ON MY MIND

What Parents of Children With Complex Medical Conditions Want Their Child's Physicians to Understand

Angela Carosella, MA
Watertown, Massachusetts.

Alexis Snyder, BA
Brookline, Massachusetts.

Erin Ward, MSEd
Methuen, Massachusetts.

We, as parent caregivers, write to you on behalf of 247 parents of children with chronic, complex, medical conditions from various locations across the United States. We are parent caregivers of a unique population of fun, bright, and talented children with incredibly complicated medical issues. Our children are unique; they do not follow a standard, 1-dimensional, format of care. They need constant, specialized, and coordinated care, and they rely on you to support their quality of life.

Parenting a child with complex medical needs is a constant challenge that lacks a training manual. Our children are diagnosed with an average of 10 medical conditions and are cared for by an average of 13 outpatient physicians and 6 subspecialists. Many children require life-sustaining technology to manage their medical needs. Ironically, the primary responsibility to coordinate this care and to navigate the health care system is left to the parents.

We, as parents, are the voices of our children. Those voices, however, are often muted by judgment or lack of understanding from many health care clinicians. Partnering with researchers from Franciscan Children's in Brighton, Massachusetts, on a Patient-Centered Outcomes Research Institute engagement project,[1] we identified and quantified the health care obstacles that parents routinely encounter during the course of medical care for their children. A series of 735 surveys were completed across 15 months, and parents ranked coordination of care and caregiver stress among the most challenging issues.

We write to help our children's physicians, who are vital links to their future, understand some of these issues. We consolidated the most compelling survey responses below. Please hear our voices and work with us to help our children live their best lives.

Top 10 Ways to Help Parents of Children With Complex Medical Conditions

1. Please, view each child you encounter as a whole person. What you do for one aspect of care affects the physical and mental aspects of the whole child.
2. Please, do not underestimate parent caregivers. Trust that we are intelligent adults, even though we are often sleep deprived and may appear unkempt. You know the textbook cases; we live each day with the constellation of illnesses and adaptive strategies. Let us work together.
3. Please, talk to our children directly in age-appropriate terms, so that they will understand their medical illnesses. Children may want a voice in their medical care if they are capable.
4. Please, share our goals to give children the best quality of life. Avoid visits to the emergency department, admissions to the hospital, unnecessary testing and appointments, and anything else that impedes our child's progress at all costs. If you can help us with these goals, you would maximize our children's life experiences and heal our souls.
5. Please, do not allow our children to remain undiagnosed or untreated because of an uncertain diagnosis. We shall respect you for doing some research or checking with a colleague about an unsolved issue.
6. Please, do not view us as difficult parents. We are struggling and trying our best. Parents are often overwhelmed and you may be our only hope for helping our child.
7. Please, do not assume parents are fine because we appear as if we are coping. Support us by adding more effective case management, transitional care, and psychosocial supports to your medical practice.
8. Please, do not refer us to medical specialists and other physicians, then allow us to navigate the system on our own. Our children require many appointments, are cared for by multiple specialists, and sometimes travel long distances to each appointment. Help us coordinate appointments to reduce our stress and anxiety.
9. Please, keep accurate, timely records of our child's medical care. If you do not remember details of a patient visit, please do not guess the information or sign the medical note of a resident without making sure it is accurate. Do not copy and paste medical information from previous notes or, worse yet, from other patient profiles. Viewing the name of another child in our child's medical record is deeply hurtful.
10. Please, respect our decisions. As parents, we are sometimes required to make difficult choices that may differ from medical opinions.

Together, our primary focus must be on the child. We must have open and honest communication without egos. We must respect points of view from each other and accept that there are differences of opinion.

Thank you. You are our lifeline and we would be lost without you.

Corresponding Author: Angela Carosella, MA, 71 Emerson Rd, Watertown, MA 02472 (acarosella@comcast.net).

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1. O'Brien JE, Nash CM. Franciscan helps families connect. https://www.pcori.org/research-results/2014/franciscan-helps-families-connect.fhfc. Accessed November 29, 2017.