Your Baby and the NICU

IMPORTANT INFORMATION FROM YOUR HEALTH CARE PROVIDERS

Take great care of the patient™
Neonatal intensive care unit (NICU) topics for parents

If you have any questions about these topics, please contact our hospital staff.

Section A
The NICU
1. What is the NICU?
2. Tools of the NICU
3. NICU staff
4. About infections

Section B
The newborn
1. About premature babies
2. How babies' senses develop
3. Cues: “How does my baby feel?”
4. Bonding with your baby

Section C
Caring for your baby in the NICU
1. Caring for your baby in the NICU: feeding
2. Caring for your baby in the NICU: about sleep
3. Screening for newborns

Section D
Taking care of yourself
1. Coping with stress in the NICU
2. Depression among parents of NICU babies

Section E
Preparing to leave the NICU
1. Going home with your baby: about the discharge process
2. Medicine(s) for your baby at home
3. The road ahead: sources of help
Dear parents: Your baby has become a patient in our neonatal intensive care unit (NICU) so that we may look after his or her special health care needs. We have provided you with this booklet to help you learn about the issues that affect your baby. Before learning about these details, it helps to have a look at the "big picture" of your baby's needs, the care he or she may need, and what you may be able to expect along the way.

Your baby is in this unit because he or she was born with a health problem and/or was born before all of his or her organs were fully formed and functioning (premature). Your baby's tiny body is still very fragile and needs time to heal and grow.

Your baby, therefore, may need some or all of the special care listed here:
- help with breathing by a ventilator
- special feeding through a tube
- medicines
- special ways of caring until his or her senses are fully mature
- a bili light to treat jaundice
- other special treatments and procedures

You play a vital role as a partner in your baby's care. On some days your baby will need lots of rest, so just sitting nearby may be very helpful for both you and your baby. On other days, your baby may be ready for more contact with you and you will learn special ways to help care for your infant.

When you have questions about your baby or do not understand something, please ask our doctors, nurse practitioners and bedside nurses. They have special training to help babies and will be happy to answer all of your questions.

Some babies stay in our NICU for only a few days, while others must be here for several months. We can't predict how long your baby's stay will be. Yet, we do know that your baby will be ready to go home once he or she is able to feed, breathe, sleep, and grow without the help of the NICU. During your stay, our goal is to provide the best possible care for your baby and your family.
The purpose of this booklet is to provide parents, guardians and family members with a comprehensive collection of information about a hospital’s neonatal intensive care unit (NICU).

**Why read this booklet?**
Gaining a basic knowledge of NICU staff, procedures and equipment may help you better understand your baby’s treatment while in the NICU.

**How do I use this booklet?**
For easy reference, this booklet is divided into color-coded sections seen in the table of contents: Section A is blue, B is red, C is gold, D is purple and E is green. You’ll find areas in the booklet where you can take notes, and a reference at the end of each section entitled "Take a closer look at these Pedriatrix topics" that directs you to additional information.

**Who publishes this booklet?**
This booklet is published by Pediatrix Medical Group through The Center for Research, Education and Quality. Pediatrix Medical Group partners with hospitals across the country to provide care to newborns in neonatal intensive care units.

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**At our Center for Research, Education and Quality we are:**
- working to improve care for newborns, children, and women facing high-risk pregnancies.
- conducting research and using findings to develop safe, evidence-based practice.
- sharing knowledge through our vast database on neonatal care.
- educating clinicians around the world by providing expertise to scientific and health care organizations.
- striving to be the best possible resource for the patients, parents, and families who entrust their care to us.

*Your Baby and the NICU* provides families with practical insight as to what to expect when a child is admitted to the NICU. If you have found this booklet helpful, or have feedback to help us make it better, then contact Pediatrix Medical Group at: parenteducation@pediatrix.com.

*This information is for educational purposes only and is not intended to substitute for professional medical advice. Always consult with a health care professional if you have any questions about the health of your baby.*
Your baby is a patient in a neonatal intensive care unit (NICU). For many parents, this is a time of worry, stress, and questions. Getting answers to your questions can help ease some of this stress. The following pages answer basic questions you may have about the NICU. Because NICUs are different at each hospital, please talk to the health care staff in your unit if you have questions that are not answered here.

**What is the NICU?** The NICU is a unit in the hospital where babies born early (premature) and/or who need special care are treated. Here’s what the letters mean:

- **N** = neonatal (*neo* means new, *natal* means birth) = new birth
- **ICU** = intensive care unit — a special section of the hospital where high-risk infants will receive medical care that is focused on his or her unique needs.

Each NICU is set up to provide a certain level of care. In some cases, a baby may need to be moved to a unit that provides a different level of care. The goal of every NICU is to help the babies’ body functions become stable so babies can grow and thrive on their own.

**What does the NICU look like?** The NICU has many small beds, some of which are open and some that look like glass boxes. The open beds are called warmers. The closed beds are called *isolettes* [ahy-SUH-lets]. These keep your baby warm and are designed for his or her special needs. Light and sounds are kept as low as possible in the NICU to help the babies rest. You’ll see various equipment in the NICU to help with the baby’s breathing, feeding, medicines and fluids. There are also monitors that keep track of the baby’s vital signs, such as heart rate, breathing and blood pressure. You may hear many alarms from these monitors. The nurses and doctors are trained to know when and how quickly to respond. Even small changes, such as the baby’s movement, can often make the alarms sound.

*“At first, all the equipment and sounds in the NICU made us nervous when we were with our baby. Once we found out what the equipment did, we felt more at ease in the NICU.”*  
*Tom & Anna, parents*

You are a vital part of your baby’s care. The doctors and nurses can work with you to give your baby the best care possible. For instance, they will talk with you about your baby’s treatment plan. Many NICUs have features to help you be a partner in your baby’s care. These might include: a chair for you to sit near your baby; rooms near the NICU, a family designated area; private spaces for talking with the doctor or other staff; and/or a private place for pumping breast milk. As your baby becomes stronger, nurses can help you to support your baby’s care in the NICU.
Can I stay in the NICU with my baby? This differs with every unit and every baby. It can be very hard for parents to leave the NICU while their baby is there and you may want to stay near your baby as much as you can. Some babies may stay a few days in the NICU, while others may stay a few months. During this time, you will have to balance your baby’s need for rest with your own need for rest.

Can I touch or hold my baby? This depends on your baby’s unique needs. Most babies benefit from being held and from their parents' touch. At first, though, some babies may not be able to handle too much movement because their bodies are very fragile. In addition, too much light, sound or touch can cause sensory overload for some babies. As soon as your baby is ready, the health care staff will show you helpful ways to touch and hold your baby. The staff can show you how to know when your baby is distressed or at ease.

Who works in the NICU? Many people who focus on different aspects of treatment will work with you and your baby. The people you see most often are the bedside nurse, the doctor (called a neonatologist or intensivist), the neonatal nurse practitioner (NNP), and the respiratory therapist (RT). As work schedules vary, you may not always see the same person taking care of your baby.

What can parents do? The most important thing you can do right now is to be an active member of your baby’s health care team. The health care team will work with you to do what is best for your baby. To be an active partner, you can:

- **Ask questions** — this can help you keep track of your baby’s care. It can also help you learn more about your baby’s needs and can help the health care staff learn more about you. In an area that is so new to you, it may help to write down your questions. Keep in mind the three basic questions listed in the blue box. This new world of the NICU is very complex, so don’t be afraid to ask the same questions over and over, until you understand.
- **Share this information with your family** — this will help them know where your baby is, how he or she is being cared for, and how they can help you.
- **Take care of yourself** — this is a stressful time for you and your family. Seek help from family and friends, and from hospital staff, such as counselors, social workers or pastors. These people are there to help you through stressful times.

**Take a closer look at these Pediatrix topics**

- equipment - A2 - Tools of the NICU
- sensory overload - B2 - How babies’ senses develop
- stressful - D1 - Coping with stress in the NICU

A1 - What is the NICU?
When you and your baby first arrive in the neonatal intensive care unit (NICU), you may feel stressed by the equipment, tubing, monitors, and alarms in this area. These are the tools of the NICU that help meet the varied and special needs of premature and/or sick babies. To be an active partner in your baby’s care in the NICU, it helps to know a bit about these tools. Below is a description of the equipment that helps support the four main needs babies have to survive outside the mother’s womb: warmth, breathing, feeding, and blood flow.

**To help with warmth:** Babies whose bodies are able to keep warm can sleep in a regular open crib. Babies who have problems keeping warm are usually placed in one of these special beds:

- **A radiant warmer** is a bed that helps keep the baby’s body temperature regulated. A sensor placed on the baby’s stomach or chest keeps track of the baby’s body heat and signals the warmer to increase or decrease heat to the baby. The glass sides protect the baby from drafts. Because it is an open bed, it is normally used for babies who need more “hands-on” care.

- **An isolette** (also called an incubator) uses moist air to keep the baby warm. Since premature babies can lose moisture through their thin skin, water is added to the air to help prevent this. Like in the warmer, a sensor placed on the baby’s stomach adjusts the amount of heat provided. Because it is enclosed, an isolette also helps to protect the baby from noise, drafts, and germs.

**To track breathing and blood flow:** A monitor checks your baby’s vital signs at regular intervals and displays the results on a screen. Nurses and doctors check these screens to keep track of your baby’s vital signs. The monitors may be grouped into one large unit near your baby’s bed, or many smaller monitors placed near the bed. Each NICU varies, so ask the NICU staff if you have questions about these. The cardiorespiratory [car-dee-oh-ress-PEER-ah-tor-ee] monitor keeps track of heart rate and breathing rate. Sensors placed on the baby’s chest send signals to the monitor with this data. Blood pressure is measured with a small cuff placed around the baby’s leg or arm. The cuff fills with air to measure the blood pressure — just like the cuff a doctor uses for adults.

“At first, the NICU made me nervous. I was afraid I would set off an alarm when I was near my baby.”

Gwen, mother
A pulse oximeter [ocks-IMM-eh-tur] keeps track of the amount of oxygen in the baby’s blood. A small sensor placed on the baby’s hand or foot sends a beam of light through the baby’s skin to measure the oxygen. This is a painless method that helps doctors know how well the baby’s heart and lungs are working.

To help with breathing, feeding, blood flow, and medicines: Infusion pumps provide fluids, food, and medicines your baby may need. These pumps are set to provide a precise amount at the rate and time that meets your baby’s unique needs. A ventilator (also called a respirator) is used for babies who need help with breathing. There are many types of ventilators. Babies who cannot breathe on their own may need a machine that inflates their lungs. Babies who can breathe on their own but who still may need help, may have a machine that provides oxygen at a pressure that makes breathing easier. This treatment is called continuous positive airway pressure (CPAP).

Other tools
A phototherapy light (called a bili light) is used for babies who have too much bilirubin [bil-EE-roo-bin] in their blood (called jaundice). Untreated jaundice can cause serious problems, so this light is sometimes used to convert the bilirubin into a harmless substance. The baby’s eyes must be covered while under this light, but the light is not harmful.

What can parents do? As parents, you play a vital role in your baby’s care. Learning about the tools of the NICU is one way to take an active role in that care. Talk with your baby’s doctors and nurses about these tools. The equipment is complex, so ask questions until you feel you understand. Learning about your baby’s care may help you reduce the stress you may feel when your baby is in the NICU.

Take a closer look at these Pediatrix topics

- four main needs babies have - B1 - About premature babies
- jaundice - F10 - Jaundice (not included in this booklet)

Ask Questions
In an area that is new to you, asking these questions can be helpful:
What is the main problem?
What do we need to do?
Why is it important to do this?

Source: Partnership for Clear Health Communication at the National Patient Safety Foundation™
www.npsf.org/askme3
There are several people who may work together in the neonatal intensive care unit (NICU) to help you and your baby. They are highly trained to work with babies who need specialized medical care. Below is a brief list of NICU staff members and what they do. The types of staff and their titles differ with each NICU, so you might not see all the people listed here.

**Neonatologist/Intensivist** — A doctor with special training to treat babies who have medical problems. This doctor will oversee your baby’s care, but may consult with other types of doctors based on your baby’s needs.

**Neonatal Advanced Practitioner** — This person is a neonatal nurse practitioner (NNP), an advanced practice registered nurse (APRN) or a physician’s assistant (PA) who has pursued further education and training in order to provide special medical care for your baby and works under the supervision of a neonatologist.

**Nurse** — The types of nurses and their functions vary with each NICU. Bedside nurses are trained to care for babies in the NICU and will be involved in the daily care of your baby. Nurses will perform tasks such as bathing, feeding, checking vital signs and giving medicines. They can answer questions about your baby and will show you how you may help in your baby’s care.

**Case Worker** — This person helps manage many aspects of your baby’s care and long-term needs. A case worker often is trained in social work and can help connect you with resources you may need along the way, such as home medical supplies and services to help with learning, motor skills, growth and counseling. Financial concerns also can be discussed with a case worker.

**Other types of doctors** — Based on your baby’s special needs, he or she may be seen by doctors who focus on certain body systems.

**This type of doctor works with these body systems and/or functions:**
- Cardiologist — the heart and structures that connect with it
- Developmental Pediatrician — the growth, learning and emotional health needs of infants and children
- Endocrinologist — the endocrine system (many glands throughout the body that produce hormones)
- Gastroenterologist — the organs involved with digestion, such as the stomach, intestines and gall bladder
• Geneticist — the health or physical problems that are passed through families
• Infectious Disease Specialist — infections that may affect the baby's well-being
• Nephrologist — the kidneys and structures that connect with them
• Neurologist — the nervous system, including the brain
• Ophthalmologist — the eyes
• Pulmonologist — the lungs and structures involving breathing
• Radiologist — reads x-rays and image scans to help diagnose and treat medical problems
• Surgeon — there are many types of surgeons, each type focuses on certain body systems and performs invasive surgeries

Others who may be involved in your baby’s care and attend to your family's needs:

**Audiologist** — This professional has special training in testing and treating problems related to hearing. Before your baby leaves the NICU, your baby may be screened for hearing loss. You may be advised to take your baby to an audiologist if tests show your baby may need additional evaluation.

