

Tips for Working with Doctors

Parenting a child with special health care needs brings a variety of joys and challenges. Among the challenges are finding appropriate medical care, and establishing a positive and respectful relationship with your child's doctors to ensure the best medical outcomes.

Be a valued team member

As a parent, you know your child better than anyone and are an expert on what has and hasn't worked in the past. You are an important part of your child's health care team.

The health care system is evolving. Previously, doctors told parents the diagnosis and how to proceed. Today, a model known as "family-centered care" encourages parents, and, when appropriate, the child, to be involved in health care decisions. While doctors provide a diagnosis and treatment options, it is important for your viewpoints in terms of your values, culture, and experience to help decide what works best in your situation. This results in the best medical care.

A big part of family-centered care is known as "medical home." The medical home is not a building, but a partnership involving the child's family, doctor, nurse, and clinic. It seeks to provide comprehensive care that includes both medical and non-medical needs. This care includes resources for your child at home, at school, and in the community, transition planning, and coordinating appointments with specialists.

The concepts of family-centered care and medical home are very important for children and youth with special health care needs. These concepts focus on team management, coordination of care, and the role of parents as part of the team.

One of your roles as a team member is to become informed about your child's diagnosis. There is information available from your doctor's office or online from a variety of reputable sources. Being informed will give you confidence as a team member and will help you make the most of your time with your child's doctors. It will also help you set realistic goals, and prioritize issues that need to be addressed.

When the viewpoints of all team members are considered, your child has the best chance of receiving excellent care.

Feeling comfortable with your doctor

Your doctor must be someone whom you can trust. It is important for you to be comfortable with your doctor's approach to medical care and communication so that you can build a mutually respectful relationship. This includes not just his or her medical expertise, but some of the more personal aspects of medicine:

- Do you feel she shows the appropriate amount of compassion towards you and your child?
- Does he ask about your struggles as a parent?
- Does she value your input?
- Do you feel like a respected member of the team?

- How does he interact with your child?
- Do you have a sense of hope when you discuss difficult issues?
- Is she friendly and interested in your child?

Your doctor should be able to diagnose and explain your child’s illness, as well as provide referrals to appropriate specialists. You should come prepared with written questions to help facilitate communication. Don’t be afraid to ask additional questions, or request further explanations, if you don’t understand. It may be helpful to bring someone with you for support. It also helps to write down the doctor’s answers so you can process the information later.

Trust your feelings. If you are not feeling comfortable with how you are being treated, you need to express your concerns. In complex situations, there are often a number of specialists involved and you will have a different relationship with each of them. It could be helpful to identify a primary care physician or one to two doctors on your team whom you trust and who can discuss information with you. If you do not feel that your child’s needs are being met, you may need to find another doctor.

Conclusion

You are the expert on your child and know him or her best. You are a valued part of their medical team. To accomplish this, you must have a comfortable relationship with the members of the team, including physicians, and you need to learn how to be a good advocate for your child.

***Resources**

Mayo Clinic website—Patient Care and Health Information:
www.mayoclinic.org/patient-care-and-health-information

Center for Disease Control (CDC)—Diseases and Conditions:
www.cdc.gov/DiseasesConditions

American Academy of Pediatrics (AAP)—Tools and Resources:
medicalhomeinfo.aap.org/Pages/default.aspx

PACER’s Health Information Center:
www.PACER.org/health