

Talking with Your Child's Healthcare Team

The people who make up the healthcare system have their own ways of doing things, and they won't always remember that what's common and familiar to them might be new or perhaps frightening to you and your family. So it's important for you to ask questions of your healthcare team and let them know about concerns that you or your child may have. It would be nice if they always remembered to check in with you about those questions and concerns, but that's not something you can count on. You may need to be assertive in making sure you are heard when you speak on your child's behalf. If you take an active role, you can become your child's best advocate and strongest support.

Parents who have cared for a child with a serious illness say that one of the biggest problems they faced was confusion about what was happening and what was going to happen to the child. They found they weren't given enough information about what was going on and were unsure why certain tests and treatments were being undertaken. At the same time, they felt that their voices might be getting lost in the ongoing conversation about the child's health and the decisions that needed to be made.

Getting stuck in this kind of confusion only adds needless stress and suffering for a family that can surely do without more of that. And it makes it hard for families to feel they have the trust and confidence they need in the healthcare team. You might not feel sure anymore that you are all on the same side, working together in the best interests of your child.

Trust is a lot easier to come by when families and the healthcare team can share information openly and honestly. The best ways to establish trust is for you to meet with the team. Such meetings can include family doctors, specialists, nurses, social workers, and others involved in your child's care. Other family members, friends, and religious or spiritual counselors might also be included.

Meeting with the healthcare team is well worth everybody's time and effort. It gives you a chance to ask hard questions, and to make certain you understand all the issues and what is at stake. It also lets the team know that you want to be actively involved, reminding them that part of their job is to keep you informed.

Getting information about your child's condition, knowing what the future might hold, planning for future tests, and making certain your worries and your wishes are being heard can relieve some of the fear and anxiety you might have.

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