**Hearing Screener** — This person may test your baby’s hearing using audiological technology known as the auditory brainstem response (ABR) test.

**Counselor** — This person has special training to help patients who are distressed and/or who need help with non-medical problems. Having a baby in the NICU is a stressful time for any parent and having someone to talk with may be helpful.

**Dietitian** — This professional focuses on special nutrition needs your baby may have.

**Lactation Consultant** — This person is a health care provider with special training in breastfeeding issues, such as the unique challenges that may occur when breastfeeding premature babies.

**Resident** — This is a doctor who has completed a medical degree and is training to practice in a certain field of medicine. In the NICU, a resident is training to become a pediatrician (a doctor who treats children), a family practitioner, or an OB/GYN and is guided by doctors in the unit.

**Respiratory Therapist** — This person helps with lung and/or breathing problems, and with care that involves a ventilator, continuous positive airway pressure (CPAP) or oxygen.

**You are a vital partner in your baby’s care:** The NICU team is here to take good care of you, your baby and family members. As a parent, you are a vital member of the care team. You can take an active role in your baby’s care by asking questions and learning what you can do to help your infant.

**Take a closer look at these Pediatrix topics**

► breastfeeding - C1 - Caring for your baby in the NICU: feeding
► ventilator - A2 - Tools of the NICU
About infections: Babies born early (premature) have a higher risk for infections. Infections can cause severe health problems for premature babies. Not all infections can be avoided, but knowing about them and ways to help prevent them can be helpful for your baby.

Why might the risk of infection be higher for my baby? There are many reasons for this:

- For premature babies, the body system that fights off infection (the immune system) is not yet fully working and/or is weakened by illness.
- The skin of premature babies is very thin and breaks easily — this allows the germs that cause infection to enter the body more easily.
- Babies who cannot have breast milk or colostrum (the mother’s first milk) are at higher risk because breast milk helps make the immune system stronger.
- Babies needing special care may be treated with equipment that has tubing, or with needles that must be inserted through the skin to provide medicines and fluids. Use of this equipment may increase the risk of infection.
- Medicines used to treat infections may become less helpful (called drug resistance) — this makes the infection harder to treat in some babies.

Keep in mind that infections often result from a mix of factors, including the baby’s current health.

Some babies may be born with an infection. In these cases, the baby gets the infection from the mother either while in the womb or during the delivery. Sometimes the mother may not have any outward signs of the infection and does not know that she has it. If the baby gets an infection while in the womb, it may cause physical problems in the baby. In other cases, the mother may have a type of germ that may not affect the baby in the womb, but may be passed to the baby during birth. If the mother has an infection, doctors may advise that the baby be delivered by cesarean section.
What causes infection? Infections are caused mainly by three types of invading agents: bacteria, fungi, or viruses. Sometimes you may hear people refer to these simply as “germs” or a “bug.” Each type of germ causes certain health problems, which are treated with different methods.

*Candida* [can-DIH-dah] is a fungus that may cause severe problems. It more often affects babies weighing less than 3.3 pounds (1,500 grams) at birth. A baby may contract this during the birth process or may get it after birth, especially if he or she needs antibiotics for a period of time to treat a bacterial infection.

*Group B streptococcus* [strep-TOE-kok-us] is a bacteria that is a common cause of infection in newborns. Many people carry this germ without getting sick from it. But it can affect babies within the first week of life or up to a few weeks after birth (called *late-onset infection*).

*Methicillin-resistant staphylococcus* [staph-y-lo-KOK-us] *aureus (MRSA)* is a bacteria that is resistant to some types of medicines. It may cause severe infection that is hard to treat.

How are germs spread? Infections can be spread to babies from other people through touching, breathing, sneezing, coughing, or from clothing. Germs may be passed to the infant from the mother during delivery. Medical devices used in the care of your baby may also cause infections. The intestine of a baby, which has many bacteria, is also a major source of infection.

Infections may vary in severity and in some cases can cause brain damage, problems with muscles and movement, breathing, and/or hearing loss.

Types of infections that may affect babies include those that occur in the:

- **Blood** (called *septicemia* [sep-tuh-SEE-mee-uh]) — Septicemia may happen in any baby, but there is a higher risk for babies who have any type of needle (catheter [KATH-i-ter]) inserted through the skin to provide medicines or food. Germs can enter the body through an opening in the skin.
- **Lungs** (called *pneumonia* [noo-MOHN-yuh]) — Pneumonia may happen in any baby, but there is a higher risk for it in babies who need a ventilator or continuous positive airway pressure (CPAP) to help with breathing. Germs can enter the body from the mouth or nose, or through tubing attached to the breathing machine.
- **Tissue covering the brain and spinal cord** (called *meningitis* [men-in-JAHY-tis]) — Meningitis may be caused by germs that invade the womb if the mother’s water sac breaks too early (called premature rupture of membranes). It can also result from germs the baby gets after birth.

Infections may affect other parts of the body, such as the skin, bones, joints, and/or the heart. Different steps are taken to treat each type of infection, based on the germ involved and any other health problems being treated. Sometimes an infectious disease specialist may be involved with care and treatment. If your infant has an infection, talk with the doctors and nurses about his or her unique needs and about any questions you may have.
How do we know if our baby has an infection? Premature babies often do not show common signs of infection, such as a fever. Also, the signs of infection may differ with each type of germ. Some signs may include problems with breathing or with feeding, and a general lack of activity in the baby. Tests of body fluids, such as blood, urine, saliva, and spinal fluid may be performed to confirm an infection.

What happens if our baby gets an infection? Treatment depends on the type of infection. Often treatment includes giving medicines. Antibiotics may be used for infections caused by bacteria and anti-fungal medicines may be used for fungal infections. With a few exceptions, most viral infections are not treated with medicines. Some babies may be treated for more than one infection while in the NICU.

Can infections be prevented? This is a complex question. Some types of infection can not be avoided but may be reduced. For example, a medicine may be given to the mother before the baby’s birth and/or to the baby right after birth, before any sign of infection appears. This may happen if the doctor thinks the baby is at high risk for certain germs (such as Candida) and/or if the mother is known to carry a certain germ.

In the NICU, infection prevention steps include:*  
- washing hands often  
- removing the baby from devices that require needles and tubes as soon as the baby is healthy enough  
- keeping the area very clean (sterile) while changing or cleaning the needles or tubes  
- giving the baby breast milk when possible

Sometimes babies with infections that are spread by direct contact may be placed in a separate room to prevent the germs from spreading to other infants. You also may see nurses and doctors wearing gowns, masks, and gloves when they perform certain care tasks with your baby, such as working with tubing or needles.

What can parents do? Although many steps are taken to avoid infection, sometimes infections occur despite our best efforts. Studies show that taking active steps to control the spread of germs can help reduce the number of infections.** Parents can take an active role in helping to control infection in the NICU by:

- learning about infections and how they are spread
- providing mother’s breast milk or even colostrum when possible
- taking steps to control infection after you take your baby home
- working as partners with your health care team to follow all prevention measures


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Take great care of the patient™
Helpful tips for keeping hands clean around your baby*

- Wash hands before and after each direct contact with your baby. Follow the key steps listed in the box at the right.
- Wash hands after:
  - using the restroom
  - sneezing, coughing, or blowing your nose
  - touching your hair or your face
  - removing gloves
  - touching objects (including medical equipment) around the baby’s bed
- Use a special antibacterial hand rub for hand cleaning if there is no soap and water available.
- Dry your hands well. Germs are more easily spread from wet hands than from dry hands.
- Ask the doctors and nurses if and when to wear gloves when you are with your baby. This is advised if you will come into contact with blood, urine, stools, vomit, or sores.
- Wash your hands before putting on the gloves. Wearing gloves does not replace the need for hand washing.
- Remove gloves after leaving the baby.
- Do not re-use gloves.
- Avoid wearing rings on fingers — bacteria can collect beneath rings.
- Avoid long fingernails or false nails — bacteria can collect beneath nails.

5 Steps for Hand Washing**

1. Wet hands with clean water and apply soap. Use warm water if you can.
2. Rub hands together so soap lathers. Scrub all parts of your hands.
3. Rub hands for about 20 seconds (this is about the amount of time it takes to sing Happy Birthday).
4. Rinse hands well with clean water.
5. Dry hands with a paper towel or an air dryer. Use the paper towel to turn off the faucet and to open doors, etc., to help keep your hands germ-free.


Take a closer look at these Pediatrix topics

▶ ventilator - A2 - Tools of the NICU

A4 - About infections
What happens when a baby is growing and changing inside the womb? The human body is a complex structure. Ideally, a baby needs 37 - 40 weeks to form inside his or her mother. Every minute of every day, changes occur in the baby. Each change signals other changes to occur — like a chain reaction. As the baby grows and develops, he or she is able to do more things, like move his or her arms and legs or suck his or her thumb.

While inside the mother, the baby grows and changes, and gains functions that will help the baby live outside the mother’s womb. Of course, each baby grows and changes at a different rate. The mother’s health and baby’s genetic make-up affect this growth and change. Even when a baby is born at full-term, many systems, such as the nervous system (the network of nerves that run throughout the body and connect with the brain) continue to grow and change for many years.

What happens if a baby is born too soon? If a baby is born too soon, many changes that should have occurred in the womb now must take place outside the mother’s body. Let’s look at the “growth charts” that show how a baby develops in the womb: this gives a basic picture of changes that still must occur for premature babies. It also helps to see what special care these babies may need after birth.

In the womb, from 0 - 26 weeks: Most of the major change happens during this time. The main organs not yet fully working include the lungs, heart, brain, and spinal cord. Most babies born before 24 weeks cannot survive outside the mother.

0 - 26 weeks — main growth and change:
- structures (such as hands and feet) and organs (such as brain and heart) form
- fine hair (called lanugo) grows over the body
- baby moves arms and legs and begins to hear sounds
- heart begins to beat
- lungs begin to move as if the baby is breathing, but the baby still gets oxygen from the mother’s blood
- eyes still closed until about 26 weeks
In the womb, from 27 - 38 weeks:
You can think of the changes during this time as “fine tuning.” The main organs and structures are formed, but still are making their way to the stage that will help the baby live outside the womb. For example, the tiny air sacs in the lungs (called alveoli) are still forming.

27 - 38 weeks — main growth and change:
- lungs are still forming
- more brain connections form and connect with the nerves throughout the body
- small breast buds appear on chest of both boys and girls
- hair covering the body begins to go away and body fat increases to keep the baby warm after birth
- bones are fully formed, but are still soft
- stomach and intestines mature to allow feeding to begin

From womb to world — what premature babies may need: At birth, all babies must adjust from a warm, dark, watery world to one filled with light, air, sound, cold/warmth, and touch. In order to cope with this, the baby’s body must adapt in 4 major ways: through breathing, blood flow, feeding, and warmth. Before birth, the baby receives nutrients and oxygen carried by the blood from the mother’s placenta. Warmth came from the fluid in the womb. When the baby is born, his or her body must adjust quickly to doing these functions on his or her own. This is a big change for all babies. It is a special challenge for premature babies because their systems are still in that “fine tuning” stage and can’t adjust in the same way as a fully mature baby.

Premature babies need special care to help them adjust to a world of light, air, sound, cold/warmth, and touch. The key idea behind much of this care is to keep the baby’s new world as much like his or her mother’s womb as possible.

What can parents do? The most important thing you can do right now is to be an active member of your baby’s health care team. Learn about your baby and the special care needed. Talk to the doctors, nurses and health care team about your baby, and about how you can help in his or her care.

Also, take care of yourself. Having a premature baby in the NICU can cause a great deal of stress for parents. Seek help from your family, community, and health care staff. Ask to talk with a social worker, counselor, or the hospital’s pastoral staff. These people are there to help you through stressful times.

Take a closer look at these Pediatrix topics

stress - D1 - Coping with stress in the NICU

B1 - About premature babies
There is much growth and change that must occur in your baby’s body. For babies born full-term (37 - 40 weeks), this growth and change occurred within the warm, dark, watery womb. For the premature baby, this same growth and change must occur in a very different world. Growth and change in the body affects the way we feel and the way we act. The same is true for premature babies. Learning about how your baby’s senses form can help you learn how your baby may feel and how to respond to your baby.

What role do the senses play? Our senses are our link between the outside world (our surroundings) and our inside world (our body and mind). When your hand hits a sharp nail, for instance, your body sends a pain signal to your brain and you shout, “Ouch!” This response is signaled by a network of nerve fibers that runs from your fingers to your brain and to other parts of the body. Think of this network as being like the wiring in a house. It is this network of nerves that helps us make sense (feel pain) of the input (the sharp nail) from the outside world. All babies use their senses to explore their world. This is why they want to touch things and put them in their mouths.

What happens to the senses of premature babies? The premature baby’s house (body) is not yet fully wired. The wires (nerves) still are linking to each other and to parts of the body, such as the brain. And just as the wires in a house are covered with a plastic casing, the wires (nerves) of the body have a similar casing. This casing (called a myelin sheath) has not yet fully formed. The baby’s wires are, so to speak, exposed, so the baby can’t make sense of input from the outside world (lights, sound, smells, touch, taste) in the same way as fully mature infants. For premature babies, this input may seem stronger — the NICU lights may seem brighter and noises may sound louder. What might seem like normal light, sound, or touch to us, may be too much for the baby to handle. This sensory overload is stressful for the baby and he or she may feel discomfort and may be fussy. This type of stress affects many parts of the baby’s body (just as it does in adults). The stress may lead to increased heart rate and breathing rate. It may lead to tummy problems, which then may result in feeding problems. All of these effects together may lead to medical problems for premature babies whose body systems are not yet able to handle this stress.

