomach into a part of the esophagus (tube that connects the mouth and stomach). Reflux may cause vomiting, apnea (short periods when your baby does not breathe) or result in failure of your baby to gain weight. Follow your infant's doctor's instructions very carefully. Reflux usually slowly improves and finally disappears at three to four months corrected age in some babies and not until nine to 12 months in others.

Colic

Colic is unexplained bouts of crying, often with stomach fullness or stomach spasms. It does not mean that your child is ill. Your baby may stiffen his or her legs, scream loudly, and pass gas or vomit. Colic frequently occurs at the same time of the day, typically during the evening hours. It generally lasts for up to three months corrected age. Constant crying is one of the most trying of the symptoms of colic. Colic is not caused by incorrect feeding methods and changing your baby's formula usually has no effect. Often no cause can be found. Some experts feel this crying is a way for baby to "let off steam" after a lot of stimulation throughout the day.

Suggestions that may help your baby include frequent burping, walking or rocking the baby, wrapping the baby warmly and snugly while you hold the baby, in a quiet place (dim lights and low noise).

There are no drugs that cure colic. Drugs often prescribed for colic are supposed to relieve spasms of the intestinal muscles and/or are sedatives. Often they do not work. We do not recommend using drugs with babies unless there is evidence they are safe and effective.

Call your doctor if:

- Your baby's appetite suddenly decreases for several feedings and he or she seems uninterested in the breast or bottle.
- Your baby begins to vomit (vomiting may be forceful or green).

Vitamins

Your baby's doctor may order extra vitamins. Please refer to your discharge instructions for the proper dose of multivitamins to give your baby. Mix vitamins in 15 milliliters (one-half ounce) of formula or breast milk so they do not taste so strong and give this bottle at the start of the feeding.

Iron

Babies grow very fast during their first year and need iron to grow. All babies need iron for proper brain growth and development. Without enough iron, babies may develop iron deficiency anemia (low blood count). Infants who are bottle-fed are usually discharged from the hospital on formula with iron (iron fortified). Iron in the formula is not the cause of colic, constipation or spitting up. Some babies will be sent home on additional iron drops.

Reminders

- Infant formula or breast milk has everything your baby needs to grow and be healthy until four to six months of age.
- Your baby will receive a specific recipe for home use. In addition, you will be given a feeding schedule at discharge.
- Talk to your pediatrician before starting cereal.

CORD CARE

Follow the guidelines below to ensure proper healing:

- Usually, the premature baby's cord has dried and fallen off by the time he or she goes home.
- Try to keep the diaper below the belly button until the cord has fallen off and completely healed. This lets air get to the cord and dry it.
- Call the doctor if the belly button becomes red, bleeds or smells bad.
- Sponge bathe rather than tub bathe the baby until the cord has fallen off and the belly button has completely healed.

USING A BULB SYRINGE

When to use the bulb syringe

A bulb syringe is used to clean your baby's nose and mouth of formula or mucus. You may use it when your baby spits up, has a stuffy nose or sneezes (this is how he or she clears his or her nose). We suggest you keep a bulb syringe close to your baby especially during feedings and when traveling. It is important to clear the mouth first and then the nose so if your baby spits up he or she will not choke. Babies breathe mainly through their nose during the first few months of life so it is also important to keep it clean.

- To use, first squeeze the bulb until it is collapsed. Then, place it in your baby's mouth and quickly release the bulb. This will bring the formula or mucus into the bulb.
- Once the mouth is clear, then clear your baby's nose. Squeeze the bulb until it is collapsed and place it in one nostril and quickly release the bulb.
- Remove the bulb syringe from the nose and squeeze the bulb quickly into a tissue to get rid of this material. Repeat for the other nostril.
- Only use the bulb syringe as needed.

Cleaning the bulb syringe

Clean the bulb syringe daily with warm, soapy water and rinse in hot water. Be sure to clean the inside of the bulb by squeezing it while the tip is in the soapy water. Rinse by repeating the procedure with clean, hot water. Allow to dry completely before using. A dirty bulb syringe can be a cause of infection.

TAKING A TEMPERATURE

If your baby appears sick, take his or her temperature. Fever is a sign of illness. However, sometimes a small baby's temperature will drop rather than rise when they are sick. We recommend using the axillary (armpit) temperature on babies less than six months of age.

Thermometers

A digital thermometer is recommended for taking your baby's temperature. You can purchase one at your local drug store. Please follow the manufacturer's recommendations. Take the temperature when your baby is quiet. Body temperature varies depending on the amount of activity, emotional stress, type of clothing worn, and temperature of the environment. When reporting fever, always tell the doctor the exact thermometer reading and where the temperature was taken: "99.7°F under the arm."

Definition of a fever

Generally, a fever is a temperature over 100°F. Ask your doctor when he or she would like to be notified if your child has a fever.

Taking an axillary temperature (under arm)

- When using a digital thermometer, press power button and wait until display appears. This indicates the unit is operational and in good condition.
- Hold the thermometer snugly in the armpit, making sure the bulb is completely covered, between your baby's arm and side.
- Hold the thermometer there until the thermometer beeps (about 10 to 20 seconds).
- Remove from under the arm and read the digital window.
- When reporting your baby's temperature, tell the nurse or doctor that it was an axillary temperature. Axillary temperatures are slightly lower than rectal or oral temperatures.

Care of thermometer

- Clean thermometer with soapy cotton ball or tissue after each use.
- Rinse in cool water.
- Store in safe place, out of the reach of children.

Call the doctor if

- Baby has fever over 100°F, and/or vague symptoms including:
 - Irritability (crying or fussy)
 - Poor feeding
 - Floppy or listless
 - Breathing is difficult
 - Coughing
 - Does not look good
- Temperature is less than 97.4°F.
- If your baby feels hot to touch, and you are unable to read a thermometer.
- Fever is present for more than three days.
- Fever with abnormal movements.

