

Taking Baby Steps — *Knowing what to do*

The numbers can seem overwhelming. Nearly 13% of the 4 million babies born in the U.S. are born prematurely (less than 37 weeks).¹ That's one in eight births! This means that daily, more than 1400 babies are arriving early!

Due to recent advances in healthcare, more than 90% of premature babies weighing more than 2 pounds will survive.² However, many of these infants are at a greater risk for ongoing health complications than full-term babies.

This is a journey that extends farther than the delivery room. It is a path that may be full of challenges, emotions, and important decisions relating to your baby's healthcare. This guide was created to help you understand some issues that you and your baby may face and to offer tools and resources to help you navigate the journey.



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Sources: ¹Martin, J., et al. National Vital Statistics Reports, Volume 57, Number 7. January 7, 2009. Births: Final Data for 2006.

²Alabsi, S. (reviewer) (2007) Kids Health (Nemours Foundation). A Primer on Premies. <http://kidshealth.org/parent/growth/growing/preemies.html>

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1

My baby was born early. What do I do now?

Babies born early will often begin their lives in a neonatal intensive care unit (NICU). This unit in the hospital is specifically designed for premature babies requiring special care and treatment. There are several levels of the NICU, based on the increasing complexity of care. However, not all NICUs are equipped to care for all types of newborn problems. Some units provide the most basic neonatal care, while others care for infants who are extremely premature, critically ill, or who require surgery. Your baby may possibly be transferred to another hospital for specialized care.

The NICU is staffed by a variety of specially trained healthcare professionals and includes highly technical equipment to meet the needs of premature infants and their families. It is important to know that some babies born early may not need to be in a NICU at all. However, if your baby is in a NICU, your first hurdle is to understand how she or he will be cared for and how you can help.

Being surrounded by doctors, nurses, and machines may seem overwhelming and may make you think that you cannot feel close to your baby. Ask questions and become informed parents about the routine surrounding your baby's care.

Which babies need to be cared for in the NICU?

While not all babies born early will need to be treated in a NICU, about 10–15 percent of all babies born in the United States every year are admitted to NICUs.³ Some of these babies are born early, or went through a difficult delivery. Others have serious health problems that develop within their first few days of life, such as infections and breathing problems.

What equipment is used in the NICU and why?

The special NICU machines and equipment that help care for your baby can seem unfamiliar and scary. Once you understand how they work and what their function is, you may feel more comfortable and confident around them. Some of the following may be used by NICU staff in your premature infant's treatment.

Feeding tube: Sometimes, if your baby is too little to be fed by mouth, nurses will place a small tube through the mouth or nose to deliver formula or breast milk into your baby's stomach.

Infant warmer: This open bed has an overhead heating system to keep your baby warm and to maintain proper body temperature.

Isolette or incubator: Protecting your baby from germs and noise, this clear plastic box has holes to allow doctors and nurses to examine or check your baby without picking him or her up.

IVs and lines: An IV (intravenous catheter) is a thin flexible tube inserted into your baby's vein with a tiny needle. When the needle is removed, the tubing remains and carries fluids and medications to your baby's bloodstream. The IV is sometimes placed into an infant's hand, arm, foot, leg, or even scalp. If your newborn needs larger amounts of medication, a bigger IV may be required. This type of IV, called a "central line," is placed in one of the larger veins.

Monitors: Your newborn is attached to monitors so that the NICU staff can constantly be aware of your infant's life signs. Small sticky pads secure wires leading to a machine that measures your baby's heart and breathing rates, blood oxygen level, and body temperature.

Bili lights: If your baby has jaundice (a common newborn condition, related to the liver, in which the skin and whites of the eyes turn yellow), these bright blue lights provide treatment called phototherapy. Your baby's eyes are covered for protection.

Ventilator or Respiator: This is a machine that helps your baby to breathe. It is connected to a tube that is placed into the infant's windpipe through the nose or mouth and it pumps warm, humidified air into the lungs.



Who ARE all these people?

Who is on the healthcare team and what are their roles in my baby's health? Some of the following people will be involved in the care of your premature baby in the NICU:

Pediatrician (or Family Physician, Nurse Practitioner, or Physician's Assistant): Your baby's primary healthcare provider after leaving the hospital.

