



**A GRASSROOTS NETWORK OF FAMILIES AND FRIENDS SPEAKING ON BEHALF OF CHILDREN WITH SPECIAL HEALTH CARE  
NEEDS**

**Special Needs Love** (*first appeared in "Literary Mama"*)

*By Vicki Forman*

My son was born weighing little more than a pound. I didn't fall in love when I first saw him, but felt instead -- taking in the lines and probes and syringes and fluids that kept his tiny, imperfect form alive -- a deep and remarkable appreciation for his strength, his will to live, his desire to be here on earth. As his hospital stay dragged on and he endured countless surgeries and procedures, I forged the first bonds of love with my son. I came to know love as fierce mother attachment, the sense that if I did not protect his defenseless self, who would? My lessons in love continued when Evan finally came home. I discovered that loving him involved taking care of him in ways I had never imagined, like watching eye exams and heart scans and EEG tests. Love meant not only having to do all this, but being able to when no one else could. That was love, doing what was necessary, no matter what.

In those early days, I also learned that love meant standing up for Evan and for myself, easing his pain and suffering and learning who he was, beneath his disabilities. To see him apart from his disabilities.

Over the years as Evan's mother, I have often wondered: if a typical mother's heart is strong, is the heart of a special needs mama even stronger? Many of my friends who have children with special needs will testify to the profound need we sense for that child to be on this planet, teaching us about love. I have felt that with Evan, and I've seen that with others. These children show us how to open our hearts in ways we never knew were possible. Perhaps that makes our hearts stronger, braver, or kinder. Or perhaps our hearts are simply, by virtue of being open, wider and more expansive. But inside this wider space we have discovered that amidst the love there is also the heartache, and within the heartache, the joy. The will to live and the will to love.

I love that my son loves his bed the way his mother does, that when I put him into his crib he smiles and sighs and says "Aaaah," the same way I do when my head hits the pillow. I love that I know this about my son even though he can't tell me directly, even though he can't say "Mommy, bed!" I love that despite not being able to see or talk, my son is without question a person, someone who loves his bed and his school and the swings.

I used to mourn the person my son was not: the boy who would talk and eat and see and run and call his friends by their names. He may still do those things some day, and more, but the progress is so slow I can no longer allow myself to think about those possibilities. And yet I wonder: what would I love about him then? Would I love his sense of humor? His voice? The songs he might sing? The facts that he fidgeted in his seat at school or told silly knock-knock jokes? Would I love the way he pushed my arm aside or argued with me, rather than accepting my help? Instead of what I love now -- his ringing laugh, his beautiful smile, the way he swings his cane around like a weapon -- what would I love? If Evan were a typical boy, What about him would I love?

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I'm not supposed to wonder who my son would be apart from his disabilities. I'm supposed to see him as a person with disabilities. I'm not supposed to think about who he might be or what I might love about him or how he might tell me he loves me. But I do. I do because I love him and because he has taught me that inside a wide-open heart, loss is sometimes a part of love.

In the case of my son, the mechanics of love include knowing I am loved back -- because of the intense mother love that helped him survive those early years, because of my care and attention and defense of him -- but not in a way that is obvious or transparent. My daughter, who is a typical nine-year-old, tells me a dozen times a day, "I love you, Mommy," or "You're such a great mommy." She will kiss me on the mouth and give me hugs and sit in my lap, all arms and legs, and just pour on the love. Not so my son. He doesn't use those words or give those hugs or kisses. He turns away from a kiss on his cheek, swipes my hand from a caress. But still I know, when I pull him from that same bed in the morning and see his smile and laugh and hear his attempt at "mum-mum," I'll know, right then, that I am loved.

A few months ago, I watched Evan crawl into the arms of the same neurologist who once brought him back from the brink of a catastrophic seizure disorder. I saw my son take shuffling steps across the room, lift his arms to be picked up and hoist his legs into this man's lap, a man who is world-renowned for his ability to help kids with seizures and all else. I met the man's gaze as he looked at me with Evan in his arms and smiled as he said to me, "Now that's love." Yes, I thought. That is. That is love.

*"Special Needs Mama" is written for the mothers at the swings, those with open hearts and kind smiles who want to know what it's like inside the world of parenting a child with special needs.*

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