



Complex Child E-Magazine

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What Truly Makes a Child Special...And Not Extra Special

by Darshani Sukumaran

Having a child with medical issues is uncharted territory. Most parents do the best they can. They have to balance their child's physical needs with their emotional needs, and that is often impossible. Parents find themselves putting out fires all around them as new health issues flare up. The child's emotional needs are put aside for the time being.

As the child's health becomes more stable, parents ask, "Where do we go from here?"

I made a big mistake in raising my children to live with their conditions. It was a mistake made with the best of intentions. I thought that if I raised them to see their conditions in a positive light--that they were extra special *because* of those conditions--it would be easier to cope. I was wrong.

My Children's Stories

Both of my children have medical issues caused by disease of the digestive system. My daughter Abi, age eight, was diagnosed with Celiac Disease the summer before second grade. The diagnosis came after years of knowing she had problems of some kind: sensory issues, fatigue, mood swings, constipation problems, and very picky eating.

Abi was my "healthy child" compared to her younger sister, Nitara. Nitara, who is now five, had suffered from digestive and health issues from birth, including severe reflux, pain, failure to eat, and failure to thrive. By three months old, she was getting most of her nutrition through a feeding tube in the nose, followed by a more permanent feeding "button" in the stomach. At 35 months old, she was also found to have EE (Eosinophilic Esophagitis). This is a disease where multiple foods trigger a type of allergic reaction in the digestive system, causing swelling and pain. Both Celiac Disease and EE are lifelong conditions that can be managed, but not cured.

I went through a series of emotions with each diagnosis: guilt that they had inherited these diseases from my husband and me, sadness that they had to go through life refusing most foods, and mourning the fact that they would always be the odd ones out at birthday parties and pizza parties. I wonder how it's going to be when they are old enough for dinner dates and office parties.

Creating Too Much Confidence

I knew it was important to try to treat my children as normally as possible, to let them know that their conditions would not stop them from exploring, learning, and growing. For example, Nitara learned to walk with a feeding pump on her back. I arranged with the girls' teachers to let them have safe food treats that they don't get otherwise. I have raised Nitara from birth to politely refuse any food offered to her by anyone other than her father or me. Nitara recently came home with a plastic ring from the top of a classmate's cupcake and was as happy as could be with that. She could have cared less about not eating the cupcake itself. I find these opportunities to reassure myself that I'm doing the right thing with her.

We were unsure how long Nitara's feeding tube would be a part of her life when it was put in. After the EE diagnosis, I had formed networks with several families where the children and adults had tubes long term. Most of the time, the tube-feeders survived mainly or solely on elemental formula and were unable to eat enough foods to make up a balanced diet. I tried to prepare myself and Nitara for that possibility.

When she started to notice she was different because of the tube, I told her the tube was because she had a special tummy. I explained that the tube was her friend and helped her grow. When it was time to change her tube, the "button fairy" would bring a small toy in exchange for the old tube.

Nitara started Kindergarten this year. I took her to visit the nurse and together we explained to the nurse how to replace the tube if it accidentally fell out at school. We had a similar conversation with her Kindergarten teacher. The teacher and I agreed that we would not tell the kids about Nitara's tube, but just make a general class rule to not push or hit anyone's tummy. We felt it was best to treat Nitara as normally as possible.

This week I was talking to a parent of Nitara's classmate, who informed me that Nitara had told some of her friends about her tube. She reportedly said she had a tube in her tummy to help her eat and it was "very cool." I never wanted her to be ashamed of her tube, but neither did I expect for her to brag about it!

With lots of food trials over two years, we're lucky enough to find a (barely) balanced diet of safe foods for Nitara, along with daily multivitamins and supplements. Nitara's feeding skills and hunger cues are coming back. Last May, Nitara came very close to having her tube removed, but did not gain quite enough weight to pass that trial. Her pediatric GI doctor is confident that removing the button is a matter of "when" and not "if."

I have recently begun to prepare Nitara for the eventual tube removal. Every time I bring it up she becomes very distraught. She says through her tears that she will miss her button, that it's her friend. I told her that she can keep her button if she likes. I promised that the button fairy would bring a big gift. I reassured her after she asked about it, that

she would not have a hole in her tummy. She would have a cute pink spot. But it was no use. Nitara does not want her button to come out.

I asked her for the hundredth time why she didn't want it out and finally she said, "Because I won't be special anymore!"

The Mistake of Linking Identity to Special Needs

It hit me then that I had made a huge mistake. In my good efforts to get her to accept her button and her disease, I had encouraged her to accept the button as part of her identity. Nitara gets a lot of attention because of her condition. She belongs to an exclusive club of people who are affected by eosinophilic disorders. We attend annual fundraisers, where last year, Nitara's photo was displayed on one of the tables along with other local children's. I used some of our vacation money to fly to a conference to meet experts and other parents.

