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## **Taking Your Preemie Home**

If your baby was born prematurely, you may greet the day of discharge from the hospital with a mixture of joy and worry. You may have waited days, weeks, or even months to take your baby home, but when the day finally arrives it can be frightening to walk away from the security of the hospital nursery.

If you're anxious about caring for your preemie at home, remember that health care professionals do not send preemies home until the babies are ready. With some preparation and planning, you'll be ready, too.

### **Health Challenges of Premature Infants**

Babies born at less than 37 weeks' gestation are considered premature, and they often begin life with serious medical challenges. They may need support for a number of medical issues, including breathing problems that require supplemental oxygen or a ventilator, temperature regulation, feeding problems, apnea (irregular breathing), or jaundice (when a baby's immature liver initially can't dispose of excess bilirubin, a yellow pigment produced by the normal breakdown of red blood cells).

Because of these needs, premature infants may have to spend weeks or even months in a neonatal intensive care unit (NICU). Fortunately, with support and growth, the immature organs recover and eventually function independently in most cases.

By the time of hospital discharge, most preterm infants do not require specialized medical care, but all continue to need good supportive care. For some, special medical needs persist even after discharge.

The hospital medical team will send your baby home with a follow-up plan of medical care that will coordinate care with your pediatrician and other medical specialists as needed.

### **Requirements for Discharge**

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Before being discharged from the hospital, a preemie must meet several basic requirements to ensure good health and fewer medical problems. Some nurseries require a minimum weight for discharge, but more often the NICU staff will evaluate the baby on these three criteria:

1. Can the baby maintain body temperature in an open crib for at least 24-48 hours, depending on how premature the baby was at birth?
2. Can the baby take all feedings by bottle or breast without supplemental tube feedings?
3. Can the baby gain weight steadily?

Most preemies meet these criteria 2 to 4 weeks before reaching their original due date. Infants who have had surgery, were born with malformations, or who spent weeks on breathing machines and oxygen are the most likely to stay beyond their original due date.

## Medical Needs After Discharge

Many preemies do not need specialized medical support after leaving the hospital, but all will need regular medical care and evaluation. This includes routine immunizations, usually on the same schedule as that for full-term babies.

Common medical problems premature babies may face in the long term include:

**Apnea.** Premature infants commonly have episodes of apnea, or pauses in breathing, that improve as they mature. Babies will not be discharged if the apnea causes a slow heart rate or a change in color. However, some nurseries send infants home on apnea monitors if the infants have mild apnea that does not cause a change in color or heart rate or require stimulation to make the baby breathe again. Other nurseries may monitor preemies until the breathing pattern reaches maturity, usually about 44 weeks' post-conceptual age.

Doctors will decide if your baby needs a monitor; if so, anyone who will be alone with the infant at home will need to attend a training session on using the monitor and learn how to perform infant cardiopulmonary resuscitation (CPR).

**Other breathing problems.** Preemies commonly have respiratory difficulties and need supplemental oxygen or a mechanical ventilator. Most recover and do not require supplemental oxygen by the time they graduate from the NICU. However, some develop a more chronic lung condition called bronchopulmonary dysplasia (BPD), which involves scarring and inflammation in the lungs. Infants with BPD may need supplemental oxygen and medications for prolonged periods even after discharge. They can be sent home on oxygen or medications to help their lungs function

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better.

If your baby will need oxygen after leaving the hospital, equipment for administering it at home and in transit will be coordinated before discharge.

**Infections.** Like other organ systems, the immune system of a premature infant does not function as well as that of older kids or adults. This places preemies at risk for contracting infections (especially viral ones) after discharge.

Although preemies can become infected with many different viruses, they're particularly vulnerable to respiratory syncytial virus (RSV), a common viral infection in young kids that's often mistaken for a cold or the flu. Although RSV causes few problems in adults and older kids, in preemies it can lead to severe illness, breathing problems, or even death, and is a common cause for rehospitalization of preemies.

An immunization is available to help protect infants from RSV. Preemies born at less than 32 weeks and any born from 32 to 35 weeks who have certain risk factors — someone smoking at home, time spent in childcare, or contact with multiple children — should receive the vaccine.