Remember: a normal temperature is approximately 98.6°F.

Treating fever

- If your baby is less than six months of age and has a fever, call your baby's doctor before giving any medication.
- Get the correct dosage from your baby's doctor.
- Do not use medicine for more than three days without talking with the doctor.
- Keep all medicine out of the reach of children.
- Children should not be given aspirin. Several studies link aspirin use in children with Reye's Syndrome - a severe illness that often is fatal.

BATHING YOUR BABY

When to bathe your baby

You do not need to bathe your baby every day as long as the diaper area and skin folds are kept clean. Although bathing is often used as a comfort measure, some babies cry or act startled when placed in the water for their bath. Premature infants who startle easily and have tremors seem to fuss more when their clothes are removed and they are placed in the water. This will improve as your baby matures and becomes older.

Bathe your baby anytime that is convenient for you. Before feedings is usually a good time since most babies fall asleep shortly after eating. If your baby has trouble feeding, it may be better to wait and bathe him or her between feedings.

Bath supplies

- Washcloth
- Towel for drying
- Large towel to place baby on
- Mild soap and shampoo
- Clothes
- Diaper
- Basin or tub

How to bathe your baby

There are two ways to bathe your baby: sponge bath or tub bath. Gather all the items you need for the bath and place them so you can reach them. Make sure the room you are bathing your baby in is warm - at least 68 to 75°F. Turn up the heat in this room if possible. Do not leave baby unattended at any time.

Sponge bathing

- You may give a sponge bath on a bed, a counter or on a table. If using a hard surface, place something waterproof and padded under the infant.
- Wash the baby's face with a washcloth without soap, then his or her scalp. The scalp needs to be shampooed only once or twice a week. Rinse the scalp with a damp washcloth several times. Take care not to get soapy water in your baby's eyes.
- Lightly soap the rest of your baby when and where needed with the washcloth or your hand. You may want to wash, rinse and dry small areas at a time. This helps keep your baby warm.
- Wipe the soap off by gently going over the body several times with the rinsed washcloth, paying attention to creases.

Tub bathing

- Before starting the bath, gather everything you will need. A bath can be given in a washbowl, dishpan, kitchen sink or baby tub.
- The water should be comfortably warm, not too hot or cold. First test the water with your elbow or wrist.
- Use a couple of inches of water in the tub until you get used to handling your baby. A tub is less slippery if you line it with a towel.
- Hold your baby so his or her head is supported on your wrist with the fingers of the same hand holding him or her in the armpit.
- Wash the baby's face with a washcloth without soap, then his or her scalp. The scalp needs to be shampooed only once or twice a week. Rinse the scalp with a damp washcloth several times. Take care not to get soapy water in your baby's eyes.
- Soap the rest of your baby's body, arms and legs using the washcloth or your hand. If the skin becomes dry, don't use the soap except once or twice a week.
- Wash only the outer ear and the entrance to the ear, not inside. Wax is formed in the ear to protect and clean it.
- Do not clean nostrils or ear canals with cotton-tipped swabs.
- Use a towel to pat dry.

Never take your hands off of your baby during the bath. Never leave the baby unattended.

Lotions and powders

Babies do not need additional lotion, oil, cream or powders on their skin. Often these products result in rashes. Oil should not be placed on the hair because it frequently leads to seborrhea – a condition like dandruff. Powders should be avoided as well because they can get into your baby's breathing passages. Skin and urinary tract infections have been linked to use of powder.

CARE OF YOUR NEWBORN'S PENIS

Circumcision

Circumcision is the removal of the foreskin from the tip of the penis so the head of the penis is exposed. Complications of circumcision include excessive bleeding, infection, pain and surgical injury to the penis. During this procedure, local anesthesia is given to prevent pain. Parents should discuss their options and reasons for having a circumcision performed on their baby.

Circumcision care

- Little special care of the circumcised penis is necessary. You may use petroleum jelly on the tip of the penis with each diaper change for the first few days after the circumcision. This may prevent the circumcision site from sticking to the diaper. After the circumcision is healed you can bathe your baby in a tub without fear of harming the circumcision or penis.
- There should be no bleeding. The head of the penis may show signs of irritation and appear whitish or yellowish in places as it heals.
- If used, the plastibell will fall off in three to five days. The rim of skin in front of the string will turn black and come off with the bell. Do not pull the plastibell even if it is barely on - the plastibell will come off by itself. You will probably find it loose in your baby's diaper. Do not use petroleum jelly with the plastibell.
- Call the doctor if the penis becomes excessively red or swollen, has unusual drainage that is green or smelly or if your baby does not pass urine for longer than eight hours.

Care of the uncircumcised baby

Care of the uncircumcised boy is quite easy. Washing and rinsing your baby's genitals (private parts) daily is all that is needed. Do not pull back the foreskin (skin covering the tip of the penis) in an infant. Forcing the foreskin back may harm the penis, causing pain, bleeding and possibly scar tissue.

DIRTY DIAPERS

Voiding (making urine)

Babies wet their diapers almost hourly. However, most of the time they are changed around feeding times, when they wake in the morning and when you put them down at night. Your baby's diaper should be very wet six to eight times in 24 hours. If the urine is dark and your baby has not wet his or her diapers six to eight times a day, your baby may not be getting enough formula or breast milk. Notify the doctor. Babies become dehydrated (lose water and fluid) quickly. Babies who are sick do not eat well or wet their diapers as often.

Stools or bowel movements

Babies' bowel movements (BM) are usually either yellow or dark brown in color by the time they go home. Frequency and color are related to individual differences and type of milk. Some babies have a BM with every feeding, and some have a BM every day or two. Do not worry about the time between BMs unless the stool is like small hard pebbles and/or the time since the last BM has been three to four days. It is normal for babies to grunt, strain and turn red when having a BM. This does not mean they are constipated.

