Family Impact | 04.06

Caring For Children With Complex Conditions, by Sharon Feder

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April 20, 2006 -- Pediatric medical professionals are assigned the task, by definition, to care for the kids who are their patients. Right there, however, initiates a dilemma: parents are already happily in that role! Clearly, the scenario everyone wants is a collaborative team consisting of parents, practitioners, other support, and most importantly - the child. However, our medical system is in a process of transformation. An 'ideal' plan as advocated by the Medical Home initiative and in serial studies commissioned by the Library of Medicine is in its infancy.

In the interim, while our culture awaits 21st century innovations that will at least attempt to coordinate care more effectively, parents are left being the center hub in a wheel that is their child's healthcare web. This is actually a multi-dimensional wheel. In addition to questions of diagnoses and treatment, there are practical needs around managing information, coordinating care and, most importantly, feelings. Layered into this web are the interpersonal dynamics of people and systems under stress and the variety of perceptions and, sometimes, misperceptions we make about each other.

In families of children living with complex medical conditions, its important for parents to enjoy time with their kids, and if possible, to find assistance so that what needs to be done has been, or is being done. Whether accomplished by independent advocates, the family practice office, or by the family themselves, it is invaluable for there to be some structure created to deal with what can sometimes be an amorphous and ever-changing landscape of questions, concerns, information and decisions.

I encourage parents to remember that there are usually many options for dealing with any situation. The advice presented by one specialist is not necessarily the best or last word. In addition, viable options for symptom relief, treatment, and even diagnosis are available in the larger world of second opinions, other sub-specialists, and complementary and alternative care. When faced with the uncertainty of unclear outcomes, we encourage parents to identify as many viable options as possible, and also to sit with the unanswered questions until they feel a clear sense of direction.

A family came to our consulting service a few years ago with reluctance to proceed with a dramatic surgical procedure their son was being advised to undergo by a regional specialist. They wanted information about alternatives to surgery. Their sense was that they would be accepting of the recommended surgery only if there were no equally positive (and less devastating) options.

Fortunately, the second opinion we recommended for them determined that a minimally invasive procedure would not only be possible, but much preferred. The family was able to proceed informed and confident into the ordeal which had a very positive outcome.

Oftentimes, clarity can only come from more information. One of our clients was a young girl with life-threatening scoliosis. Her parents had taken her to a renowned regional medical center for treatment. After experiencing the failure of two major surgeries, her family was very hesitant to proceed with yet another massive surgical procedure.

Her family needed to have all of her medical records (which in her case dated to her birth) collected and organized. What helped significantly was the summarization of every medical encounter into a timeline record which could be quickly reviewed by all current and future medical professionals. This enabled ready access to details of her health history and medical interventions that would ordinarily have been buried in the 700 pages of medical records.

Most importantly, the family needed to feel positive and hopeful about whatever direction was decided upon. They felt the recommended procedure would only suitable if they saw evidence that addressed the likelihood of success and appropriateness of the procedure, as well as possible risks and any alternative options available.

Scores of journal articles on the type of surgery being recommended, along with viable alternatives were reviewed by medical researchers and physician and nurse consultants. A comprehensive list of questions was developed to address the many concerns raised by the research so that, should the surgery be performed, the family would be assured every possible aspect had been considered carefully.

The young girl was, instead, approved for a procedure she had previously been denied on medical grounds, and which the family had been most hopeful about. The prepared research, questions and summarized health history made a significant difference in the outcome of this situation.

Sometimes, what is most needed is the opinion of nationally or internationally recognized experts. This was the case with another young girl living with severe infantile scoliosis and a connective tissue disorder. Her mother, herself, is one of the leading advocates on Infantile Scoliosis treatment alternatives, yet the experimental nature of the procedure and the overlying concern of the connective tissue disorder led the family to experience much justified uncertainty. Again what was needed was information.

Historical medical records were organized and summarized and two experts in the filed of connective tissue disorders - one a regional expert, the other a national expert; and a regional anesthesia expert - were contacted to consult with the girl's orthopedic surgery team. Concerns based on research were thoroughly addressed prior to surgery and the precautions suggested greatly facilitated a successful outcome.

In order to consult with these experts, it is often necessary for there to be a medical intermediary or consultant. These specialists received innumerable requests to consult from people across the globe. A structured consult, providing reimbursement for their time, allows them to focus the necessary attention to issues and questions raised.

Families who experience ongoing medical problems and procedures may become more sensitive over time, rather evolving into hardened veterans. Sometimes small procedures seem the hardest of all, as a parent may have their defenses down, and this little trauma becomes a portal for experiencing the fear, grief and sadness from the much larger issues. Some children may adapt by being less present or less engaged in their surroundings. Other kids, being sensitive to tension they sense around them, may try to hide pain or symptoms so as not to create a larger burden for their families. Kids may even hold on tightly to physical problems and be resistant to healing, as it is familiar to them, and may also offer them protection from more aggressive kids, or might provide what they perceive as special bonding time with a parent.

For some kids and families, a post-trauma syndrome can develop. It is very important for families to be sensitive to these possibilities and to ask for help. Assistance may be as simple as homeopathic 'Rescue Remedy' or special time together, or might include an emotional assessment by a trusted expert.

In addition to owning their feelings about what is going on with them, kids with health concerns also need to grow into the role of being involved in decisions that affect them. Some children are ready to become actively involved in their medical care and decisions as they become more mature, while others may need some coaxing, and moving in to it gradually. One of our clients, a teenaged girl who is paralyzed, is involved in every medical decision made about her life. Another pre-teen boy we work with is reluctant to step up to that responsibility and prefers to distance himself from the whole subject.

Accepting responsibility for their bodies will have the effect of increasing sound decision-making as a child becomes more independent. If a child is shielded from the details of their condition, the parents are apt to feel less comfortable with the child's transition as they become older. This is not such a direct path, however, because the child who is hyper-aware of their condition can become involved in self-actualizing symptoms. A delicate balance of knowledge without hyper-vigilance is required and this may take much time to establish and much awareness to adjust as the child grows.

Likewise, family members deal with fears and concerns in a wide variety of ways. Often, the urgency or enormity of a situation leaves little or no time for the necessary bonding whether that be within couples, between siblings or even between families and their doctors.

Many families become adversarial with members of their medical team as a result of stress. As mentioned initially, the job description for both parents and practitioners is to care for the child. Even with best intentions, relationships can go awry. This is why some structure to managing the care of a child with complicated medical issues can be so very helpful.

Collecting and organizing medical records, preparing for appointments with well-considered questions, accessing necessary research through medical libraries or private research consultants and most importantly, remembering to ask ourselves and our children how we feel- often - will surely lead to more positive experiences. We can't change the physical reality of complex medical conditions. We have enormous power in the ability to change how we respond to the challenges.

Ed. Note: *The opinions expressed above are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. This publication is not in any way involved with, or endorse, the services offered by Lynx Collaborative Care Network . Anyone with a medical problem is strongly encouraged to seek professional medical care.*