Registered Nurse: A healthcare professional who has completed a nursing program. A NICU nurse has specific training in the care of premature and sick newborns. Some nurses, such as Nurse Practitioners and Neonatal Clinical Nurse Specialists, have received more specialized training.

Neonatologist: A pediatrician with specialized, advanced training in the care of sick, or preterm, newborn babies.

Respiratory Therapist: A healthcare professional trained to care for babies with breathing problems.

Occupational and Physical Therapists: Healthcare professionals who help to improve your infant's muscle strength and coordination.

Social worker: A professional who helps you get the information you need from your baby's doctors, helps arrange your discharge planning, and is trained to aid in coping with the emotional aspect of your baby's stay in the NICU.

Lactation Consultant: A person with special training who can explain the benefits of breast-feeding and can help you to make it comfortable for you and your baby.

Registered Dietician: Nutritional expert, with special training in pediatric nutrition, who will help to make sure that your baby is getting the proper nutrients for healthy growth and development.

Pharmacist: An expert in medicines and their side effects who can answer questions about your baby's medications.

What are all of these emotions I'm feeling?

As you cope with the reality that your baby needs specialized care in the NICU, it is important to understand that it is normal and expected that your emotions may be very strong and may swing from one extreme to the other. You may at first feel shock or loss and then develop fear and anxiety. You may even blame yourself, or feel stress about the uncertainty of your baby's condition, or about the future. When you can't bond with your baby in the way that you expected, you may feel angry, or even helpless and hopeless. Know that it is okay to be frustrated as you try to understand what exactly is going on in the NICU. You may be making important decisions about your baby's care, or you may even feel excluded from the decision-making process.

Balancing your "life outside of the NICU" may also be a challenge.

Work, other children, family members and finances are only some of the other responsibilities that may need your attention. Step back and take a deep breath. Accept help when offered from family members or friends. Understand that the family-centered care mission of many hospitals will also support you and offer resources to help you and your family provide comfort and care to your baby.

Becoming an informed parent

Communication is key and knowledge can be a powerful tool. The more questions you ask about your baby's condition, the more information you will get that will help you to be active in your baby's care. Some of the questions you may want to ask the neonatologist or nurses caring for your infant are:

How long will my baby be in the NICU?

What needs to happen before my baby can go home? (e.g., certain body temperature, feeding routine, breathing sounds)

What, specifically, is the problem and what can I do to help my baby?

What medicines will my baby have to take?

Will I be able to touch, feed, and hold my baby?

Will any follow-up be needed because of a test, procedure, or diagnosis?

It may help you to learn more about the definitions of NICU terms. Go to http://www.marchofdimes.com/prematurity/21278_11036.asp or visit www.aap.org for a quick reference.

How can I bond with and feel close to my baby in the middle of all of this?

Even though the NICU machines may seem overwhelming and frightening, don't let them keep you from asking how you can be with your newborn. Your baby was born early and may be given full-time care, but your bond with your baby while in the NICU is just as important as a parent's bond with any other newborn. You just have to figure out how to do it, with the help of the NICU staff.

The best way to start showing your baby your love is to spend time in the NICU watching your infant's behavior. Ask your nurse to explain and to show you how to do this. Learn when your baby is stressed out and needs to rest, as well as what time of day your newborn is typically most alert. Most importantly, learn what type of attention your baby prefers from you. Depending on your infant's condition, you may be able to feed or breast-feed. However, for some very premature babies, touching is very stressful. If this is the case for your baby, ask the doctors or nurses what type of contact is best. Even holding a hand or stroking your baby's head may be a gentle and reassuring touch for both of you.

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What's going on in the hospital?



If your baby is admitted to the NICU, it may be hard to sort out all of your fears at first—from general concerns about survival to what specific health problems might arise. Although your baby may look like just a tiny newborn, premature babies are prone to some medical problems, mostly because their internal organs aren't fully developed and ready to function on

their own. Generally, the earlier an infant is born, the higher the risk of complications. Education is your best resource. Learn about common health complications of babies who are born early. Your knowledge may calm your fears and will certainly benefit your newborn. Try to stay focused on your baby's progress and on how you can help aim towards a positive outcome.

