

Becoming a Partner in Your Child's Health Care

As the parent of a seriously ill child, you are an important part of your child's healthcare team. Thinking of yourself that way can be very helpful. It can help you remember that as a partner, you have the same right to receive information and have your voice be heard as any team member. You can let the rest of the team know how *you* want to be involved and make sure that you are always sharing in the decision-making process.

Here are some things to think about as you step into your full role as a partner in your child's healthcare team:

- Set clear goals for your child's care in your own words. Let the team know what it is you hope for. Ask them what you can reasonably expect.
- Find out whether the goals and opinions of other team members are the same as yours. If they are not, make sure you can talk openly about the differences as you work to make decisions together. You can seek help in resolving conflicts from the hospital's ethics committees. And remember that you have the right to a second opinion from other medical specialists.
- You are the person who is most able to say what is in the best interest of your child. When you speak with and listen to your child, remember that you will be called on to speak *for* him or her as well.
- Ask yourself which treatment options and recommendations seem appropriate to you, thinking about how they will affect your child and whether they feel ethically right. "What *should* be done?" is as important a question as "What *can* be done?"
- Let the rest of the team know about your culture and religious or spiritual beliefs so that they can give your beliefs and practices the respect they deserve. Ask for an interpreter if language differences seem to be getting in the way of good communication, or for help from someone in your community to help build a bridge across a cultural divide.
- Make sure that any uncertainty about the outcome of your child's illness is explained to you and that you understand what you've been told. There are many times when doctors cannot accurately predict the chances of survival or how long an illness will progress. Unfortunately, "We don't know" may be the best answer they can give to some of your most pressing questions. But you can still ask team members what they think is going to happen and what their best guess is about timing.
- Find out the reasons for any recommendation the team is making. Ask them why they believe it is the right course of action, and then ask yourself if you agree. Talk with the other team members about ways in which the plan they are proposing is in or out of line with the goals you and your child have set for his or her care.