

## **What Other Parents Have Said Was Important to Talk about with the Healthcare Team**

Parents who have seen their children through serious illness, and in some cases through the process of dying, have much to offer. They have had time to look back on their experiences and draw lessons from them. Those lessons can be helpful to you as you try to get the best information you can from your child's healthcare team.

Here are some questions that were important to parents who have walked the road you are on. Some of them may be hard for you to ask, but hearing the answers will allow you to make good decisions as an essential partner in your child's health care.

- What quality of life will my child have...for the near term? after a recommended treatment? in the future?
- How bad is the disease? What usually happens as it progresses? What does this mean for my child?
- Can my child get better? Is there a cure? Have we tried everything available to us? Are we sure there are no other options?
- Are there complications? Are they major or minor? Why did they happen? Might there be complications later on?
- What is the worst outcome? Could my child die? Could my child be disabled? How might this happen? When?
- Does a recommended treatment or surgery make sense for my child?
- Is a recommended treatment part of normal care? Has it been done before? How successful has it been with other children?
- Can you explain this to me in a way that I can easily repeat to other people so they will understand it too?
- Why are you recommending this? Does it fit in with my goals or my child's goals for his or her health care?
- How or what will this plan add to my child's comfort or safety. Does it help? Could it hurt?
- How much time do you think my child has to live?