Following is a list that includes some conditions that premature babies may experience in the NICU. Keep in mind that the ones listed may not be relevant to your baby's situation and if you have any questions, ask your baby's healthcare provider.

Prematurity and the heart

The heart of a fetus inside the womb works very differently than the heart of a baby outside the womb. When a baby is born prematurely and the heart is not fully developed, it may not be ready to support this tiny, new life.

Here are some of the defects that could affect a premature baby:

- *Patent Ductus Arteriosus*

This heart defect happens when the heart's open blood vessel does not close after birth.

- *Septal defects*

Commonly known as “a hole in the heart,” usually causing abnormal blood flow, some septal defects can cause enlargement of the heart.

- *Heart valve abnormalities*

The heart has valves that act like one-way doors to help blood flow properly into and out of the heart. When the valves do not work well, the heart is overworked.

- *Tetralogy of Fallot*

This condition actually refers to a combination of four defects of the heart that affects proper blood flow and delivery of enough oxygen to the rest of the body.

- *Transposition of the Great Arteries*

In this condition, the two major blood vessels that carry blood between the lungs and the heart are switched. Therefore, the blood does not carry enough oxygen for the body's needs.

Prematurity and breathing

Lung tissue that is not fully developed at birth can make breathing difficult for premature babies. Since the lungs are most mature when a baby is born full-term, doctors will try to delay premature births as long as possible. Even one or two days more in a mother's uterus can make a difference in how well a baby can breathe when entering the outside world. Some babies born early can be affected by the following conditions:

- *Apnea*

A pause in a baby's breathing that lasts longer than 15 seconds is called apnea. This is fairly common in premature infants, because the part of the brain that controls breathing may not yet be fully developed.

- *Respiratory Distress Syndrome (RDS)*

This condition is common in premature babies because their lungs have not produced enough of a substance called “surfactant,” which prevents the small air sacs in the lungs from collapsing. As a result, the baby develops difficulty breathing.

- *Bronchopulmonary Dysplasia (BPD)*

Sometimes called Chronic Lung Disease, this condition happens most often when the lungs of premature babies develop abnormally. The resulting inflammation and scarring in the lungs make it difficult for the babies to breathe.

- *Persistent Pulmonary Hypertension (PPHN)*

This condition limits the amount of blood flow and oxygen delivered to the lungs, which leads to breathing difficulties.



Prematurity and sight and sound

Because their systems are not fully developed at birth, premature infants are at a greater risk for vision and hearing problems than are full-term babies. If you suspect that your newborn cannot hear or see, ask the doctor for help immediately. If a condition is detected early, there is a better chance that it can be fixed. Following are some eye and ear conditions that might affect premature babies:

- **Acute sensitivity to noise**

While some infants born early may have hearing loss, others are highly sensitive to noise and will startle easily.

- **Strabismus (crossed eyes)**

As a baby grows and develops, this condition may go away on its own. Sometimes, the doctor will refer parents to an eye specialist for an evaluation or treatment.

- **Retinopathy of Prematurity (ROP)**

This is a disease of the eye in which tiny blood vessels grow abnormally in the retina. It may lead to bleeding and scarring of the retina (which is responsible for relaying messages from the eye to the visual area of the brain). Untreated, it can lead to vision loss.

What about risks of infection?

Premature infants' immune systems are not fully developed, so they are more at risk for getting infections than older children or adults. Here are a few of the infections that could affect babies born early:

- **Respiratory Syncytial Virus (RSV)**

RSV is a common virus that can cause serious respiratory infections, such as bronchiolitis or pneumonia, especially in babies born early. Premature babies are more at risk for developing severe RSV disease because of their underdeveloped lungs and immature immune systems.

- **Pneumonia**

A mild cold may lead to pneumonia (a serious lung infection) in which there is inflammation of the small passages in the lungs that can cause difficulty breathing.

- **Meningitis**

This refers to an inflammation of the lining of the spinal cord and the brain, caused by a bacterial or viral infection.

