

Helping You Navigate This Journey

Your Search for Information & Answers

You've gotten to this point in your child's illness where you're likely questioning lots of things.

While there seem to be endless and confusing discussions with the Medical team about what choices need to be made, you are not alone.

There are places to turn for help—this website, as well as asking to talk to your child's Social Worker, Child Life Specialist, or the Palliative Care Team at your child's hospital, to begin figuring out what to do and where to go from here.

One step at a time...but know we are here for you.



Your Priorities & Goal Setting for Your Child's Care: What's Important to YOU?

No doubt, you, your spouse, your child, and the rest of your family are, or have already been, through a lot with your child's illness. And some days, as a family and/or individually, you deal with it well, and other days, not so well. That's OK. The important thing now is to take some time to think about what YOU want to have happen next. You all need to be able to live with the decisions you make as unfortunately, there are no guaranteed outcomes on this journey you're on.

What is your MOST important goal for your sick child now?

Is it to continue trying to find a cure?

Is it to keep him/her comfortable and hopefully pain free?

Is it the knowledge that you are doing the right thing in speaking for your child?

Only you can answer this question, but it's an important one to spend some time reflecting on by yourself, and then once you know how you'd answer it, discussing it with others in the family—your spouse, your other children, grandparents, and your child

Continue to ask yourself these questions throughout this journey with your child, wherever it may lead, and then discuss your thoughts and feelings with others in the family with whom this matters. Keep the lines of communication open.

Guidance from Other Families: What They Have Told Us Was Most Important to Them

Families who have suffered the loss of a child have taught us some important lessons. This is what they say was most important to them while their child was sick, or worse yet, dying. Which of these are important to you?

- To be with your child, especially being able to hold and touch your child
- To be helpful to your child
- To be informed of your child's changing condition
- To understand what is being done to your child... and why
- To be assured that your child is comfortable and not in any pain
- To be comforted yourself as this is hard on you (and on all the family)
- To be able to vent your emotions. To have people who will listen to you when you need to get some of the pressures, fears, concerns, frustrations off your chest.
- To be assured that your decisions were right for you, your child
- To find meaning in the life and the dying of your child
- For you to be fed, hydrated, and rested. You need help in taking care of you and your family

Your Child's Involvement & Priorities: What's Important to THEM?

If your child is old enough, have you asked him/her what he or she wants to have happen at each major decision point you've faced in their illness? If yes... good for you and good for your child! If not, why not start now. If developmentally, you think your child is old enough to know what's going on (and maybe even if you don't), ask him/her what they're thinking about all this. What do THEY want to have happen here?

The American Academy of Pediatrics has very strongly recommended telling children about what is happening to them. As parents, our first instinct is to protect children from anxiety and fear. However, even very young children, less than six, have a remarkable ability to accept the truth about what is happening to them. Children are very trusting. When we don't tell them, they lose that trust. Most of us teach our children the value of honesty. In this time of crisis, the child will be confused if they believe they are not told the truth about what will happen. The imaginations of older children lead them to fear things that don't exist. Some older children and most adolescents, especially those who are chronically ill, have a very adult understanding of their illness.

They can and will pick up on our own fears of blood testing and intravenous devices, so explaining to them what is going to happen, will help to decrease their stress and pain. Many hospitals will help you talk to your child about decisions around their care, the procedures and test they'll be going through, why they need to take a certain medicine, etc. You can also ask to be with your child for some of these procedures such as blood tests, or when intravenous catheters or tubes are placed in them.

More importantly, we should realize that children have ears and can listen. They know when they are being left out and when something serious is happening. When they are not told, they become fearful and confused. Children look to their parents for guidance. They want to know what to do. They will think that they are protecting you from the scary things they have thought about. When the children try to protect the parents, and the parents try to protect the children, decisions are more difficult, and helping becomes more difficult.

Remember to keep asking them what THEY want to have happen here. When they make hard decisions that you may not agree with (like expressing a desire to stop a particular treatment like chemo), be willing to accept and support them in that decision (even if it goes against what YOU may want to have happen).

You may feel that you don't know how to begin talking with your child about all this, or that you emotionally can't handle these discussions, but you can. Ask for help--your Social Worker, a Child Life Specialist, a Palliative Care Specialist, your own Family Doctor or Pediatrician. What a relief not to have to do this alone...and to not have to hide things from your sick child or from others in the family.

