

# Preparing for your baby's medical care after the NICU

There are a number of things you need to do to set up your baby's medical care once she's home. This may seem overwhelming at first. If you've been involved in her care in the NICU, you may already have done many of these things.

## **Choose a health care provider for your baby.**

Once your baby leaves the hospital, she needs follow-up care. You may already have chosen her health care provider. But if your baby came early, you may not have had a chance to find someone. It's important that you find a health care provider who's a good fit for you and your baby.

Your baby's provider may be a pediatrician, family physician or nurse practitioner. All of these providers have the training to take care of babies.

If your baby has special medical needs, you may want to find a provider who has experience caring for children with your baby's condition. The NICU staff, hospital social worker or case manager can help you find one. Some hospitals have a clinic where your baby can get care after she leaves the NICU. Ask the NICU staff if your hospital has one of these clinics.

## **Ask these questions to help you choose your baby's provider:**

- Do you have experience caring for children with conditions like my baby has?
- Do you accept my insurance plan?
- How do I pay if you don't accept my insurance?
- What are your office hours?
- Will you see my baby at each appointment or are there other doctors you work with?

- What happens if my baby gets sick at night or on a weekend?
- How do you handle emergencies?
- What hospital(s) can you admit patients to?
- Do you have a separate waiting room for sick children?

## **Learn about your baby's medicines.**

Some babies go home from the NICU still taking medicines. Learn how to give your baby his medicine before he leaves the hospital. Write down all the directions.

## **When giving your baby medicine, make sure you know:**

- Where you can get the prescription filled (at a grocery store, a drug store or a pharmacy)
- How much medicine to give, how often to give it and when to stop giving it
- If you can give it before, during or after feedings
- If the medicine needs to be refrigerated, prepared or mixed
- What to do if you miss a dose
- If your baby needs more than one medicine, if you can give them together at the same time

This resource includes some medical terms you may hear in the NICU. You can find out what they mean in the *Words to know* section at the end of this resource.

**You also need to know:**

- What position your baby should be in
- What to do if your baby spits up or vomits the medicine
- If there are side effects from the medicine and what to do if your baby has them

To track your baby's different medicines and when to give them, use a chart. Ask the nurse to help you make the chart.

**Preparing to use your baby's medical equipment at home.**

Some babies need medical equipment when they leave the hospital. Taking your baby home with medical equipment may make you nervous and stressed. There's a lot to think about and plan for if your baby needs medical equipment at home. You can do some things to get ready while your baby is in the NICU.

**Equipment and supplies your baby may need at home**

Babies go home from the NICU on equipment based on their medical condition. Your baby may go home using one or more of these types of equipment:

**apnea monitor** — A machine that detects when your baby stops breathing for a few seconds. An alarm goes off to let you know your baby has stopped breathing.

**gastrostomy tube** (also called g-tube) — A feeding tube that goes directly into the stomach.

**mechanical ventilator** — A machine that helps your baby breathe or breathes for him when he's not breathing on his own. It works by pushing warm air and oxygen into the lungs through a breathing tube. The provider sets the amount of oxygen, air pressure and number of breaths per minute for your baby.

**nasal cannula and oxygen tank** — A nasal cannula is a soft plastic tube that goes into your baby's nose. The nasal cannula is connected to an oxygen tank which provides oxygen to help your baby breathe.



**tracheostomy tube** (also called trach) — A breathing tube that's put into your baby's windpipe through a hole in the neck.



Some of these types of equipment use electricity and some require additional supplies like gauze, tubing, and backup batteries. Talk to your baby's health care providers to learn about what equipment and supplies your baby needs.

## Getting ready to bring your baby home on medical equipment

Before your baby's discharged from the NICU, talk to her providers about medical equipment she needs when she gets home. Your NICU case manager can help order equipment and schedule training sessions for you to learn how to use it. Your case manager also can help you arrange for in-home nursing care if your baby needs it. This is when a nurse comes to your home to care for your baby.

Here are some things you can do as you get ready to take her home:

- **Care for your baby with the medical equipment she needs.** For example, if your baby has a tracheostomy tube or a gastrostomy tube, clean and care for your baby's skin and the tube so you feel comfortable doing it on your own. Your baby's providers can show you what to do. Also, you can ask them to help you make a schedule for when to give your baby medicine and for certain kinds of care, like cleaning her feeding tube.
- **Room in with your baby.** This means you take care of your baby in the hospital like you will at home. Rooming in is a good way to get comfortable taking care of your baby while the NICU staff is right there to help.
- **Get your home organized.** For example, you may want to move your baby's bedroom to the main floor to make caring for him easier. Put all of your baby's medical supplies in a cabinet or drawer in the kitchen and label it so everyone knows where the supplies are. Use things like shower caddies, shoe organizers that hook on a door and plastic bins to organize medical equipment.
- **Make sure the electricity in your home works with your baby's equipment.** If you have an older home or your baby needs more than one kind of equipment, you may need to update your electric system. An electrician or someone from the equipment company can come to your home to check your system. If you rent your home or apartment, talk with your landlord about what you need.

## Planning for the day your baby goes home

Here's what you can do to make sure everything goes smoothly the day you bring your baby home:

- Have everything you need to care for your baby at home. Make sure you can easily get to the equipment, like oxygen tanks, and supplies, like tubes, that you'll need right away.
- Plan for the car ride home. Have someone sit in the backseat with your baby and keep your baby's supplies handy. You should have portable equipment for the car and have all batteries charged. If your car ride is long, find a place to stop for a break and to care for your baby, such as feeding him or changing his diaper.

*“As a nurse, I was familiar with a lot of the equipment in the NICU. But when we took Roxanne home, I found myself focusing on her oxygen levels and apnea monitor. I was really afraid to let her be a “normal” baby. It took a while, but I finally stopped seeing only the fragile, small baby and started to see her as the healthy, strong kid she is today.”*

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# Words to know

**apnea** (AP-nee-uh) — When a baby stops breathing for more than 15 seconds.

**apnea monitor** (AP-nee-uh MON-uh-tur) — A machine that detects when the baby stops breathing for a few seconds. An alarm goes off to let you know the baby stops breathing.

**case manager** — A person who may oversee a baby's discharge from the hospital, help set up home care services and supplies and follow up with families about insurance coverage for their baby's NICU stay.

**family physician** (FAM-uh-lee FUH-zish-uhn) — A doctor who takes care of people of all ages.

**formula** — A milk product that can be fed to a baby instead of breast milk.

**health care provider** — Also called provider. The person who gives medical care.

**health care team** — A group of health care providers who work together to care for a baby.

**in-home nursing care** — When a nurse comes to a family's home and provides medical care to the baby.

**nasal cannula** (NAY-suhl KAN-yoo-luh) — Small plastic tubes that go into your baby's nose to help him breathe. Air and oxygen go through the tubes into your baby's lungs.

**NICU** — Also called the neonatal or newborn intensive care unit. The place in the hospital where newborns go for special care.

**neonatal nurse practitioner** — Also called NNP. A nurse with special training to take care of sick babies. The NNP works with the baby's neonatologist, can do some medical procedures and may direct your baby's care.

**pediatrician** (pee-dee-uh-TRI-shuhn) — A doctor who has special training in taking care of babies and children.

**premature birth** — When a baby is born before 37 weeks of pregnancy.

**provider** — See health care provider.