“When my baby was in the NICU, it didn’t seem she liked to be held or talked to. I felt sad about this and wondered if I’d be able to bond with her. When I learned how my baby’s responses were affected by the growth and change still occurring in her, I was better able to respond to her needs.”  
Chloe, mother
**How do the senses form in a premature baby?** In the womb, each of the baby’s senses forms in a certain order at a certain time. As the baby’s wiring becomes more complete, the senses are able to form. And, as each sense forms, it helps more wiring to form, which then helps other senses to form. Outside the womb, this precise and timed process can be disrupted by too much input from sound, light, and touch that he or she would not have had inside the womb. This can disrupt many aspects of the wiring process still taking place, and may lead to long-term problems with growth, learning, movement, and controlling mood. Knowing how the senses form inside the womb helps us understand how the outside world might feel for your baby and why certain care is needed in the NICU. NICU nurses will show you special ways to handle your baby while his or her senses continue to mature. Here, we take a brief look at each sense and how it might affect your baby.

**Sight**

**Inside the womb**, a baby develops mainly in the dark. The eyes remain closed until about 25 - 26 weeks. The mother’s hormones help the baby’s body track the cycle of days and nights. After about 32 weeks, the baby begins to detect and react to light coming from outside the womb. As the baby reacts to this light, his or her body refines more functions, such as movement.

**Outside the womb**, a baby still is gaining body fat between 27 - 38 weeks. A premature baby may have very thin skin (as thin as tissue paper), because it does not yet have a full layer of fat. This includes the skin of the eyelids. If the skin is very thin, too much light can enter the baby’s eyes. When babies are able to open their eyes, they can’t always close them until they are about 32 weeks old. These factors combined can cause the baby to be exposed to too much light, too soon (such as from lights in the room or from sunlight). Too much light can make the baby tire easily.

**To help babies cope with light**, there are a few things the hospital staff can do to keep the baby’s world as much as possible like the womb:

- dim the lights in the NICU
- cover the baby’s eyes with a special shield
- place a cover over the baby’s bed

In premature babies, the nerves that link outside input with the body and brain are not fully mature. So, lights, sounds, and touch often feel more intense for the baby.

Knowing how your baby’s senses form inside the womb helps you know how the outside world might feel for your baby and why certain care is needed in the NICU.
New studies are looking at whether babies can be helped by light that’s cycled to mimic day and night phases. After about 32 weeks, it is thought that babies can be introduced to these light cycles.*

**What can parents do?** While in the NICU, you will learn about your baby’s unique and changing needs. After about 32 weeks of age, most babies can handle more input through their eyes. At this stage, your baby may be more able to watch your face and to look at other objects. This, in turn, helps the eye structures and eye-brain connections to progress. As eye formation progresses, the baby’s eye skills improve. This helps the baby to focus on objects (at 10 - 12 inches) and to follow moving objects with his or her eyes. Just being able to look at your baby and for him or her to look back at you, can help you bond and can help your baby’s development.

**Sound**

*Inside the womb*, sound waves must travel through layers of the mother’s tissue and fluid before reaching the baby. Thus, sound is muted for the growing baby. The baby hears his or her mother’s voice more clearly than other sounds, because the sound of her voice travels straight to the womb and is not blocked by tissue. A baby begins to respond to sound (to listen) at around 16 weeks gestation, but the inner and outer structures of the ear are not developed until 24 weeks. The rhythm and pitch of sounds also can affect the baby’s heart rate. This change in heart rate can last for up to an hour afterward.

*Outside the womb*, sound is no longer muted by tissue or fluid and therefore may be more intense for a baby. This sound may sometimes be painful. We now know that stress and disturbed sleep, due to noise, can slow the baby’s growth.

To help babies cope with sound, NICU staff try to minimize noise around the babies. Too little sound is not good for babies, but precisely how much sound is best is not known.

**What can parents do?** It is hard for babies to hear the difference between separate sounds. To help your baby, it is best to keep background noise (such as other voices or music) very low. The most vital sounds for the baby are the parents’ voices. As you learn your baby’s **cues**, you’ll be able to tell how much sound your baby can handle.

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Premature babies have a higher risk for hearing problems. This risk is higher for babies born at a very low birth weight* (less than 3.3 pounds or 1,500 grams). This problem is called auditory neuropathy [noo–ROP–uh–thee]. It is caused by damage to the nerves that run between the ear and the brain.

This nerve damage can be caused by many things, such as severe jaundice; not getting enough oxygen at birth; bleeding in the baby’s brain; medication exposure; infections in the womb; and hearing problems that run in the family.

Hearing problems can be found with a special test. Most states require babies’ hearing to be tested before leaving the hospital. This test is called a hearing screen. The Joint Committee on Infant Hearing advises that all babies who have been in the NICU for more than 5 days should have an auditory brainstem response (ABR) test.**

It is important that babies receive a hearing screen. Babies rely more on hearing than on sight during their first 6 months of life. Hearing loss can lead to a delay in learning how to talk. This can disrupt the child’s ability to learn and to relate to others. Even if the result of your baby’s hearing screen is normal, your doctor may advise a repeat test after you leave the hospital if the baby has any risk factors for hearing loss.

Touch

Inside the womb, touch is the first sense to form. Touch begins to develop around 8 weeks gestation. Over many weeks, the baby’s body develops the network of nerves that make up the sense of touch. Even while in the womb, a baby can feel things. By 32 weeks gestation, nearly every part of the baby’s body can feel heat, cold, pressure, and pain. At birth, the sense of touch is the most finely tuned of all the senses.

Outside the womb, a gentle touch may feel intense to a premature baby, but this differs with every baby. Also, the skin of a baby can be very fragile and can tear easily. Since there are many ways in which babies must be touched, doctors and nurses focus on the unique needs of each baby and use the baby’s own cues when providing care. Babies often will display jerky movements, however this is normal.

To help babies cope with touch, NICU nurses watch closely for signs that a baby has discomfort and the nurses arrange care by these cues. These cues include the way the baby acts, as well as vital signs, such as heart rate and breathing. These signs help nurses know how much touch the baby can cope with and the best times to give the baby the needed care. There also are special things that can be done to help reduce pain during care tasks.

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Can my baby feel pain? Yes. Babies can feel pain, so your baby’s care plan will include ways to minimize pain as much as possible. For instance, doctors and nurses may:

- assess babies often for pain – look for facial signs, as well as vital signs, such as heart rate and breathing, that may indicate discomfort
- combine care tasks, such as feeding and changing, so the baby is touched and moved as little as possible
- give the baby a sweetener, a pacifier, and/or breast milk during care tasks that may cause pain, such as heel sticks for blood tests (research shows these methods may help reduce pain*)
- use special positions to help the baby cope with pain

Pain-relief medicines may also be given for painful procedures. Very strong medicines can disrupt the baby’s sleep, and can lower blood pressure and breathing rate, so their use is balanced with the baby’s need for pain relief.

What can parents do? A baby may be helped by grasping his or her hand or by holding him or her in a special way (called tucking). Most babies also may be helped by kangaroo care. This is a special way for mothers and fathers to hold their baby skin-to-skin. Kangaroo care also has been shown to help mothers produce more breast milk, and to help parents bond with their baby. Nurses also may show you how to give your baby a gentle massage if your baby is ready. Massage has been shown to help some babies.**

Taste and smell

Inside the womb, taste begins to develop at about 14 weeks. Babies can taste many things in the womb, such as the fluid that surrounds them (called amniotic fluid). Foods the mother eats also create tastes and smells. Although the structures of the nose begin to form between 11 - 15 weeks, babies can detect odors in the amniotic fluid through special cells in the nose area.

Kangaroo care has been shown to help premature babies sleep, eat, and grow.*** It also helps parents bond with their infant.

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At birth, babies show a preference for certain tastes and smells and are drawn to the odor of breast milk. Newborns also are drawn to the smell of their own mother and this helps them learn how to suck and then to feed.

**Outside the womb**, these smells can have a calming effect on your baby and may help soothe the baby during tasks that cause pain, such as heel sticks for blood tests.

**What can parents do?** Babies may be soothed by smells they recall from the womb. This includes the scent of their mother and of breast milk. Helping your baby be aware of your scent can help calm him or her at certain times. Work with your baby’s nurses to find out how this can be used in your baby’s care. It is best to avoid smells that your baby would not be exposed to in the womb (such as perfume, lotions, hair spray, etc.).

**Learning about your baby’s senses and special ways to respond to them can be helpful** to your baby and can be a useful way to take an active role in your baby’s care. Talk to your baby’s nurses to learn more about your baby’s cues and how cues can help you respond to your baby’s needs.

Premature babies are like a puzzle and the pieces of that puzzle still are falling into place. It is helpful to remember that what affects one part of the puzzle also affects other parts. That is, what happens in the outside world of the baby (light, touch, taste, sound, smell) affects the baby’s inside (the wiring of nerves and brain). And this, in turn, affects the baby’s growth, learning, and the way he or she relates to others. Despite our best efforts, we can’t make a premature baby’s world exactly like the mother’s womb. But, we can help by being aware of babies' senses and by giving each baby the unique care he or she needs.

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**Notes**

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**Take a closer look at these Pediatrix topics**

- **cues** - B3 - Cues: “How does my baby feel?”
- **jaundice** - F10 - Jaundice (not included in this booklet)

B2 - How babies’ senses develop
Having a baby in the neonatal intensive care unit (NICU) is a journey parents travel with their babies. But it’s a journey of many unknowns. For instance, many parents wonder, “How is my baby feeling? Is he content? Is she feeling pain? Why does his body look so limp? Why does she sometimes turn away when I talk to her?” These are just a few of the unknowns and many parents of premature babies feel confused about what feels good to their infant and what doesn’t. In recent years, doctors and nurses have compiled a list of common movements and facial expressions seen in premature babies that let others know if the baby is content, or feeling discomfort or pain. These often are referred to as your baby’s cues.

**How might cues differ in premature babies?** All babies give cues. In premature babies, these cues change quickly from week to week. There are two main ways in which the cues of premature babies may differ from those of full-term babies:

- Cues may be more subtle — movement in premature babies is often very slight compared with that of full-term infants. So, your baby may give cues you don’t notice at first. You may have to watch closely to see some of your baby’s cues.

- Cues may seem different or may be a response you don’t expect — for instance, your baby may seem fussy and unhappy at the slightest touch. Or, your baby may not seem to respond much at all, called flattened affect. In general, these responses occur because his or her wiring (network of nerves) is not yet mature.

**How do cues help with my baby’s care?** Nurses in many NICUs use these cues to provide care focused around your baby’s needs — a general term for this is developmental care. During care tasks, such as feeding or taking a blood sample, nurses watch for the baby’s unique cues to help guide them in their care of that baby. Knowing the cues for pain can lead them to give the baby pain relief as early as possible and may help avoid giving medicines the baby may not need. The baby’s responses are also affected by hunger and by where the baby is in his or her sleep cycle (asleep, awake or somewhere in between).
What can parents do? Nurses may help point out your baby’s cues so you can learn how to respond to them. As you learn about your baby’s unique cues, it may be helpful to keep in mind these tips:

- **Learning cues helps parents and babies.** Learning how to read your baby’s cues while he or she is still in the NICU will help you support your baby sleeping more deeply and being more relaxed. It often helps improve the baby’s vital signs, such as heart rate and blood pressure.* As your baby learns to relax, you will find this eases a great deal of stress for you.

- **Look for the big picture.** Sometimes a mixture of cues is needed to get the full picture of a baby’s message. For instance, if a baby extends his legs and frowns, it may mean he is in pain. But if he just extends his legs, this may simply be a reflex action and may not mean anything else.

- **Strike a balance.** As parents, you are vital to helping your baby continue the growth and change that still needs to occur. But also be aware that these changes occur slowly. A premature baby’s senses can easily reach overload. If your baby turns away from you due to overload, calmly waiting for him or her to turn back again can often be your best response. While this can be very hard to do, it is very helpful for babies while they are in this process of change.

- **Expect change.** Like the pieces of a puzzle, your baby’s organs, tissues, network of nerves, senses and emotions are still coming together. This evolution is an ongoing process and each piece of the puzzle affects other pieces. So, your baby’s response to others and to the world around him or her will change as part of this larger process. Your baby’s cues will change as these systems grow and change.

### Your baby may show only some of these cues:

Here is a list of common cues and signals your baby may be giving. Use the column on the right to write down your baby’s unique cues. This can help you keep track of your baby’s own responses and can be a helpful aid to other caregivers.

**“I am content.”**

- calm face
- sucks on fingers
- grasps and holds on to people or object
- braces feet

- relaxed posture
- clasps hands together
- easy breathing pattern
- looks mellow

**My baby’s unique cues are:**

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B3 - Cues: “How does my baby feel?”
Your baby may show only some of these cues:

“I’m stressed. This is too much to handle right now.”

- breathing may seem very labored (called dyspnea)
- face changes to a grimace, a worried look, or a frown
- breathing may stop from time to time (called apnea)
- arches his or her back
- becomes very pale
- stiffens and extends arms and legs
- skin looks mottled in color
- spreads fingers (often called the stop sign)
- nostrils flare
- holds hands in front of face
- hiccups or yawns more than usual
- turns away from other people
- stares with eyes wide open
- cries and can’t be consoled
- body becomes limp

“My baby’s unique cues are:

“This hurts. I’m in pain.”

When in pain, a baby shows many of the same cues as for stress, and it can be hard to tell between stress and pain. For babies born before 32 weeks, studies show there are 7 signs that may mean pain:* 

1) fingers spread (stop sign)
2) fisting of hands
3) extending legs
4) frowning
5) increased heart rate
6) squirming
7) arching back

Babies who have been exposed to many painful measures may become used to the pain (sensitized) and thus may show fewer responses to pain.