I have always tried to point out the many things that make my children special. For example, Nitara is a really good singer, gives great hugs, and loves kittens, but she gets the most initial attention for having a button and a special diet, since I have to constantly educate people about it. Her health status is a common subject when talking to family members who want to know how she's doing.

So now Mama's got some back-peddling to do. My best intentions have backfired. I asked a couple of nurse friends online for advice and they said it's a very common mistake that parents make. Parents feel guilty for the health issues their children face, and they try to turn a bad thing into a good thing. Obviously, one can't ignore the health issues, as they often determine how children are able to live their lives, how they feel, and how they play and learn. Many children have to spend time in a hospital where their health issues often overshadow who they are as people. The child feels helpless, swept away in her illness.

What Truly Makes Children Special

Yesterday I had a heart-to-heart talk with my daughters about what makes people special. I brought up some children they know. For example, a girl with glasses. I asked if she took off her glasses, would she not be special anymore? They both agreed that she was special because of who she was: "She's so cute and she does a little dance at recess when she's happy." I asked if a boy in Nitara's class took off his leg brace, would he still be special? Nitara answered, "No, he would still be naughty!" I asked Abi if she would still be special if she didn't have Celiac Disease. At first she said no, but then she paused and said, "I am special because I'm a good artist, I love my birds, I'm good at swimming, and I love my family."

And then I asked Nitara if she would still be special if she no longer had a tube in her tummy. She knew where this conversation was going, and at first she was resistant to answering. But then she said, "I will still love my pet parakeet, I will still love swimming, and I will still be able to sing beautiful songs."

I have a feeling this battle is not over. It took five years to get to this spot and it may take some time to get beyond it. If and when it's time for Nitara's button to come out, I'm sure there will be some tears of sadness even though she has not actually used the button for a while. She does not get to choose if it stays or goes, but I can let her choose if she would like me to remove it or the doctor.

There will be a period of adjustment when she realizes she will no longer get attention for having a button. She will have to let go of that part of her identity, and for a five-year-old, that will be a hard thing to do. But Nitara is a strong, resilient, confident, and generally happy little girl. She will be fine.

Strategies for Creating True Confidence

Similar to veterans of war, reentering the "normal" world after a long convalescence is an adjustment period of finding your identity again. It is important that parents not ever let that identity get lost in the first place. Even when the child's life is totally impacted by his or her medical condition, fight to remind that child of who he or she is, over and above the medical issues.

It is important to give the child some power over choices, but also let them know that some of the procedures are necessary and non-negotiable. For example, a child might need an injection, but they can choose which thigh it goes in. It doesn't take away the fact that it's going to hurt, that it's awful that the child needs one.

Nor should parents compensate the child's pain by giving him or her a reward for enduring the procedure, a mistake I often made. Hopefully the button fairy will retire soon! A reward is like a big colorful band-aid, but a band-aid does not take away the medical condition. It just covers it up momentarily.

Give the child positive attention in other distinct areas of her life, such as showing everyone the child's most recent artwork, or telling the child over and over that she gives the best hugs ever. Children should be empowered to explore their feelings, perhaps under the guidance of a counselor if necessary. I wish I had been handed a list of people I could talk to about our family's struggle to cope and adjust when Nitara first became sick, people who specialize in counseling families of sick children, and the children themselves.

Lessons Learned...and Applied

Next month I will be starting nursing school. I will be spending the next sixteen months learning how to care for the many physical needs of patients. I will be taught how to assess their conditions from moment to moment and make quick decisions. But how do I care for a patient's emotional needs? How will I keep in mind that my patients are not just a collection of diagnoses, emergencies, and meds? How will I take the time to connect with them when I will probably be working for an overburdened health care system and have little time to get to know each of them?

I will do it by remembering this lesson that my children have taught me. Of course it's necessary to talk to the patient and their family about the patient's health. I will also try to talk to them about something else. When Nitara was in the hospital as an infant, and I was struggling with sleep deprivation, worry, and postpartum depression, I remember one nurse more than the others. She took the time to ask if I had any more children. What was my other daughter's name? What does her name mean? Did I grow up in this area or did I move here later? She said that Nitara was the cutest baby ever. Her kind words, which took all of a few seconds at each bedside visit, made a world of difference to my mental state and my ability to cope. It made me focus on something other than our family's health crisis. It took me away from that moment, and that did as much to heal me as anything else. I was able to relax and hold my daughter and look beyond her new yellow NG tube taped to her face, and look into her beautiful brown eyes.

Children are certainly our greatest teachers. They teach us not only by what we do right in their lives, but also by the mistakes we make with them. Sometimes I wonder who is growing up faster: my daughters or their mama.