



# What Parents Wish They'd Known



Reflections on Parenting a Child with Down Syndrome





**T**hey say hindsight is 20/20. At some point, haven't we all revisited something or someone from the past and seen it in a new and surprising light? Looking over our shoulder, an enemy may emerge as a friend in disguise. A crisis may appear as an opportunity. A burden may look more like a blessing. Sometimes, such perspective leads to regret—if only we'd known then what we know now! But the truth is, we couldn't have known. Only by experience do we enjoy the rich fruits of understanding. And this understanding is of great value to others, as well as to ourselves.

This booklet offers glimpses of understanding to individuals beginning a momentous journey: parenting a child with Down syndrome. The glimpses are given by other parents who have been journeying for some time—months, years, even decades—and who pause here to describe the vistas that have opened to their view. The following pages feature their answers to the question, "What do you know now about parenting a child with Down syndrome that you wish you'd known from the start?"

It's my hope that these responses will be encouraging and refreshing to fellow travelers. The insights shared cannot provide a shortcut through the struggle that most new parents face in the early months following their child's diagnosis. But they can offer support along the steep and rock-strewn path, hope for what awaits around the bend, and light to guide the way.

—Kathryn Lynard Soper, mother of Thomas (4 years old)

I wish I'd known that it wasn't the end of the world.

—Joseph, dad to Janna (3 years)

I wish I'd known Down syndrome does NOT make being my son's mommy, or loving him, difficult or different.

—Kathy, mom to PJ (8 ½ months)

I wished I'd known just how much like a "typical" newborn my baby would look like when she arrived. I was a bit scared and feared the unknown, but was pleasantly surprised: Ten fingers, ten toes, two eyes, two ears, a mouth and a nose . . . PERFECTION.

—Robyn, mom to Amarli (7 months)

I wish I'd known to listen more and assume less.

—Chris, mom to Stevie (3 years)

I wish I'd known that I could be the best advocate for my child. I didn't even know what the word meant, but I know now that I have no problems standing up for Hope, and this has made me better at standing up for all my children.

—Debra, mom to Hope (4 years)

I wish I'd known the pure joy, happiness, pride, love, and dedication that my baby would show us all. I wish someone would have told me that this baby was going to change my outlook on life, make me a better mother to his siblings, a better wife to his daddy and a better person to this world.

—Carmen, mom to Jaemen (3 years)

I wish I'd known how much having a child with a disability in my life would change the person that I am.

—Robert, dad to Hope (4 years)

I wish I'd known that I would say and feel so often, "You're so smart!" or "You are the cutest kid in the whole world!" I wish I'd known I would use words like "sparkling," "vivacious," and "infectious laughter" when describing my child. I underestimated her.

—Nancy, mom to Gabriella (3 years)

I wish I'd known that my daughter would be so able. To clean her own room. To charm grown men. To plant the garden with me. To play dress-up with other little girls. To read and write. To be a friend that cares and shares. She is so able.

—Jeni, mom to Joy Daisy (6 years)

I wish I'd known how very joyful and in love I would be every second of every day. When my son was born, I worried, can I do this? I cherished that worry because it meant his was a life worth worrying about. I'm glad I know now that I don't have to worry.

—Kitty, mom to Nathanael (2 years)

I wish I'd known what a wonderful teacher my older son would be. He is Owen's inspiration for everything—walking, talking, playing, climbing, eating, etc. Jason treats Owen like a kid, which is exactly what Owen is.

—Tricia, mom to Owen (2 years)

I wish I'd known life wouldn't be defined by the myths and misconceptions I had about Down syndrome, but instead, it would be as "normal" as normal gets, and my son would fill my life with love and joy beyond comprehension or measure.

—Sandy, mom to Lucas (19 months)

I wish I'd known that my son would develop a personality like any other child. I spent so much time wishing his babyhood away wanting to know what he was going to be like. I wish I had relaxed and enjoyed the sweet baby I had.

—Ann, mom to John (5 years)

I wish I'd known that this unexpected journey that began 4 years ago would not be one of sadness, but of unspeakable joy, filled with more love and pride than I ever thought possible.

—Shirley, grandmother to Aleena (4 years)

I wish I'd known . . .

Not everything I read would happen to my child.  
I would love her more than anything else on Earth.  
Her hugs and kisses are real, from her heart.  
She is just like any other kid.  
She would make me a better person.  
Her laughs are the best music.

—Jennifer, mom to Brook (2 years)

I wish I'd known that my baby wasn't going to die. We were left with so many unanswered questions and I thought for sure that it meant she would die within hours.

—Renee, mom to Kennedy (4 years)

I wish I'd known how incredibly in love I would be with my daughter, how much fun this whole process would be, and how amazing our friends really are.

