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A Life Turned Upside Down: Parenting Children with Special Needs When You Also Have a Disability

by Keely M.

I think the most difficult part of being disabled and raising three children with special needs is the loss of a once "normal" life.

In what seems like a lifetime ago, we were the quintessential all-American family. My husband Ryan and I both worked full-time jobs for the same company and we had a beautiful little baby girl named Jessica. I was blessed to have a job in which my daughter was able to go to work with me. Life was perfect and we were living the dream. How very quickly that all changed.



Our Family

As Jessica grew, both the pediatrician and I noticed that she suffered from developmental, sensory, cognitive, hearing and health problems, and she was diagnosed eventually with PDD-NOS, a high functioning form of Autism. She was also diagnosed with seizures. At age seven, Jessica's health has now deteriorated, and her doctors feel that she has a Neuromuscular Disorder.

A year after Jessica was born, we had a son we named Hunter, and he suffered from major health problems from the beginning. He was eventually diagnosed with mild cerebral palsy and subsequently was given a few more additional diagnoses.

When Hunter was a year old, I was hospitalized due to severe neural and vision deficits, and eventually I was diagnosed with progressive Multiple Sclerosis (MS). Since then, I have been diagnosed with other health problems unrelated to MS.

Two years later, we were surprised to find out that I was pregnant again. I saw specialists throughout my pregnancy and was informed that all the tests confirmed my baby was going to be healthy and would not suffer from any of our other children's health problems. When Matthew was born, he had major health problems from the beginning, much like his brother, and was eventually diagnosed with mild cerebral palsy and a few more diagnoses.

The causes of our multiple health problems are unknown at this point. We saw a geneticist last February and she feels that we definitely have some sort of genetic disorder in our family. She is positive that I was misdiagnosed and that a genetic disorder is the cause of my disabilities. We are in the process of trying to find out what that genetic disorder may be.

Adapting

In the past seven years, our dream of a "normal" family has been replaced with the challenge to adapt and thrive. Let me tell you, this is the hardest thing we have ever had to do. I have spent my life raising other people's children, first as the fun babysitter that all the local parents wanted to hire, then as a second mother to my friend's children for ten years, and finally as a preschool teacher for four years. Nothing I had been taught or learned prepared me for the life we now live.

I was once a very active athletic person who dreamed of coaching my children's athletic teams, volunteering at their schools, going on their field trips, taking them on excursions, and playing with them at the park. I went from being a totally hands-on mom to a mom who needs a caregiver for herself and her children. Accepting that I need help was devastating, but I am thankful that we have the help we need. My husband Ryan went from being my partner to being a caregiver to our whole family. Ryan is now our sole

income provider except for my disability checks. We struggle financially, but by the grace of God and my ability to bleed money from a stone, we pay our bills every month.

Lessons Learned

Even though our life is not what we would have chosen, I am thankful for the lessons we have learned. We have grown and matured in so many ways. Our challenges have taught Ryan and me to support each other one hundred percent. Our relationship is stronger and healthier than it has ever been. We have learned to work together and face each challenge as a team. We talk about everything and make decisions together. We may not always agree with each other, but we have learned to respect each other's opinion.

We have made the best of what we have been handed. We have learned to slow down and enjoy life and each day as it comes. We learned to enjoy every accomplishment that our children make. We accept our children's abilities and limitations and push them to strive for more.

Everyday our children teach us the meaning of perseverance, love, hope, and joy. Because life is teaching them these lessons early, I am positive that they are going to do something great in this world. They all are wise beyond their years.

Even though our dream of a "normal" family will never be, we have learned to change our dreams as life shows us the way. Right now, our dream is to one day find out what causes our family to have all these health problems and start some sort of treatment, if it is available.

If that is not a possibility, we will create another dream and go on living the best life we possibly can.

Keely M. lives in Sacramento, California and is a stay-at-home mother of three inspiring children, one girl, Jessica, who is seven, and two boys, David "Hunter," who is six, and Matthew, who is four years old. In her former life, she was a Preschool teacher, a substitute Physical Education Teacher, and a girl's JV Athletic Coach. Since her children have been born, she has become an advocate, striving to get the best possible care for her children. In her free time, she is a dreamer, an amateur writer, an amateur photographer, an amateur singer, and a web surfer. You can visit her blog at <http://when-it-is-raining-cats-and-dogs.blogspot.com/>