

Taking your baby home on medical equipment

The idea of taking your baby home from the neonatal intensive care unit (also called NICU) can be very exciting. But taking him 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, and other things once he's home.

What type of equipment and supplies might my baby 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:

- **Gastrostomy tube (also called g-tube)** — A feeding tube that goes directly into the stomach.
- **Tracheostomy tube (also called trach)** — A breathing tube that's put into your baby's windpipe through a hole in the neck.
- **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.
- **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.

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

How can you get ready to bring your baby home on medical equipment while he's still in the NICU?

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.

What can you do to plan for your baby's discharge day?

Here's what you can do to make your baby's discharge day go smoothly:

- **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.
- **Find time to celebrate.** Discharge day is a day to celebrate, especially if your baby has been in the NICU for a long time. Decide how you want to involve family and friends in your baby's discharge. Let your friends and family know your plan ahead of time.

Taking care of yourself

It's important to take care of yourself so you're at your best to take care of your baby. Here's what you can do:

- **Connect with other NICU parents.** Visit shareyourstory.org, the March of Dimes online community where you can talk with parents who understand what you're going through.
- **Ask the NICU social worker about local programs and support groups for NICU parents.** A social worker is a person with education and training to help people solve problems and get access to services.
- **Ask a family member or friend or hire an in-home nurse to stay with your baby for a short time.** You may need to take a break every now and then, even if it's just to take a nap or take your other children to the park.
- **Ask for and accept help from others.** Tell them exactly what you need them to do for you.

How can I manage my baby's care at home?

Working with more than one health care provider and keeping track of medical supplies is a lot to manage. Here are some ways to keep organized when caring for your baby at home:

- **Manage her medical care.** Find a way to keep track of your baby's medical appointments. This may be on a calendar in your kitchen or on your phone with an alert to remind you. Think about if it will be easier to have a few appointments in one day or if it would be better to have them on separate days. When your doctor makes a change to your baby's care or medication, make sure this is also shared with your baby's in-home nursing care agency and equipment company.
- **Coordinate in-home nursing care.** Your baby's nurse writes down everything that happened in a medical chart while she takes care of your baby. Consider having a different place to write down things like how your baby slept overnight or an activity that he enjoyed. Ask the in-home nursing care agency for information on their sick and vacation policies for staff so that you know what to expect. Also, think about where the nurse can be in your home and any rules you have in your home.
- **Keep track of equipment and medical supplies.** Keep a list of your baby's equipment and medical supplies, including order numbers, size and quantity. The equipment company can give you a checklist. Be sure to re-order supplies with enough time, as shipments can sometimes be delayed. Always be prepared when you leave the house, make sure you have your baby's supplies even when you're just going to the park.
- **Plan for emergencies.** Share information about your baby's medical condition with your local fire department and emergency or first responders so they know what to expect in case they're called to your home for an emergency. Invite them to come to your home to meet you and your baby. Also, contact your utility companies to let them know your baby's health care needs. They may have a priority list for repairing power outages or plowing snow. Make a plan for if the power goes out. Have back-up batteries and know how long they will last.

