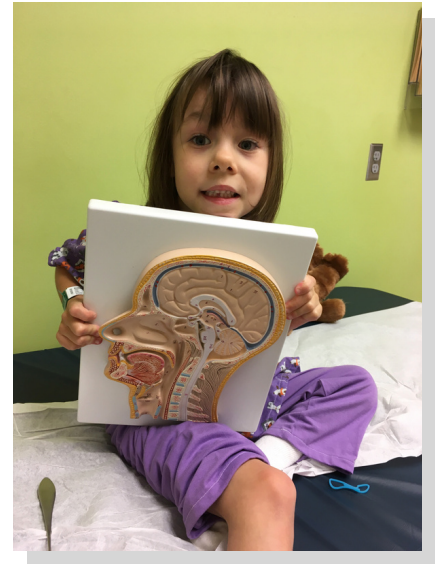


Partnering with Your Child's Health Care Team: DURING AN OFFICE VISIT

As your child's most consistent caregiver, you know your child/ youth with special health care needs (CYSHCN) in ways that no one else does. You having an active role as an equal member of your child's health care team is essential.

Developing partnerships with your child's health care team will help your child receive the best healthcare.

Start with clear communication between you and providers. Be sure to share any cultural preferences and identities that are important to your family's care.



**COMMUNICATE
OPENLY WITH
YOUR CHILD'S
HEALTH CARE
TEAM**

- You have a responsibility to be a good communicator, so does your child's health care team. Communication should be open, honest and respectful. Taking notes can be helpful. You can also ask the provider to write down instructions for you, such as medication start and stop schedules.
- Speak up if you do not understand a word or term being used, a specific treatment or need further information. Be honest and straightforward in sharing your thoughts or concerns.
- Be sure to listen and not just be forming your response. Taking notes can be helpful. Repeat back to the doctor your understanding of what has been discussed, what the plan is and the time frame for following up. This will give the provider the opportunity to correct any misunderstanding and clarify any information.
- Ask questions to help broaden everyone's thinking such as:
 - What else should we be doing or consider?
 - What will we learn from this test/procedure and what will we do with that information?
 - Are there other doctors that should be involved?

**DON'T BE
INTIMIDATED**

- Sometimes you may feel hesitant when talking with health care providers because of their medical credentials or they may seem in a rush and you don't feel they have the time to answer your questions. Please remember that you are the most important member of your child's health care team.
- They do have specialized expertise that you need, but you and your child also have special expertise and experience. Your child's provider can learn from you and your child. Providers should really listen and respect the knowledge you bring to the team, if they don't you may need to look for a new provider.

**ASK FOR A
WRITTEN
CARE PLAN**

- A care plan can help you and the provider be proactive about planning care and it can be a tool that helps you share important information with others such as specialists, therapists, child care, school providers or other family members.
- A care plan should list your child's diagnoses and conditions, along with other providers involved in your child's care, medications, goals for care, family goals, a plan for upcoming tests or treatments and follow up care, and information about your child's unique needs.

**ASK FOR AN
EMERGENCY
CARE PLAN**

- An emergency care plan is designed to be a short one-page form that you can use to quickly provide the most important information about your child that might be needed in an emergency. It should include information about typical protocols that should be used when your child is sick and procedures that should be avoided even in an emergency.
- The Emergency Care Form was developed by the American Academy of Pediatrics and the College of Emergency Physicians and is available to complete and download: <https://www.acep.org/by-medical-focus/pediatrics/medical-forms/emergency-information-form-for-children-with-special-health-care-needs>

**USE A CARE
NOTEBOOK**

- A care notebook can be used to assist you in maintaining a record of your child's care, services, providers and notes. Many families bring their child's care note- book with them to medical appointments, therapies and on vacation.
- Here is a sample care notebook template <https://www.ecac-parentcenter.org/wp-content/uploads/CareNotebook-English-Completely-Fillable.pdf>
- Some clinics offer families a free care notebook, ask your child's health care team if they have a care notebook.

**THERE MAY
BE TIMES
YOU
DISAGREE**

- You can disagree with your child's providers without being angry or unpleasant.
- Express your own feelings without blaming others, use "I" messages, rather than "you" messages. Such as, "I'm very concerned about this issue and feel it's important for us to decide today what we will do about this therapy".
- Think about if and when it might be helpful to compromise; for example, could you agree to try something being recommended for 2 weeks and then get back together to talk about how it is working?

**A DIAGNOSIS
MAY TAKE
TIME**

- Many children have special needs or symptoms that are hard to categorize.
- Your provider may have a difficult time giving a specific diagnosis if there are many possible diagnoses. Discuss your concerns about with your child's providers and ask question about what the next steps will be to figure out a diagnosis. And remember you can always ask for a second opinion or a referral to a specialty provider.