- **Sepsis**

Sepsis is a blood infection. Because their immune systems are not fully developed, babies born prematurely may get sepsis if an infection spreads into their bloodstream.

Prematurity and eating

Premature infants may have difficulty not only taking in formula or breast milk from a nipple or a bottle, but they may have trouble digesting the nutrients as well. These are some of the feeding and digestive issues they may have:

- **Sucking reflex issues**

Some premature babies have trouble sucking and swallowing effectively and will need to be fed through a tube that is placed through the nose into the stomach. This is called "gavage feeding."

- **Hypoglycemia**

This is commonly known as "low blood sugar." Babies need a constant supply of sugar in their blood to give them energy. They can get this sugar from the nutrients in breast milk or formula. If their sugar level falls too low, they may become very tired or have convulsions. Premature babies are especially at risk because they may find it hard to feed and to get the nutrients they need.

- **Necrotizing enterocolitis (NEC)**

Damage to the intestines from either poor blood flow or infection is known as NEC. Premature infants may be more likely to have this condition because their intestines are not fully developed to handle digestion.



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What does it mean to be the parent or family member of a baby who is born early?

Although you may be very concerned about your newborn's health, you also may have anxiety about how this tiny, new life will affect you and your family. It is normal to be worried about how you will face physical, practical, and personal challenges. Remember to take care of yourself, so that you can focus on your baby's needs.

Physical Concerns

Your worries about the physical growth of your newborn may make you feel stressed, because you may think that there is little you can do to help. In fact, there are many things that you can do to support your baby in the NICU. Some relate to your physical contact with your premature baby and others relate to your care for your own physical well-being.

Holding my baby

It is natural and expected that new parents of all babies will be eager to hold and cuddle with them. If your new baby is hooked up to monitors with wires, you may feel nervous and worried that your touch will get in the way of your baby's treatment. Don't be scared of the machines — speak to the nurses and doctors involved in your child's care and find out if and how you can hold and be close to your baby.

If it is possible, “kangaroo care” has wonderful benefits for both you and your baby. Kangaroo care is the practice of holding your diapered baby on your bare chest (if you are the father) or between your breasts (if you are the mother) with a blanket draped over the baby's back. Being close to you like this can help your baby not only to maintain body warmth and regulate breathing and heart rates, but also can help him or her to get to know you — your scent, touch and the rhythms of your speech and breathing. By holding your baby skin-to-skin, you will gain confidence in your ability to give something to your baby that only you can give — your touch, your care, and your love.

Feeding my baby

Before your baby arrived early, you probably had visions of what it would be like to feed him or her. Maybe you had even already decided whether or not to breast-feed or to bottle-feed formula. Now that your baby is in the NICU, you may have to change your plans.



Breast-feeding: While breast milk has many health benefits, especially for premature or sick babies, understand that your baby may not be able to suckle properly. Although this may be disappointing, know that your nurse, or lactation consultant, can show you how to use a breast pump. Your baby will still get the nutrients from your pumped breast milk, even when it is delivered by tube to his or her stomach (“gavage feeding”). If your infant is able to suckle, be patient with yourself as you both figure out what feeding positions work best, with the help of your nurses or the lactation consultant.

Formula feeding: While babies can also thrive on formula, it is possible that you may need to wait a bit for your baby to be able to suckle from a bottle. “Gavage feeding” (feeding baby through a tube) may be necessary in this case for awhile. Ask your nurse how you can help in this process.

Changing my baby

Diapering your baby in the NICU can be challenging, especially when handling a tiny body that may be connected to wires, tubes, or respiratory equipment. Premature infants don't have a lot of muscle tone. However, you can hold them gently, and securely, by using two hands. They will need to be turned onto their backs for a diaper change. Until you get used to doing this, ask your nurse for help.

I am so tired! I can't get any sleep.

Having a premature newborn in the NICU is physically and emotionally tiring. You are probably spending most of your free time in the NICU with your baby and sleeping less than you normally do. The worry and stress you may feel about your baby's health can make you even more tired. Make sure that you take care of yourself. If you get the rest you need, you may have more energy to deal with the challenges of your baby's experience in the NICU. And, maybe more importantly, you can have more energy to give your love and attention to this tiny new life. Talk with your nurse and hospital social worker about what kind of help you might need at home.