Constipation

If your baby's stools are like little pebbles, he or she is constipated. Call the doctor if your baby is having frequent problems with his BMs and check with your baby's doctor before using any medications or suppositories. If the problem continues for several days or your baby cries for a long period when having a BM, call your doctor. If your baby has infrequent BMs but is eating well and does not seem uncomfortable, do not worry.

Diarrhea

Diarrhea is a large increase in the number of BMs your baby usually has, or stools that become looser in consistency. Normal BMs are soft with some form or are mushy/pasty. Diarrhea is watery stools or stools with a water ring around them. Diarrhea can be a symptom of illness or food intolerance. Babies dehydrate (lose fluid and water) easily and quickly with diarrhea. If your baby has frequent watery stools in a short time (six to eight hours), call your baby's doctor.

Signs of dehydration

- Dry mouth or thick saliva.
- Small amounts of dark urine in diaper.
- Soft spot (fontanel) on head sinks in when baby is held upright or in sitting position.
- Skin forms a "tent" when pinched and stays pinched up.
- Baby may be fussy, sleepy, not hungry or difficult to wake up.

Call your baby's doctor if he or she has any of these signs.

OUTINGS

When to take your baby out

Your baby can be treated mostly like a regular newborn. The following guidelines may be helpful in knowing where you may take your baby, especially during the first few months:

- Avoid outings when the weather is rainy, windy or exceptionally cold or hot. Try to keep your baby away from adults and children with colds or other illnesses.
- Dress your baby according to the weather. As a guideline, dress your baby with about the same type of clothing that you are wearing. Be careful not to overdress your baby. On days with the temperature above 80°F a blanket is usually not necessary. Avoid direct sunlight.

Places to take the baby

- You can take your baby "out," but limit your trips to around your house/block, the porch, homes of close friends and relatives, and doctors' visits.
- Avoid places with large crowds (grocery stores, church, shopping malls, etc.) during the first months. It is difficult to control well-meaning people who want to look and touch your "cute little baby."

YOUR HOME

Visitors

Many friends and relatives want to visit you when your baby is finally home. They will want to hold and shower him or her with love and affection. These friends and relatives are well-meaning but may bombard you and your baby with too much help. Ask friends and relatives with any illness in their family not to visit and ask them to look but not to touch, wake or handle your sleeping baby.

Handling the baby

- Clean your hands before touching baby.
- Only parents and immediate family (or very close friends) should handle your baby the first few weeks at home.
- Handling by a lot of people tends to affect your baby's feeding and sleeping schedule – especially after everyone has gone home. Babies may also become fussy after being handled excessively or passed between different people. They are very aware of the changes.
- You may use the statement "Dr. ___ said only a few people should handle the baby the first month."

Smoking

For your infant's health, there should be no smoking in the house, in the car or around the baby. If you or a family member smokes, this may be a good time to try to quit or cut down. Smoking cessation programs are available through the hospital or health department (check with your baby's nurse or see the smoking cessation section).

Temperature of your home

Your baby has been able to stay warm without help from an incubator or special beds for some time. Babies do not sweat or shiver to help maintain their normal temperature. Below are some guidelines that may help.

- Keep the house temperature between 68 to 75 degrees.
- Keep baby out of drafts, away from windows, fans and air conditioners.
- Look and touch baby to tell if he or she is hot or cold.
- Signs of temperature problems may be cool hands and feet.
- Do not leave your baby unprotected in the direct sun. Keep your baby covered and check with your doctor before using sun block lotion on your baby's skin when outside.
- On particularly warm days your baby may need extra breast milk or formula.

Dressing the baby

- Dress your baby the way you feel comfortable.
- Clothes that fit close to the skin are more warming than loose clothing.
- Do not overdress your baby.
- You may put a cap on your baby's head when the air is cool (babies lose heat from their heads). Do not put a hat on your baby when he or she is sleeping in the bassinette or crib.

ILLNESS

Signs of illness

All babies get ill. You should become aware of any signs that may alert you that your baby is sick. Some signs that may indicate illness include:

- Your baby not feeding as well as normal. Your baby may not seem hungry and may not take as much of the feeding as normal.
- Your baby vomits all or most of the feedings.
- Your baby has frequent, watery stools that are green or bloody, or have mucus in them.
- Your baby does not pass as much urine as usual and there are fewer wet diapers. He or she should have at least six to eight wet diapers in a 24-hour period.
- Your baby cries more than usual and he or she cannot be calmed and comforted easily by your usual means. Your baby may refuse to sleep.
- Your baby does not seem as active as usual. He or she may sleep more or may be difficult to wake.
- Your baby has trouble breathing (breathes faster and harder and may draw in chest muscles with each breath or may have noisy breathing).
- Your baby has a fever. Contact the doctor if your baby's temperature is over 100°F axillary (under arm).
- Your baby's color appears pale, bluish or marbled-looking.
- Unusual rash or skin irritation.

Call the doctor if your baby appears sick or starts to act differently. It is best to have your baby checked or to receive the advice of the doctor.

FUSSY BABIES

What can I do if my baby has increased fussiness, increased activity or difficulty falling asleep?