In winter months, the first dose of vaccine generally is given prior to discharge, then monthly throughout the RSV season, which runs from late fall through late winter or early spring. Preemies discharged at other times of the year may also need immunizations once wintertime arrives. Some infants who were especially premature may also need to be vaccinated for a second RSV season.

Preemies can be given the injections at home by a nurse or in the doctor's office. The vaccine does not always prevent RSV infection but can lessen its severity. Ask your doctor whether your baby should receive RSV immunizations.

Appropriate developmental follow-up is important for very premature babies. Many ex-preemies continue to see specialists, including early-intervention specialists, neurologists, ophthalmologists, and physical therapists, for several years to measure their vision, hearing, speech, and motor skills.

## **Preparing for Discharge**

The discharge of a preemie from the hospital isn't a single event, but a process. That process is designed to assure the medical staff that the infant can survive and thrive outside the hospital, and it prepares parents to take care of the baby on their own.

Some hospitals offer parents of preemies a rooming-in period that allows them a brief stay in a hospital room with the baby so they can gain some experience in taking care of the infant's needs. Although

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they're apart from the nursery and functioning as solo caregivers, the parents have the security of knowing that help is just down the hall.

As your preemie progresses, you can get ready for the big day and the weeks that follow by:

- checking medical records and insurance coverage
- choosing a pediatrician and making medical appointments
- learning CPR and receiving specialized training
- making a decision about circumcision
- outfitting your vehicles with car seats
- attending a discharge debriefing

## **Check Medical Records and Insurance Coverage**

As soon as possible after the birth of your baby, call your insurance company and ask to have your baby added to your policy; many insurers require that you do this within a few days of the birth.

Some insurers will provide home nursing visits for premature infants or even more extensive nursing care for infants with complex medical problems. Nursing providers and social service workers can help you determine what your insurance coverage will provide.

Also, set up a file for medical records, financial statements, and correspondence you're likely to have with the hospital and your insurance company.

## **Choose a Pediatrician and Make Medical Appointments**

Don't wait until the last minute to choose a pediatrician. In addition to the usual questions, ask whether the doctor cares for many premature infants. Ask when you should schedule the first visit with the pediatrician — usually with a week of discharge from the hospital (unless the pediatrician has assumed care of the infant prior to discharge from the NICU).

Discuss with the NICU staff whether your baby will require home nursing or visits with medical specialists other than a pediatrician. If so, ask for referrals and for the telephone numbers of those health care providers.

In addition, your baby might need to undergo routine tests, including blood, hearing, and vision tests. Make sure you understand the tests needed after discharge.

## **Learn CPR and Receive Specialized Training**

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To be prepared for emergencies, consider taking a course in infant CPR before your baby comes home from the hospital. (CPR training is required for all parents whose children are on apnea monitors.)

Make sure your partner takes the course, as well as grandparents or other caregivers who will be alone with the baby. The NICU staff may be able to recommend a program; in some hospitals, the nursery staff actually trains parents of preemies in CPR. The American Heart Association and the American Red Cross also can provide information on training.

If your baby is to be sent home with special equipment — such as an apnea monitor or oxygen tank — you'll be trained to use it. Make sure you understand what to do if something goes wrong.

Check to see if your county or state grants preferential parking stickers to parents with children on home oxygen. Call the local rescue squad to make sure they have equipment to handle a premature infant emergency and, if you live in a rural area, make sure they know how to get to your home.

## **Make a Decision About Circumcision**

If your baby is a boy, you'll need to decide about circumcision. Full-term baby boys usually can be circumcised before they leave the hospital; generally, the same applies to a healthy preemie.

## **Outfit Your Vehicles With Car Seats**

Before heading home, your preemie will need to be in an infant-only car safety seat with a three-point harness system or a convertible car safety seat with a five-point harness system. Most car seats need to be modified with padding or head supports so that a preemie's head stays in a position that keeps the airway open. A preemie often does not have the muscle control required to keep the head upright or to move it if he or she is having trouble breathing.