Practical concerns

You may find that living under the weight of concern for your baby's physical well-being becomes even more difficult when you remember all of the practical responsibilities you also have to take care of. If you feel like all of these duties are pulling you in many directions, try to focus your attention on one issue at a time.

I have a job. How can I go to work?

Facing all of the newness and uncertainty of life in the NICU is a challenge that could easily take up all of your time and focus. But, your attention may still be needed at your job, too. It may be hard to concentrate at work when you are away from your baby. You may even feel guilty about leaving the NICU. If you do have to leave your baby in the NICU and go to work, take comfort in knowing that your premature infant is getting quality care while you are away. Sometimes, that reassurance can make it easier to get things done at work, so that you can return to your new baby as soon as possible.

Who is paying for this? What if I have no insurance?

Care in a NICU is expensive. While your infant's health can take up most of your attention, try to learn about what payment will be asked of you and where you can turn for help. If you have private insurance, check with your provider to find out what NICU costs are covered. Some plans pay for the entire NICU hospitalization and others only cover specific costs. If you have Medicaid, speak with your NICU social worker to find out if there are any costs that Medicaid does not cover. If you have no insurance at all, or if the bills are still too costly for you, consider applying for Medicaid or Social Security insurance programs. Visit the Center for Medicaid Services website at www.cms.hhs.gov/MedicaidGenInfo/. Call 800-772-1213 for more information about Social Security insurance. If your baby is prescribed medication that you cannot afford, there are also resources available to help provide it free of charge. RxAssist is an online directory of pharmaceutical companies who run these patient assistance programs. Visit www.rxassist.org for more information. You can also talk to the hospital social worker about where to look for help to cover insurance bills or prescriptions.

How can I handle the balancing act of my job, my family, and my baby?

When a full-term baby is born, most parents need to make room in their lives for the new addition. They may struggle with exhaustion at work as they care for a new baby at night. Parents of babies who stay in the NICU may feel even more of a struggle. They may have to choose between taking time off from work when their baby is in the NICU, or waiting until he or she comes home. In fact, 61% of American families have two working parents and most need both incomes to

survive. This balancing act can be even more complicated if there are other children at home. Trying to give your job, your children at home, and your infant in the NICU all the attention that you feel they each deserve is a big challenge! Keep an open line of discussion with your healthcare team, as well as with friends and relatives at home, and try to accept help when it is offered to you.

Family concerns

You are probably looking forward to bringing your baby home from the NICU to join the rest of your family. But, before that happens, you are probably wondering how this tiny new life will fit in. If special medical equipment will be needed at home, the effects of that may concern you as well. These thoughts are normal. It may take some time to make all of these adjustments.

Will I have enough time for my other children?

While your newborn is in the NICU, you are most likely spending a lot of time at the hospital caring for your premature baby. This will mean less time spent with your other children. Try to find time to do even the little things that make up your children's routines. Talking over a meal, or in a car ride to school, or reading stories together can be comforting and also can show them how special they are to you. Remember that it is the quality of time spent with you, not just the quantity, that will mean the most to your children at home.

How will my other children feel about their place in the family with a baby born early?

Children can be deeply affected by a full-term baby's arrival. Their feelings can be even stronger when their brother or sister is born early. Speak openly with your child and make sure that they know how their baby brother or sister is doing. This honesty will help your children feel like they are an important part of the caring process. Young children may feel upset or threatened by the changes in family routines. Older ones may be worried about a sibling's health. Offer reassurances. If possible, include the children in visits to the NICU so that they can see the baby for themselves.

What if my other kids get sick?

It is possible that your other children may get sick while your baby is in the NICU. It is very important that you do not allow them to visit the NICU when they are ill. Proper handwashing will help reduce your risk of getting sick. This is especially important in the clean environment of the NICU.

How do I stay connected to my significant other?

