



Talking to Your Child's Doctor: When Your Child Has a Serious Illness

I have an appointment tomorrow to talk with the pediatrician about my daughter's condition. Sometimes what the doctor says is so hard to hear that I am afraid I won't be able to take it all in.

After another sleepless night caring for your child with a serious illness, you may find yourself at the pediatrician's office, blurry eyed, tired, and cranky—add to that worry and stress, and it's a wonder you can remember anything when you walk out the door. Below are ideas to help you make the most out of each office visit.

Here are a few things you can do to prepare.

- 1. Before the appointment, write down your child's symptoms and your observations,** such as:
 - Has he or she been eating and drinking?
 - Is he or she going to the bathroom?
 - Has he or she had a fever?
 - Does he or she have any new symptoms?
- 2. Make a list of your questions and concerns before the visit.**
- 3. Take a pad and pencil with you** to your appointment so that you can write down what your doctor says and review it later when you have more time to digest the information. A tape recorder is also helpful. Better yet, have a friend or family member go with you to take notes.
- 4. Make sure you understand the illness or symptom and the treatment options.** Ask your doctor questions such as:
 - Does my child need any new testing—x rays, cultures, blood work?
 - How do you know he or she has [diagnosis]_____?
 - Are there other names for my child's condition?
 - How will this condition affect my child's body?
 - What treatment do you recommend and why?
 - What are the side effects of the treatment?
 - Are there other alternatives?

Things you can do to prepare. (CONTINUED)

5. **Remember, you don't have to 'get it all' in one visit.** Most illnesses, especially serious ones, evolve with time and so does the doctor's understanding both of the illness and of your child. Ask—if the doctor doesn't offer—when you can call/visit with more questions.
6. **If you need things repeated, ask again.** Don't be afraid to ask to have information repeated as many times as needed. Your child's doctor will want you to have a good understanding of the diagnosis and recommended treatment.
7. **Remember there are no stupid questions.** If you don't understand what you have been told about your child's illness, tests, or treatments, ask more questions, so you don't end up back in the office or in the emergency room unnecessarily.
8. **Don't be afraid to ask for another opinion.** Often your doctor can recommend someone if you choose to get a second opinion.
9. **Don't believe everything you read on the Internet or in the newspaper.** If you want to do more research on your child's diagnosis, ask your child's doctor to recommend reputable and credible websites, like the American Academy of Pediatrics' website (www.aap.org). Print out any information you find and bring it to discuss at your next doctor's visit.
10. **Remember as a parent you know your child best.** You can often read your child's face, gauge his or her emotions and anticipate his or her responses. This is valuable information for the doctor to have when treating your child.

For more Information:

Caring Connections

www.caringinfo.org · caringinfo@nhpco.org · 800.658.8898 · 877.658.8896 Multilingual

Partnership for Parents

A program of the Children's Hospice and Palliative Care Coalition

www.partnershipforparents.org · www.padrescompadres.org