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Family Matters: Seeing with the Heart

by Erin

I spent years learning to speak French, beginning in elementary school in England, and ending in my college years to fill a language requirement. Never having had the opportunity to use it, however, I now remember little more than basic conversational phrases, many of which would offend native speakers if I dared try to speak them with my French American accent. Ironically, the most useful piece of information I learned from my years of instruction has nothing to do with the spoken language, but is instead a sentiment expressed in a book, Antoine de Saint-Exupéry's *Le Petit Prince*, read during class:



"On ne voit bien qu'avec le coeur. L'essentiel est invisible pour les yeux."

or

"We only see clearly with our hearts. What matters is invisible to the eye."

As a parent of a child with complex medical needs, this sentiment is very powerful. When brought to mind, it is a strong reminder of what is truly important during a challenging journey.

After my daughter's traumatic birth, she was in the NICU for weeks hooked up to a ventilator with multiple lines and catheters extending out from her body. Delivered under general anesthesia, I met her for the first time in her Plexiglas bassinets in the NICU. It

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was frightening as a parent to see my child so breakable and untouchable, surrounded by medical equipment and personnel at all times. It was so terrifying my husband and I considered not taking or sharing pictures of her this way because we thought it would scare family and friends. We also thought for an instant that we might not want to remember the painful images of a beginning so dramatically different than her big sister's.



From the moment she grasped our fingers, however, we started seeing her with our hearts. Indeed, our love for her helped us to see that her medical paraphernalia was a tool she used to fight to be with us. In addition, because we did not know how long she would survive, we wanted to be able to remember and cherish every moment with her. Our love for her gave us unconditional acceptance of this important part of her journey, making it safe to photograph her with her machines, lines, and catheters.

While she was hospitalized and traveling down a confusing and uncharted path, we also faced many difficult decisions about her care. Prior to making each decision, we initially gathered information in order to try to see from her doctors' perspectives. Our hearts, however, made the ultimate decision to do whatever it took to maximize her quality of life while she was with us.

Later, after we brought her home from the hospital, we found our love for her allowed us to accept unconditionally every medical challenge her journey brought. But over the years we have experienced indications that she is quite a confusing sight to non-family and friends who have not witnessed similar challenges. We have encountered staring at her Nasogastric (NG) tube adhered to her face, appropriately inquisitive children inquiring about her unusual feedings (which were often followed by unnecessarily embarrassed parents ushering their children away), and quick puzzled looks when individuals catch a glimpse of her open-mouthed-tongue-out-ecstasy while going over bumps in her adapted stroller.

Thankfully, each of these encounters with individuals seeing her only with their eyes is matched by similar encounters with individuals who can see her with their hearts. An understanding nod, smile, or explanation indicates that they have had a child on an NG tube or know a family member or friend who faces similar challenges.



Over the years, we have also faced moments where we see glimpses of a “normal life” and have naturally found ourselves longing for aspects of a simpler life. Wishes for a friend’s stylish wardrobe (without concerns that clothing might be marred by spit up), social life (with a plethora of qualified affordable babysitters to choose from), sleep (without disruption or nurses in the home), and exotic vacations (without medical equipment and associated travel challenges) are common when you are coping with all the challenges associated with caring for a child with complex needs. However, at these times we too are seeing with our eyes, not knowing the challenges other families with superficially “simpler” lives face that only they can feel with their hearts.

Furthermore, our hearts quickly remind us that a “simpler life” would not have included our sweet child, her powerful bond, and all the things we have learned about life and

ourselves along her journey. With this strong reminder, we are better able to realize, most importantly, that *although our eyes may show us what we want, our hearts show us what we need*. Ultimately, in our case, our hearts show us that we need our family life and our journey the way it is. That is, if we see clearly with our hearts, *our family matters*.

Erin is a stay-at-home Mom to Brooke, a very sweet, determined, non-verbal, non-mobile and 100% G tube fed child. Brooke suffered severe oxygen loss and reduced blood flow around the time of her birth, which caused chronic kidney failure, severe brain injury, microcephaly, cortical visual impairment, mixed cerebral palsy, sleep apnea, epilepsy, neurogenic bladder, and reflux. Erin has also been blessed with two very caring and entertaining siblings for Brooke, seven-year-old Katherine and three-year-old Ethan. Erin documents how Brooke interacts with her siblings on [Adapted World](#). Erin has a PhD in Clinical Child Psychology and although she is currently not practicing she draws upon her experience when trying to ensure Brooke obtains the services she needs.