

A Life Less Perfect

By Lisa Peters

Before my son Nicholas was born, my life was perfect.

I ran in an invisible race with neighbors and friends. A race to see who had the greenest lawn, the smartest kids, the whitest teeth. I was a member of an elite group, devoted to raising elite children. We spent our time at BBQ's and soccer games tallying our points in our quest to grab that glittering gold ring of perfection.

As we admired our children, and our lawns, we never stopped to realize that on our faces we wore rose-colored glasses and, in our hearts, we felt an emptiness that searched for a deeper meaning to our lives.



On January 18, 2002, like a thin layer of glass, my perfect life came shattering down by the purest sound of six horrifying words ... "Your son has Prader-Willi syndrome." And suddenly I could not breathe.

I sobbed for my poor, weak, little child. I sobbed for myself. I sobbed for the perfect life we would never have together.

There were no flowers, no cards, no congratulatory notes from family and friends...my son entered the world in silence. No smiles, no laughter, no fanfare. No one welcomed him. Everyone was sad.

Where in a perfect life would this little child fit? It was as if his very existence threatened to tarnish this utopian world we had created. My tiny son was a giant monster of truth that threatened to expose the meaninglessness of a life built out of playing cards. And all who lived in these fragile card houses could not understand how to celebrate the birth of this little child.

My son lay limp upon his bed. A yellow feeding tube was taped to his cheek and traveled up his nose and into his stomach. Taped to his tiny skull another tube pumped antibiotics into his fragile veins. Around his floppy body a brace made of thick straps and stiff Velcro held his weakened hips in place. Feeding machines and IV poles surrounded him like quiet metal soldiers standing at attention. Everywhere alarms sounded...a constant reminder that this was hell and we now lived in it. Around me in the NICU, I saw only despair ... parents with children struggling to live.

Like my newly born infant, I was abruptly and cruelly removed from the warmth of my womb-like perfect life. I was thrust head-first into a cold and terrifying new imperfect world.

This was my new home. I felt sick.

Every movement I made felt unnatural and awkward. My mind was frozen. My body moved like a robot. I did not want to look around me, for everywhere I looked, I saw pain. I felt like a soldier on the battlefield, frozen by the ghastly sight of the slain bloody carcasses at his feet. And yet, like this soldier in a war he did not create, I too could not escape my fate.

The rose-colored glasses I once blindly wore were smashed into smithereens. My eyes, unaccustomed to this new light, could not stop crying.

In his sad and traumatic entrance into this world, my imperfect son had given me a sad, beautiful and precious gift, the gift of sight. The ability to see the world not as I wanted it, but as it truly was. I saw the pain and sadness...the frailty of life.

When he finally came home from the hospital, I had to hold him carefully or his head would flop quickly forward. And when it did, he couldn't breathe. I felt helpless.

I questioned God, what had I done to my son? I felt guilty.

When I took him to restaurants or the mall, people would ask questions, "Why does your son have a tube in his nose?" I felt embarrassed.

When I handed my fragile son to the doctor at Children's Hospital for eye surgery, I felt scared.

So many endless days brought so many endless hurtful, hard emotions. I felt so very tired.

And when my tired body seemed like it could bear no more...my floppy little child began to get stronger. And as he did, I began to feel a lost emotion...happiness.

After almost a year, Nicholas finally held up his head. That tiny little infant who struggled to breathe was now able to see the world. I felt joy.

When his g-tube was removed, and the words "failure to thrive" were removed from his chart, there were tears. No more questions to answer. I felt relieved.

When he pushed away his metal walker and took steps for the first time, I wept.

Slowly, I began to realize that these tortuous feelings, these hardships were somehow very important for me to experience. For it was these extremes, these awful, uncontrollable feelings, and hardships, that gave my life new meaning. I understood myself a little better. I understood others a lot better. And although these emotions left me feeling fragile and vulnerable, I couldn't help but wonder if this is God's intention?

As I became accustomed to my new sight, I saw we were surrounded here on earth by many hidden angels. Intelligent, kind human beings who were devoting their lives to curing and healing the sick. Why hadn't I seen them before? Why hadn't I appreciated them? And once again this imperfect child had enabled me to see. I could see the special souls that traveled among us here on earth. Selfless, gifted souls devoted simply to the healing of others. These guardians would now be a part of our lives forever. This horrifying new life of ours now seemed a little less scary.

There were other angels here on earth now visible to me for the first time ... special parents of children with Prader-Willi syndrome whose paths were as treacherous as ours. And with these special few we shared our advice, our tears, our love ... and a unique brotherhood was forged...for we could truly understand each other! I listened to the words of these parents I had never met. I listened to these strangers with quiet hearts and somehow my hardened spirit was now a little lighter. Why? I do not know for I was still sad. But somehow by releasing tears, and listening to others, I began to accept and understand this challenging life.

I began to accept that my son is not like others in this world. I began to accept that this was not a curse but a blessing. To me he was unusually happy, loving and kind. I was amazed by his keen perception of human beings and his unique ability to make even the grumpiest of grouches smile brightly. He lives to dance and laugh and love. He has a warm heart and a gentle spirit. And although he is my child, he has also been my teacher.

Each of us are blessed with special gifts and although his gifts are hidden, buried beneath a weakened body, his gifts are no less special. I do not have a son who can run very fast, I have a son with the precious gifts of empathy and human compassion.

I now realize that my life with Nicholas will not be like the lives of so many others ... ordinary. It is an extraordinary life. A life filled with high highs and low lows. I would not trade one day of feeling that terrible pain because now I know the terrible happiness that is on the other side waiting for me. What I have learned is to appreciate both. For it is these feelings, this blending of the good and the bad, that somehow seem to bring me closer to understanding my purpose here on earth.

This awareness, this blending of heart and spirit, has helped me to embrace my son and enjoy this journey we are sharing together. It is a sad, sweet, beautiful trip. It is a life less perfect. It is a life more meaningful.

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