

Hello Reader

Please know that I don't consider myself any sort of ideal mom. Most of the time I am either second guessing myself, feeling guilty about not doing enough or about doing too much of something else, about not being more patient, about not being the perfect mom, wife, advocate, daughter, sister, friend, etc.

But I realized that the things I like the least about the world of special needs are the feelings of being alone, and of not having any sort of "directions"; as in "here's what your child(with special needs) is going to need and what you need to do to get it." And I realized that there are so many of us that are out there trying so hard to find our way and get our kids what they need, with no directions or real guidance. I thought if by sharing my story I could share just one thing that might help someone else or let one new mom facing some sort of diagnosis know that they are not alone – that would be worth it. Because when it comes down to it, raising any child can be difficult, and doesn't come with directions. But raising a kid with special needs is a whole different definition of difficult. And us special needs moms – well yea, I guess we really are something special.

My Story

Annalee was born 3 months premature and weighed 1 lb., 10 ozs – a micro-preemie. I will never forget the feeling of helplessness and plain terror as we tried to keep her alive, healthy, and get her to thrive those first couple of years. Progress was painstakingly slow. Back and forth to hospitals and ICUs. Complicated equipment at home. I learned early on to take one day at a time and not look too far into the future. There were simply no guarantees. Incredibly, in spite of the dire outlook and prognosis, and the eventual diagnosis of cerebral palsy with all the challenges and uncertainty that diagnosis brought and continues to bring, we are so lucky in that Annalee was and is – always – just so very HAPPY!

This road we're on – the "special needs" journey, is a multi-faceted, emotional roller-coaster. Everything is more extreme; the highs and the lows, the good/the bad, the kind/the mean, the light/the dark, beauty and ugliness. Every single day seems to bring each of these things—and sometimes in quick, random succession. An example; I was picking Annalee up at school in a rainstorm one afternoon. All the handicapped parking spots are filled? One by one, in the pouring rain, I asked those without a handicapped vehicle tag to move, and most were embarrassed and willing. Except one rude mom, who refused, and told me to "lighten up". I was in tears on the drive home, thinking of the mean, ugly world that Annalee was destined to exist in without me someday. We drove through McDonald's for an ice cream cone and for no reason at all, the cashier says to me with a smile – "here you go honey, this one's on the house.....and God Bless You"! I'm not sure what made me cry harder, the mean woman or the kind one, but it's the kind one that gives me hope for Annalee's future.

On this journey, there is also very little "down" time and when there is, I am wary that some sort of change is right around the corner or that I'm not doing enough. This can be good, as it forces me to constantly assess our situation and be prepared for whatever is coming next, but it is also exhausting and overwhelming too. Can I admit that sometimes I wish for "typical" or "normal"? Yes, sometimes I do. Sometimes I just hate "Holland" (see "Welcome to Holland"). But there is no

value in wishing....so I've learned not to waste my time wishing for things to be different. I landed in Holland with a precious gift and the most important job; to love this special little girl, to raise her as best I can and to give her the best future that I can. I try to focus on the highs, the good, the kindness, the light and the beauty, instead of all the rest. I am blessed to have a husband who has been my partner on this journey, through all the ups and downs along the way. And some precious people I can lean on for support when I need to (thanks mom!).

16 years later and Annalee has grown into a beautiful young lady. I think about the odds she has beaten, the surgeries, the therapies, the challenges that she faces everyday without complaint and I am in awe at how far she has come and of the positive effect she has had on me and on everyone around her. Her work collecting recyclable cans and bottles and donating all of the money to a wounded warrior is just one example of how she thinks of others first (even though she obviously has expensive, complicated needs of her own). She has always had a special light that shines through in everything she does and everywhere she goes. It touches everyone she meets immediately. Good people, kind people are drawn to this light and I find myself marveling at the wonderful people and experiences I would never have had, if not for Annalee.

Being Annalee's mom has taught me so many things -- I have learned to speak up, to demand more, to set difficult priorities, to say no, to ask for help, to make painful choices, to trust, to have faith, to accept, to let go, and to believe in magic and miracles. Annalee is my inspiration, my reason to get up and face each day and whatever it brings, with a positive attitude for everyone and everything that comes our way. She is a radiant light in this world that brings out the best in everyone around her. I am honored to be her mom and so incredibly proud of the beautiful person she has become.

I would like to thank Lynn for pulling this exhibit together and taking the time to recognize moms like me and all the other beautiful moms and their special children. When Annalee was a baby I chronicled every ounce she gained, every inch she grew, every tiny little milestone she achieved. I wrote letters to her telling her how much I love her and what she meant to me, all my hopes and dreams for her to be happy and to know love. I keep them all in her baby journals which are tucked away in her hope chest. As she got older and things became less fragile but more complicated and busy, I stopped tracking every little thing. Participating in this exhibit has made me stop, look at how far we have come and appreciate all that we have. The photos capture so much love -- what a wonderful gift you have given me. Thank you Lynn Damon!