

Becoming an Advocate for Your Baby

A guide for parents

Becoming a parent is a life-changing experience. This is especially true for parents of newborns in the NICU.

As a parent of a premature or ill infant, you may feel helpless at times. Everything in the NICU is new and unfamiliar, and in many ways, you have to rely on the doctors and nurses to know what is best for your baby.

But you are a vital part of your baby's care team, and there are many things you can do to help make your baby's hospital stay better. You can learn to partner with the care team and provide important insights into the best way to care for your baby. In the process, you will become an expert on your baby's care needs and an advocate for your baby.

How can I become an advocate for my baby?

Your relationship with your baby is special. Being the parent makes you the most qualified person to be your baby's advocate. And, there are things you can do to help you be the best advocate possible:

- **Learn more about your baby.** Spend time at your baby's bedside. Watch and listen. Find out what your baby is like.
- **Ask the care team a lot of questions.** You cannot ask too many questions. If needed, ask the same question over and over again until you understand the answer.
- **Get to know the team members who care for your baby.** Read the handout "Your Baby's Care Team." As your baby's advocate, feel free to ask the care team to explain what is going on. Make sure you feel your concerns are heard, and that you understand your care options.



Always ask the care team to explain anything that you do not understand.



“I learned to be my child’s biggest advocate. I learned that if I had questions, I needed to ask them, and that my concerns would be fielded with warmth and thoughtfulness.”

-- Kylie’s Mom

“Prepare to meet people who will impact your life in many ways. Trust your judgement and ask for nurses that you trust and bond with to care for your child when they are working. It will make your days and nights less lonely if you have someone you trust alongside you.”

-- Timmy and Tessie’s Mom

- **Don’t wait – write down questions and concerns when you think of them.** After a busy day in the NICU, it can be hard to remember all the questions that came up during the day. And, it can be very hard to remember what you wanted to ask during rounds, once you are talking face-to-face with the doctors and nurses.

Writing things down also helps you think through your questions so that you make sure that you get the information you need.

- **Ask about your baby’s care plan.** You may have a lot of choices to make during your baby’s stay in the NICU. When you know the care plan the providers have in mind, it can help you learn more about the choices you may have to make. Planning ahead while also being flexible can help keep your baby’s care plan on track.
- **Trust your instincts.** No one knows your baby better than you do. And, you may notice subtle changes in your baby that might not be obvious to someone else. Share what you observe, ask questions, and insist if you have to. Your care team respects your insights as a parent.

Resource: Hand to Hold’s *Advocating for Your Baby* Resource Library

Questions?

Your questions are important. Talk with a member of your baby’s healthcare team if you have questions or concerns.

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