

Marcy White

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As Jacob and I make our way down the crowded aisles at the grocery store, I am acutely aware of strangers glancing at us. They see a mother and son shopping together. But we stand out because we are different.

Jacob can't sit or stand without support, so I can't secure him in the seat at the front of the cart, or have him stand at the end, holding onto the metal basket as I push a food-filled wagon through the store. Instead, we make our way down the aisle with me pushing him in his wheelchair and him balancing our selected items on his lap.

Like many kids his age, Jacob does not enjoy this errand. As soon as I stop pushing him to grab an item off the shelf, he complains. Jacob knows what he wants, but unlike his peers he can't run ahead and explore on his own. This frustrates him, so he screams. As I try to console him, he screams louder.

While many parents can treat their little helpers to a candy or a bag of chips at the end of a shopping expedition, I don't have this reward at my disposal because Jacob can't eat.

My seven-year-old son has Pelizaeus-Merzbacher disease, a rare neurodegenerative disorder that affects all aspects of his life. Jacob cannot sit by himself, walk or speak. He is fed by a tube that was surgically implanted into his stomach when he was an [infant](#). But he understands what is said to him and loves listening to silly jokes.

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Ever since he was born, Jacob has had a special effect on people. There is something intangible that



draws people, and makes them fall in love with him. Year after year, I have watched my son attract people to him and melt their hearts with his infectious laughter and mischievous grin.

But when they leave, he changes. He screams, he protests and he cries. Gone is the charm, the lovable smile and the twinkle in his green eyes. I am left with an angry little boy who is inconsolable. Why can't I elicit the same wonderful qualities that his nurses and friends do so effortlessly?

I am in charge of Jacob's care, his schedule and his endless appointments. I am the one who accompanies him to the doctors he hates. I am the one who holds his hand and walks with him in the hallways of hospitals while we wait for hours for the dreaded visits.

I feel like a nasty mother who allows therapists to subject him to painful and difficult exercises. It's no wonder he prefers his caregivers whose main goal is to entertain and please him.

As Jacob's mother, I know he is receiving the care he needs. His frequent screaming in my presence is purely behavioural, designed to manipulate me into giving him what he wants. My heart beats quickly as I run through the list of things that might calm him down, like chasing our cat Spot, helping him strum his red guitar, reading a book or telling him a story.

When nothing else works and I am at a loss for what to try next to quiet his screams, I [resort](#) to the phone call. At this point, Jacob has been yelling for so long and with such vigour that his face is red and his hair is so wet he looks like he just had a shower. Listening to his favourite person, Belle, on the telephone is a guaranteed mood changer. It's the one thing that will always calm him down and make him smile.

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In my weaker moments I feel sorry for myself. I am upset that I can't soothe him. I am his mother; I should be his favourite person.

When the crisis is over and peace has been restored, I look at my curly-haired child and know that his behaviour, in some way, is typical for any child.

Most parents will agree their children behave better with those who aren't their parents. And Jacob, in this respect, is a regular child. Intellectually I know this, but it hurts. It's heartbreaking to witness someone else pacify my child, something I repeatedly try but fail to do.

Compared to Jacob, his healthy twin sisters are easy to parent. At 4½, they are typical children. When they are upset or hurt, they run to me. They get angry when I go out and leave them in the care of someone else. As their mommy, I can make everything better. My kisses fix their boo-boos and they love it when I play with them. Why can't I fill the same role for my son?

I try.

In September, after a stressful doctor visit, I brought Jacob with me to buy a coffee. He enjoyed sitting on my lap, watching the cars drive by the store. It has become our special outing, on our way home from an appointment or when we have a free hour on the weekend.

I look forward to these moments of quiet and peaceful interaction with my son. When I ask if he wants to come for coffee with me, he smiles and slowly nods his head. My heart expands and I feel a whoosh of love for my little boy.

It is hard being the one he associates with dreaded appointments. It is challenging to find things Jacob likes to do with me. But I will persist because I love spending happy times with my son. I will keep trying to be the one he wants when he is sad. Because I am Jacob's mom.

*Marcy White lives in Toronto.*

*Illustration by [Steve Adams](#).*

11/30/2009 7:02:32 PM

My heart goes out to you! While I understand 'somewhat' your situation---it is very important for you- the caregiver and the mother-- to ensure you take time out to fuel yourself- to care for yourself. Without you being strong- you will not be able to continue to be strong for your son!

He is very blessed to have you as his mom!

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In my experience, the tendency to be better behaved with strangers than with those that love you most extends into adulthood. When my father was in the hospital for an extended period, he was absolutely charming to his doctors and nurses but when left with my mother and me, was pretty miserable!

11/30/2009 9:04:22 AM

Thanks for sharing your story, Marcy. I spent 25 years working with people who have severe handicaps similar to those of your son, and one thing I noticed over and over again, is that while caregivers like me are often put on a pedestal, parents are often demonized. Yet in my opinion, parents like you are the ones who deserve the accolades. It is much easier being a caregiver and being able to walk away at the end of a shift. But a parent can never walk away. I hold you in the highest regard, and would encourage you not to be hard on yourself. Your journey is a difficult one, and it deserves the greatest compassion.

11/30/2009 9:23:09 AM

I would also suggest Ian Brown's essay on being a parent of a needs child.

11/30/2009 9:35:00 AM

Marcy, the reason Jacob takes all his angst out on you is because he loves you the most and he knows that you, too, love him the most and your love will always be there, no matter how badly he behaves. My husband has very kindly reminded me of this fact whenever my heart breaks in a million pieces over the way my own son treats me sometimes. I have a feeling this situation exists in every home in every mother-son dynamic. I know this reassurance doesn't take away the very real hurt you feel, but I hope it eases it. I'm so sorry for you and Jacob, and hope you find other quiet, peaceful, one-on-one moments to share, like having coffee together. I'm sure you already know the joy of reading books together.

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At the end of the day, he knows you are there for him no matter what, and that you love him no matter what, even if sometimes you don't like what is happening. There is no greater gift you can give than that. Thank you for also making me pause and realize just how blessed I am, and how often I really do forget. I hope you both get to enjoy many coffee outings together.