Try one or more of the following:

- Turn down the lights.
- Reduce the noise around the baby (radios, TV, loud talking).
- Hold infant close.
- Rock infant slowly (most babies like to be held straight up and down).
- Give baby a pacifier.
- Provide background noise (fan that isn't blowing directly on baby or sound machine playing white noise).
- Provide firm, calm touch to the mid-chest, back or feet of the baby.
- Give infant a warm, soothing bath.
- Touch trembling body part firmly and calmly – this will help the trembling stop.
- Watch for signs of baby tiring and decrease stimulation.
- Avoid bouncing or jiggling your infant before bedtime.
- Speak in a soft voice.
- Play soft, soothing music or hum.
- Rock baby gently and slowly.
- Swaddle baby in a soft blanket when holding your baby.
- Avoid waking up sleeping infant unless for feeding.
- Give your baby a warm bath prior to bedtime.
- Take your baby for a stroller ride.

How can I play with my baby?

Your baby is more likely to respond to you when he or she is awake with eyes open, not actively moving and quietly alert. While adults can talk, listen, see and move all at the same time, your baby may not be able to handle too many things at the same time. Your baby will be more likely to watch your face or listen to you when you hold him or her upright (12-18" from your face). This will encourage head control and balance between muscle groups.

It is important for your baby to spend time on his or her tummy developing muscle strength and coordination. Always stay with your baby when he or she is on his or her tummy.

Acknowledgments: Operation PAR. St. Petersburg Florida, Dan Griffith, PhD. Developmental Psychologist, NAPARE, Chicago Illinois, Therapy Skill Builders POSITION STICKERS, Tim Healy, MS. RT. Infant and Child, Developmental Specialist, Santa Anna California, Texas Children's Hospital Helen Harrison, The Premature Baby Book

CHOKING

Preventing choking

Choking can be prevented most of the time. Follow these guidelines to prevent choking:

- Do not prop the baby's bottle.
- Do not give children under four years of age peanuts, popcorn, grapes, hard candy, gum or foods on which they may choke.
- Baby's toys should not have small parts that can break off.
- Baby should not be able to get to small objects like marbles, jacks, etc.
- Jewelry should not be placed on babies or children under three years of age.

How the choking baby acts

- The baby may make gasping movements, but not make any sounds.
- The baby may turn blue.
- The baby may cough and gag.
- The baby may recover from choking, but continue to wheeze or cough.

What to do if baby chokes

- Look inside the baby's mouth to see if there is an object.
- If you can see the object, remove it. Do not try to find it with your finger if you cannot see the object. This may push it in farther.
- If the baby cannot breathe, cough or is turning blue, call 911.

Please see your nurse to sign up for an Infant CPR class to learn what to do if your baby chokes.

SAFETY

Cribs

Your crib and other baby furniture should meet the standards of the Consumer Product Safety Commission. Cribs should have:

- Slats not more than two inches apart.
- No crossbars on the sides.
- Sides, when at their lowest point, are not more than four inches above the mattress.
- No cutouts in the head or footboards where the baby could trap his or her head.
- Rail height at least 22 inches from top of railing to mattress at its lowest level.
- A firm mattress the same size as the crib so there are no gaps to catch arms or legs.
- Cribs with sides that go up and down are no longer recommended.
- Wood surfaces free of splinters and cracks, and have lead-free paint.

Jewelry

Each year, many infants and toddlers die due to suffocation from breathing small objects into their breathing passages and lungs. Infants and toddlers should not wear jewelry of any kind. Necklaces, baby rings, bracelets, religious pins and pacifiers on strings are dangerous to the child's safety. Pierced ears are not recommended for children until they are at least four years of age. Earrings can cause:

- Infections.
- Pressure sores on the head and ears because the baby is unable to turn and lift his or her head.
- Scar formation on the ears from the earring backs.
- Suffocation due to the baby breathing parts of the earrings into his or her lungs.

Kitchen

- Do not pour hot liquids when holding a baby or when a baby is close to you.
- Do not hold a baby when working at the stove.
- Use the back burners on the stove.
- Pot and pan handles should be turned toward the back of the stove.
- Cover the controls if they are on the front of the stove.
- Do not use tablecloths. Infants and toddlers can pull at them.
- Have a fire extinguisher in the kitchen.

General safety

- Keep toilet seats and tops of aquariums closed securely.
- Keep infants away from buckets of water.
- Do not ever leave a baby in the direct sun.
- Do not leave the baby in a parked car.
- Wash flame-retardant clothing according to the labels directions.
- Use safety straps on infant seats, high chairs, strollers and infant carriers every time.
- Use safety gates on all stairs.
- Cover all unused electrical outlets.
- Do not let a baby chew on electrical cords. Check regularly and repair any cord that is broken.
- Keep all medicine and cleaning supplies out of baby's reach, locked up and in its original container.
- Do not leave children under the age of six in a room alone with the baby.
- Be careful when walking with a baby in your arms. Avoid rugs and mats on slippery floors.
- Use safety catches on cabinet doors when the baby begins to crawl.
- Do not use plastic bags on the baby's mattress or pillow. Do not store baby's toys in plastic bags and store plastic bags away from the baby.
- Install smoke detectors on every level of your home. Test batteries monthly; replace yearly.
- In case of fire or emergency, plan an escape route and decide on a place to meet.
- Post Poison Control telephone number (1-800-222-1222) near the telephone.

Toys

Toy size should be at least 1 1/4 inches by 2 1/2 inches and should not have buttons, beads or objects on them that can be pulled off and swallowed. Do not let your baby play with anything that is small enough to fit inside a roll of toilet paper.

INFANT ABDUCTION PREVENTION

In the hospital

- Be aware of hospital security measures.
- Wear your bracelet until your infant is discharged. If unable to wear your bracelet, keep it with you at all times.
- Infants are transported in isolettes or bassinets.
- All hospital employees have name badges and should be wearing them.
- Never leave an infant unattended, even for a few minutes or to use the bathroom.
- Never give your infant to anyone without proper identification.
- Know the hospital's visitation and telephone policies for obtaining information about your infant.
- Know the hospital staff and ask questions if something does not feel right.
- Report any unusual behavior, like someone asking questions about the infant or hanging around the nursery for no apparent reason, to hospital employees.

