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COLLABORATION/ PARENTING: NICU

## Communicating with Intensive Care Medical Staff

Parents vary in their styles of information gathering. Particularly when their baby or child is in an intensive care unit (NICU or PICU), some parents want just the basic facts about what is happening right now; others want to know every detail. Information-sharing styles can vary among doctors and nurses, too. Some parents' styles may be a better match with the styles of some staff members than with those of others. For instance, if you as a parent just want to know what is certain or the bottom line, you may feel more comfortable with health care teammates who don't mention all the details, uncertainties, possibilities, and worries. If teammates want to give you that information or share their intuitions or guesses, you can explain that you appreciate their candidness, but that to cope, you need to know only what they are *certain* is happening today and what it means.

If, on the other hand, you want to be fully informed of all the details and possibilities, you may feel more comfortable with teammates who believe parents should know everything the medical staff know. If a doctor is reticent about sharing information, explain that you need and want to be fully informed, to know all that's going on and what staff are thinking, because it helps you cope. Having the details you need also lets you feel more involved and that you are an important member of your child's health care team.

Working with medical caregivers who share your communication style may feel easy. Once caregivers with differing styles know what you need, most will also be

responsive to your style and pace. Still, dissimilar styles can make communication challenging at times.

## **Bridging Communication Barriers**

Communication barriers are practically inevitable in the busy, highly charged intensive care setting. Naturally, parents cannot absorb information as quickly and efficiently as their health care teammates might like. Sometimes, personalities clash. Parents and medical staff also have different perspectives, which can sometimes hamper communication. And some parents simply want more information than they are being given. To overcome these barriers, it is especially important for parents and medical staff to work together, to appreciate each other's contribution to the problems *and* the solutions.

Because the perspectives of parents and health care providers differ, it is very important that your child's health care teammates

- Have care conferences at which they allow ample time to talk to you about what is going on *and* stay with you as you formulate questions
- Respond to your questions directly and honestly
- Recognize, based on your questions, what you want to be told; provide the hard answers openly and compassionately; and most important, stay with you as you face those answers
- Remain open to questions, even ones you've asked before
- Keep the lines of communication open over time to give you the chance to work through your disorganized thoughts and crystallize your unformed questions
- Recognize that you may need to hear things more than once to absorb them and their implications
- Say what they mean

- Avoid exaggerations or representing guesses as facts
- Watch for your reactions and encourage you to seek clarification when you need it
- Reassure you when, in the context of the intensive care unit, your child's condition is considered normal or even mild, or if your child's medical course is common
- Respect your role as loving parents who are involved and advocating for their child.

(For more guidance for Professionals, see "A Note to Caregivers" in the Professionals Pages.)

Likewise, it is important for you, the parent, to

- Realize that your teammates cannot read your mind—you must ask for what you need
- Keep track of your questions, so that you can make the most of your meetings and conversations
- Ask the questions that most trouble or embarrass you, or that you fear are "too stupid"; doing so lets your teammates know what reassurance you need, and their responses can also help you trust their ability to take care of your baby or child
- Stay informed about topics of concern by other means (videos, books, the Internet)
- Make it clear (especially if you feel you aren't getting straight answers) that for you, coping with the truth is easier than being patronized and "protected"
- Seek out multiple ways of meeting your emotional needs; don't rely only on the medical team. Talk to a counselor, social worker, or member of the clergy; go online or join a support group.
- Consider yourself to be your child's most important caregiver. Looking at your role from that perspective should reduce feelings of suspicion, competitiveness,

or timidity, and you'll be less likely to project unkind motives onto your teammates.

- Instead of assuming that your teammates are withholding information from you, assume that it's an oversight and ask them to tell you what you need to know.

When your child needs intensive care, you need support from staff, not protection. With support, you can face your child's medical reality, which may include challenges, uncertainties, hopes, and possibilities. With support, you can cope with the attendant fears and sorrows, which enables you to be with and nurture your little one through any medical crisis.

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