While your baby is in the NICU, you and your partner can give each other tremendous support. However, it is possible that the stress of the NICU experience will affect your relationship. Expect that there will be times when you both have different thoughts and feelings and ways of coping with what is happening to you and to your baby. Try to understand each other. If you make time to listen, your support for each other will help you both lean on your strengths and manage your differences in a way that may help your relationship grow.

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Now that my baby is discharged, how do we manage at home?

Congratulations! The big day you've waited for is finally here. You are taking your baby home! Although, up until now, your baby's every breath has been monitored by trained professionals, soon all of your baby's care will be your responsibility. So, excitement is probably mixed with a lot of nervousness. Remember that it is normal to be anxious about leaving the familiarity and support of the hospital. All parents can feel that way. Be sure to ask questions and understand your instructions for at-home care, as well as for scheduled visits to the pediatrician or nurse practitioner. Being informed will help you properly chart and understand how your baby is doing. Knowing what to look for, and how to react, will allow you to have a great affect on your baby's health, growth, and development.

We are being discharged! But, now what?

Your excitement is building at the thought of bringing your baby home from the NICU. Here is a list of a few of the simple, but critical, things you should take care of as you plan for life at home with a new baby:

- Clean your house to protect your baby from dust, smoke, animal hair and germs.
- Make sure you have a car seat. Visit the American Academy of Pediatrics at www.aap.org for tips on how to choose the proper one for your newborn. Your nurse can also help you decide what kind of car seat is best for your baby and will make sure that your baby is safe in the seat before you leave the hospital.
- Have a crib, diapers, thermometer, clothing, and blankets available.
- Start using a breast pump, if planning to breast-feed, or buy several weeks' supply of formula.
- Make appointments with your baby's healthcare provider for follow-up checkups and immunizations.

Once you are prepared, you will likely have many questions about how to care for your baby at home. It is okay to ask for help or advice. Your NICU staff can be a great resource. They can help guide you through this transition. It may be scary knowing that you are now fully responsible for this tiny, new life. Focus on the following to keep your newborn healthy:

Feeding

Most premature babies are able to breast-feed or drink from a bottle before they are sent home from the hospital. It is likely that your baby will be at least as hungry as any other newborn and will need to feed eight to ten times a day. He or she will likely have six to eight wet diapers each day. Keep a chart of how much and when your baby feeds, as well as how many diapers are wet each day. This information will be helpful when you visit the doctor or nurse practitioner.

Handwashing and Care at Home

Because their immune systems are not yet fully developed, infants born early are more at risk for getting infections than older children. Understand how important it is that everything that touches your baby is clean and washed. No one should smoke in your home. All hands that touch your baby should be washed with warm water and soap. No one who is sick should visit. Try to stay at home as much as possible when you first leave the hospital with your premature baby. Except for scheduled visits to your baby's healthcare provider, try to limit trips to public places for the first several weeks.

Immunizations

Immunizations (also called vaccines or shots) are given to premature babies on the same schedule that they are given to full-term infants. Ask your baby's healthcare provider for this schedule.

When do I call the doctor?

After your baby's health was monitored 24 hours a day by trained NICU personnel, it may be a little scary for you to have to make decisions about when to contact a doctor if you believe your baby is sick. Call your baby's healthcare provider if you think something doesn't seem right to you.



Do I need special equipment?

Many infants leaving the NICU do not need special medical equipment when they leave the unit. However, some babies will be sent home with medical equipment for you to manage. If your baby is sent home with any of this equipment, make sure your NICU nurses or your baby's healthcare provider explain to you

how to properly use it. The three most common types of equipment that you might see are:

Apnea monitor—This machine is connected to your baby with soft sticky patches or with a belt around the chest. It sounds an alarm if your infant's breathing stops or if the heart is beating irregularly.

Oxygen tank—The most common reason that babies need oxygen at home is that they have lung conditions that make it hard for them to breathe on their own. Oxygen gets to your baby from the tank through soft plastic tubing that goes into your baby's nose. Remember that oxygen is extremely flammable and you must never have it in the same room where there is a burning fireplace, lit cigarettes, or sparks.