“My baby’s unique cues are:

Care that may help reduce the pain felt and/or that may treat pain quickly include:

- giving the baby something to suck
- placing blankets around the baby in bed to help support the baby’s body
- wrapping the baby in a blanket
- rocking the baby
- putting something near the infant that has the mother’s smell on it
- staying with the baby until the baby recovers from the stressful event

Ask questions. Talk to your baby’s doctors and nurses about all aspects of your baby’s care. They are aware that learning about your baby’s cues and care can be a complex task, so continue to ask questions until you feel your questions have been answered. The questions listed in the blue box can help you get started.

Notes

Take a closer look at these Pediatrrix topics

- sensory overload - B2 - How babies' senses develop
- sleep cycle - C2 - Caring for your baby in the NICU: about sleep

B3 - Cues: “How does my baby feel?”
The contact between parents and their infants often is described as a dance. That is, a parent responds to his or her baby’s actions (behaviors) by making a face, sounds and movements. The baby, in turn, responds back to the parents. In healthy infants and parents this bonding is a close and constant dance, with each partner taking a step at a time.

What can happen with bonding if a parent and/or child is ill or stressed? For some premature babies and their parents, the baby’s early birth, along with being in the neonatal intensive care unit (NICU) may delay bonding — the process of parents and baby feeling connected with each other. This can be a common issue because there are many things that may disrupt the process in which parents and babies have time to be with and to learn about each other.

Issues that may affect bonding include:
- the baby’s fragile health
- the schedule of care in the NICU
- the parents’ fear and worry for their baby
- the premature baby’s tendency to be less alert than a full-term infant or respond less to the contact with his or her parents
- the mother’s need to regain her strength and health
- the parents’ need to cope with their feelings about the birth event and with the problems they and their baby may now face
- the baby’s need for special care (ways of holding, feeding, etc.) that parents have to learn
- the parents having to learn their baby’s cues
- the baby’s constant change in growth and health

Nearly all premature babies and their parents face some of these issues. When a baby is born prematurely, the problems with physical and/or health challenges he or she may face also may affect the infant’s and parents’ emotions. It is this area that we often may overlook.

What does bonding do? The bonding process affects our emotions and our bodies. Studies show that a premature baby’s bond with his or her parents affects the way the baby grows, functions, feels and behaves for many years.* Bonding can improve the baby’s and the parents’ emotions (feelings and mood) and the baby’s physical state (body function and growth).

How bonding affects emotion: Your baby’s contact with you is the way he or she learns about other people. For your baby, watching you is like looking in a mirror. Your baby’s actions create a response from you. You reflect feelings back to your baby, which helps complete your baby’s experience. That is, your baby reacts but has not yet had enough contact with people to know what kind of response his or her reaction will create.

Through this dance with you, your baby learns how you and others react to him or her. And this has some effect on how your baby feels about him or herself. All of this combined helps your baby learn how to balance his or her emotions — a process called emotional self-regulation. This is the degree to which a baby is able to self-comfort or self-console when he or she is upset. It is the way all humans learn to bring emotional and physical lows and highs back into balance.

Infants who cannot achieve this balance may have extreme emotional ups and downs. For instance, when the baby cries, he or she may get so caught up in the crying that he or she can’t stop. The baby then needs a great deal of outside help (rocking, cuddling) to calm down. As a baby learns how to self-calm (or to regulate), he or she is then able to have longer times of contact with the mother or father and, thus, can achieve more growth and change.

How bonding affects a baby: Every bit of contact with your baby affects his or her emotions and body at the same time. For instance, it helps keep your baby’s heart beat, breathing rate and body warmth balanced. It also adds to the cycle of growth and change in your baby’s network of nerves (the nervous system). As these nerves grow and connect with other parts of the body, your infant becomes better able to balance emotion. Since babies explore their world using ALL of their senses (taste, smell, touch, sight, sound) the contact with you helps growth in all of these areas. Studies of NICU babies show that contact in response to each baby’s unique needs helps some babies sleep more deeply and may help reduce the need for pain medicines.*

**Bonding with your baby is good for you too.**
Bonding with your baby helps stimulate the production of hormones, which may help parents feel content and less stressed. These hormones can signal a mother’s body to produce breast milk, which is healthy for the mother and the baby.

**Shouldn’t bonding be a natural process?** Even with healthy infants, parenting and bonding is not always a natural process or something you should know by instinct. There are often things you have to learn about your baby. It is known that simply taking care of an infant’s physical needs (feeding, clothing, bathing) does not mean the infant will thrive. Infants need the loving bond with another person in order to have the best physical and emotional growth.

**What can parents do?** There is no simple method for bonding with your baby. But knowing what can affect this process for premature babies can help you know what to do and may help improve your baby’s physical and emotional growth. Here are a few tips to help you and your baby keep up the bonding dance of care:

- **Keep your balance.** There may be times when contact with your baby creates discomfort for him or her. Keep in mind that premature babies tire easily and may be stressed easily. Your baby’s stress may simply be a sign for you and does not mean your baby is not bonding with you. It is common for parents to worry and want to focus on their baby. Keeping a balance between too much and too little focus can help both you and your baby.

- **Keep going.** Your baby is always growing and changing. Just when you get used to one set of cues and learn how to respond, expect these cues to change. You may have to learn new cues and respond in new ways.

- **Watch those cues!** Be aware of your baby’s cues — the signals that tell you how he or she is feeling and how much contact your baby can handle at that time. Keep in mind that these cues are a road map that can help improve your contact with your baby.
Communicate to your baby clearly. Parents of premature babies need to give very clear cues in response to their baby. This response often must be more direct and more patient with your infant than would be needed with a full-term baby. For instance, your baby may need more time to switch from being a patient in the NICU to being a baby who is able to enjoy your input.

Seek help with bonding. Being good at bonding is hard for all parents and can bring more challenges for parents of premature babies. Your NICU nurses and doctors can help you learn about your baby’s unique needs and how to respond to his or her cues.

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Premature babies may tire quickly and may be easily stressed. Patient contact with your infant can help the bonding process.

Ask Questions

In an area that is new to you, asking these questions can be helpful:

- What is the main problem?
- What do we need to do?
- Why is it important to do this?

Source: Partnership for Clear Health Communication at the National Patient Safety Foundation™

www.npsf.org/askme3

Take a closer look at these Pediatrix topics

- cues - B3 - Cues: “How does my baby feel?”
- senses - B2 - How babies' senses develop

B4 - Bonding with your baby
At birth, all newborns need a great deal of energy and nutrients from food to help their bodies grow, and to adjust to life outside the womb. Babies who are born early (premature) and/or with a very low birth weight (VLBW) (less than 1,500 grams or 3.3 pounds) may be smaller, may grow at a slower rate, and may have problems with learning and with motor skills as a result of feeding problems.* We know that babies born early undergo rapid growth and change and often do not yet have all the skills required for feeding. They also may have other health issues, such as breathing or stomach problems, that may disrupt the feeding process.

Yet, feeding is more than a process of giving food. It also is a time in which parents are partners with their baby and learn how to respond to their baby’s cues. Because the baby’s network of nerves is still growing and changing, such cues may differ from those of a healthy, full-term baby. Thus, parents of premature babies may have trouble trying to adjust to their baby’s feeding cues. In this topic sheet, we look at the “big picture” of feeding, and at ways to address the unique needs of premature babies and their parents.

**Goals of feeding = food + skills + bonding**

The main goals of feeding are to:
1) provide food for growth and healing; 2) help your baby achieve new skills; and 3) learn cues that help you respond to your baby’s needs and that help the baby learn how to respond to you (this is part of the bonding process). We’ll look at each of these goals below.

1. **Food: What special nutrition needs do premature babies have?** A key goal for feeding while your baby is in the NICU is to help your baby obtain the extra nutrients needed for growth and health.

   In the womb, the baby grows and changes very quickly for the first several weeks. The baby obtains nutrients, such as calcium and iron, from the mother’s bloodstream. Calcium is needed for strong bones and for other body functions. Iron helps build healthy blood cells and promotes growth of the nervous system (the network of nerves connecting the body and brain). As the baby moves around, he or she pushes against the wall of the womb — this helps strengthen the baby’s bones.

   At birth, the baby’s growth and change is disrupted. The body still is growing quickly, but now does not get nutrients (such as calcium and iron) from the mother. The lack of calcium and lack of movement

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against the womb wall may decrease bone strength and growth. Rapid growth of the baby’s organs causes a decrease of iron in the baby’s blood. Iron also may be decreased in babies who lose a lot of blood after birth. Studies show that babies born early have only half the amount of iron as babies born at full-term. The iron deficiency can sometimes delay growth of motor skills and learning. As the baby grows, his or her body uses up energy and protein faster than the baby can absorb it from food. This increases the risk that the baby will not gain the weight needed to grow and to heal.

**How will my baby be fed after birth?** Some babies born before 32 - 34 weeks gestation may need assistance to get the nutrition they need to grow. Breast or nipple feeding, which may be too tiring for some infants, may be supplemented or replaced with tube feedings. Infants that cannot tolerate nipple or tube feedings may receive nutrition through a vein. This is called *parenteral nutrition*.

Providing nutrients through a vein, or through a tube in the mouth or nose, may increase a baby’s risk for ►infection. Doctors are aware of this risk and will remove your baby from the tube when your baby is able to feed without it.

When your baby is ready for breastfeeding, your health care team will work with you to achieve this. If your baby feeds with a bottle, doctors may advise using a special nipple that helps adjust the proper flow of milk. This gives your baby time to rest and to breathe while feeding. In general, your baby’s feeding skills improve as your baby grows.

**2. Skills: Premature birth may lead to feeding problems for mothers and babies.**

For babies, problems may include:

- **Feeding skills** — Babies born early cannot yet put all their feeding skills together. The ►network of nerves that connects their brain and body is not yet fully formed. This affects the baby’s skills with sucking, swallowing, and breathing, which are required in order to feed from a bottle or breast. This skill usually doesn’t develop before 32 - 36 weeks in the womb.

- **Breathing problems** — Even if your baby can suck and swallow, he or she may not be able to breathe well while feeding if the heart and lungs are not fully functioning. Other breathing problems, such as ►respiratory distress syndrome (RDS), also may disrupt feeding.

- **Fatigue** — Feeding requires a lot of energy and may easily tire a premature baby.
For mothers, if you choose to breastfeed, problems with feeding may result from:

- Stress — Being in the NICU with your newborn is a very stressful time. Worries about your baby’s health, being away from your baby, and/or recovering from the birth are only a few reasons for parents to feel stressed. For a mother, stress and other aspects of the birth can disrupt her body’s process of breast milk production (by slowing the body’s release of two hormones, oxytocin and prolactin, that start milk flow in breast tissue).

- Delayed onset of milk — With most full-term births, the mother’s body makes breast milk within 30 - 48 hours after birth. This process is called lactogenesis [lack-toe-JEN-eh-sis]. In premature births, this process can be delayed by the mother’s body. Just as the body of a premature baby is going through many changes, so is the mother’s body. If your baby is born before your own body has gone through the steps required to produce milk, then your body may need time to begin this process. In some cases, holding your baby skin-to-skin (called kangaroo care) may help “jump-start” your body into producing milk. Also, this process may be helped by trying to pump milk within 6 - 12 hours after birth and 6 - 10 times per day.

- Medical problems — Illness and/or medicines given to you before birth may reduce the volume of milk you can produce. Also, it may be a challenge for some mothers to produce enough milk often enough for the baby’s needs. Always check with your doctor when you are given a new medicine to find out if it affects breast milk. After your baby is born, be sure to let your care team know if you would like to breastfeed your baby.

Talk with your doctor, nurse, or a lactation consultant (a person who helps women with breastfeeding questions) for help with any of these issues.

3. Cues: How can I know what my baby wants and what he or she feels? Many studies* show that feeding time is a time during which parent and baby respond to each other’s cues very closely and when parents remain alert to the baby’s unique needs. The baby’s response, in turn, creates a physical and emotional response for the parent.

With premature babies, feeding becomes not only a time to connect with your baby, but also a time to help coach your baby in the skills needed for feeding. Whether you feed your baby from the breast or from the bottle, baby and parents can work together as one system.

There is no single list to describe every baby’s feeding cues. Your baby’s signals to you will depend on his or her unique needs at that time. As a parent, one way you can help your baby is to be aware of these signals and to think about what they might mean. Filling out the chart below can help you keep track of your baby’s feeding cues. Finding ways to respond to different cues is not always easy – talk with your health care team for help with these cues.

<table>
<thead>
<tr>
<th>Cue</th>
<th>What does this mean for my baby?</th>
<th>What are some ways to respond to this?</th>
</tr>
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<tbody>
<tr>
<td>Long pauses in sucking</td>
<td></td>
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<tr>
<td>Rapid breathing</td>
<td></td>
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<tr>
<td>Dribbling milk</td>
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<tr>
<td>Closed mouth, tongue at roof of mouth, head turns away from nipple</td>
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<td></td>
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<tr>
<td>Increased heart rate</td>
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<tr>
<td>Long pauses in breathing</td>
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</tbody>
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**What can parents do?** Feeding is important to your baby’s health and growth. Learn about your baby’s unique needs for feeding and what you can do to help.

In the NICU, talk with the health care team about questions, such as:

- Can I hold my baby skin-to-skin?
- How will any medicines I am taking affect breast milk and my baby?
- Is breast milk the only food my baby needs right now?
- Is there a quiet/private place I can go to breastfeed and/or to pump milk?
- About how many times per day should I try to pump milk and/or breastfeed my baby?
- What is the best type of breast pump to use?

It is helpful to tell the nurses when you will be at the NICU, so they can try to schedule feedings for those times.

