An overview of:
Your Baby
and the NICU

Important information from your health care providers.

Take great care of the patient®
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 purpose of this booklet is to provide parents and guardians basic answers to questions 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. Also, visit www.pediatrix.com/forparents to download an expanded version of *Your Baby and the NICU*.

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*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.*
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 stands for neonatal (neo means new, natal means birth) = new birth

ICU stands for 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 babies’ body functions become stable so they 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.

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.
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.

NICUs are places where babies receive specialized care. Your NICU may look slightly different from this one.

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.

**What can parents do?** The most important thing you can do right now is to be an active partner 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 new to you, it may help to write down your questions.

- **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.

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**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](http://www.npsf.org/askme3)
When you and your baby first arrive in the 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.

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

Gwen, mother
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-res-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.
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.
There are several people who may work together in the NICU to help you and your baby. They are highly trained to work with babies who need specialized medical care. The following is a 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, 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.

Parents are vital members of their baby’s health care team.
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 to the parents. In healthy babies 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 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.

- **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.
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 skills in association with 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.

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.
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.
- Breathing problems — Babies 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.
- 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 some cases, holding your baby skin-to-skin (called kangaroo care) may help “jump-start” your body into producing milk.
- 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.

Talk with your doctor, nurse, or a lactation consultant (a person who helps women with breastfeeding questions) for help with any of these issues.
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?
- 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: fortified milk, tube feeding, and breastfeeding.

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.
- Feed your baby according to his or her needs.
- 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.

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 two 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.
Babies born early may develop medical problems which require special help in the NICU. The following information is provided to help you understand some of the potential medical problems and special procedures that premature or sick babies may experience. For comprehensive information about each medical topic listed below, visit www.pediatrix.com/forparents.

**Air leak syndrome** — Air leak syndrome is a term used to describe problems that happen when air collects within a baby’s chest, but outside the normal air cells of the lungs. The air then creates pressure on the lungs and makes breathing very difficult. It is a serious problem that can damage the lungs and other organs. Air leak can happen in babies born full-term, but it is more common in babies born early (premature) because their lungs are very fragile. The risk for air leak is higher if the baby needs to be given oxygen to help him or her breathe. But air leak also can happen on its own at the time when the baby is born. Sometimes air leak can be a result of surgery.

**Apnea** — Apnea [ap-NEE-uh] is a problem in which a baby temporarily stops breathing while sleeping or resting. Many newborns have short pauses in their breathing (less than 20 seconds). But a baby is said to have apnea if he or she stops breathing for at least 20 seconds, or has a slowed heart rate, or has a bluish color to the skin with a shorter pause in breathing.

Apnea occurs in almost all babies weighing less than 2.2 pounds (1,000 grams) at birth because their bodies are not yet fully mature. Babies born before 27 weeks also have a higher risk. The earlier a baby is born, the higher his or her risk for apnea. Short periods of apnea often do not need treatment. But treatment is needed if the apnea occurs often and with long periods of slowed heart rate and decreased levels of oxygen in the blood.
Blood transfusion — A blood *transfusion* [trans-FYOO-zuhuhn] is a process in which blood is given to your baby. This is a common need in premature babies and full-term babies born with health problems.

Brain injury — Brain injury or *encephalopathy* [en-sef-uh-LOP-uh-thee] of prematurity is a term used to describe injuries that occur with tissues that involve the brain in babies born early. Types of brain injury may include:

- **Intraventricular hemorrhage (IVH)** — blood leaks into the ventricles due to increased pressure in the baby’s fragile blood vessels. IVH sometimes causes a build-up of fluid in the baby’s skull (called *hydrocephalus* [hie-druh-SEF-uh-luhs]), which causes the head to enlarge.

- **Periventricular leukomalacia (PVL)** — damage to the white matter. PVL can occur in certain spots throughout the white matter or it can be spread throughout the tissue (called *diffuse damage*).

- **Hypoxic ischemic encephalopathy (HIE)** — a general term used to describe damage due to a lack of oxygen and blood flow to the brain.

Chronic lung disease (CLD) or bronchopulmonary dysplasia (BPD) — CLD is one of the most common problems that can affect babies born early (premature). It occurs if growth in parts of the baby’s lungs is disrupted, which then alters lung structure and function. CLD or BPD can lead to continued lung problems for some children. Because severe CLD can cause decreased oxygen to parts of the baby’s body, it also can lead to problems with the baby’s heart, and with hearing, motor skills, speech, and learning.

Congenital heart disease (CHD) — CHD is a term used to describe a group of problems present at birth that affect the structure of the heart and/or the large vessels near the heart. *Congenital* [kuhn-JEN-i-tl] means a problem present at birth. There are many types of CHD. Some types may be detected before birth and, in some cases, may be treated before birth. Other types are not found until the baby is born.
The effects of CHD range from mild to severe and depend on the type of heart defect and on the child’s general health. At one time, most infants born with CHD did not survive. Today, there are new treatments for CHD that are helping many children survive and lead a healthy life.

**Congenital malformations** — Congenital malformations, also called birth defects, are problems that happen while the baby is still in the womb. *Congenital* [kuhn-JEN-i-tl] means a problem that is present at birth. *Malformation* means the structure and often the function of a body part or organ is affected.

There are many types of congenital malformations that may affect organs (such as the heart, lungs or brain) or body parts (such as eyes, hands, fingers or feet).