Feeding tubes and syringe—Babies, who at discharge are still unable to suck or swallow well, may still get nourishment through feeding tubes ("gavage feeding"). A flexible thin tube is inserted through the nose or mouth into the stomach. Then, you can use a syringe to deliver breast milk or formula into the tube.

Continuing medical care—When are regular doctor's visits scheduled?

Preventative medical care is very important to the growth and development of your baby. Be sure to understand that you will be making many trips to your baby's healthcare provider for immunizations and checkups. This plan to keep your baby healthy is one of the most important responsibilities you have as a parent. Ask your infant's healthcare provider for a schedule of recommended visits.

The first checkup — What happens and what information do I need to share?

The first well-baby exam usually begins with a physical exam during which a healthcare provider measures your infant's length, weight, and head circumference. He or she will mark this information on a graph to track the appropriate infant growth and development. In addition to a complete head-to-toe exam, a family

medical history will be taken, and the healthcare provider will ask questions about what the baby can do physically and how often and how much he or she is feeding. If you are unsure, nervous, or concerned about anything, this will be your chance to ask your healthcare provider about it. It is a perfect opportunity to understand what behavior and growth is considered "normal."

How do I figure out if my baby is developing normally, even though he or she was born early?

If your baby was in the NICU, you may be anxious about what proper growth and development to expect. You may even begin to compare your premature infant with full-term babies who are the same age. This can be discouraging if your baby does not seem to have mastered the same skills, or to be a size similar to full-term babies born at the same time. This is completely normal. However, take comfort in knowing that babies who are born prematurely are sometimes referred to by two different ages: "chronological" age, which is the age of the baby calculated from the baby's date of birth; and "corrected" or "adjusted" age, which is the age of the baby calculated from the baby's due date.

For information about the developmental milestones of babies who are born early, visit the March of Dimes® website at www.marchofdimes.com/pnhec/298_10203.asp, or talk with your doctors and nurses. Remember that you need to adjust your expectations of your baby's development according to his or her due date (corrected/adjusted age). Although your infant's healthcare provider will look at the changes in your baby at each well-baby visit, you will always know your baby best. Ask questions if you think your child is not progressing as you feel that he or she should.

Does my baby need special services?

As you take special care to look at your baby's development, understand that pediatricians and child development experts will evaluate a baby's skills in five developmental areas:

- Gross motor skills—how your baby moves his or her entire body
- Fine motor skills—how your baby uses his or her fingers or hands
- Language skills—how your baby verbally communicates
- Social skills—how your baby plays with toys and people
- Cognitive skills—how your baby thinks

After an evaluation, you may learn that your baby needs special professional services to deal with certain developmental delays. If these delays are spotted and treated early in life, it is more likely that a baby will overcome them or learn to deal with them effectively. Most states will allow NICU graduates to be evaluated to see if they need special supportive therapy. If your child has a delay that is eligible for supportive therapy in your state, an early intervention program will be designed and your child will get the help he or she needs.



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How do I advocate for my baby and for others?

“Being Their Voice”

Your voice as a parent of a baby who was born early can be used to help in many ways. One of your roles is to be your child’s voice. That’s what being an advocate is—speaking up to be sure your baby gets the care he or she needs.

Another important role is self-support. Use your voice to ask for help from friends and family and to seek support groups that include parents who have shared similar experiences. Don’t forget the importance of being good to yourself. Your emotional well-being is essential to the growth of your child and support groups can surround you with helpful resources to keep you focused and positive.

You may feel later that this experience has changed you and that you want to help other parents navigate the premature journey. This is another form of advocacy. Staying connected to families you have met, as well as reaching out to others who will walk this road after you do, may become part of your own personal healing and growth process.

Advocating for my child

Looking into the sweet, innocent eyes of your newborn, it can be overwhelming to consider your responsibilities as a parent. This tiny life is fully dependent on you. You will likely become your baby’s loudest cheerleader, focusing on your baby’s best interests. Trust your instincts and try to make sure you are focused on what is best for your child. Delivering your baby (or giving birth) early is difficult and you may need to readjust your visions of your child’s future from what you thought it would be.