At Home

- Never leave your infant unattended.
- Never leave your infant or child in a car alone for any reason.
- Know who is caring for your child:
 - Get background information.
 - Require references.
 - Interview candidates/childcare settings. Do not leave your infant alone with the childcare provider during the interview.
- Be careful about public birth announcements (newspapers, yard art, Internet, etc.) for giving too much personal information.
- Keep your eyes on your infant when in public.
- Only allow people who you know very well into your home.
- Never let a stranger hold your baby.

SAFE SLEEP

While in the neonatal nurseries, your baby will be positioned so that it benefits his or her development. During your baby's stay in the hospital, your nurse will be transitioning your baby to a back-lying position. At discharge the goal is to have your baby comfortable sleeping on his or her back.

To prevent infant deaths due to soft bedding, the US Consumer Product Safety Commission, the American Academy of Pediatrics, and the National Institute of Child Health and Human Development are revising their recommendations on safe bedding practices when putting infants down to sleep. Here are the revised recommendations to follow for infants under 12 months:

- Place baby on his or her back on a firm tight-fitting mattress in a crib that meets current safety standards.
- Remove pillows, quilts, comforters, sheepskins, pillow-like stuffed toys and other soft products from the crib.
- Consider using a sleeper or other sleep clothing as an alternative to blankets, with no other covering.
- If using a blanket, put baby with feet at the foot of the crib. Tuck a thin blanket around the crib mattress, reaching only as far as the baby's chest.
- Make sure your baby's head and arms remain uncovered during sleep.
- Do not place baby on a waterbed, sofa, soft mattress, pillow or other soft surface to sleep.
- Your baby should sleep by himself in a bassinette, crib or pack and play at all times. Do not use sleep positioner devices.

Placing babies to sleep on their backs instead of their stomachs and removing all other items (as listed above) from the crib has been associated with a dramatic decrease in deaths from Sudden Infant Death Syndrome (SIDS).

Acknowledgments:

U.S. Consumer Product Safety Commission

www.cpsc.gov

1-800-638-2772

American Academy of Pediatrics

<http://www.aap.org/>

National Institute of Child Health and

Human Development

"Back to Sleep" Campaign

1-800-505-CRIB

Home Safety Checklist

Using this checklist, go through your home and make it a safe place for your baby to live.

BABY'S ROOM

- Are the slats on the crib less than two inches apart? Yes No
- Is the crib far enough away from a window, curtains or blinds? Yes No
- Are screens secured on the windows and are curtain pull cords out of baby's reach? Yes No
- Do you keep small objects, such as safety pins, buttons or scissors out of baby's reach? Yes No
- Do you avoid hanging toys across the crib or on the crib post? Yes No
- Do you buy only children's flame-resistant sleepwear? Yes No

GENERAL SAFETY

- Are the exits from your house unobstructed (not blocked)? Yes No
- Are all space heaters, kerosene stoves or wood-burning stoves in good working condition and out of baby's reach? Yes No
- Are all plants kept out of baby's reach? Yes No
- Are all unused electrical outlets covered? Yes No
- Are all electrical cords in good condition and beyond baby's reach? Yes No
- Do you have a working smoke detector in a hallway outside sleeping areas and test the batteries once a month? Yes No
- Do you have Poison Control Center's phone number (1-800-222-1222) by your phone? Yes No
- Are matches, cigarettes and lighters kept out of baby's reach? Yes No
- Do safety gates at the top and bottom protect all stairways? Yes No
- Are all medicines and vitamins properly capped with "child-proof" caps and locked or kept out of baby's reach? Yes No
- Are all perfumes, shaving cream and/or cosmetics stored out of reach? Yes No
- Is your home's hot water heater temperature adjusted to 120°F or below? Yes No

KITCHEN

- Are hot foods and/or hot liquids kept out of baby's reach? Yes No
- Are cleaning supplies/household products kept in original containers? Yes No
- Are cleaning supplies kept out of baby's reach or locked? Yes No
- Are foods stored separately from cleaning supplies? Yes No
- Are all knives and sharp objects locked up or kept out of reach? Yes No
- Are electric appliance cords kept out of reach? Yes No

Staying Connected cover tab goes here

STAYING CONNECTED

The neonatal staff enjoys learning about your child's progress after you leave the hospital. Families may stop by the unit for a visit or send cards and pictures to share with your doctors and nurses. Our address is:

Levine Children's Hospital
Neonatal Intensive Care Unit or Neonatal Progressive Care Unit
1000 Blythe Blvd.
Charlotte, NC 28203

Annual Neonatal Spring Fling

The Spring Fling is an annual event for the families of our neonatal graduates. It is a wonderful time to meet other families, visit with the doctors and nurses and learn about community resources, all while enjoying snacks and games. Invitations are sent to our families detailing the date, time and location.

Family Advisory Council

The Family Advisory Council (FAC) is a group of parents or guardians whose child has been a patient at Levine Children's Hospital or in one of its outpatient clinics. Council members meet monthly and also participate at a variety of speaking engagements, special events and other community-based committees.

The FAC:

- Supports and strengthens communication and teamwork among patients, family members and hospital staff.
- Provides input and feedback regarding the delivery of services for children and their families.
- Works with hospital leadership to improve the quality of care provided to children and their families.
- Serves as a resource as requested by hospital administration on developing services, programs and new facilities.
- Brings the needs of the community to the attention of hospital staff and administration.

Contact the family-centered care coordinator at 704-381-7251 to learn more.

Family Advisors

Family Advisors participate with Levine Children's Hospital staff on hospital-based committees that focus on a particular subject or area of care. Membership on the FAC is not required to serve as a committee member. Most committees meet on a monthly basis.

