

Facts & Arguments Essay

My family isn't typical



I worried about having more children after my son was diagnosed with a severe neurodegenerative disorder. But our girls were a welcome addition to our family

Marcy White

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Jacob's five-year-old twin sisters know their big brother can't speak. They know he eats by a tube surgically implanted into his stomach and they know he can't move by himself. They also know he understands what they say and he loves to watch them play.

Jamie, the lankier twin with curly hair and blueberry eyes, knows how to make her seven-year-old brother laugh. Her off-tune, high-pitched singing always results in an ear-to-ear grin from her brother's gap-toothed mouth. The more he laughs, the more Jamie chants, and the more she chants, the more he laughs. They enjoy their game, and I love watching every second of their interaction.

The decision to have more children after Jacob was diagnosed with Pelizaeus-Merzbacher disease, a severe neurodegenerative disorder, was colossal. Was it selfish of me to bring a healthy child into a family with a child who required constant care?

During the first few years of Jacob's life, I lived as though I was in a bubble. Most days were spent at home, fearful of exposing Jacob to simple germs that could be life threatening for his weak immune system. My friends were welcome in my house, but their children were not. Aside from the unknown viruses that kids harbour, it was too agonizing for me to watch healthy kids run, speak and eat, activities Jacob was unable to master.

When Jacob was younger, life was excruciating. My son was in constant pain and each ear-piercing scream was like a red-hot dagger slicing through my heart. There were no hints that he would ever be comfortable and happy.

When I started exploring the idea of a sibling for Jacob, I thought it would be terrific for me. It would allow me to re-enter the "normal" world and experience the joys of parenthood as a "typical" parent, a mother who was fortunate enough to teach her child how to count to 10, ride a bicycle and hold a crayon. My parenting experience had consisted mostly of medication administration, physical therapy and frequent doctors' appointments. It was easy to see that a healthy child would bring some much-wanted normalcy into my life.

But late at night, when Jacob was in the care of a night nurse because he cannot be left alone, I wrestled

over what to do. What impact would having a disabled older brother have on a younger sibling? Would a sibling detract from the attention Jacob needed?

I reasoned that Jake would have the opportunity to interact with another child, something he rarely did but seemed to enjoy. The stories I heard from others led me to believe that Jacob's hypothetical sister or brother would not be negatively affected by growing up in our family. With proper guidance, he or she had a tremendous opportunity to thrive and become a special person because of being his sibling.

When Jake was 2½, he became a big brother to healthy twin sisters. The twins were a welcome surprise, although twins aren't rare in our families.

As infants□, Sierra and Jamie were a handful in the way that all babies are, but it was so much easier parenting these two girls than it was caring for their brother at the same age. I knew that if the girls were hungry they would eat, if they were tired they would sleep, and if they cried they were not at risk of choking. They never needed me to thread a suction tube down their throat to clear their airways.

It was evident that Sierra and Jamie were a welcome addition to our family. The increased activity in our house pleased Jacob. He smiled when we placed him on the sofa with a sister on either side of him. His eyes sparkled when he was positioned in the front of the double stroller listening to his little sisters' babble, squished in the seat behind him.

As I watched my girls explore their surroundings, I had a mix of emotions running through me. I wavered between awe at the ease with which Sierra and Jamie knew how to hold a rattle or turn the page in a book, and soul-numbing sorrow knowing that Jacob was unable to hold his beloved guitar by himself.

The girls were early talkers, and curious. As Sierra was nearing her third birthday, she asked me why Jacob can't walk. Her innocent question scared me. I knew that at some point they would notice that Jacob was different from their friends' older brothers. It was important to me that the girls feel comfortable asking questions about their brother, and I was determined to give them honest and age-appropriate answers that would help them understand Jacob but not scare them.

She was satisfied with my response that his legs don't work the same way hers do, but I knew this question would shortly be followed by other, more challenging ones.

When Sierra and Jamie blew out the candles on their Dora the Explorer birthday cake on their third birthday, Sierra pushed her hair away from her face and asked if I could put some cake in Jacob's feeding tube so he could have some too. She knew her brother does not eat the same way she does, but she wanted him to enjoy something she loves. As my eyes filled with tears, I told her that I was very proud of her attempt to share her cake with her brother.

My family is not typical. Jacob still requires constant care, but making him an older brother was the right decision for us. Jake's younger sisters are happy, smart and curious girls. They have a special brother with a contagious laugh that can be heard any time they try to tickle him.

Marcy White lives in Toronto.