Communicating With/Talking to Your Child's Healthcare Team

As you move throughout this medical process with your child, there are questions you may want to ask of your child's healthcare team. Doing this shows you are ready, willing and able to be your child's advocate, even if you don't feel like you have all the answers or know what to do yet.

One of the most important things parents have taught us is that confusion caused by lack of information, uncertainty about why things are done to our children, and most of all, the fear of not being heard, adds unnecessary suffering to families like yours with a seriously-ill child. The most valuable tool in establishing trust is a meeting with all your child's caregivers. Trust in the healthcare team is one of the most important qualities in helping to make certain that we are ALL doing the right thing for your child.

Medical teams have expert knowledge about the tests, procedures, treatments, but may not be experts at helping you understand what all of this means. Most families and doctors have found that a team meeting that involves your Doctors, Nurses, Specialists, Social Workers, and others involved in your child's care is very worthwhile. You should also be able to bring important members of your family, friends, and others supporting you. Meetings like these help to educate and empower you as your child's advocate by showing your child's healthcare team you want to be involved in making more informed choices about your child's care.

Team Meeting Considerations

Here are some things to think about as you consider asking for a team meeting with your child's healthcare team:

- Who do you want to be there from the healthcare team? Which specialists? Which doctors?
- Who do you want to be there from YOUR team to support you? Your spouse/significant other, your family doctor or pediatrician, the child's grandparents, other siblings, other relatives, a religious or spiritual person you trust...who else?
- Remember that you/your child's Social Worker will be helpful in a meeting like this
- Think about bringing a trusted friend who's been supporting you through your child's illness. Get them to ask the hard questions maybe, when you can't.
- You should write down questions ahead of time. Meeting in large groups is often intimidating for some families and you may forget to ask something that's important to you.
- During the meeting, take notes if you find that helpful.
- Your child may know there is a meeting. What are you going to tell them? If you're not sure how to handle this with your child, ask your Social Worker or the Child Life Specialist for help. Perhaps the two of you can talk to your child together.
- What is your greatest fear? Tell the team what that is.
- How much do you really want to know? Some families want every technical detail, others just the bottom line. Tell the team how you work best.
- Are there test results you haven't seen or heard about? If yes, ask now. And if you were given the results, do you understand what they mean for your child's condition? If not, ask to have them explained again...in words YOU understand.
- Ask for clarification if you're not sure what's being told to you. Ask to have the information explained in a way that makes sense to you. If you do better with pictures, ask for someone to draw or show you a picture to help you understand.
- If you want to do some more research on your child's condition and treatment options on your own, ask for other resources (e.g., websites, pamphlets, etc.).

- If you do not speak or understand English well, ask that an interpreter be provided to help translate.
- Don't be afraid to ask for another (and another, and another) meeting with your child's healthcare team as things change in your child's condition.
- Ask about what you should expect to see happen next? What are the signs you need to be watching for that something is changing with your child?

Becoming a Partner in Your Child's Healthcare Team

As a parent, you are a partner in your child's care with your child's health care team. So think about making decisions for your child via shared decision-making with the healthcare team so your voice is heard, your wishes are known, and you are involved in your child's care and comfort.

Some things other parents like you have told us are important to talk about with your child's doctors and nurses include:

- What quality of life does or will my child have (now, after a recommended treatment/surgery, in the future, etc.)?
- What is the extent of the disease? How bad is it? What usually happens as it progresses? What does this mean for my child?
- Is it reversible? Can it get better? Is there a cure? Have we tried everything available to us? Are we sure there are no other options?
- Are/Will there be complications? Are/will they be major or minor? Why did (or why might) they happen?
- What is the worst outcome? Could my child die? Could my child be disabled? How? When?
- Does it make logical and medical sense? Has it been done before? How do you know? How successful/unsuccessful has it been on other children?
- Can you explain this to me in a way so that I know I can explain it to someone else? Like my parents and family?
- What are you recommending this? How does tie to/go against my or my child's goals for his/her healthcare?
- How or what does this option/treatment/path add to my child's comfort; safety. Does it help? Could it hurt?