



Complex Child E-Magazine

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When No One is Listening: Advocating Successfully with Your Child's Medical Team

by Deb Millard

Children with complex health care needs experience many different types of challenges throughout their lifetimes, including coping with multiple invasive medical procedures, handling follow-up appointments with a vast array of specialists, enduring frequent--and at times long--hospitalizations, managing pain, stress, and anxiety, as well as many other issues. Many of these children also struggle with expressive communication due to a variety of medical and developmental issues and don't have the resources to clearly communicate what they are thinking, feeling and going through.

As parents of children with complex health care needs, you carry a tremendous amount of responsibility as you care for them and act as their advocates. What you don't often realize is that along with this responsibility also comes the right and empowerment to share your knowledge and be an incredibly valuable member of your child's medical team.

Teamwork

When working as part of a team, it's always important to utilize good "people skills," but this is especially true as you work to advocate for your child. Many times you will feel emotional, exhausted and sometimes extremely frustrated when trying to obtain the things your child needs. It's vital to have a strategy to successfully advocate for your child, and to do your best to stick to it. When working with medical professionals, these basics will go a long way toward helping you be a successful member of your child's team and getting your child the support and care he or she needs:

- Treat others the way you'd like to be treated, with kindness, respect and as an equal member of your child's team.
- Be friendly and approachable. This seems obvious, but many times your vast knowledge of your child's issues can appear "threatening" to medical professionals. *Remember that you are the expert on your child, and the medical professionals are the experts on the medicine.* You need them as much as they need you to make things work for your child.
- Take note of and remember the names of those who work with your child. Get to know each of them in a more personal way, and care about them as people.
- Say "thank you" when someone does something for you or goes out of his way to

- help you.
- Ask questions, lots of questions... sometimes even when you know the answers. This empowers medical professionals to be the experts, and to come to the conclusions you need them to come to on their own.

As a vital member of your child's medical team, it's also very important to prioritize your concerns. When issues occur, seriously consider which are irritations or inconveniences, and which are a real threat to your child's health and wellbeing. Sometimes as parents, the extreme fatigue and stress experienced can make it very tempting to blow small issues out of proportion. This can cause a problem when you later need to bring up much more significant issues for your child. By instead just coping with the smaller things, you will find the medical professionals are much more willing to listen to you when you need to have a serious discussion about your child's pain, anxiety or new symptom management. Remember the lesson of the boy who cried wolf!

You, as a parent, have the best knowledge about your child's baseline behaviors and symptoms. You will sense when your child is starting to have a problem, sometimes just as the problem is beginning, and often before a medical professional or test will pick up on it. Some of this is parental intuition, and some is simply the result of spending more time with your child than anyone else, and knowing his baseline extremely well. Many times, though, you may be afraid to trust--and act on--this intuition and knowledge when you are around medical professionals.

It's important to realize how valuable your first-hand knowledge and intuition are, and to believe in your instincts as a parent. When you know something is not right with your child, trust that instinct, and push the team to figure out what's wrong.

Resolving Conflicts

When you know your child is in pain, or developing new or different symptoms, what do you do if you've spoken to his or her medical team and you feel like no one is listening? Most parents don't realize they have the ability to do something about this situation. It is vital to remember that you are your child's voice, and your child needs you to be his or her advocate. If your child is experiencing pain or having symptoms that you feel are not being managed appropriately, there are several things you can do.

1. Think through your concerns and write them down on a piece of paper as concisely as you can. Give specific examples using dates/times/events, and list medical data if warranted that will help to explain your concerns.
2. Discuss the situation with someone you know well. Your spouse or a close friend are good choices. Discuss the "concerns list" you made, and have them help you think it through. This is just to check your emotions, fatigue, and overall wellbeing. As parents in these situations, you can often get so tired and emotional that it is important to have a sounding board to be sure you are on track. Have this person talk through the issues with you, and if needed, adjust your concerns

- list.
3. Often, at this point, it is also wise to seek out the input and help of an advocate who understands the ins and outs of the medical system. This person may be a social worker, care coordinator, key worker, nurse practitioner, member of the palliative care team, or other medical professional who will help you manage the process. Discuss your concerns list with your advocate and make a plan to move forward.
 4. Work with your advocate to set up a meeting with the head of your current medical team. If your child is at home, this person would most likely be his or her pediatrician, or the specialist running his or her care. If your child is inpatient, this would probably be the attending doctor on the floor or unit where your child has been admitted. During this meeting, your goal is to discuss your list of concerns and work together with the doctor and your advocate to come up with a strategy to address the issues you have raised. If the issues involve pain management, this is a good time to ask for a consult with your hospital's pain or palliative care teams, if they are not already involved.
 5. If you find that your meeting with the head of your child's care team has not resolved your concerns, it is time to seek out another medical opinion. If you are at home, it may be one of your child's other specialists. Or perhaps you should consider taking your child to a new specialist for a second opinion. If your child is inpatient, it is time to call in one of your child's specialists, someone you trust and feel comfortable with. Discuss your concern list and the outcomes of your meeting to get that person's opinion on the situation and current care plan.
 6. If you are still not able to resolve your concerns for your child, it is time to take the next step and call a team meeting. You, as a parent, have a right to do this for your child. Whether you are home or in the inpatient setting, your advocate is the best person to help you set up and facilitate this meeting. The meeting should involve your child's main doctor and specialists, as well as any nurses, therapists, or other care team members you feel are important to have present. If one of the issues is pain, it's important to include the pain or palliative care teams in this meeting. Use your concerns list to help facilitate the meeting and remember your goal is to come up with a plan that includes specific dates/times that next steps will take place.
 7. Hopefully you have not gotten to this stage, but if you have, and you and your advocate agree that the above steps have not resolved your concerns appropriately, you need to consider two things. First, call another team meeting and discuss your concerns again and seek a strategy to resolve them. The best possible strategy is to find a way to make things work with the existing team, maybe considering replacing some of the specialists. If you find there is no way to resolve your concerns with the existing team, then you need to consider if this medical team or hospital placement is best for your child. If not, seriously consider a different team, or if you are inpatient, a possible transfer.

The Importance of Good Relationships

Remember that you are the voice for your child, and it is important to check your emotions, use kindness, and prioritize both your concerns and your child's needs when advocating for your child. Don't be afraid to trust your instincts as you care for your child and then speak out in a polite, yet bold way to get your child what he or she needs.

As you walk through the journey of life with your child, you will experience many joys, struggles and challenges together. Developing affirming, healthy, collaborative relationships with the members of your child's medical team can make an enormous difference in the quality of care he receives.

When your child has issues with pain, or struggles with symptom management, working in a positive way to resolve these concerns will not only provide your child with the care and support he or she needs, but will also maintain positive relationships among the team that provides your child's care. The effort you put into this process will make a huge difference in the quality of life for your child and family. It is well worth it!

Deborah Tiel Millard worked full time caring for her son Connor, who struggled with significant medical and developmental challenges for over eight years before he passed away due to complications of mitochondrial disease and hemophagocytic lymphohistiocytosis (HLH). She now utilizes her experience as a Parent Liaison supporting parents of children with special needs at a private school in NJ. Deb also supports children and families through Connor's House, which she co-founded in September 2008. Connor's House is a non-profit organization in NJ that supports children with complex health care needs, together with their families, by creating a community of support that helps them to embrace each day and live life to its fullest. To learn more about Connor's House please check out: <http://www.connorshouse.org>