Other opinions

Part of this “cheerleading” is making sure that your baby is receiving the best quality care available. Don’t be afraid to ask opinions from other members of the healthcare team about your

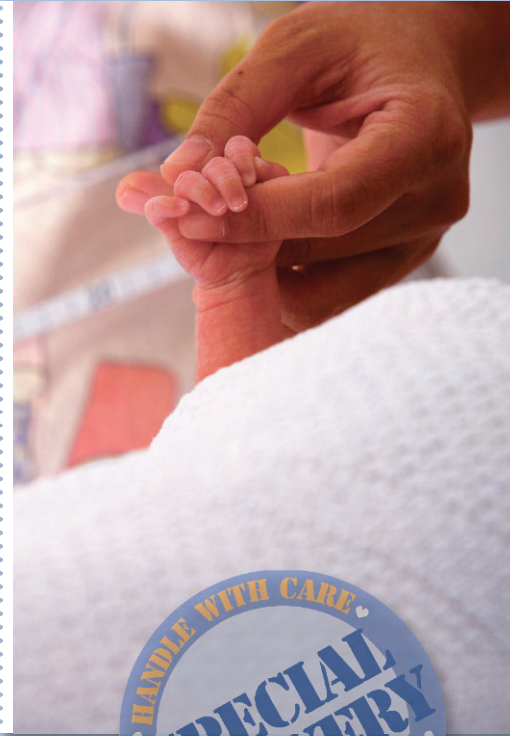
baby’s health and development, so that you can make informed decisions along the way.

Speaking out

As your baby’s advocate, you may have to develop a new set of skills to do this job well. Make sure you are well-informed about your baby’s growth and look into new treatments or services, if needed. Sometimes, this means that you will have to speak up and keep communicating with caregivers, doctors, nurses, and social workers. Although this may take time, patience, and practice, you will likely be able to see the benefits as your child grows.

Finding services for your baby

Do some research, or ask for help, to determine your rights to services and benefits as the parent of a premature baby. Many states offer free evaluations for graduates of a NICU. These evaluations can determine if your child shows signs of developmental delays or disabilities. Depending on the results, your child may be eligible for free or low-cost therapeutic services. Talk with your baby’s healthcare provider to find out if you can arrange for an evaluation.



Support and Resources

There are many written resources, as well as interactive websites and support groups that can be a source of strength for you while you navigate this premature journey. You may be able to receive help offered from family and friends, but it can really help you to exchange stories with other parents who walk a similar path. Become familiar with, or ask for help to find, organizations that help people just like you. Some groups can support not only you in your own experience, but they can also connect you to other families in similar situations. These connections can be very valuable to help you cope. They may also help you learn what additional questions you may need to ask when you are trying to make the best decisions for your family.

- The March of Dimes® “Share Your Story” online community will connect you with other families who understand your journey. Visit www.shareyourstory.org.
- MOST (Mothers of Supertwins) gives information and support to parents of multiples. Visit their website at www.mostonline.org, or call (631) 859-1110.
- PremieCare is the daughter organization to MOST and is a mentoring and networking organization focused on hospital- and community-based parent and premie support. Visit www.premiecare.org, or call (631) 859-1110.

Being a “Voice” for other babies who are born early and their families—Advocacy

When and if you feel the time is right, later in your journey, you can shift your focus to the needs of premature babies other than your own. You might choose to be a more public advocate and become vocal about legislation that would benefit families of babies born early. Or, you may be more comfortable as an advocate closer to home, by sharing your experiences with families of new premature babies in the NICU. Either way, your efforts will likely have a profound effect on others who are also touched by prematurity, as you have been.

The “Premie Act”

One example of the benefits of speaking out on behalf of all premature babies is the “Premie Act” that was signed into law in December, 2006. This bill expands research on premature births, improves education for all expectant mothers, and provides better treatment for premature babies. Supported by advocates, groups such as the March of Dimes®, and politicians around the country, the “Premie Act” illustrates a commitment to reducing preterm labor and delivery, as well as infant death due to prematurity.

Becoming involved in this type of vocal advocacy will benefit not just your premature baby, but also others who are not even born yet. If you are comfortable, voice your concerns to your legislators. That type of communication can lead to the legislation of bills such as the “Premie Act.”



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