

Meeting with Your Baby's Healthcare Providers

By Sue L. Hall, M.D.

These suggestions are tips to help you be proactive and prepared for meetings with your baby's healthcare team, so you will feel somewhat more "in control" of your NICU experience. You have every right to be partners in the care of your baby, and you are the best advocate your child has.

Preparing for the Meeting:

1. Ask for the meeting with your baby's healthcare team (including the doctor) to be held in a private place.
2. Ask if you can meet with the doctor of your choice, if possible. Choose a doctor with whom you already have a relationship and in whom you trust; choose someone you can understand!
3. Be sure you and your significant other attend together. Invite other family members or support people to be present if you wish. They may be able to hear and absorb information that you may not, and they may be able to ask questions you haven't thought of.
4. If you have other children, try to find child care before the meeting. It will be hard for you to attend to the content of the meeting if your kids are present, and some of the discussion that takes place may not be appropriate for your other children to hear.
5. Consider doing some research and reading before the meeting to give you some understanding of your baby's issues. Seek out reliable sources in books, the internet, and other premie parents.
6. Develop your own list of questions either from information you have been already given by the healthcare team or from your own research.
7. Spend time in the NICU with your baby getting to know him/her really well.

At the Meeting:

1. Visit with your baby before and after the meeting; this will help you feel connected with your baby.
2. Ask for a translator if your native language is not English. Hospitals are required to make translator services available to all families.
3. Ask to include your significant other via a conference call if s/he cannot be present.
4. When the meeting starts, ask if one of the hospital staff can take notes for you. This will leave you free to concentrate on asking your list of questions and to process the information you are receiving. Also ask to have the baby's diagnoses written down for your future reference.
5. Consider starting the meeting by stating what you are most worried about and what you want to be sure to discuss at the meeting, so your concerns can be addressed.

6. Be prepared to tell the healthcare team what you understand your baby's condition to be.
7. During the meeting, rephrase and repeat back what you are hearing to make sure you understand. Ask for clarification if you don't completely understand what the doctors are saying or any medical terminology they use.
8. Don't be afraid to ask questions.
9. Ask for visual aids if they would be helpful to your understanding (diagrams, pictures, xrays).
10. Let the medical team know your preference for involvement in decision-making.
11. Don't be afraid to express your emotions.
12. Ask for the cause of your baby's problems.
13. Do not blame yourself for anything that has happened with your baby. If necessary, ask directly if you are to blame.
14. If you are given bad news, ask if there's a range of possible outcomes for your child. Ask what the medical team's degree of certainty is. Ask if they have data to back up their conclusion.
15. If you are given bad news, ask what you can still hope for and what is considered to be the likely outcome. Try to find the positives.
16. If you are asked to make difficult decisions, ask what the impact of your choices will be on your child's future and your lifestyle.
17. If you need time to think about a decision, say so.
18. If you have personal, religious or cultural reasons for wanting to handle a medical situation a certain way, especially if it is different than what the healthcare team is recommending, try to explain your position so it can be taken into account.
19. Be an advocate for your child.
20. If you would like a second opinion, feel free to discuss this with the medical team.
21. Let the medical team know what you would like them to do to help you.
22. Ask if there are resources the medical team can recommend for you to for follow-up with. Books to read? Websites with reliable information? Early intervention services for your child? Parent support groups for you to become involved with or peer-to-peer contacts to connect with?
23. If you think you will want or need one, ask if you can have a follow-up meeting.

After the Meeting:

1. If you need time alone after the meeting, make your wishes known.
2. Consider debriefing with the NICU's social worker afterwards.
3. Don't forget to visit your baby before leaving the hospital.
4. Try to accept the unknown, and to understand that doctors don't have all the answers.
5. Be flexible; things change.

6. Rely on your faith or whatever coping mechanisms have helped you get through tough times before in your life, including accepting support and help from trusted family members and friends.
7. Reach out to others and ask for help if you need it.
8. Acknowledge that you will feel a variety of emotions. Try not to ride the NICU emotional roller coaster; instead ride the merry-go-round and get off whenever you need to.
9. Take care of yourself and focus on your own health. Recover from your delivery. Get mental health help if you need it. Use your OB as a resource.
10. Don't worry about every fear.
11. Let go of guilt.
12. Don't be afraid to bond with your baby.
13. Remember that half of what you worry about will never happen, and the rest you can handle.

References

Boss RD, Donohue PK, Arnold RM. Adolescent mothers in the NICU: How much do they understand? *Journal of Perinatology* (2010);30, 286-290.

Izatt S. Educational perspectives: Difficult conversations in the neonatal intensive care unit. *Neoreviews* (2008); 9;e321.

Levetown M and the AAP Committee of Bioethics. Communicating with children and families: From everyday interactions to skill in conveying distressing information. *Pediatrics* (2008); 121:e1441-1460.

Sharp MC, Strauss RP, Lorch SC. Communicating medical bad news: Parents' experiences and preferences. *Journal of Pediatrics* (1992); 121(4), 539-546.

About the Author

Dr. Hall is a practicing neonatologist, consultant to The Newborn Channel, and the author of *For the Love of Babies: One Doctor's Stories About Life in the Neonatal ICU*. Visit her website at www.suehallmd.com.