As a precaution, many hospitals require that parents bring in their car seat for a test. The baby is placed in the seat and attached to a cardiopulmonary monitor that evaluates the heart and breathing.

Some babies have respiratory problems that prevent them from traveling in a traditional infant car seat. If that's the case with your baby, discuss using a special restraint system with your neonatologist or doctor.

If your baby will be on oxygen or an apnea monitor at home, you'll also need to use these devices while traveling in the car. Once in the car, secure them carefully so in the event of a crash they won't be dangerous to passengers. If you have any questions about whether your vehicle is properly outfitted for the ride home, talk to the hospital staff before you leave.

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Because of potential breathing problems, it's generally recommended that parents limit the time a preemie is in a car seat to an hour or so. If you'll be traveling longer than that, ask your doctor if it is OK for your baby.

## **Attend a Discharge Debriefing**

Although it varies from hospital to hospital, expect a meeting to review medical care after discharge, confirm follow-up appointments, and allow you time for questions about your baby. All debriefings should include a thorough discussion about caring for your preemie once you're home. Make sure you understand all the instructions and advice, and ask questions.

When you leave with your baby, make sure you have the telephone number for the NICU. These professionals can be a valuable resource, especially in the gap between discharge day and the baby's first doctor's appointment.

## **At Home With Your Baby**

Expect to live quietly with your preemie at first. Because their immune systems are still developing, preemies are susceptible to infections. Therefore, you need to take some precautions. Visits outside the home should be limited to the doctor's office for the first several weeks, especially if your baby is discharged during the winter months.

Because doctors' offices commonly have several kids with viral infections, try scheduling your appointment as the first of the day or request to wait in an examining room instead of the main waiting area. Ask the doctor how limited your baby's contact with other kids and adults should be during these first weeks.

Most doctors recommend not visiting public places with preemies. And limit visitors to your home: anyone who is ill should not visit, nobody should smoke in your home, and all visitors should wash their hands before touching the baby. Talk to your doctor about specific recommendations — some family visits may need to be postponed to allow your little one's immune system to grow stronger.

Babies' success at feeding and sleeping is important to their health. Expect your preemie to sleep more than a full-term baby, but for shorter periods. All babies, including preemies, should be put to sleep on their backs to reduce the risk of sudden infant death syndrome (SIDS).

Most preemies need 8 to 10 feedings a day with no more than 4 hours between each — any longer and the baby may become dehydrated. Six to eight wet diapers per day show that the baby is getting enough breast milk or formula.

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Take advantage of these quiet weeks together to enjoy skin-to-skin contact, also known as kangaroo care. Most intensive care nurseries encourage parents to begin kangaroo care prior to discharge; the nursing staff can show you how.

In a warm room at home, dress your infant in only a diaper, then place the baby on your chest and turn your baby's head to one side so that his or her ear is against your heart. Research indicates that kangaroo care can enhance parent-child bonding, promote breastfeeding, and improve a preemie's health.

## **Taking Care of Yourself**

Parents spend a tremendous amount of time caring for a preemie during the first few months at home. But it's also important to be good to yourself and not underestimate the stress of delivering earlier than expected.

Women are supposed to have 6 to 8 weeks to rest and recuperate after giving birth, but a baby's premature birth may reduce that recovery time. In addition, those long days in the NICU take a physical and emotional toll.

You might have a wide range of emotions during these first months. If your preemie has serious medical problems you may feel angry that the baby is sick or grief for the loss of that healthy, perfect baby you dreamed of bringing home. And as with all women recovering from pregnancy, mothers of preemies may experience the hormonal shifts of baby blues or more serious postpartum depression.

To make the adjustment of living with your new baby easier, accept offers of help from family and friends — they can babysit your other children, run errands, or clean the house so you have time to care for the baby or rest.

Treat yourself well by getting enough rest, eating well, and exercising moderately. Seek support and encouragement from doctors, nurses, veteran parents, support groups, or online communities.

And if you're overwhelmed or depressed, do not hesitate to get professional help for yourself so you can fully enjoy your new baby.

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