

Becoming a Good Decision Maker

In order to make good decisions about your child's care, you need to gather good information. But with so much going on and so many facts and choices to consider, it can seem very hard to sort it all out. Sometimes you might feel like your head is swimming with too much information.

Parents who have lived through the serious illness of a child have said that the things that helped the most when it came to making good decisions were: trust in the healthcare team; having information about the likely results of treatment; knowing how the same illness affected similar children; learning about issues related to quality of life for a child who survives, such as medical complications and physical handicaps; and being certain their wishes were known to the healthcare team.

Here is a set of questions that can help you begin to sort through the many issues you are facing:

- Do you fully understand your child's health condition? Have you asked the healthcare team to explain anything you are not sure of or done research on your own?
- Do you understand what treatment options are being offered and what the results of each one are likely to be?
- Do you feel that all the options have been explored? Have you asked your child's healthcare team if there are other possible approaches that can be discussed?
- Have you talked to your child about his or her health? Have you talked about what options are being recommended? About what the physical, mental and emotion effects of each option are expected to be? About how likely each one is to lead to stability or improvement?
- Given what you know about your child's condition at this point, do you know what your goals are for his or her care now? Do you understand that your goals may change over time?
- Do you know what your child's goals are? Do you feel able to hear what your child's wishes are even if they are not the same as yours?
- Have you weighed the possible rewards of further treatment against the possible risks, as well as the pain and discomfort it may cause your child?

If you have answered "yes" to all these questions, then you could probably make a list right now of the important information you already have that will help guide your decisions. That information falls into three main areas: the status of your child's health, the meaning of the treatment options, and the goals that you and your child have for the future.

Each family looking at its list will come to its own decisions. Some will choose to continue treating the child's illness aggressively. Others will decide that the time to fight the illness is over and turn to helping the child live out the rest of his or her days in peace and comfort among loved ones. What's important is that you make decisions that feel right for you, your child and your family.

And of course you will want to make those decisions based on your best understanding of the situation. There are very few times you can be sure what the outcome of your decision will be, so when you look back it will be good to know that you thought through your choices and discussed all the possibilities. Especially in the case where a child dies, families are often troubled by "what if" questions, wondering if things might have worked out better if they'd made different choices. Knowing you made the best decisions you were able to at the time can help you put those troubling thoughts to rest.