Carolinas HealthCare Foundation

The Carolinas HealthCare Foundation and the Children's Miracle Network raise funds to support many programs and services at Levine Children's Hospital. This money comes from a variety of sources including private grants, individual gifts and community fundraising events. The Foundation has made it possible for our community to have excellent healthcare programs for children where it matters the most: close to home.

References tab

DICTIONARY

A

A & Bs: apnea and bradycardia.

Ambu Bag: a piece of respiratory equipment; used with a face mask and placed over baby's nose and mouth, or attached to ET tube or trach tube; squeezed to give the baby oxygen and inflate the lungs.

Anomaly: malformed body part.

Anoxia: lack of oxygen.

Apnea: lack of breathing for 15 to 20 seconds.

Areola: dark area of the breast around the nipple.

Asphyxia: lack of oxygen and blood flow to the body.

Aspiration: breathing fluid (formula, stomach contents, meconium—baby's first stool) or objects into the lung.

B

Bacteria: germs which make you sick; treated with antibiotics.

Bagging: squeezing the ambu bag covering the baby's nose and mouth to give him or her oxygen and inflate his or her lungs; also used with a breathing tube in the baby's throat (endotracheal tube) or a tracheotomy (special airway placed by surgeon).

Bilirubin (bili): breakdown product of red blood cells; too much in the blood causes jaundice, a yellow color of the skin.

Blood Gas: a lab test to determine how much oxygen and carbon dioxide the baby has in his/her blood.

ABG: arterial blood gas; drawn from a UAC or arterial line.

CBG: capillary blood gas; baby's finger or toe is poked to draw blood for test.

BP: blood pressure.

Bradycardia: slow heart rate; usually less than 100 in a newborn or premature baby.

Breech Delivery: baby is born bottom, feet or arm first.

Bronchopulmonary Dysplasia (BPD): lung problem caused by oxygen, ventilators and prematurity.

Bubble: See CPAP

C

Candida Albicans (monilia or yeast infection): infection that causes thrush and other "yeast" infections; seen most often in baby's mouth or diaper area.

Caffeine: medication given by IV or mouth to help stimulate breathing in premature infants.

Carbon Dioxide (CO₂): gas breathed out when the baby exhales.

Cardiologist: doctor who specializes in the heart and circulation of blood.

Cardiopulmonary Resuscitation (CPR): method to revive a person whose heartbeat and breathing have stopped.

Central Nervous System (CNS): the brain and spinal cord.

Computerized Axial Tomography (CAT Scan or CT Scan): computerized x-ray that takes special pictures of the baby.

Complete Blood Count (CBC): blood test that looks at the types and number of cells in the blood; used to see if the baby has anemia (low blood) or an infection.

Continuous Positive Airway Pressure (CPAP): air or oxygen delivered under a small amount of pressure to help an infant breathe easier.

Circumcision: removal of the foreskin from the penis.

Cytomegalovirus (CMV): a virus the baby can get before birth that causes birth defects and illness; can also develop after birth and cause illness.

Colostomy: surgical opening made in the large intestine which is connected to the outside of the belly to permit elimination of stool (BM).

Colostrum: thin yellow or clear breast milk that is present before the true breast milk comes in; high in calories.

Congenital Abnormality: birth defect; malformation or abnormality present at birth.

Congestive Heart Failure (CHF): heart is not able to pump blood well because of malformed heart, illness or infection.

Corrected Age: length of pregnancy (gestational age) plus the baby's calendar age.

Chest Physiotherapy (CPT): vibrating, tapping or clapping on the baby's chest with a hand or soft pad to loosen secretions or mucus in the lungs.

Cerebrospinal Fluid (CSF): fluid made and stored in the ventricles of the brain; same as spinal fluid.

Cyanosis: blue color of baby's skin, fingernails or inside of mouth and tongue; caused by a lack of oxygen.

D

Diuretic: drug used to get rid of extra body water.

Doppler: special blood pressure machine.

Down Syndrome: chromosome abnormality (Trisomy 21) where the baby has varying physical problems and varying degrees of mental retardation.

Diphtheria, Pertussis, Tetanus (DPT): one of the baby shots or immunizations.

Dyspnea: difficult breathing.

E

Echocardiogram (echo): picture of the heart taken using a similar process as an ultrasound of your abdomen (uses sound waves instead of x-rays).

Edema: swelling or puffiness.

Electrocardiogram (EKG): tracing of the electrical impulses of the heart.

Electroencephalogram (EEG): tracing of the electrical impulses of the brain.

Electrolytes: chemicals in the body that make it function well; can be checked by drawing blood for lab work.

Endotracheal Tube (ET tube): small plastic tube placed in the nose or throat and connected to a ventilator or breathing machine. The tube is in the baby's breathing passage (trachea) and delivers oxygen and pressure to the lungs.

ER: emergency room.

Exchange Transfusion: removing most of the baby's blood in small amounts and replacing it with fresh blood in small amounts; most often used for a very high bilirubin level.

Extra Corporeal Membrane Oxygenation (ECMO): process used to circulate a baby's blood in a special machine while the lungs rest. It is like a type of heart pump used on adults having heart surgery. Babies may stay on the pump for more than a week and will also be on a breathing machine.

Extubation: take out the endotracheal (breathing) tube (ET tube).

F

Fontanel: soft spot on the top of the baby's head; another soft spot is toward the back of the baby's head.

Fraternal Twins: twins formed from two fertilized eggs; they do not look alike. There can be a boy and a girl or two girls or two boys.

Full Term: baby born between the 38th and 42nd week of pregnancy or gestation.

G

Gastrostomy: surgical hole on the tummy into the stomach; a tube is placed in the stomach to feed babies unable to eat by mouth.

Gavage Feeding: feeding by a tube placed in the baby's nose or mouth into the stomach.

