

NICU Parent Quick-Guide

KEY ADVICE FOR THE NICU JOURNEY AND BEYOND

- You are the most important member of your baby's care team.
- Ask questions, understand your baby's care plan, and speak up—your voice matters.
- Even small moments of involvement make a big difference. Your baby knows you.
- Trust your instincts—you know your baby.

KEEP THIS IMPORTANT INFORMATION AT YOUR FINGERTIPS.

Save the number to the NICU in your phone. You can call to check on your baby any time, day or night.

NICU phone number: _____

Learn the hospital rules for siblings, family members, and friends.

NICU visiting policy: _____

Safety practices: Follow handwashing and infection control guidelines to protect your baby and others.

Save the name and phone number for the NICU social worker and/or hospital advocate in your phone so you can easily reach out when needed.

Social worker contact: _____

Know how to get to the NICU. Ask about parking, public transit, or transportation assistance. If you need help with transportation, talk to your social worker.

Transportation information: _____

If you need an interpreter, ask how to get in-room language support.

Interpreter contact information: _____

Created in Collaboration with **Today Is a Good Day & NICU Alumni**



NICU To-Do List

Get organized and know what needs to be done.

- ☐ **Get a breast pump.** If you are providing breast milk for your baby, call your health insurance company or talk to the hospital social worker to find out how to rent a hospital-grade pump for home.
- ☐ **Find financial help.** Add your baby to your health insurance and ask to speak with a case manager to learn about your coverage and NICU-related programs. Ask your social worker to help you apply for Social Security Insurance benefits (SSI) or other programs if you and your baby qualify.
- ☐ **Sign up for NICU support groups.** You can do this in the hospital or virtually.

In the NICU

- ✓ **You are the most important member of your baby's care team and your baby's voice in the NICU!**
Your baby's nurse is your partner. They can explain what is discussed during rounds, care updates, and how you can be involved.
- ✓ **Use a journal or app on your phone to jot down milestones, important dates, and questions for the care team as they come up.** Keeping everything in one place makes it easier to remember, celebrate, and share with your care team.
- ✓ **Participate in rounds.** This is your opportunity to understand the plan of care for your baby and their goals for the next 24 hours. Ask when they happen. If you can't attend, request a call. Prepare questions in advance.

Rounds take place at: _____

- ✓ **Touch your baby.** Ask when you can hold your baby skin-to-skin. Learn how to give hand hugs. Your baby needs your loving touch.

Take notes on ways to touch your baby: _____

- ✓ **Be involved.** Find out when your baby's care times are and learn how to help. Ask the care team to let you know when your baby is having any procedures, so you can be there to support your baby whenever possible.

My baby's care times are: _____

- ✓ **Celebrate milestones.** Every small step forward matters!
- ✓ **Get lactation support.** If you are providing breastmilk for your baby, ask if you can talk to a lactation consultant. Find out if there are pumping rooms you can use.

The lactation consultant's contact information is: _____



- ✓ **Get support for making decisions.** The B R A I N plan has steps that can help guide you:
 - **BENEFIT?** (What good comes from this choice?)
 - **RISK?** (What could go wrong?)
 - **ALTERNATIVES?** (Are there other options?)
 - **INTUITION?** (What does your gut say?)
 - **NOTHING?** (What happens if we wait or do nothing?)
- ✓ **Have concerns? Speak up.** Ask the charge nurse, nurse manager, or patient advocate if needed. They want you and your baby to have a good experience while you are in the hospital.
- ✓ **Take care of yourself and your partner.** Take breaks when needed or take turns with your partner or support person to be with your baby in the NICU. Ask about in-person or virtual counseling, support groups, and peer mentors in your NICU.

Mental health resources: _____

- ✓ **Find support.** Today is a Good Day provides support for NICU families through care packages, virtual resources and programming, a podcast, emotional support tools, and more. Email: programs@todayisagoodday.org for more information.

Getting Ready to Go Home

Know what to expect as you prepare for discharge.

- ☐ **Choose a pediatrician.** Make sure the NICU sends your baby's medical records to your selected pediatrician and that you get a copy, too. You may need to work with the Medical Records Department to fill out a release of information.
- ☐ **Get a car seat.** If your baby was born early, you may want to consider purchasing a seat that is safe for babies as small as 4 pounds. If you need help getting a car seat, ask your social worker about community car seat programs.
- ☐ **Complete discharge teaching.** Your team will help you learn about caring for your baby, safe sleep, infant CPR, what to do if your baby gets sick, and more.
- ☐ **Ask about early intervention.** Get referrals and a list of providers near you if your baby needs therapies like PT, OT, or speech therapy after discharge.
- ☐ **Understand medications.** Learn the what, when, and how for your baby's medications. Fill any prescriptions before discharge.
- ☐ **Learn about equipment.** If your baby needs special medical equipment at home, learn about why it is needed and how to use and care for it. Ask the NICU team for help if you need a "letter of medical necessity" for your insurance to cover the equipment.
- ☐ **Track appointments.** Keep track of your baby's appointments with the pediatrician, specialists, or NICU follow-up clinic. Always put appointments in your calendar. Write down questions you have and take notes during the appointment.
- ☐ **Support for you.** Support after NICU. The NICU experience doesn't end when you leave the hospital. It can have a big impact on your mental health. Ask your social worker to help you find counseling or support groups.
- ☐ **Online Support.** NICU Alumni has a Grad Guide and podcast, as well as discharge planning support and equipment guides and an example template of a letter of medical necessity, to help with the transition from NICU to home with your baby.

For more information, support, and resources, check out **Today is a Good Day** and **NICU Alumni**.