**Hypoglycemia** — The amount of sugar in our blood, called blood sugar or blood glucose, is the fuel that keeps all of our body systems working. If this level dips too low, it is called hypoglycemia. Hypo means low. *Glycemia* [glahy-SEE-mee-uh] means sugar in the blood. The human body needs a certain amount of sugar in the bloodstream to help fuel body systems, such as the brain and muscles. Without it, these systems can’t function well. Although the body stores some sugar in the muscles and in the liver, one of the main ways the body obtains the needed sugar is through food.

**Jaundice** — *Jaundice* [JAWN-dis] is a term used to describe a yellow color in a baby’s skin and in the white parts of the eyes. Jaundice sometimes appears when there is a high level of a substance called *bilirubin* [BIL-ee-roo-bin] in the baby’s blood that causes the yellow color. A high level of bilirubin is called *hyperbilirubinemia*. Hyper means too high. Bilirubinemia means bilirubin in the blood. Bilirubin is a waste product formed when red blood cells die. Too much bilirubin in the body can lead to a type of brain damage called *kernicterus* [ker-NIK-te-res].
Meconium aspiration syndrome — Meconium aspiration syndrome may affect a baby’s lungs and occurs mainly in babies who are born at term or post-term (42 weeks or more). This syndrome occurs if the baby breathes in a waste substance, called meconium [mi-KOH-nee-uhm], before birth or during delivery, which then causes injury to the lung tissue.

Necrotizing enterocolitis (NEC) — Necrotizing enterocolitis is a gastrointestinal disease that mainly affects babies born prematurely and those born with extremely low birth weight (ELBW) (less than 2.2 pounds or 1,000 grams). Babies who have had respiratory distress syndrome (RDS), or patent ductus arteriosus (PDA) have a higher risk for NEC, but it can affect any baby. N stands for necrotizing [NEK-ruh-tahyz-ing], which is a process that causes tissue to die. EC stands for enterocolitis [en-tuh-roh-koh-LAHY-tis], which is inflammation of the intestine.

Patent ductus arteriosus (PDA) — PDA is a problem with a baby’s heart. P stands for patent, which means open. DA stands for ductus arteriosus [are-teer-ee-OH-sus], which is the small blood vessel that passes between the two largest blood vessels just outside the heart. The DA helps protect the baby’s lungs from working unnecessarily while in the womb, since the baby is not breathing before birth and receives oxygen through the placenta. After birth, the DA no longer is needed. In most healthy, full-term infants the DA closes within several days after birth. If it does not close it is called a PDA.

Babies who are born prematurely have a higher risk for PDA. In general, the earlier the birth, the higher the risk, though any baby can have a PDA, even a full-term baby. Babies born before 28 weeks in the womb or who weigh less than 2.2 pounds (1,000 grams) at birth have the highest risk. A large PDA can lead to problems with the lungs, stomach, intestines, and kidneys if it is not treated.
Peripherally inserted central catheter (PICC) line — The PICC line is a thin tube that is inserted into a vein in order to give medicine and fluids directly into the infant’s bloodstream. It is used if your baby needs to be given medicine, blood or fluids many times over several days, weeks or months. Many infants are given an umbilical catheter for this purpose during the first several days after birth. But the risk for infection and blood clots is increased with long-term umbilical catheter use, so a PICC line is often used if your baby still needs medicines and fluids after the first several days following birth. A PICC line also may be used to give liquid nutrients (called parenteral nutrition) if your baby cannot yet have food by mouth.

Persistent pulmonary hypertension of the newborn (PPHN) — PPHN is a problem in which the blood pressure in a baby’s lungs is too high. PPHN occurs mainly in babies born at full-term or near-term, but it sometimes occurs in babies born prematurely. Although most infants recover from PPHN, it can cause severe problems in some babies.

Respiratory distress syndrome (RDS) — RDS is a problem in which a baby, usually a premature infant, has trouble breathing. RDS happens when the baby’s lungs do not produce enough of a series of soap-like chemicals called surfactant [ser-FAK-tuhnt] to make the lungs less stiff so they can work well. Babies born before 37 weeks may not have enough surfactant in their lungs. RDS can be a serious problem in premature babies and requires treatment.

Retinopathy of prematurity (ROP) — ROP is a problem with a baby’s eyes. Babies who are born premature are at high risk for developing ROP, which affects approximately 75 percent of babies born before 26 weeks. ROP may go away without treatment or without lasting effects, but for some babies, ROP can lead to serious problems, such as blindness, or other eye problems later in life.
Surgery — There are many reasons why a premature baby or a baby with health problems might need surgery. In some cases, the need for surgery may be known before the baby is born. In other cases, the need for surgery may occur shortly after birth or during the baby’s stay in the NICU. Your baby’s health care team will advise whether the surgery is needed right away or if there are other steps that may be taken before surgery. If your baby requires surgery, the health care team can help to answer your questions.

Umbilical catheter — A catheter [KATH-i-ter] is a thin tube that is placed in the body in order to draw out blood to be used for testing or to allow fluids and medicines to be given. This device serves as an open passage that allows doctors and nurses to perform these functions as needed.

An umbilical catheter is inserted into the umbilical cord in one of two ways; either into a vein (called an umbilical venous catheter or UVC) or into an artery (called an umbilical arterial catheter or UAC).

While in the womb, the blood vessels in the umbilical cord served as the highways through which the baby exchanged blood, oxygen, and nutrients with the mother’s placenta. These vessels shrivel up after birth, but can remain open for a few days after birth. The umbilical cord may be used for this type of catheter because the blood vessels in the arms and legs of premature babies are so tiny.
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 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 on the previous page (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 on previous page 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.

✔ 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?

Keeping a record of your baby’s unique needs helps you create your baby’s bridge to care.