

7 Things You Don't Know About A Special Needs Parent

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About 6 million kids in America [receive special education](#), according to the U.S. Department of Education. One out of every 10 children under the age of 14 has some type of special need, which includes any physical, cognitive, or medical disability, or chronic or life-threatening illness.

My 3-year-old son Jacob is one of them.

He has a disorder of the [18th Chromosome](#). The 18th Chromosome has various named disorders, including Ring 18 and the more well-known Trisomy 18 (which affects Rick Santorum's daughter, Bella). My son has the more rare 18q-. Only 1 in 40,000 Americans have Chromosome 18q-, which means that less than 7,800 Americans are affected by this disorder.



Because of this disorder, Jacob has had serious medical and developmental issues. He has had heart surgery, kidney tract surgery, bronchoscopies and endoscopies, slept with an oxygen tube, and has had dozens of medical tests and sees numerous specialists. We've been in and out of hospitals and doctors' offices since he was three months old. He also has severe developmental delays and receives speech therapy, occupational therapy, physical therapy and behavioral therapy.

Raising a child with any disorder, condition or special need, is both a blessing and a challenge. A challenge for the obvious reasons, and a blessing because you don't know the depths of victory and joy until you see your child overcoming some of those challenges (sometimes while smiling like a goofy bear).

Chances are that you know a special needs parent, or you may be one yourself. As a special needs parent, I often don't share my feelings on this aspect of my life, even with my closest friends, so I decided to compile a list here with the goal of building understanding (I was largely inspired by [this beautiful post](#), authored by another parent to a child with a chromosomal disorder). I don't claim to speak for every special needs parent out there, but from the ones I know, some of these are pretty universal. If I've missed any, please leave a comment below.

1. I am tired. Parenting is already an exhausting endeavor. But parenting a special needs child takes things to another level of fatigue. Even if I've gotten a good night's sleep, or have had some time off, there is a level of emotional and physical tiredness that is always there, that simply comes from the weight of tending to those needs. Hospital and doctors' visits are not just a few times a year, they may be a few times a month. Therapies may be daily. Paperwork and bills stack up, spare time is spent researching new treatments, positioning him to sit a certain way, advocating for him in the medical and educational system. This is not to mention the emotional toll of raising a special needs child, since the peaks and valleys seem so much more extreme for us. I am always appreciative of any amount of grace or help from friends to make my life easier, no matter how small, from arranging plans around my schedule and location, to watching my son while I am eating.

2. I am jealous. It's a hard one for me to come out and say, but it's true. When I see a 1-year-old baby do what my son can't at 4 years-old (like walk), I feel a pang of jealousy. It hurts when I see my son struggling so hard to learn to do something that comes naturally to a typical kid, like chewing or pointing. It can be hard to hear about the accomplishments of my friend's kids. Sometimes, I just mourn inside for Jacob, "It's not fair." Weirdly enough, I can even feel jealous of other special needs kids who seem to have an easier time than Jacob, or who have certain disorders like Downs, or autism, which are more mainstream and understood by the public, and seem to offer more support and resources than Jacob's rare condition. It sounds petty, and it doesn't diminish all my joy and pride in my son's accomplishments. But often it's very hard for me to be around typical kids with him. Which leads me to the next point...

3. I feel alone. It's lonely parenting a special needs child. I can feel like an outsider around moms of typical kids. While I want to be happy for them, I feel terrible hearing them brag about how their 2-year-old has 100 words, or already knows their ABCs (or hey, even poops in the potty). Good for them, but it's so not what my world looks like (check out [Shut Up About Your Perfect Kid](#)). It's been a sanity saver to connect with other special needs moms, with whom it's not uncomfortable or shocking to swap stories about medications, feeding tubes, communication devices and therapies. Even within this community, though, there is such variation in how every child is affected. Only I understand Jacob's unique makeup and challenges. With this honor of caring for him comes the solitude of the role. I often feel really lonely in raising him.

4. I am scared. I worry that I'm not doing enough. What if I missed a treatment or a diagnosis and that window of optimal time to treat it has passed? I worry about Jacob's future, whether he will ever drive a car, or get married, or live independently. I am scared thinking of the hurts he will experience being "different" in what's often a harsh world (not to mention that I fear for the physical safety of the person who inflicts any hurt upon my son). I am scared about finances. Finally, I fear what will happen to Jacob if anything were to happen to me. In spite of this, my fears have subsided greatly over the years because of my faith, and because of exposure to other kids, teenagers, and adults affected with Jacob's disorder. When I met some of these amazing people at a conference last year, the sadness and despair that I was projecting onto Jacob's future life (because it was so unknown) melted away when I saw the love and thriving that was a reality in their lives. The fear of emotional pain (for both me and Jacob) is probably the one that remains the most.

5. I wish you would stop saying, "retarded," "short bus," "as long as it's healthy..." I know people usually don't mean to be rude by these comments, and I probably made them myself before Jacob. But now whenever I hear them, I feel a pang of hurt. Please stop saying these things. It's disrespectful and hurtful to those who love and raise the kids you're mocking (not to mention the kids themselves). As for the last comment, "as long as it's healthy," I hear a lot of pregnant women say this. Don't get me wrong, I understand and share their wishes for healthy babies in every birth, but it's become such a thoughtless mantra during pregnancy that it can feel like a wish against what my son is. "And what if it's not healthy?" I want to ask. (My response: you will be OK. You and your child will still have a great, great life.)

6. I am human. I have been challenged and pushed beyond my limits in raising my son. I've grown tremendously as a person, and developed a soft heart and empathy for others in a way I never would have without him. But I'm just like the next mom in some ways. Sometimes I get cranky, my son irritates me, and sometimes I just want to flee to the spa or go shopping (and, um, I often do). I still have dreams and aspirations of my own. I travel, dance, am working on a novel, love good food, talk about dating. I watch *Mad Men*, and like a good cashmere sweater. Sometimes it's nice to escape and talk about all these other things. And if it seems that the rest of my life is all I talk about sometimes, it's because it can be hard to talk about my son. Which leads me to the final point...

7. I want to talk about my son/It's hard to talk about my son. My son is the most awe-inspiring thing to happen to my life. Some days I want to shout from the top of the Empire State Building how funny and cute he is, or how he accomplished something in school (he was recently voted class president!). Sometimes, when I'm having a rough day, or have been made aware of yet another health or developmental issue, I might not say much. I don't often share with others, even close friends and family, the depths of what I go through when it comes to Jacob. But it doesn't mean that I don't want to learn how to share our life with others. One thing I always appreciate is whenever people ask me a more specific question about my son, like "How did Jacob like the zoo?" or "How's Jacob's sign language coming along?" rather than a more generalized "How's Jacob?" which can make me feel so overwhelmed that I usually just respond, "Good." Starting with the small things gives me a chance to start sharing. And if I'm not sharing, don't think that there isn't a lot going on underneath, or that I don't want to.

Raising a special needs child has changed my life. I was raised in a family that valued performance and perfection above all else, and unconsciously I'd come to judge myself and others through this lens. Nothing breaks this lens more than having a sweet, innocent child who is born with impairments that make ordinary living and ordinary "performance" difficult or even impossible.

It has helped me understand that true love is meeting someone (child or adult, special needs or not) exactly where he or she is -- no matter how they stack up against what "should be." Raising a special needs child shatters all the "should bes" that we idolize and build our lives around, and puts something else at the core: love and understanding. So maybe that leads me to the last thing you don't know about a special needs parent... I may have it tough, but in many ways I feel really blessed.

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