

“Walk the path you’re given”

This has been my touchstone since I learned that the child I was expecting, the son I so longed for, has Down syndrome. I don’t think I read it in any magazine, or heard it on TV, but it floated in my mind at some point after the diagnosis, and has taken up residence there. It cheers me on during the tough times, and reassures me when things are good. It has become a sort of life philosophy, the first of many gifts my son brought to our lives.

If you have just learned you are expecting a child with Down syndrome and have chosen to continue the pregnancy, it is so important that you know you are not alone! If I were to meet you, I would hug you and tell you that many other parents have been where you are, and many will follow. You are not crazy. You are simply welcoming your child into the world.

You may right now be spending lots of time on the Internet, frantically looking up what it means to have Down syndrome. You may be speaking with doctors who have suddenly become overly professional, or worse, behaving surprised that you want to keep your baby. You may have told family and friends about the diagnosis only to get opinions you’re not sure you want.

I’m glad you found this website, and I hope our story makes you feel less unusual, less like the only person who ever knowingly kept a baby with Down syndrome, and more like a parent.

The thing is, all you get from statistics and doctors and many websites is the list of all the “things” that can be wrong with your child. What a challenge it’s going to be. And of course, it’s true that raising a child with Down syndrome is somewhat different from raising a typical child.

It’s different, but then again, not so different. Because a child with Down syndrome is a *child* – a living, breathing, feeling, smiling, crying, laughing, pooping, sleeping, eating child. A child with blue eyes or brown, wispie hair or curls, dimples or not, a unique voice. A child who will reach out to her mother for a hug. A child who will play tug-of-war over his blankie with his dad. I know, because I have one. A beautiful five-year-old boy who loves to watch Toy Story, and knows lots of sign language, and really loves ice cream sandwiches, and crawls into our bed at four a.m. just to cuddle. A boy who has a belly laugh that can stop traffic. And when I say “I love you” to him, he says “I love you, too”.

We had our son’s diagnosis at nineteen weeks of the pregnancy, November 19th, just before Thanksgiving. It was an incredibly difficult time, made more so by the fact that three of his four grandparents thought we should consider abortion. That was pretty shocking, and for a while made us feel judged for having him. We also did not have much help in our obstetrician, who said he had never had a family continue a pregnancy with this diagnosis. We got mixed reactions when we told our immediate family members, and although we did have some wonderful supporters, still we felt very much that the people around us thought we “picked this” and so shouldn’t complain.

We didn’t complain, but boy did we ever grieve. Even though we decided to keep our baby, it was a loss nonetheless. A loss of the child we thought we were having, of the life we thought we were going to live. And we did a lot of the grieving privately because we didn’t want anyone else to tell us we had made a bad choice. After the initial reactions we got, we decided to keep our news private until toward the end of the pregnancy, because it was just so hard.

Eventually, after we had gone through much of the intense grief, we did share our son’s diagnosis. Just about 3 weeks before our due date, we called a few key friends and family members and asked them to announce our son’s impending arrival, including the fact that he has Down syndrome. We asked them to assure everyone that we were ok and ready to welcome our child with as much joy as our other children. That they could certainly call us, and visit, just to make sure that they told us “Congratulations” and “isn’t he beautiful!”. What a blessing this turned out to be! When our son was born, we were surrounded by people who knew just the right thing to say.

Our lives are certainly changed – it has been hard to listen to friends and family who told us they would have taken a different road. We move a little slower sometimes. We wait longer for each developmental milestone. But it’s also true that our lives have changed for the better. We are very different parents, I think, than we would have been without him. We are much more patient, we accept each of our children for who they are, not what we thought they would or should be. We are among the truly blessed who know that no child is perfect, yet every child is perfectly who they are. We hold each other a little closer having gone through the tough times. And our lives have been touched by a whole other set of people – teachers, doctors, therapists, and families that we never would have known. It is a very rich life.

We are not sorry that we chose to bring our son into the world, to walk the path we were given. And I know for sure that he is not sorry to be in it.