

The following is a reprint from the book, *You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities*, edited by Stanley D. Klein, Ph.D. and Kim Schive, Kensington Books. The following story was written by Casey Cunningham, executive director of the Chesapeake Down Syndrome Parents' Group, Inc. and member of the NDSS Affiliate Advisory Board. It is reprinted here with her permission.

An Evolution of Emotions

My son has *Down syndrome*. It was my first thought at his birth. The moment I looked into his eyes, I heard the words as though whispered from somewhere else, though no one in the room had spoken. *Down syndrome*. I knew it with certainty and dreaded the affirmation that would come later from the doctors and their tests.

Suddenly I looked into a total eclipse of my son's future. A permanent one, for if I remembered my high school biology, the difference lay encapsulated in every single cell in his body - an extra chromosome. I knew there could never be a cure for such a "defect," and the weight of that knowledge was almost unbearable. What I knew of Down syndrome was little, but none of it was good. Mental retardation. That was the one thing I knew for sure. My son would one day become an adult physically, but mentally his progress would be limited.

Nevertheless, I already loved his child. I loved him even before he was conceived, for I had longed for a child desperately. I cherished each moment I was pregnant and waived any tests that would have jeopardized the tiny life within me. Thus, my son had kept his secret until birth.

As his father held him so proudly in that delivery room, I, too, kept the secret. His father would learn soon enough that a dark cloud loomed in our future; there was no need to point it out now. *We had a child*. He was beautiful; he was healthy; he looked just like my husband. Together we would all find a way to deal with the Down syndrome aspect of this new little life.

My son *has* Down syndrome. It soon became a statement of fact. He *has* blond hair; he *has* blue eyes; he *has* Down syndrome.

Yes, the Down syndrome presented a challenge to us as parents determined to help him develop to his fullest potential. But aren't all parents similarly challenged? Don't we all want each of our children to develop to his or her fullest potential?

The differences lie in the way each child is challenged and, sometimes, in the timing - when and how the challenge is presented. My son's challenge was conveniently bundled up and labeled for us immediately, present from the moment of his conception. Almost from the start, we knew what we were dealing with.

And over time, I came to realize that our child was more like typical children than not, that life holds no guarantees for anyone, and that life's very unpredictable nature is what makes it so special. That is what we truly love about each child is his or her uniqueness, not that which makes them just like every other child.

My *son* has Down syndrome. I have noticed that there now is a certain amount of pride in my voice when I say these words. I have learned that, contrary to my first fears, my son's future is very bright. What I initially saw as a total eclipse was caused by a lack of knowledge and vision.

The more I learned about Down syndrome, and about my own son's abilities, the more comfortable I became. I learned that as his parents, we have the ability to help him learn and achieve more than he would if we were simply to be bystanders. I have seen how hard he works to attain certain milestones, and it makes me so much more appreciative of his individual determination and strengths. My love for him is complete, and his Down syndrome has become an inseparable part of that love, just as it is an inseparable part of him. I am very proud of all that he has accomplished, and I take nothing for granted. I look forward to discovering what his future holds.

I'm often in the company of other moms who talk with pride about their children and all the things they are doing - something everyone expects of them. Now I join in. I talk about my son and all he is doing, even though this is something no one seems to expect. And with love, acceptance and, yes, even pride, I add, "*My son has Down syndrome.*"

Casey says her advice to new parents is always the same: simply love your child for who he or she is. Don't worry about the future. Love and enjoy your child now, and the rest will fall into place.