**At home:** Most babies are not sent home from the NICU until they are able to feed well, but some premature babies still will need help with feeding at home. This help may include:

Producing breast milk can be a challenge for mothers of premature babies. Keep in mind that this is due to your body’s natural process. Over time, many mothers are able to produce enough milk for their baby’s needs.
- Fortified milk: If your baby is not growing enough or has problems with feeding, doctors may give you a nutrient mix to add to some feedings. This is called fortified milk. Your baby’s doctor, nurse, or dietitian can tell you what it contains and how to mix it with the milk. This is a normal treatment and does not mean there is anything wrong with your breast milk.
- Tube feeding: In some cases, infants who are feeding with a tube may be sent home with the tube still in place. This happens only if doctors think the benefits of being at home outweigh any risks of feeding with a tube at home. If your baby needs this type of help, your NICU team will teach you how to help your baby with this type of feeding.
- Breastfeeding: If you breastfeed your baby, try to pump extra breast milk before bringing your baby home. This will signal your body to keep producing milk, so you will have enough for your baby. Talk to your baby’s doctor, nurse and lactation consultant about when to begin weaning your baby.

**Helpful Tips: Feeding**

- Feed your baby in a calm, quiet place.
- Ask your NICU team to show you how to hold your baby for feeding.
- With either bottle or breast, watch your baby to see if he or she:
  - can latch onto the nipple and stay on to suck
  - can let go of the nipple on his/her own
  - can suck and swallow well
  - stays awake while feeding
  - (you may be able to hear your baby swallow)
  - is relaxed and content after feeding
- Feed your baby according to his or her needs. At first, most premature babies need to be fed about every 3 hours to make sure they are getting enough milk. As your baby grows, feeding may occur less often. If your baby is growing well, he or she may need feeding only “on demand” (when hungry). Your baby’s health care team can help advise you about what is best for your infant.
- Seek help from your NICU team if you have problems with any type of feeding or with pumping milk.

**About breastfeeding**

**Does breast milk help my baby?** Yes. Studies show that mother’s breast milk is the best food for almost all infants.* Doctors will advise if your baby also needs extra nutrients (protein, vitamins, carbohydrates, and fats) added to the milk. Keep in mind that breast milk feedings are helpful for both you and your baby.

For babies, studies show that breast milk is best and is helpful for those born with a low (less than 2,500 grams or 5.5 pounds) or very low birth weight (less than 1,500 grams or 3.3 pounds).** Breast milk of mothers who give birth early (prematurely) is higher in the nutrients and other agents that help fight infection and promote health.*** It is known that babies given breast milk are more likely to have:

- reduced risk for ▶ infection, ▶ retinopathy of prematurity (ROP), and ▶ necrotizing enterocolitis (NEC)

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• a shorter stay in the NICU
• improved growth and function of the baby’s network of nerves — this helps improve vision, learning, and motor skills during childhood
• fewer ear infections, lung problems, and diarrhea during the baby’s first year (which may help prevent future hospital stays)
• reduced risk for sudden infant death syndrome (SIDS), type 1 and type 2 diabetes, childhood obesity, and some other medical problems

For mothers, producing breast milk may have benefits, such as:
• reduced risk for cancer of the breast, ovaries, and uterus • protection against hip fractures later in life
• reduced stress and better bonding with your baby

Women are advised not to feed their breast milk to their baby if they have:
• taken certain strong medicines or drugs (most medications are compatible with breastfeeding but tell your doctor about any medicines or drugs you are taking)
• infections, such as HIV, herpes, or tuberculosis
• active sores on the breasts

Practice makes perfect: If your baby is not yet able to feed from your breast, your doctor may advise non-nutritive breastfeeding. Think of this as feeding practice for your baby. It simply means holding your baby to your breast so that he or she can get to know your taste and smell, and can learn how to latch onto the breast. This also helps you learn how to breastfeed your baby. Studies show that babies’ vital signs (such as heart rate and breathing rate) are more stable when the baby is breastfeeding (or trying to) than when bottle feeding.*

What happens if I can’t breastfeed? Although it is known that breast milk is best for most babies, some women are unable or choose not to provide breast milk. In this case, there are 2 options for babies:
• Donor milk — This is breast milk given by mothers who produce more milk than their baby needs. Your health care providers can give you more details about donor milk.
• Formula — Some formulas are well designed to promote growth and weight gain in premature babies.

Take a closer look at these Pediatrix topics

rapid growth and change - B1 - About premature babies
Cues - B3 - Cues: “How does my baby feel?”
network of nerves - B2 - How babies’ senses develop
bonding - B4 - Bonding with your baby
infection - A4 - About infections
respiratory distress syndrome - F17 - Respiratory distress syndrome (RDS) (not included in this booklet)
stress - D1 - Coping with stress in the NICU
retinopathy of prematurity - F18 - Retinopathy of prematurity (ROP) (not included in this booklet)
necrotizing enterocolitis - F12 - Necrotizing enterocolitis (NEC) (not included in this booklet)
sudden infant death syndrome (SIDS) - C2 - Caring for your baby in the NICU: about sleep

How can sleep help my baby? Newborns spend most of their time asleep. Sleep is required to maintain growth and health in humans. Most full-term newborns sleep about 16 - 20 hours each day. Although losing a bit of sleep does not affect most adults, even a small lack of sleep has a huge effect on babies. For babies born early (premature), sleep promotes the extra growth and changes that are still needed by the brain and other body systems. But, there are unique issues that affect the ability of premature babies to benefit from sleep. Taking a brief look at what happens during the sleep period helps us understand how to address the special sleep needs of infants born early.

Sleep: the basics
While in the womb, the fetus has regular cycles of sleep and movement. These cycles are linked to physical changes. For instance, between 28 - 34 weeks, changes in the baby’s heart rate are linked to dreaming during sleep. In most humans, the timing of being awake or asleep is controlled by the amount of light received. Light affects a gland in the brain (called the pineal gland), which then sets off a sequence of events in the body that affect the need for sleep. This whole process is called circadian [sur-KEY-dee-uhn] rhythm. You could think of this as a natural body rhythm needed for growth and health. Since the need for sleep builds up over time, the body forces you to fall asleep even if you try to stay awake. If you don’t obtain the type of restful sleep your body needs, this natural body rhythm can be disrupted.

Knowing that sleep, growth and health are linked, you can get a picture of your baby’s growth and health by watching how he or she sleeps. To do this, your health care team looks at the baby’s sleep cycles, known as active sleep (AS) and quiet sleep (QS). These cycles begin to appear between 27 - 32 weeks in the womb. Each cycle consists of a group of behaviors that show how your baby is able to respond to the world around him or her.

Your baby has many cycles of active sleep (AS) and quiet sleep (QS) every day. As the baby matures and his or her nerve network becomes more complete, the QS cycle takes over as the main form of sleep. For most full-term babies, the QS cycle takes over around 2 to 3 months after birth. This may take longer to occur in babies born early.
Here’s what happens during the sleep cycles:

**Drowsy**
- baby is moving from awake to asleep
- baby’s movements may seem more smooth and with a few mild startles or jerks
- eyes open and close, but eyeballs appear dull and eyelids look heavy

**Quiet Sleep (QS)**
- called the sorting time — baby’s brain sorts through input it receives while awake, which helps strengthen the complex network of nerves
- is the cycle that is most needed for rest and healing
- signs of QS may include:
  - even, rhythmic breathing
  - little to no body movement
  - lack of eye movement
  (premature babies still may make some noises and movements during QS, but these are less clear than during the AS cycle)

**Active Sleep (AS)**
- also called awake sleep or REM sleep
- baby dreams during this cycle, the brain is very active and its network of nerves continues to grow and connect with other parts of the body
- signs of AS may include:
  - uneven or fast/slow breathing
  - face movements (smile, frown, grimace) and sounds (sucking, whimper)
  - twitching arms, legs, hands and/or feet
  - sucking and swallowing motions
- in full-term babies, AS is the main part of the sleep period for the first few months after birth

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**How does sleep differ in babies born early?** The unique needs that affect every premature baby also affect his or her sleep cycles. Sleep is affected not only by being in the NICU itself, but also by the changes that still must occur in the baby’s body. Ways in which sleep differs for premature babies include:

- A premature baby may move more quickly between being awake and being asleep.
- Moving between being awake or asleep (called transitioning) is harder for premature babies and full-term infants who have severe health problems. These babies also have trouble holding or remaining in either state. This is one way to help assess the baby’s growth and health.
- Sleep may be disrupted by care tasks in the NICU, by certain medicines, and/or by health problems in the baby, such as apnea or other breathing problems. If the rhythm of awake/asleep stages is disrupted (for instance, by staying awake too long), the baby is likely to have a shorter QS cycle during the sleep period. Often, NICU nurses group the baby’s care tasks to avoid waking the baby too often.
Other special needs during sleep: Placing your baby on his or her back to sleep has been shown to be safe for most babies. Yet, this can cause a premature baby’s soft skull to become slightly out of shape, a problem known as *positional plagiocephaly* [pley-jee-uh-SEF-uh-lee]. This problem often goes away as the child grows older, but it can remain in some children. This problem can sometimes be avoided by gently turning the baby’s head, from time to time, during sleep. **Do not roll your baby onto his or her side during sleep because this may increase the risk for SIDS** (see below). Talk to your baby’s doctor and nurse if you have questions about this problem and how to treat it.

Do premature babies have a higher risk for sudden infant death syndrome (SIDS)?

For many years, SIDS has been a leading cause of death among all newborns. It is still not fully known what causes SIDS, but the rate of SIDS has begun to decline in the U.S. Babies born before 37 weeks have a higher risk for SIDS. Parents now are advised to follow certain steps* to help avoid SIDS. The list below includes some ways to address the special sleep needs of premature babies:

**DO**

✓ Place your baby on his or her back for sleeping. Studies** show that sleeping on the back is safer than sleeping on the tummy. Sleeping on the tummy increases the risk for SIDS in most babies, especially in premature babies.

✓ Give your baby a firm surface for sleeping (the baby cannot keep his or her airway clear when lying on a soft bed). Use a crib that meets safety guidelines.

✓ Talk with your doctor or nurse about whether to use a pacifier during sleep (a pacifier may help the baby keep his or her airway open while sleeping).

✓ Allow your baby some time on his or her tummy while awake to help increase skills in pushing up. Watch your baby closely during this time, then turn him or her onto his or her back to go to sleep, or if you need to step away from the crib.

✓ Tell other caregivers (grandparents, babysitters) not to place the baby on his or her tummy or side for sleeping (the rate of SIDS increases if a child who is used to sleeping on his or her back is placed on the tummy or side for sleep).

✓ Set up a sleep routine for your baby. Have your baby sleep in the same place and put him or her into bed when drowsy, not fully asleep. Try not to get into the habit of letting your baby sleep only while you are holding him or her.

**DON’T**

✗ Do not use a crib bumper.

✗ Do not leave loose items in a crib.

✗ Do not allow your baby to sleep on the couch or recliner, or on any surface not approved for infant sleeping.

✗ Do not smoke around your baby.

✗ Do not sleep with your baby in bed with you (the baby can sleep in the same room as parents, but not in the parent’s bed).

✗ Do not over-dress the baby or wrap him or her tightly in blankets as this may cause the baby to become too warm.


What can parents do to help their baby sleep? There are things you can do in the NICU and at home to help support restful sleep, and promote growth and healing for your baby.

In the NICU

- Ask about cycled lighting — The process of dimming lights at certain times to mimic day and night cycles. For babies older than 32 weeks, cycled lighting helps the baby’s body set up his or her internal body clock (the circadian rhythm). Studies* show that for infants older than 32 weeks, cycled lighting increases the babies’ activity during the day, helps them gain weight, and helps them have more restful sleep at night. Since every NICU differs in design and function, talk to your baby’s health care team to see if this might help your baby.
- Ask about kangaroo care — A special way to hold your baby, skin to skin. This can help your baby fall asleep, make the sleep more restful, and can help the baby sleep longer.
- Stay with your baby until he or she is asleep and watch for a few moments. This can help your baby stay asleep longer.
- Learn your baby’s unique patterns for waking up and going to sleep. Before care tasks, such as feeding, help your baby to wake up gradually. You can do this by gently stroking and talking to your baby and by increasing the light in the room.

At home

For parents and their premature babies, going home can be a happy event, as well as a big step with unique challenges. Here are a few tips to help your baby adjust to sleeping when you go home.

- Decrease noise and light — Because the baby’s network of nerves still are growing and changing, premature babies are less able to tune out sound and light, which may cause them to wake often during the night.
- Keep a calm and quiet area — A busy or crowded area can disrupt the baby’s ability to sleep and, again, to tune out all the action around him or her. Limit the number of visitors for a while to avoid too much activity around your baby.
- Give your baby time to adjust — Moving from the NICU to home is a change for your baby, which can sometimes be a challenge. Your baby may need a week or more to adjust to the change in routine and in patterns of care, as well as to the new sights, sounds, and smells. At first, you may find that your baby cries more at home than in the NICU. With time, your baby will adjust to these changes. Playing soft music and providing a night-light for the first few nights at home may help your baby adjust. Gently decrease your use of these during the first week, so your baby won’t need to have these in order to sleep.

• Use slow, gentle movements during care tasks. Keep care tasks brief to avoid making the baby too tired. For instance, avoid bathing, diapering and feeding all at one time. Give your baby time to rest and recover after doing these tasks.

• Avoid drinking alcohol and smoking — Alcohol in the mother’s milk can decrease the length of time your baby sleeps and the amount of time your baby spends in the QS cycle. Smoking increases your baby’s risk for SIDS.

• Refer to the tips on the next page for help with nighttime sleeping.

• Remain aware of your baby’s cues, the signs that tell you when your baby is ready to fall asleep or to wake up. Record answers to the questions below to help you get started. Sometimes it can be hard to know what these cues are, so talk with your baby’s health care team for more help with learning your baby’s sleeping cues.