Comments

[Catsdesire](#) 4/1/2010 6:39:58 AM

I think every child deserves a brother or sister. Congratulations on the fine family you have. Your last paragraph says it all: "My family is not typical. Jacob still requires constant care, but making him an older brother was the right decision for us. Jake's younger sisters are happy, smart and curious girls. They have a special brother with a contagious laugh that can be heard any time they try to tickle him."

[Rob_T](#) 4/1/2010 1:45:39 PM

Wow. I try and read these essays everyday, and usually I do. I must say what you wrote was a wonderful sharing of human emotion. I am thankful I read it, and am thankful you wrote it. Your essay makes me want to be a better person.

[Grant Guy](#) 4/1/2010 6:01:33 PM

The author found that caring for twin babies was easier than caring for her disabled son. Wow. That explains a lot about the kind of care that a disabled child needs.

Finally she says "As my eyes filled with tears, I told her that I was very proud of her attempt to share her cake with her brother." My eyes filled with tears and I was only reading the article!

[ccdd](#) 4/1/2010 6:10:27 PM

I meet parents who spin the wheel of genetics fortune after they have a child who has severe abnormalities. Sometimes they lose again. At what point does reason finally overtake foolishness? I hope that anyone doing this has some kind of genetic counselling.

[WinniMiss](#) 4/1/2010 6:19:49 PM

Congratulations! Marcy White, congratulations for caring for your son, congratulations for having the twin girls, and congratulations for sharing this article with us. We know what you speak about - our eldest was a son with Duchene Muscular Dystrophy - we then had two healthy girls. All three are blessings from God.

[LouLou1](#) 4/1/2010 7:09:23 PM

Thankfully, there are mothers like you in this world. Clearly the idiots who responded above me have never had even the smallest responsibility of looking after a hamster, let alone a child who needs constant care. Shame on you. There but for the grace of God go I.

I repeat that thankfully there are mothers like you in this world to care for this lovely young boy that God has graced this earth with. Your two lovely twin girls have learned lessons that only such a special young boy could teach them -- they will grow up to be sensitive, caring young ladies. To all those who left stinging comments -- shame on you -- you know not of what you speak.

[AC75](#) 4/1/2010 7:44:09 PM

At the risk of repeating previous comments and so sounding trite, thanks to yet another contributor to this column. Humanity is really not that hard to find if you look for it, but finding it so regularly here is inspirational to myself and apparently, to others.

My wishes of courage to you in your ongoing challenges, and joys, of parenthood.

[Bird79](#) 4/1/2010 8:43:14 PM

Every child deserves love and laughter. Having a child with "abnormalities" is the decision of God and the Parent/s. What the author does for a living, has NOTHING to do with this article or with her beautiful heart and family. The comments about gibbled up children, naivety or spinning the wheels on genetic fortune... unless you are in the exact situation, you are the ones who are naive.

Marcy, I am proud of your open heart and mind and you should have only happiness and health in your family.

[SybilJackson](#) 4/1/2010 9:24:21 PM

In my family it was the youngest of three who required full-time care and there was no outside help available while my brother was alive. My parents were opinionated and strong-willed people but there was never a word of complaint about the care he required. There is a special place in heaven for parents like them. This sort of situation takes its toll on family life but it teaches you life-long compassion.

Unfortunately that's a quality a few of the posters here don't seem to have.

[Hookipa](#) 4/2/2010 10:13:50 AM

@ccdd (and others) For those who aren't aware of modern medicine and genetics, once a disease is

identified with an DNA "signature", like PMD, there are several ways to prevent additional affected children. Firstly, since PMD only affects males, you can confidently have girls. Today one can screen in-utero for gender with simple chromosomal tests which can be performed at most hospitals. More exact DNA tests for diseases like PMD can also be performed at various labs around the world for a relatively small fee. One does not even have to wait for a pregnancy to do such DNA testing. There is something called Preimplantation Genetic Diagnosis (PGD), also known as embryo screening http://en.wikipedia.org/wiki/Preimplantation_genetic_diagnosis. Families can chose which embryos to implant (and which not to implant) for subsequent pregnancies.

For all those naive posters who implied that Marcy and her husband acted recklessly, perhaps a little education prior to posting nasty comments will prevent you from looking foolish in the future.

[Crystal Glass](#) 4/3/2010 10:54:17 AM

John Stalvern writes: I have no children

...and we are very, very grateful.

This was a truly beautiful essay. Thank you for sharing it, Marcy. :o)

[Ernie Richards](#) 4/3/2010 10:43:49 AM

John Stalvern and Going to Brown Town: What is your problem. This is an excellent essay about a difficult decision.

I also have no children. However if I did and any of them had "problem" I would hope never to make your acquaintance. All children are a thing of wonder and joy, no matter there abilities.