10 Tips to help you get what you need

Good communication is important all the time, but it is vitally important when your baby is admitted to the Neonatal Intensive Care Unit (NICU). While having a baby in the NICU is stressful, it can seem even worse if you don’t feel like you understand what is going on. Fortunately, the NICU staff is here to help. With the right support, all parents can learn to navigate the NICU and become strong, capable, and informed advocates for their babies.

By learning the skills you need to communicate clearly and effectively with your baby’s care team, you will build strong relationships based on mutual respect and trust – and your baby will benefit. These tips will help you talk to your baby’s care team.

1. Ask questions
   Be prepared to ask a lot of questions about your baby’s care. You may want to write down questions as you think of them. Ask for help learning what the medical words and abbreviations mean. Sometimes, when you are being told a lot of information all at once, it can be confusing, and it can be easy to forget. Try keeping a journal and writing down important information. Then you can look at it later and think about it. Also be sure to write down the names of everyone caring for your infant. It will help you remember who they are.

2. Make sure that you understand
   Parents should expect the doctors and nurses to listen to their questions and answer them appropriately. As the baby’s parent, it is your right to have your questions answered. However, it is also up to you to make sure that you understand what they tell you. A good way to do this is to ask the doctor or nurse if you can repeat back the answer you heard. This can prevent many misunderstandings in the NICU.

3. Be a part of the team
   While the doctors and nurses provide the highly specialized care your baby may need, always remember that you, as parents, are the most important people in your baby’s world. Be there for your baby and help with his/her care. Be at your baby’s bedside as much as possible and learn all you can about your baby’s condition. Not only is it important to your baby, it shows the medical team that you are ready to assist in your baby’s care. Even if you can’t be there, call and ask for updates. The doctors and nurses will welcome you as an important member of the team the more they see you and talk to you.

4. Be respectful and expect respect in return
   Be respectful of the rules and routines in the NICU. These rules and routines are based on best practice standards in the NICU, and they are in place to help your baby. Likewise, you should expect the respect of the NICU staff. When you make a request, it should be acknowledged with an appropriate response. As a NICU parent, you should never be ignored. Remember that you are the most important person in your baby’s world. Also be respectful of the other families in the NICU. Their needs may be different from yours, but they also deserve respect while in the NICU.
5. Be flexible
As your baby’s condition changes, be flexible. Infants’ needs change continually, and the routine and care that worked yesterday may not work today. Be flexible and open-minded as your baby’s care needs change. Remember that you are part of a larger NICU community of parents who are also asked to be flexible.

6. Ask to review your baby’s medical record
You are entitled to your child’s medical information, but most hospitals have policies about looking at the chart while the baby is in the hospital. You can make requests to look at your baby’s chart at any time, but it is always best to sit down and do it together with your baby’s doctor. They will be able to help you understand what is in there and what it means. Looking at it together will open the lines of communication and build trust between you and your baby’s medical team. After your baby is discharged, you may obtain a copy of the medical record by requesting it from the hospital’s Medical Records Department.

7. Learn how to be a problem solver
When there are problems, be prepared to offer solutions. For example, if something has happened that you are worried about, talk to the doctor, nurse practitioner, charge nurse, or nurse. Explain your concern and give any suggestion you might have to make the situation better. Remember that you are your baby’s advocate, and express your concerns and possible solutions for the sake of your baby. If you have concerns about a specific nurse, talk to the charge nurse to express your concerns.

8. Tackle breakdowns in communication
If there is a problem you need to talk about, seek out the charge nurse, then the manager of the unit, and then the director of the unit until you get to someone who can assist you. Explain the problem as calmly and clearly as possible and ask for help. The person in charge can help you talk to the person you are having a problem with and fix things.

9. Be patient
Be patient with your baby, the medical team, and most of all, yourself! Sometimes things get better very slowly. Sometimes things might get worse before they get better. Remember that the medical team is doing everything possible to help your baby improve, but it takes time. During your baby’s NICU journey, look for strength and support in the people around you.

10. Be grateful
Being grateful is probably the last thing on your mind when your baby is in the NICU. Nobody expects to be in the NICU, but it is the best place for your baby right now. It’s okay to feel sad, scared, and disappointed. Talk to someone. Talking about your feelings helps you come to terms with the situation and allows you to look for something, no matter how small, to be grateful for. Try to find something good in each day – an improvement in your baby’s condition, a helpful explanation from the doctor, the caring touch of a nurse, or the friend who brought your family a meal. A grateful attitude will go a long way in helping you through this journey, even on the worst days.

Ask for help
Please remember that you can always ask for help. Don’t be afraid to enlist the support of your OB/GYN, primary nurse, social worker or any other medical professional for help. The NICU staff is there because they care about getting the best possible outcome for you and your baby.
Let them help.

For more information from Hand to Hold: