



# Complex Child E-Magazine

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## Lessons Learned...Lives Changed

by Varsha Daryanani

I remember the days before I had my first baby. Life was straightforward then...I had a great job, I was happily married and we had the luxury of being able to travel to exciting places. Fast forward to today and my life has changed 180 degrees. I have a different job now – I am a full-time mom to a special needs child.

Raising a special needs child has brought tremendous challenges to my daily life. I've had to learn about medical issues that I didn't even know existed, I've had to fight for my child's rights to medical care and I've had to accept that my life with a special needs child will never be "normal." We will always get people staring at us while we walk through the mall, we will always plan our lives around whether our daughter can join us in extra-curricular activities and we will also have to deal with insensitive remarks from those who don't know any better and ask questions like "What's wrong with her?"

There is no doubt that my life has changed forever...but some of these changes have been for the good. I've learned lessons from my daughter that no book, no professor nor family member or friend could ever teach me.

- 1) Don't worry too much about the little things – enjoy time with your child instead!

I'll be the first to admit that I used to be obsessive/compulsive about keeping my house clean and organized. These days, I don't worry if there are dirty dishes in the sink or clothes that need to be washed. I try to spend as much time as I can with my daughter...sometimes I read her a book, sometimes I take her for a walk or sometimes we just cuddle. I know the thought may sound morbid, but I just don't know how many years we'll have with her and I don't ever want to look back and wish that I had spent more time with her.

- 2) Inchstones are just as important as milestones.

We all know how exciting it is when our children reach certain milestones. But when you have a special needs child, sometimes they never reach the "normal" milestones. Our kids are unique – they have inchstones instead. Special needs children work twice as hard to do certain activities, so celebrate each step as if it's the greatest accomplishment in the world...because to me, it really, truly is.

3) Time off is just as important as time management.

Our schedules can get crazy with doctor's appointments, therapy, school, etc. In March, my daughter had 11 appointments every week...talk about crazy!!! As parents of special needs kids, we spend hours arranging and attending medical and therapy appointments, arguing with the insurance company over covered benefits and advocating for services for our children. In addition, we still have to cook, clean, grocery shop and keep the household running. Somehow, amidst the chaos, we manage to do what's essential and leave the rest. For me, sanity comes in the form of time off. Whenever I can, I go to the gym or read a book or go shopping – ALONE! I find that time to myself allows me the chance to recharge and keep a positive attitude.

4) You will make mistakes...and that is OK!

What more can I say – nobody is perfect!

5) Compassion will open your eyes.

When you are immersed in the world of raising a special needs child, you are immediately introduced to other children who may also have disabilities. I've learned to respect and celebrate those who have differences. I've also gained compassion for those with special needs because I see through my daughter's eyes how challenging life can be for them.

6) Reach out to others who may be in the same boat as you.

When my daughter was a year old, I joined a mommy & me class so that I could meet other moms in my neighborhood. Because of my daughter's developmental delays, we enrolled in the infant class. Although the women in the class were all very nice, I did not really connect with any of them because they didn't have to deal with feeding tubes or seizures or therapy sessions. I felt alienated and alone. When the session was over, I tried to find a special needs mommy & me class but I couldn't find one in my area. I searched all over the internet and finally found a network of moms who deal with all of the same issues that I do. I felt so relieved to "meet" others who could relate to my ups and downs. The women on that message board have been my backbone the last couple of years. And now that I have had almost three years of experience raising a special needs child under my belt, I take every opportunity to reach out to other moms who have special needs children. I approach them in the hospital, at therapy and even at the mall. It's such a nice feeling to help others and also refreshing to talk to others who actually understand.

7) Value what's important and treasure them as they are.

Contrary to popular belief, having a meaningful life does not depend on what school you go to or what kind of job you have. For our special needs children, a meaningful life means having the love and support of family and friends. With this love and support, our children prosper and often prove doctors wrong. To this day, I am utterly amazed by how strong our children are. Some of them may not be able to speak or gesture, but their smiles speak volumes. No matter how much pain they endure, they always manage to crack a smile – and a smile from these kids not only lights up the room, it lights up our hearts.

*Varsha Daryanani is a full-time mom to Alisha, a 2-1/2-year-old diagnosed with Wolf-Hirschhorn Syndrome and Cerebral Palsy. Prior to becoming a mom, Varsha was a Commercial Real Estate attorney for a mid-size California law firm.*