Gestation: length of time from first day of mother's last menstrual period to the time of birth; full-term is 40 weeks gestation.

Gram (gm, G, GM): weight in metric system; one ounce = 28 grams.

H

Heel Stick: method to prick heel (finger stick is used also) to get blood for lab tests.

Hematocrit (hct or "crit"): percent of red blood cells in the blood. Your baby may receive a transfusion based on the hemocrit.

Hematologist: a doctor who specializes in blood problems.

Hernia: inguinal hernia: lump under the skin in the groin or scrotum caused by the intestines pushing through a weak place in the belly wall; a common preemie problem; may be fixed by surgery before the baby leaves the hospital; may occur at home after discharge. If so, notify the baby's doctor.

Hernia: umbilical hernia: a pushing out of the navel or belly button caused by the intestines pushing through a weak place in the belly wall; usually goes away by the age of two; fixed by surgery after two to three years of age, if still present.

High-Risk Baby: baby at risk for developmental problems; includes babies with intracranial hemorrhages, birth weight less than 1200 grams, long term breathing machine (ventilators), less than 30 weeks gestation, small for gestational age babies, congenital infections, meningitis and birth defects.

High Frequency Oscillatory Ventilator (HFOV): breathing machine that uses fast breathing rates for infants with special lung problems.

Hydrocephalus: extra spinal fluid in the spaces of the brain due to a blockage in circulation or absorption; head may become large.

Hyperbilirubinemia: high bilirubin level (yellow jaundice); common in newborns. Some babies are placed under a special light (bili light) or blanket to help the body breakdown the bilirubin. The baby gets rid of the bilirubin in his stools (bowel movements).

Hypoxia: lack of oxygen.

I

Identical Twins: twins that occur from the division of a single fertilized egg; they are the same sex and look alike.

IDM: Infant of a diabetic mother.

Ileostomy: surgical opening made in belly and the small intestine is brought to the outside to allow elimination of stool.

Immunization: medicines given to protect the child against harmful childhood diseases; given by mouth or by shot.

Inborn: baby born in the same hospital with a neonatal intensive care unit.

Indomethacin: medicine given to close the patent ductus arteriosus (vessel outside of the heart that can make the baby's breathing and heart problems worse).

Intermittent Mandatory Ventilation (IMV): number of breaths per minute given by the ventilator.

Intracranial Hemorrhage (ICH): bleeding in or around the brain.

Intravenous (IV): tube or needle placed in the vein to give fluids, medications or blood.

Intraventricular hemorrhage (IVH): bleeding into the ventricles in the brain.

Intubation: placing a small tube in the baby's windpipe (trachea) to give oxygen and pressure by an ambu bag or breathing machine.

In Utero: inside the womb or uterus.

Isolette: an incubator (plastic box) the baby is placed in to keep him warm while he or she grows.

J

Jaundice: skin and whites of the eyes become yellow; caused by a high bilirubin.

K

Kilogram: unit of weight in the metric system; 1 kg = 2.2 pounds; 1 kg = 1000 grams.

L

Lactation: making milk in the breast.

Lactose: sugar in breast milk or formula.

Lasix: medicine that helps get rid of extra body water; a diuretic.

LC: lactation consultant.

Letdown Reflex: flow of milk into the nipple.

Low Birth Weight Infant (LBW): baby who weighs less than five pounds at birth; can be premature or full-term.

Lumbar Puncture (LP, spinal tap): procedure where a hollow needle is inserted between the bones in the back to withdraw spinal fluid.

M

Meconium: baby's first bowel movement; green-black color and sticky; sometimes baby has a stool while in the uterus before birth.

Meconium Aspiration: breathing the meconium and amniotic fluid into the lungs.

Meningitis: infection of the lining of the brain and spinal cord.

Meningocele: birth defect where the tissue lining the brain and spinal cord come out through an opening in the skull or spinal column.

Milliliter (ml): unit of volume; 5 ml = 1 teaspoon; 30 ml = 1 ounce.

Mucus: sticky material made in the nose and throat.

Murmur: swishing sound made by blood flowing through the heart; many heart murmurs are not associated with problems.

N

NPO: nothing by mouth.

Navel: belly button; umbilicus.

NBICU or NICU or NICN: Newborn or Neonatal Intensive Care Unit.

Necrotizing Enterocolitis (NEC): an infection of the intestines which sometimes results in part of the intestines dying; the dying part is removed by surgery.

Neonatal Period: first 28 days of life.

Neonate: baby during the first month of life.

Neurologist: a doctor who specializes in problems of the brain and nervous system.

Naso-gastric Tube (NG tube): small plastic tube placed through the baby's nose into his or her stomach used for feeding; sometimes the tube is placed in the stomach to keep it empty when the baby is sick and not feeding.

Nippling: sucking on a bottle filled with formula or breast milk.

Nystatin: a medication that is swabbed in the mouth or applied to the skin to treat yeast infections.

O

Oxygen (O₂): gas in the air that we inhale; normal amount is 21 percent.

Occupational Therapist (OT): person who treats problems involving the use of muscles; also may work with babies who have trouble eating.

Ophthalmologist: doctor who specializes in eye problems.

Oral-gastric Tube (OG tube): small plastic tube placed through the baby's mouth into his or her stomach used for feeding; sometimes the tube is placed in the stomach to keep it empty when the baby is sick and not feeding.

Orthopedist: doctor who specializes in bone problems.

Outborn: baby transported from another hospital for care after his or her birth.

P

PCVC: tiny catheter or tube placed into a vein to give fluids or nutrition for a long time.

Patent Ductus Arteriosus (PDA): small vessel outside of the heart that sometimes fails to close after birth; sometimes it is closed with medicine or by surgery; can cause the baby to have breathing and heart problems.