My baby’s unique cues for sleep

What are my baby’s patterns when he or she falls asleep? ________________________________

________________________________________________________________________________

How long does my baby sleep? ________________________________

________________________________________________________________________________

What are my baby’s unique movements during active sleep (AS)? ________________________________

________________________________________________________________________________

What are my baby’s unique movements during quiet sleep (QS)? ________________________________

________________________________________________________________________________

What support in bed helps my baby remain asleep? ________________________________

________________________________________________________________________________

What helps my baby recover after care tasks? ________________________________

________________________________________________________________________________

What helps my baby move gently from sleeping to waking up? ________________________________

________________________________________________________________________________
Nighttime sleeping tips for babies born early

When you take your baby home, you may have many of the same questions about sleep as other parents of newborns: How often will my baby wake? Should I let her cry when she wakes? What if I put him down to sleep and he wakes right up again? What can I do to calm my baby? While there is no single answer for every baby, there are some basic tips that can help your baby (and you) achieve a restful sleep.

- Premature babies have more cycles of sleeping and waking periods throughout the day than full-term babies. A full-term newborn sleeps about 16 to 17 hours per day and wakes every 3 to 4 hours throughout the day and night. A premature baby will wake more often and stay awake for a shorter time. It is the baby’s changing network of nerves (the nervous system) that affects these cycles. While full-term babies may move easily from one state to another, premature babies often need more help with this.

- As your baby matures, he or she will begin to sleep more during the night than during the day. This often begins around 3 to 4 months of age in full-term newborns, but often begins around 7 months for babies born early.

- Premature babies wake more often during the night.* By 8 to 9 months, most full-term infants can sleep through the night without waking the parents. At this age, babies continue to wake through the night, but learn how to fall back to sleep without help from the parents (called self-soothing). Most premature babies will require more time to learn these self-soothing skills. Many factors affect self-soothing, such as the baby’s bedtime routine and the room where he or she sleeps. It is also affected by the growth and change in the baby’s network of nerves. As this network matures, the baby will improve at self-soothing.

- Crying does not always mean your baby is hungry. You may notice that your baby’s cry sounds different with different problems. When your baby cries at night, also check the baby’s body temperature, position in bed, and diaper. And keep in mind that many premature babies need extra help getting back to sleep.


**Take a closer look at these Pediatrix topics**

- apnea - F3 - Apnea of prematurity (not included in this booklet)
- kangaroo care - B2 - How babies’ senses develop
- going home - E1 - Going home with your baby: about the discharge process

**C2 - Caring for your baby in the NICU: about sleep**
What is a newborn screen? A newborn screen is a blood test that shows if your baby is at risk for some problems of genetics and/or metabolism. Metabolism refers to the many chemical processes that occur in our bodies to keep us healthy. If a part of this process does not work as it should, this is called a metabolic/genetic disorder. Genetic disorders are caused by a problem with substances (chromosomes and genes) that act as instructions for the body. Metabolic disorders can sometimes be a problem that is passed through families, although this is not always the case. Some of these problems may be unique to the baby and neither parent is a carrier of the disorder.

Although most of these problems are not common, testing for them early in the newborn’s life may help slow down any disorder that may exist and/or may help prevent damage from it.

Why have this screening test? There are 3 main reasons to have your baby tested:

- **Testing may slow down and/or prevent health problems in your baby.** Metabolic/genetic disorders can’t be identified by simply looking at your baby. Many of these problems do not show any signs until they have caused some type of damage (such as brain damage) that leads to long-term problems with motor skills, learning, and memory. Some babies may show signs of a problem within 24 - 48 hours after birth, such as continual vomiting, limp arms and legs, or a strange smell to the urine and/or the breath. But these signs often are hard to tell from other medical problems. Finding out about these problems early in the infant’s life can help the infant, the parents, and the family, if it helps prevent long-term damage.*

- **State laws now require all newborn babies to be offered tests for some rare disorders before leaving the hospital.** The types of tests required vary from state to state. You can contact your doctor or your state’s health department to find out which tests are required in your state.

- **The test may show if you or your baby is a carrier for a certain condition.** Therefore, even though your baby does not have the condition, you or your baby could pass the problem along to other offspring in the future.

What problems does this test look for? The test looks for many conditions, all of which are caused by a missing enzyme in the body. Some problems you may have heard about, such as phenylketonuria [fen-lkee-toh-NOOR-ee-uh] (also called PKU), sickle cell anemia, or cystic fibrosis. The test varies from state to state. Check with your doctor and/or with your state health department to find out which conditions are included in your baby’s screening test.

What can be done for these disorders? Treatment depends on the disorder and may include providing a special nutrient in the child’s diet or removing certain foods from the diet. Treatment also may include treating any problems caused before the condition was found.

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**When is the screening test done?** Testing is recommended to be done in the first week of life. The exact timing depends on when feedings are started and whether the baby has other health problems, because these may affect the results of the screening test. If your baby is transferred to another hospital, be sure to check that one of the hospitals performs the test.

**Would test results be any different for a premature baby?** Some of the special care a baby receives in the NICU can disrupt the test results. This care may include 1) **transfusions** of red blood cells, 2) a type of feeding process called **total parenteral nutrition (TPN)**, or 3) steroid or thyroid medicines that the mother may have taken during pregnancy. In this case, your baby’s doctors and nurses will balance the baby’s care needs with the right timing to perform the screening test.

**How is the test done?** The test requires a small sample of blood from your baby. This often is done by taking a small drop of blood from your baby’s heel. The drop is placed on a piece of filter paper and sent to a lab for testing.

**How soon will we have the results?** This can vary by state or hospital. The American Academy of Pediatrics advises that test results should be reported to the baby’s doctor within 2 weeks of the baby’s birth.*

**Does this test find every possible problem?** No. The conditions tested for depend on what the state law requires. Talk with your doctor and/or your state health department to find out about tests that may be given for other conditions.

**Does a “positive” test result mean my baby definitely has one of these problems?** No. The test shows if your baby may have a problem. If this happens, you will be advised to have another test done and to have your baby checked by a doctor. The test results, along with any signs or symptoms, will help doctors know if your infant has one of the disorders.

**What can parents do?** Parents play an important role in their infant’s health care. Here are a few ways you can play a role in your baby’s newborn screening test.

- Contact your baby’s doctor or your state health department if you have questions about the test and what to do next.
- Find out the results of the test. Take your baby for another test if you are advised to do so.
- Use the sources provided to find out more if the test shows your baby may have a problem.
- Take your baby for all checkups and referrals to specialists as advised by doctors.
- If your child has special health care needs, contact your state health department to find sources of help.
- Tell the person doing the test if you were given a steroid or thyroid medicine during pregnancy. These sometimes may affect the results of the screening test.

►**Take a closer look at these Pediatrix topics**

►**transfusions - F8** - If your baby needs a blood transfusion (not included in this booklet)
►**total parenteral nutrition - C1** - Caring for your baby in the NICU: feeding

When your baby is in a neonatal intensive care unit (NICU), stress quickly becomes a big part of your life. Talk to any parent who has been there and you’ll find there are many reasons for feeling stressed at this time. Here are a few thoughts from some of these parents:

“"We never know what will happen next — one day, our son is doing well, but the next day there’s a problem. Our feelings and hopes go up and down all the time.

The watching and waiting is hard. I want to feel like I can take some sort of direct action to make my child better.

This is something we never expected. We thought we were about to have a healthy child, but then everything changed so quickly.""

If you have had even a few of these feelings, you are not alone. For parents of a baby in the NICU, life becomes a whirlwind of actions and emotions. Hope, one minute, may be followed by worry or sadness the next. For some parents, the uncertainty may last for months. Yet, no matter how long it lasts, the stress that comes with it can affect your physical health and emotional health, as well as that of your baby and your family.

Studies show that parents of babies in the NICU face unique stressors,* such as:

A change in your role as parent — The role change for a parent is one of the greatest sources of stress. Being in the NICU disrupts your normal forms of contact with your baby. For instance, at first you may not know if you can touch, talk to, or feed your baby. Parents of babies in the NICU report that their biggest stressors are not being able to hold or to help care for their baby, to protect him or her from pain, or to share their baby’s birth with other family members.**

Feeling a lack of control — It is very hard for parents to know their baby is in pain and that they can’t take direct action to stop it. Some parents may feel confused about the way their baby acts or behaves while in the NICU. All of these feelings can make parents feel they have no control over events. In some cases, parents also may feel guilt that they cannot help their baby, may have caused an early birth or could not prevent him or her from being ill.


Parents’ health — Mothers who have just given birth may be trying to recover from the birth, may not feel well, and may feel a terrible loss at being separated from their baby. Fathers of these infants often feel the double stress of having a spouse in one unit and an infant in another.

Time — The stress for parents can last for a while, even after your baby is released from the NICU. Some studies have found high levels of stress in parents up to six months after discharge. Mothers of high-risk, very low birth weight (less than 1,500 grams or 3.3 pounds) infants were found to have some degree of distress even when the child reached two years of age. For parents who endured a high-risk pregnancy, this stress may have begun several months before the birth.*

What is stress?
Although stress is common, many people do not really know how it occurs or all the ways it can affect their lives. Here are a few main points about stress that often are overlooked:

• Stress affects the mind and the body. It not only affects thoughts and feelings, but also affects the body in ways you can feel (such as increased heart rate) and in ways we cannot feel (such as an increase or decrease in your immune system response). This is why some people get a cold or other health problem when stressed, or why an existing illness may worsen. In some women, stress also can affect their ability to breastfeed their infant.
• The effects of stress occur even when you don’t know it (for instance, through increased blood pressure or other physical effects).
• A person’s stress also affects family and friends. If you think of family members as being like ripples in a stream — when a ripple occurs several more follow. Likewise, when one family member is very stressed, it affects the others. When families are under a great deal of stress, problems often also arise between family members.
• Men and women react to stress in different ways.** Women tend to feel more stress than men. They also are more likely to look for ways to minimize the stress and thus are more prone to feeling depressed. Men may be more likely to discount the stress and to ignore their own feelings.

What are some signs of stress? At a time when many events and feelings seem to rush by and you are so focused on your baby, it is easy to forget about how you are feeling and coping. Keeping your own emotions balanced can be very hard during stressful times. Often, you don’t even know you are feeling such stress until it lets you know it’s there. That is, the stress that builds up inside during these times begins to show signs, physically and emotionally, that it’s there. These signs may include illness (both short-term problems, such as a cold, as well as long-term problems, such as a chronic illness). Other signs may include behaving in ways that are out of character — you may think, “it’s not like me to act like this.” For instance, this could be exploding in anger at little things. Or crying at what you once would have thought to be a small

problem. The parents’ relationship also may be affected by the stress. Sometimes people adopt habits, such as drinking, smoking or binge eating, that they feel relieves the stress. You may become overly anxious, depressed, or too focused on small things. You may find it hard to focus, think clearly, or make decisions. All of these are signs that the stress is becoming too much for you and are ways in which your body and mind attempt to help you feel in control of an event in which you have no control.

How do I really know when the stress is too much to handle on my own? There’s no right or wrong answer, but a general guideline used by mental health experts is that when these actions or feelings begin to disrupt your daily life or your ability to carry out daily functions, then it’s time to seek help from a person trained in this area. Although sharing your feelings with others is helpful during stressful times, you often miss the signs that the stress is affecting you.

What are some ways to deal with stress? What does coping with stress really mean? Briefly, it means learning how stress affects you, how to deal with it as best you can, and learning how to limit its impact upon you and your family. Since the event(s) causing the stress won’t simply go away, you have to figure out how to deal with it.

Keep in mind that people react to life events in different ways and have different coping skills to handle (or not to handle) extreme stress. The key idea behind any type of coping is to express — which means to allow the stress to escape from both body and mind. Here are a few ways to do this.

**Talk** — In one study of NICU parents, those who did not talk about their feelings also were more likely to have signs of *acute stress disorder* (ASD). It is known that when people hide their emotions, they do not allow the body or the mind to process the trauma. If they don’t process the trauma, then they don’t adapt to it or find ways to cope with it.

**Be active** — Both sports and hobbies are active ways to release energy and stress, and to express feelings through actions, words, art or music.

**Breathe** — When under extreme stress, the body prepares for fight or flight by sending energy and oxygen to muscles and away from the brain. At this time, you also may focus on the cause of the stress and forget to breathe deeply. When vital oxygen does not reach the brain, you feel unable to think and to make decisions.
This often is why you may hear others say to take a deep breath when stressed.

**Be aware of how you are feeling** — Be aware of your own body’s signals for stress. Think about healthy ways to address it that work for you.

**Rely on family support** — Families often provide vital support during extreme stress. In a study of NICU parents, those in families that pulled together and expressed their feelings showed fewer signs of extreme stress.* But this means finding ways to support each other. In the study, family members who tried to cope with their own stress by controlling others in the family had a negative effect on the family system.

**Be involved in your baby’s care** — A major source of stress for parents is the loss of your role as a parent. Being an active partner in your baby’s care can help reduce feelings of helplessness and anxiety.** For instance, you may be able to help feed your baby or help with other care tasks. Talk to your baby’s doctors and nurses about ways you can partner in his or her care.


►Take a closer look at these Pediatrix topics
►depressed - D2 - Depression among parents of NICU babies

D1 - Coping with stress in the NICU
Depression is a problem that is widely misunderstood. It may affect any parent who has endured the stress of having a baby in the neonatal intensive care unit (NICU). Although it can be a common problem during such a stressful time, it may be overlooked by health care staff, family, friends and by parents themselves. The effects of depression range from mild to severe. Many people often feel ashamed of their low mood and try to hide it from others. Yet, this approach may lead to worse depression that can have a lasting effect not only on you, but also on your spouse, your family, other children and your new infant.

