COLORADO
Assistance for those
SERVICES FOR
with both vision
CHILDREN WITH
and hearing loss
DEAFBLINDNESS

(303) 866-6681 or (303) 866-6605

FACT SHEET

Tips for Successful Medical Appointments

By Marty Elquist

Many parents have children with rare disorders or syndromes and know more about the particular disorder of syndrome than many physicians. However, many parents are overwhelmed with fear, hope and undying love for their child that they become emotionally vulnerable when working with medical professionals. Parents often feel that their expertise about their children is overlooked and they become too upset with the physician to effectively advocate for their children. Finding medical professionals who understand and validate parents' emotions as well as listen to their expertise about their children is ideal and difficult to find for many parents.

Advocating for Your Child

The first step in becoming an effective advocate is to be assertive. Assertiveness, which is very different from aggressiveness, does not mean being hostile, angry, or insulting. Instead, assertiveness is being direct, not beating around the bush. It is expressing your feelings and ideas without feeling embarrassed. Most importantly, it is sticking up for what you, the expert, think your child might need even though some medical professionals might disagree.

Techniques that can help a parent exhibit a positive, assertive attitude are:

- Be informed and prepared
- Look for a win-win situation and think about areas where you are willing to compromise.
- Stay focused on one issue at a time. Try to not be led off track. Sometimes an answer will lead you in another direction and the primary issue does not get resolved. Trying to tackle too many items at once will lead to only partial solutions to several issues.
- Set goals for yourself. If you are not comfortable being assertive, pick one small issue and stand strong behind your beliefs. Once you are comfortable being assertive with smaller issues, you can move onto bigger, more complex situations.
- Remember that you are a member of the health care team and have an **important** ***active*** role in making decisions about your child's health care.

Communicating Effectively:

Concentrate on having a positive, respectful conversation. This is a two-way conversation where both partners ask questions and discuss conce4rns and hopes. It is not monopolized by one person. It is also important to keep in mind that doctors are human and can be very frustrated about the lack answers to your questions. One doctor or service provider is highly unlikely to solve all problems or provide all answers. In fact, many families who have children with dual sensory impairments have numerous doctors and service providers.

Ask your doctor if there is a good time during the day to call with questions. Does he/she want you to call the office nurse first or have direction conversations with him/her? What is the best method of communication? Does your doctor welcome e-mail or does he/she prefer you call?

Other effective tips to enhance communication include:

- Use appropriate facial expressions and maintain eye contact
- Keep your voice firm, but positive
- Use appropriate body language and gestures
- Listen… and repeat what you heard the person say.
- Ask questions for clarification.
- Use “I” instead of “you” messages. “I feel that Jane’s Phenobarbital dosage is way too high.” Instead of **“You”** prescribed the wrong dosage for my daughter.”

Facilitating Successful Appointments

Before: Be prepared by keeping a journal of observations about your child’s behavior, illnesses, appetite, etc., and bring the journal to each doctor’s appointment. This journal could potentially identify a pattern that might influence the type of medical treatment your child receives. Also keep a log of the tests performed and the results. This is especially important if your child sees multiple doctors.

Write down your questions from most to least important. It is too easy to forget what you wanted to ask the doctor if your questions are not in writing.

If possible, let your child know why you are going to the doctor and what is going to happen. Bring some of your child’s favorite items to the appointment to help comfort him/her.

During: It is always a good idea to take a family member or a friend along with your. Make sure that you write down the responses to your questions as well as other information that is discussed. Write down the treatment or care plan and make sure you understand what the doctor proposes. Ask questions if you are not familiar with certain meds or procedures or unsure about why your child needs them. Repeat the plan back to the doctor to ensure you are on the same page. In the written plan, make sure you write down follow-up dates and time limits (e.g., anticipated test results, assessment of a new medication’s effectiveness, dates for other procedures or treatments).

After: Discuss the appointment with your family member or a friend who attended with you. Make sure you both understood things the same. As soon as possible after the appointment look over your notes together and elaborate on sections you were not able to complete during the appointment.

If you are uncomfortable with the treatment/care plan outlined by the doctor, write down your concerns and address them. If you still feel uncomfortable or if the doctor is non-responsive to your concerns and/or your child, you might think about switching physicians.

Additional Resources

Allhouse, C., & Goldberg, P.F. (2003). *Working with doctors: A parent’s guide to navigating the health system.* Minneapolis, MN: PACER Center, Inc. **NDSIP#130.109**

Washington State Department of Social & Health Services. (2002). *Building early intervention partnerships with your child’s doctor: Tips from and for parents.* Olympia, WA: Author. NDSIP#140.1

Fact Sheets from the Colorado Services for Children with Combined Vision and Hearing Loss are to be used by both families and professionals serving individuals with vision and hearing loss. The information applies to students from birth through 211 years of age. The purpose of a Fact Sheet is to give general information on a specific topic. More specific information for an individual student can be provided through personalized technical assistance available from the project. For more information, call (303) 866-6681 or (303) 866-6605.

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