Peripheral Arterial Line (PAL): catheter is inserted into artery for measuring blood pressure and drawing lab work; usually inserted into radial artery (RAL).

Periodic Breathing: a type of breathing pattern; the baby will stop breathing for a few seconds then breathe quickly.

Persistent Pulmonary Hypertension of the Newborn (PPHN): circulation and breathing changes at birth. In PPHN, the baby's blood flow does not change and continues to bypass the lungs and when this happens, the body and brain do not get enough oxygen.

Phenobarbital: drug used to treat seizures.

Phototherapy: treatment of yellow jaundice or high bilirubin by placing the baby under bright light (bili light) or on a blanket (bili blanket).

Physical Therapist (PT): person who treats problems of the muscles.

Placenta Abruption: placenta pulls away from the wall of the uterus (womb); there is often bleeding. A caesarean (C-section) delivery is often needed.

Placenta Previa: placenta is located in an abnormal place (over the opening of the womb); bleeding during the pregnancy can occur. A Caesarean (C-section) delivery is often needed.

Pneumogram (sleep study): 12- or 24-hour recording of the baby's breathing and heart rate patterns to see if there are unusual patterns during sleep or feeding.

Poly-Vi-Sol and ADEK: vitamins and minerals that are given by mouth to supplement the nutrients found in breast milk and formula.

Postpartum: time lasting six weeks after mom delivers a baby.

Postural Drainage: method of positioning a baby so mucus can drain from the lungs.

Premature Baby (preterm baby): baby born before the end of the 37th week of pregnancy.

Premature Rupture of the Membranes (PROM): the bag of water (amniotic fluid) the baby floats in leaks or breaks before labor.

Prenatal: before birth.

Prevacid: a medication given by mouth to help decrease reflux.

Primary Nurse: nurse who is responsible for providing care and coordinating care of a specific baby for entire time baby is in the unit.

Pulse Oximeter (sat. monitor): machine that reads the oxygen saturation of blood. The pulse oximeter is taped to baby's hand, finger or toe.

R

Residual: formula still in the stomach before the next feeding.

Respirator: machine used to breathe for the baby; also called a ventilator.

Respiratory Distress Syndrome (RDS): a breathing problem of prematurity caused by lack of a fluid called surfactant that keeps small air sacs in the lungs open; also known as Hyaline Membrane Disease (HMD).

Retina: the back of the eye.

Retinopathy of Prematurity (ROP): eye disease in babies; causes include use of oxygen, use of ventilators and prematurity. The mild form may heal on its own, but severe ROP may lead to the retina becoming detached (loose) and blindness.

Rubella: virus that causes German measles.

S

SIDS: Sudden Infant Death Syndrome.

Seizure: abnormal electrical activity in the brain, which causes unusual muscle twitches.

Shunt (VP): tube that drains spinal fluid from a ventricle in the brain to the belly.

Strabismus: eyes that cross or turn outward due to muscle weakness.

Subarachnoid Hemorrhage: bleeding in the area around the outside of the brain.

Synchronized Intermittent Mandatory Ventilation (SIMV): ventilator breaths are timed to the baby's breaths.

T

TTN: transient tachypnea of the newborn.

Tachycardia: rapid heart rate (above 160 beats per minute in a newborn or premature).

Tachypnea: rapid breathing.

Term Baby: baby born between the 38th and 42nd week of pregnancy (gestation).

Thrush: fungal (yeast) infection of the mouth; baby has white patches on the tongue and insides of the mouth.

TORCH titers: test for viral infections toxoplasmosis, rubella, cytomegalovirus, and herpes.

Total Parenteral Nutrition (TPN) or Triple Mix: nutrition given by fluids through a vein.

Trachea: windpipe or breathing tube.

Tracheotomy: surgical opening made through the skin and into the breathing tube (trachea) so air can get to the lungs when there is a blockage; also done to babies requiring long-term ventilation management.

U

UAC: umbilical artery catheter.

UVC: umbilical venous catheter.

Ultrasound: method of taking pictures inside the body using sound waves.

Umbilicus: belly button; navel.

Upper Respiratory Infection (URI): a cold; infection above the lungs.

Urinary Tract Infection (UTI): infection of the bladder.

V

VS: vital signs (temperature, pulse, respiration, and blood pressure).

Ventilator: machine used to breathe for the baby; also call a respirator.

Ventricle: chamber in the heart; also the name of a sack in the brain where spinal fluid is made and stored.

W

Wheeze: whistling, humming, raspy sound made during breathing.

Y

Yeast Infection (Candida albicans, thrush): fungus that causes an infection; common after antibiotic therapy. Seen most often in the mouth and diaper area; treated with mycostatin oral suspension and mycostatin cream.

RESOURCES

Levine Children's Hospital

CarolinashHealthCare.org/Levine-Childrens-Hospital

Support Groups

Preemie Parenting

www.preemieparenting.com

Family Support Network

www.fsnn.org/home

Parent to Parent Support Network

www.p2pusa.org

Web MD

www.exchanges.webmd.com/parenting-preemies-exchange

Breastfeeding

<http://kellymom.com>

www.breastfeedingrose.org

<http://www.healthychildren.org> (search breastfeeding)

<http://newborns.stanford.edu/Breastfeeding/MaxProduction.html>

Developmental Care

www.prematurity.org

www.kangaroomothercare.com

www.kidshealth.org

www.healthychildren.org (search prematurity)

NC Infant/Toddler Program

www.bearly.nc.gov

National Center for Infants, Toddlers, & Families

www.zerotothree.org

OTHER WEB RESOURCES

March of Dimes

www.marchofdimes.com

Exceptional Parent Magazine and Website

1-877-372-7368

www.eparent.com



Carolinan HealthCare System
Levine Children's Hospital