Causes: Depression can sometimes be a hidden problem among parents of premature babies. It is well known that depression, in any person, is caused by a mix of factors, such as a family history of depression, a chemical imbalance, and life events. One of the main factors is severe and prolonged stress. For parents of babies in the NICU, stress may be physical, emotional, and quite prolonged. Parents endure the acute event of their baby’s birth and/or ill health. They may have had a stressful pregnancy and their own ill health. They then may face the prolonged stress of caring for a baby who may have a range of physical and emotional needs. The added problems of learning to cope with the subtle changes in their infant’s cues and learning how to bond with their baby often adds to feelings of stress and depression. Many studies now show that babies born early present more challenges as they get older and that parents of multiple births have a higher risk for depression because these stressors are compounded. Add to this mix other emotions, such as guilt, fear, worry, grief and many others, and the triggers for depression are set.

**NICU parents and depression: A few facts**

- Depression after birth of a child can affect both parents. Up to 53 percent of parents of premature infants may be affected by depression to some degree.*

- Depression is more than just sadness. It brings with it both physical signs and emotions all wrapped into one. A key feature of severe depression is feeling a profound loss of a sense of self and a loss of control over life’s events.

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You are not alone — depression affects 1 in 10 women at some point during pregnancy and after birth.*


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Brought to you by Pediatrix Medical Group through The Center for Research, Education and Quality. To learn more, visit: pediatrix.com/forparents

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How do I know if I’m depressed? It can be hard to tell. Often, you may be so focused on your infant that you are not aware you are feeling depressed. It often builds up over time and can sneak up before you notice it. Friends or family members may notice it, but you may not believe them. Since it is easy to confuse stress with depression, mental health experts advise that one way to know if depression is affecting you is if your mood and the way you feel disrupts your ability to carry out daily activities. Some key signs of the onset of depression may include:

- anxiety
- binge eating
- crying often
- fatigue
- fear of being alone
- feeling guilty or hopeless
- feeling overwhelmed
- low mood most of the day
- sleep problems
- low mood nearly every day
- lack of appetite
- guilt
- panic attacks
- obsessive thoughts or worries

Keep in mind that symptoms may range from mild to severe and differ in everyone. Many symptoms may get worse with lack of sleep.

How can depression affect me as a parent? Along with the signs listed above, depression also can affect your actions as a parent. For instance, you may feel distant from your baby and may engage less with your baby. For some women, it also may decrease the ability to breastfeed.*

How can my depression affect my baby? Many studies now show that depression in either the mother or father may lead to problems with the baby’s behavior and physical health. Infants use ► cues to mirror their parents’ emotion, forming their own self-image using their parents’ reaction to them as a guide, and rely on this process in order to ► bond with the parent. Babies of depressed parents may have problems keeping their own moods in balance. Studies show that infants of depressed parents may have poor sleep patterns,** increased heart rate, decreased muscle tone, poor eating, and slower growth. Studies also found these infants to be less active and harder to console.***

Many people are not aware of the domino effect emotions may have within families. The issues that affect one member may also affect others. Everyone changes their own behaviors and feelings in order to adjust to the other person, which can lead to a downward cycle that affects the entire family.

What can be done to help depression? While there are no quick answers to this question or simple steps to follow, there are a few ways to help you begin to address depression:

- **Keep in touch with others.** Don’t be afraid to share your feelings with others. In some cases, simply talking to friends or family can help you keep stress under control and may prevent the onset of depression. You can also ask the NICU staff if they know of support groups consisting of other parents who would like to talk and share their own stories.

- **Try to take action once you find out a problem exists.** Seek help from a mental health worker, such as a counselor, psychotherapist, psychologist, psychiatrist or a member of the clergy. You can find sources of help at the hospital and/or within your community. The medical and nursing staff may also help recommend someone to you.

- **In some cases, taking medicine along with talk therapy may be helpful.** If a doctor advises this, ask about the risks and benefits of the medicine, especially if you are breastfeeding. Since any type of medicine that mothers take can get into breast milk and affect the baby, it is best to talk with your doctor before taking any medicine.* If, at any time, you think you may be in danger of hurting yourself, your child or someone else, seek help right away. You can phone one of the hotline numbers listed on the NICU Resources page, phone 911, go to a hospital or ask someone you know to help you find help.

- **Help yourself and your baby at the same time.** Studies show that treating depression in parents should target not only the parents’ symptoms, but also should address the parent-infant bond.** A child life specialist or a psychotherapist who has special training to work with infants can help with this. Using kangaroo care (skin-to-skin contact with your baby) can be helpful. Not only is it known to help with bonding, but it also causes the mother’s body to release oxytocin, which may help improve mood for some women.***

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Factors that may increase your risk for depression

<table>
<thead>
<tr>
<th>Depression before pregnancy</th>
<th>Alcohol or other drug abuse</th>
<th>Unsupportive spouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history of depression</td>
<td>Premenstrual syndrome (PMS)</td>
<td>Depressed spouse</td>
</tr>
<tr>
<td>High levels of stress and worry</td>
<td>Breastfeeding problems</td>
<td>Other life events</td>
</tr>
<tr>
<td>Pre-term or high-need infant</td>
<td>Sudden stop to breastfeeding</td>
<td>Problems with marriage or partner</td>
</tr>
<tr>
<td>Little to no social support</td>
<td>Child care stress</td>
<td>Depression at other times in life</td>
</tr>
<tr>
<td></td>
<td>Unemployment</td>
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</tbody>
</table>


Keep in mind that taking time for yourself can also help you address depression. One option is to ask others to help care for your children from time to time, so you can take time to help yourself find your way through this complex problem.

Although depression can be a very difficult problem to live through, most people recover from it. Knowing the signs of depression and when to seek help for yourself and your family are key steps in finding a way forward.

Notes

Take a closer look at these Pediatrix topics

- stress - D1 - Coping with stress in the NICU
- cues - B3 - Cues: “How does my baby feel?”
- bond - B4 - Bonding with your baby

D2 - Depression among parents of NICU babies
When can my baby go home? In most cases, parents can take their baby home once the baby is able to do certain things without help:

- **Breathe** — Your baby must be able to breathe without any help from equipment. The baby should have a period of time with no prolonged pauses in breathing (that is, no apnea). In a few cases, babies may be sent home with oxygen support and parents are shown how to use this.
- **Eat and grow** — Your baby must be able to suck from the breast or a bottle and must be gaining weight at a healthy rate.
- **Keep warm** — Your baby must be able to keep his or her body heat stable while fully clothed in an open crib. In most cases, babies who weigh more than 4 pounds (2,000 grams) can maintain their temperature.

Sometimes, a baby must remain in the neonatal intensive care unit (NICU) a while longer if he or she still has other health problems. You may be asked to “room in” with your baby (stay overnight in the NICU) shortly before discharge to help you learn how to address any issues your baby may have during the night.

What is the purpose of a discharge process? Babies born premature or with health problems have unique needs that also must be met at home. Leaving the watchful care of the NICU staff can be stressful for parents. For instance, along with the issues listed above (breathing, feeding, keeping warm), other unique needs that may be addressed at home include:

- checking your baby for signs and symptoms of infection and jaundice
- safely giving your baby medicines
- learning about infant cardiopulmonary resuscitation (CPR)
- learning about car seat safety (small babies may have breathing problems when placed in a car seat, so you should know how to use a car seat)
- tracking the growth and change in your baby’s motor skills and emotional balance (neurodevelopment)
- follow-up visits to check for healthy growth, nutrition, hearing, and vision in your baby

Problems may quickly become serious for premature babies after discharge; yet, studies show that thorough follow-up care and prompt treatment of problems can help avoid further health problems and returns to the hospital.*

With so many details to track, it is helpful to have a structured discharge process designed around your baby’s unique needs. The purpose of the discharge process is to make sure all aspects of your baby’s needs are addressed before you go home. This includes looking not only at aspects of your baby’s health, but also at the unique needs he or she may have at home, any special training required, and linking you to sources of help within your community. The people involved in the discharge process may include your baby’s nurses, doctors, a social worker or care coordinator, and the baby’s primary care doctor. The discharge process varies with every NICU — for some, it may occur within one day; for others, it may occur over several days. Hospitals also will have forms for you to sign and/or discharge requirements to discuss with you.

The American Academy of Pediatrics advises that the discharge process should include:

- educating parents about their baby’s needs
- helping parents find and contact a primary care doctor for the baby
- arranging for follow-up care
- developing a plan of care for home
- locating and coordinating other services for support and help at home
- assessing the baby for medical problems


What should parents do? There are many key actions you should take to help your baby make the move from the NICU to home. Below is a general list of key steps you should follow.

- ✔️ Work with your baby’s health care team to make sure the steps listed in the box above take place and to make sure all your questions are answered.

- ✔️ Know what tests have been done for your baby before leaving the hospital and what tests still need to be done.

- ✔️ Record details about your baby, such as tests performed before discharge, medicines to take home, training received, and other details.

- ✔️ Make a list of the names and phone numbers of your baby’s main doctor and any other health care providers.

- ✔️ Know when your baby is due for checkups and be sure to take him or her to every checkup advised, including recommended visits to a specialist.
To bring home your baby:

- Ask if a copy of your baby’s discharge summary is available.* This is a copy of the medical notes made about your baby while in the NICU that gives details about health problem(s), treatment, medicine(s), follow-up needs, other types of medical help advised, and what information parents have been given. Make a copy for your baby’s primary doctor and keep a copy of this file at home — it may be useful if you change doctors or move to another town/state.

- Know what signs may show your baby is having health problems and who to contact if this occurs. Make sure you receive training about car seats, giving medicines, and other special issues about your baby’s care. Read to keep up-to-date about special aspects of your baby’s care, such as feeding and sleep.

- Look into costs involved with your baby’s care. If you have health insurance, find out what is covered. If you do not have health insurance or if your plan does not cover all your baby’s needs, find out about other sources of help.

- Take time out to care for yourself. Keep in mind that you have been through a stressful time and that reducing your own stress also will be helpful for your baby.

It is important that you get all of your questions answered before you bring your baby home.

**Building bridges to care.** Leaving the NICU is a change for you and for your baby. The discharge process is like crossing a bridge from one care setting to another. Not only do you need to know what to do and how to handle issues at home, but you also need to be sure there are doctors and nurses available to help you, your baby, and your family through the years ahead.

**Moving forward . . . talk to your baby’s doctors and nurses about these issues:**

- How soon can I return to work?
- When can I place my baby in day care?
- When can I leave my baby with other care providers?

**Take a closer look at these Pediatrix topics**

- **Apnea** - F3 - Apnea of prematurity (not included in this booklet)
- **Emotional balance** - B1 - About premature babies

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When you and your baby are ready to leave the neonatal intensive care unit (NICU), doctors may prescribe medicines to give your baby at home. Here are a few tips to help you make sure you are ready to give medicine safely.

**Before you leave the hospital, check and double-check.** Hospitals are advised to provide patients (or their parents) with a complete list of medicines the patient will be taking after discharge, as well as instructions about how to take the medicine.* When you are prescribed medicines to take home with your baby, health care staff are advised to ask you to repeat the instructions they give you about the medicine. It also is a good idea to carry a list of your baby’s medicines with you at all times. If you need to seek urgent care for your baby, having this list handy is very helpful to doctors.

Mistakes with medicines are one of the most common types of medical errors.** These errors have a higher risk of causing harm in babies than in adults. Babies are at higher risk when taking medicines because:

- most medicines are made for adults, so they have to be prepared in a special dosage and/or formula for babies
- a baby’s body is less able to process medicines (especially if the baby is very small and/or ill)
- babies cannot tell you when they feel ill due to a medicine, so parents often don’t know if the medicine has certain side effects

A time to be extra careful with medicines is when your baby changes doctors, is admitted to the hospital, transferred to another hospital, or is referred to a different type of doctor for certain health problems. These often are called transitions in care. It is helpful to have an updated list of your baby’s medicines that you can give to his or her doctor at these times. Hospital staff are now advised to check your list against any other medicines that might be prescribed for your baby.*

**Giving your baby medicines at home: what can parents do?** Studies show that parents are more likely to make a mistake when giving medicine to an infant or toddler, than when giving it to an older child.* The effects of medicines vary with every baby, mainly because the dose given is based on the baby’s weight. If your baby was born early and/or with a low birth weight, medicine dosages will differ from those given to healthy, full-term infants of the same age. A key safety step for parents is to make sure you are always giving your baby the correct dose and giving it exactly as prescribed by his or her doctor or nurse.


Here are a few more helpful safety tips:*  

### Things to know about your baby’s medicines:
- what it is and what it does
- amount to be given
- timing for each dose
- how to give the medicine
- side effects to be aware of
- where to find help if you have questions
- the name of the medicine (the brand name and the generic name)
- what to do if your baby vomits the medicine

**Phone 911 if your baby needs urgent treatment.**

- Read all of the information you are given about the medicine. This includes reading the package label. If there is anything you don’t understand, always ask the doctor or nurse.
- Always talk to your baby’s doctor if you have questions or if you are confused before stopping any medicine or changing the dosage advised. If your baby has a severe reaction to the medicine, **phone 911**.
- You may be given a device (a small cup, spoon or dropper) to measure the medicine dose. Use only this device when you are giving the medicine to your baby. If you were not given a device to measure the dosage, find out if you need one.
- Do not give your baby any other medicines until you have checked with his or her doctor. This includes any medicines for which you do not need a prescription.
- Do not give your baby’s medicine to his or her siblings or to any other child.

