Tribute to Dad

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This story came to me on one of the autism lists I subscribe to. It's such a beautiful tribute to a very special dad.

I thought I'd write about my husband of 12 years. My husband and I were married when he was 21 and I was 23. Within 3 months of the wedding I was pregnant with our first child. We were very excited and had no inclination that anything could or would be wrong with our baby. As it turns out we had a few ultrasounds and none of them showed the whole spine or head so we were sent for a better ultrasound which at the time was a level 2 (oh how technology has improved in just 11 years). So as it turns out we found out at 26 weeks of gestation that Andy's (my son) head was about half the size of what it was supposed to be and his body was normal size (so he wasn't just a small baby) and he had hydrocephalus on top of that which was taking up over half his already tiny brain. So we were basically told there was little chance he would even make it to birth and an even smaller chance that he would live if he were born.

A few weeks later they tried again to see his spine and it turned out that he has spina bifida. (his spinal column was open and his spine sticking out, not covered by skin or anything). Well to make a long story short we had people we didn't know around the country praying for us and within a few weeks Andy's head was in the 2% which was in the normal range at least. Andy did live and in fact is happy and healthy.

He does have physical disabilities and mild mental delays. He's 11 years old he walks with braces on his legs, uses a wheelchair sometimes and has had 23 surgeries. He is in special classes and is a great kid.

A few years after Andy was born I got pregnant with Kyle. This pregnancy was difficult. Prior to becoming pregnant with either child I was very active and in great shape. I was into gymnastics, in the air force and just loved to run and exercise. After Andy I had back problems because of reasons unrelated to his condition I had to be hospitalized and on bed rest for 5 weeks prior to delivery which really messed up my back. I also developed cysts in my wrists which have never gone away.

So with Kyle things got worse I started having more back pain, and I got my first migraine. They didn't stop coming while pregnant. When Kyle was born we noticed his head looked bigger than his shoulder width, which I immediately noticed and felt bad about that being the first thing I saw. He also had a ridge on his head which the doctor attributed to being born, however he was a c-section birth which wouldn't squish the head the way vaginal birth does. So anyway it turns out Kyle was always crying and screaming, he wanted to eat constantly but would throw up the food. He ended up having craniosynostosis, his head was fused shut and had no room for his brain to grow. So he had surgery to open it up at 4 months. Kyle went on to have 3 more. I noticed fairly early there was something going on with him, that he wasn't responsive and wasn't developing normally but doctors kept reassuring me it was ok. I didn't let it go and finally at the age of 3 he was diagnosed as severely autistic.

It's been a long road, Kyle is now 8 and although his speech is doing really good he speaks and understands about as much as a 2 year old, his OCD is really severe, and he still tries to run away frequently which is terrifying. He doesn't always respond, I'm sure you get the picture.

So on to what this is really about, my husband. Joey has been there through the whole thing. My health has decreased through the years, I now have arthritis in my lower and upper back and neck, Thoracic outlet syndrome, narcolepsy, other generalized pain and fatigue issues, blood pressure problems and memory issues, as well as migraines and vision changes. So keeping up with the kids is a challenge. This isn't about me though it's about my husband.

Every therapist I've ever worked with (we've been lucky to keep with the same speech therapist for 11 years who is a God send), as well as every case manager we've ever had for either child and pretty much everyone else I've ever talk about are shocked at how dedicated my husband is to both myself and our children.

Most people I know with narcolepsy have been divorced because it's a very difficultdisorder to live with and evenmore so for someone else to live with a person who has it. Add in all the other issues and well it's not an easy life. I take care of the kids most of the time, but my husband works, cleans, cooks, and does all the physical aspects of taking care of the kids when I can't. He even catheterizes my older son and gives him his bowel program. My husband does way more than his fair share of the work and I don't know what I would do without him. I can't drive due to the narcolepsy, I tend to pass out randomly in the car which obviously isn't safe, so he takes us all to our appointments by taking off work and therefore is very in tuned to the medical stuff that's going on.

He knows a lot more than most working fathers do. Our case manager was shocked at how much he knew when I was at the hospital with my other son and she came over for a visit (we were supposed to be home by then but weren't released on time). I asked Joey to stay and conduct the meeting. He is usually a little uneasy because he isn't the one taking the phone calls and doesn't know what we've been talking about, but when it comes to knowing his kids he absolutely does as much as I do. I realize that without all my issues this isn't very common in fathers of special needs children, but Joey deserves the father of the year award because he works harder than any father I've ever met and he rarely complains about it.

So God Bless my amazing husband and father of my two amazing children.