### My baby’s medicines

<table>
<thead>
<tr>
<th>Baby’s name:</th>
<th>Date:</th>
<th>Current weight:</th>
</tr>
</thead>
</table>

My baby takes this medicine (**circle one**) morning afternoon bedtime

<table>
<thead>
<tr>
<th>Name:</th>
<th>for this reason:</th>
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</table>

I give my baby this amount: ________________ by

I give it to my baby (**circle one**) before meal with meal after meal

My baby takes this medicine (**circle one**) morning afternoon bedtime

<table>
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<tr>
<th>Name:</th>
<th>for this reason:</th>
</tr>
</thead>
</table>

I give my baby this amount: ________________ by

I give it to my baby (**circle one**) before meal with meal after meal

**Take a closer look at these Pediatrix topics**

**discharge - E1 - Going home with your baby: about the discharge process**

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*Centers for Disease Control & Prevention. For Parents: Young Children and Adverse Drug Events. From www.cdc.gov/ncidod/dhqp/ps_forParents.html#q3

E2 - Medicine(s) for your baby at home*
It is a happy time when you can finally take your baby home from the neonatal intensive care unit (NICU). For many parents, it may also be a stressful time with many questions. Like all new parents, you are about to begin a journey filled with many unknowns. Yet, if your baby has spent a few days or more in a NICU, you may have even more questions, such as:

What can I do to help my baby have a healthy future?
How will I know if my baby needs help?
Where can I find help for problems that may arise?

The purpose of this topic sheet is to give you a broad idea of issues you may encounter with your baby. It is based on what is currently known about babies who have been born early (premature) and/or with a low birth weight, and/or who have been ill. Keep in mind that this is only a guide to help you along the road ahead.

First: A good place to begin this journey with your baby is to make a list of your baby’s strengths and talents — to know what your baby can do. This can help you find ways to support your newborn’s unique strengths (such as feeding skills, speech and movement, etc.), as well as to find out in which areas your baby may need extra help. Use the box below to list the strengths you (and your baby’s nurses and doctors) observe in your infant.

My baby’s strengths are:

• ____________________________________________
• ____________________________________________
• ____________________________________________
• ____________________________________________
• ____________________________________________
• ____________________________________________

This topic sheet is simply a tool to help you address any issues that may arise along the road ahead. If problems are addressed early, it is often easier to limit their effect on your baby.
Next: looking at the big picture. Having spent time in a NICU, you are very aware that your baby began life in a way that is different from other newborns. You may already know if your baby has special needs, such as delayed growth, hearing or vision problems, or other health problems. Studies show that, along with these issues, infants born early and/or with a low birth weight also have a higher risk for learning or behavior problems that may affect their ability to progress at school. Although the impact of this decreases by 36 months for many children, it is vital for parents to be aware that problems may occur and to take their baby for all checkups or referrals to a specialist as advised by their baby’s doctor. Many of the problems affect learning, motor skills and language. These problems may appear around pre-school or school age and can affect your child in ways you may not notice right away. With careful follow-up from your baby’s doctor, many problems can be decreased or avoided.

How can I know if my baby may need special help? Along with taking your baby for all checkups with health care providers, you can help track your baby’s progress by asking yourself these questions:*

- How does my baby respond to light, touch and sound?
- Is my baby losing weight and/or not eating?
- Is my baby sleeping well?
- Is my baby learning new skills (such as talking, walking, playing)?
- Has my baby stopped learning new skills?
- Has my baby lost skills he or she had learned earlier?

What can parents do? A key step for parents is being aware of problems and being prepared to address them. Take your baby for all checkups advised by doctors as this plays a key role in helping you keep track of his or her health needs throughout childhood.**

Ask questions and more questions! Talk to your baby’s doctors and NICU team about your questions. This is your first line of help for your baby. They can point you to other sources of help.

Keep yourself up-to-date. The more you can learn about your baby’s unique needs and how time in the NICU may affect him or her, the better you will be able to tackle any issues that arise later.

*B Massachusets Family Voices. From www.massfamilyvoices.org
Be prepared for visits to your baby’s doctor. Your baby’s feeding skills and sleep habits are vital factors that affect his or her health. Doctors will ask about these issues, among others, during your baby’s follow-up visits. It can be helpful for you to keep a written list of daily actions, such as how often your baby sleeps and for how long, how often your baby feeds and for how long*, as well as other things you notice about your baby and questions you may have. Take your list to your baby’s follow-up visits to help the doctor understand your baby’s health and address any problems at an early stage.

Find out about local sources of help, such as:

<table>
<thead>
<tr>
<th>Breastfeeding support</th>
<th>Infant/child health assessment program</th>
<th>Language services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community health worker</td>
<td>Women, Infants and Children (WIC) program</td>
<td>Smoking cessation</td>
</tr>
<tr>
<td>Family planning</td>
<td>Mental health services</td>
<td>Social worker</td>
</tr>
<tr>
<td>Financial planning</td>
<td>Group shelter/housing authority</td>
<td>Unemployment office</td>
</tr>
<tr>
<td>Parent hotline/support group</td>
<td>Public health nurse home assessment</td>
<td>Genetic counseling</td>
</tr>
<tr>
<td>Medicaid program</td>
<td>Programs for children with disabilities</td>
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</tbody>
</table>

Take care of yourself. Being a parent is hard work. Studies show that parents and family members of children with health problems may have increased stress as a result of these problems.** As a parent, it can sometimes be hard to talk to others about these issues. Keep in mind that your baby’s health care team knows that healthy parents are required in order to have a healthy baby. The health care staff can help put you in touch with many types of people to help with the following:

<table>
<thead>
<tr>
<th>Single mother</th>
<th>Disturbed mother/baby relationship</th>
<th>Employment problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teen mother</td>
<td>Inadequate support system</td>
<td>Parent abused as a child</td>
</tr>
<tr>
<td>Crime and/or legal problems</td>
<td>Substance abuse</td>
<td>Abuse or violence in your home</td>
</tr>
<tr>
<td>Depression in either parent</td>
<td>Housing problems</td>
<td></td>
</tr>
<tr>
<td>Need for financial help (such as food stamps, WIC or Medicaid)</td>
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</table>

Farewell

You now are able to eat, breathe, sleep and grow without the help of the NICU, and it’s time to venture along the road ahead with your parents and family. You have been a bright star among us in the NICU and you have helped make our lives very special. We wish all of you a healthy and happy journey in life.


Where can we find help for our baby and family? You may find the following sources below helpful. Most of these sources can be accessed with a computer. If you do not have access to a computer, your local public library or your baby’s doctor’s office may be able to help you access these websites.

- **American Academy of Pediatrics** provides information about child health: [www.aap.org](http://www.aap.org).

- **The American College of Emergency Physicians** provides an *Emergency Information Form for Children with Special Needs*, a blank form for parents to complete and keep with their child’s health records: [www.aap.org/advocacy/blankform.pdf](http://www.aap.org/advocacy/blankform.pdf)

- **American Board of Internal Medicine Foundation** provides a list of support organizations for parents, families, and caregivers of children with health care needs: [www.abimfoundation.org](http://www.abimfoundation.org)

- **Centers for Disease Control and Prevention** provides information about child development through its program, “Learn the Signs: Act Early”: [www.cdc.gov/ncbddd/autism/actearly](http://www.cdc.gov/ncbddd/autism/actearly)

- **Early Childhood Learning & Knowledge Center**, operated by the U.S. Department of Health and Human Services, provides information and resources for parents about child health and development: [http://eclkc.ohs.acf.hhs.gov/hslc](http://eclkc.ohs.acf.hhs.gov/hslc)


- **Family Voices®**, a national organization that supports family-centered care for children with health care needs, provides information and support tools for parents, including a list of state health programs for parents: [www.familyvoices.org/toolbox](http://www.familyvoices.org/toolbox)

- **Healthy Steps for Young Children** is a national program designed to help children develop during the first three years of life. For more details and to find out if there is a program in your area, visit: [www.healthysteps.org](http://www.healthysteps.org)

- **The National Early Childhood Technical Assistance Center**, operated by the U.S. Department of Education, helps parents of infants, toddlers and pre-school children with special needs find early childhood services in their area: [www.nectac.org](http://www.nectac.org)

- **New Health Partnerships: Improving Care by Engaging Patients**, created by the Institute for Healthcare Improvement, provides resources and support for patients and their families to manage their own care within the health care system: [www.newhealthpartnerships.org](http://www.newhealthpartnerships.org)

- **Zero to Three®**, a national, non-profit organization that promotes the health and development of infants and toddlers and provides information about many topics for parents: [www.zerotothree.org](http://www.zerotothree.org)

E3 - The road ahead: sources of help
<table>
<thead>
<tr>
<th>Topic</th>
<th>Sources for help</th>
</tr>
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</table>
Healthy Steps for Young Children, www.healthysteps.org  
World Association of Infant Mental Health, www.waimh.org |
| Depression & Stress       | American Counseling Association, www.counseling.org  
American Psychiatric Association, www.psych.org  
Mental Health America, www.nmha.org  
National Mental Health Information Center, www.mentalhealth.samhsa.gov |
| Hotlines                  | NDMDA Depression Hotline - Support Group, 800-826-3632  
Suicide Prevention Services Crisis Hotline, 800-784-2433  
Suicide Prevention Services Depression Hotline, 630-482-9696  
US Suicide Hotline, 800-784-2433 |
| Discharge & Going Home    | American Academy of Home Care Physicians, www.aahcp.org  
National Association for Home Care & Hospice, www.nahc.org/consumer  
National Family Caregivers Association, www.nfcacares.org  
National Transitions of Care Coalition, www.ntocc.org |
| Disability                | The March of Dimes, www.marchofdimes.com |
| Infection Control         | Centers for Disease Control and Prevention, www.cdc.gov/features/HandWashing |
|--------------------------------------------------------------------------|----------------------------------------------------------------------------------|-------------------------------------|
| Centers for Disease Control & Prevention                              | www.cdc.gov/ncidod/dhqp/ps_forParents.html#q3                                    |                                     |
| U.S. Food & Drug Administration: How to Give Medicine to Children     | www.fda.gov/FDAC/features/196_kid.html                                               |                                     |
| **Multiple Births**                                                    | MOST (Mothers of Supertwins)                                                       | www.mostonline.org                   |
| National Organization of Mothers of Twins Clubs, Inc.                  | www.nomotc.org                                                                     |                                     |
| The Triplet Connection                                                 | www.tripletconnection.org                                                           |                                     |
| **Newborn Screening**                                                  | Centers for Disease Control and Prevention A Parent’s Guide to Genetics             | www.cdc.gov/ncbddd/ehdi/parentbook/default.htm                                    |
| National Newborn Screening and Genetics Resource Center                | http://genes-r-us.uthscsa.edu/parentpage.htm                                       |                                     |
| U.S. Department of Health and Human Services, Maternal and Child Health Bureau | www.mchb.hrsa.gov/screening                                                         |                                     |
| **Premature Babies**                                                   | The American Pregnancy Association                                                 | www.americanpregnancy.org            |
| March of Dimes                                                          | www.marchofdimes.com/prematurity                                                   |                                     |
### For general information, see …

<table>
<thead>
<tr>
<th>Organization</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency for Healthcare Research &amp; Quality</td>
<td><a href="http://www.ahrq.gov">www.ahrq.gov</a></td>
</tr>
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<td>American Academy of Pediatrics</td>
<td><a href="http://www.aap.org/parents">www.aap.org/parents</a></td>
</tr>
<tr>
<td>American College of Obstetricians and Gynecologists</td>
<td><a href="http://www.acog.org/publications/patient_education/">www.acog.org/publications/patient_education/</a></td>
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<td>Maternal &amp; Child Health Library</td>
<td><a href="http://www.mchlibrary.info/families.html">www.mchlibrary.info/families.html</a></td>
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<tr>
<td>National Initiative for Children’s Healthcare Quality</td>
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</tr>
<tr>
<td>National Institute of Child Health and Human Development (NICHD)</td>
<td><a href="http://www.nichd.nih.gov/health/education">www.nichd.nih.gov/health/education</a></td>
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<tr>
<td>National Library of Medicine, Medline Plus</td>
<td><a href="http://www.nlm.nih.gov/medlineplus">www.nlm.nih.gov/medlineplus</a></td>
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<tr>
<td>National Patient Safety Foundation</td>
<td><a href="http://www.npsf.org/paf/">www.npsf.org/paf/</a></td>
</tr>
<tr>
<td>Sidelines National Support Network</td>
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<tr>
<td>U.S. Dept. of Health and Human Services</td>
<td><a href="http://www.healthfinder.gov">www.healthfinder.gov</a></td>
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### Find the research

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<td>Neonatology on the Web</td>
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<td>NICHD Cochrane Neonatal Review Group</td>
<td><a href="http://www.nichd.gov/cochrane/default.cfm">www.nichd.gov/cochrane/default.cfm</a></td>
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<tr>
<td>NICHD Neonatal Research Network</td>
<td><a href="https://neonatal.rti.org">https://neonatal.rti.org</a></td>
</tr>
</tbody>
</table>

### For help in talking with your health provider, see . . .

Questions are the Answer
www.ahrq.gov/questionsaretheanswer/

Quick Tips When Talking with Your Doctor
www.ahrq.gov/consumer/quicktips/doctalk.htm

Speak Up: Understanding your doctors and other caregivers
www.jointcommission.org/NR/rndonlyres/58522693-0927-42B5-8860-B12004CFBEF0/0/speakup_understanding.pdf
Section F
Medical topics

1. Air leak syndrome
2. About brain injury
3. Apnea of prematurity
4. Chronic lung disease (CLD) or bronchopulmonary dysplasia (BPD)
5. Congenital heart disease (CHD)
6. Congenital malformations
7. Babies born with low blood sugar (hypoglycemia)
8. If your baby needs a blood transfusion
9. If your baby needs surgery
10. Jaundice
11. Meconium aspiration syndrome
12. Necrotizing enterocolitis (NEC)
13. Patent ductus arteriosus (PDA)
14. The PICC line
15. The umbilical catheter
16. Persistent pulmonary hypertension of the newborn (PPHN)
17. Respiratory distress syndrome (RDS)
18. Retinopathy of prematurity (ROP)