—Francine, mom to Sofia (3 years)

I wish I'd known that my son would attend his local school, and would have lots of friends who just accept him and like him for who he is. I wish I'd known how happy and normal our family would be.

—Naomi, mom to Callum (5 years)

I wish I'd known . . .

That it was OK to feel broken-hearted when we first heard the news  
That having a child with Down syndrome is NOT a life sentence  
That my son would have his own agenda for doing things  
And that it's a privilege to be his mom.

—Sara, mom to Nathaniel (9 years)

I wish I'd known that, although they say our kids "stay little longer," they still grow up too fast.

—Meredith, mom to Brianna (2 years), Emma (5 years, adopted), and Micah (1 year, adopted)—yes, all three with Down syndrome!

I wish I'd known that my daughter would  
bring me only happiness, not pain.

—Destiny, mom to Lily (9 months)

I wish I had known that my son would have received two awards at the end of second grade: one for achievement in the Accelerated Reader program, and the other for being a "Number 1 Best Friend."

—Vicki, mom to Aaron (8 years)

I wish I'd known that children with Down syndrome are just as loveable, kissable, snotty, tantrum-throwing, bubble-blowing, huggable, and milestone-making as their siblings.

—Ava, mom to Daniel (3 ½ years)

I wish I'd known that I didn't have to be afraid, that it would all be just as it should be.

—Rhonda, mom to Alex (8 years)

I wish I'd known how deeply in love I would be with my son, and how I wouldn't know what to do without him and his diagnosis of Down syndrome.

—Vonda, mom to Noah (9 years)

I wish I'd known how much joy and happiness Olivia would bring, not only to me and my wife, but to everyone around her.

—Mike, dad to Olivia

I wish I'd known that she would survive two heart surgeries and continue to thrive despite leaks within her heart. Her tiny heart was once a great big hole, but it's full of a great big love that we get to experience each day.

—AJ, mom to Janna (3 years)

I wish I'd known he would be so full of life! He is intelligent, creative, a sports nut—just like his siblings. He's a social butterfly, a love bug, an amazing little boy. I wish I would've known he would be more like us than different.

—Jennifer, mom to Brady (3 years)

I wish I'd known . . .

That his sisters would love him so much

That he would have an awesome throwing arm

That he would have lots of friends

That he would read and love books

That he would do all the wonderful things little boys do.

—Anjie, mom to Adam (5 years)

I wish I'd known I would look at Avery and NOT see Down syndrome. I see her as this amazing, smart little cookie—strong-willed, self-reliant, and cute as a button. She walks around like a little queen in a parade, waving, hugging, and talking to everyone.

—Kathleen, mother to Avery (3 years)

I wish I'd known having identical twin boys both with Down syndrome would bless our family more than we could have ever thought. They work together, play together, and show us how to take life one day at a time, and enjoy every moment.

—Stacy, mom to Caleb and Isaac (2 years)

I wish I had known that she would get through her heart surgery, that she would crawl and walk and play just like any other kid, that she would be able to communicate so well, and that life would be so normal.

—Karyn, mom to Talitha (2 years)

I wish I'd known that it isn't that hard, and that my daughter isn't different from any other little girl her age. All my dreams for her can come true!

—Kelly, mom of Alexis (2 ½ years)

I wish I'd known how normal and silly moms of kids with Down syndrome really are! I thought they were all supermoms that were like angels in the flesh—now I know the truth!

—Cas, mom to Jirah (2 years)

I'm actually glad I didn't know much about Down syndrome when my son was born. I think if I had, it might have ruined those moments and that connection I had with my son the moment I saw him. I would have thought of the negative, not of the fact that I had a little boy who I loved and was perfect.

—Judah, dad to Jaemen (3 years)



I wish I'd known that it was ok to grieve and scream, cry, vent and be angry. I wish that a facility or network had been in place to reach out to me, instead of the other way around. I wish that every parent coming home today could see my girl and how she smiles and loves.

—Amy, mom to Larkin (2 ½ years)

I wish I'd known not to believe everything the doctors said my child would not achieve, such as breastfeeding. I wish I'd known the immense gratitude my son would bring to my life just by reaching up and touching my face. I wish I'd known that I would never feel shame for having a child with Down syndrome.

—Andrea, Mom to Alex (10 months)

I wish I'd known the new lesson on love that AJ would teach me would fill my heart in a way I wouldn't have thought possible. I wish I had known of all the positive changes I would see in my other children.

—Ibby, mother to AJ (2 years)

I wish I'd known I was strong. My husband and I always thought we were the people who couldn't handle raising a child with Down Syndrome. Actually, there's really nothing to "handle."

—Stephanie, mom to Megan (4 years)

I wish I'd known how very joyful and in love I would be every second of every day. When my son was born, I worried, can I do this? I cherished that worry because it meant his was a life worth worrying about. I'm glad I know now that I don't have to worry.

—Kitty, mom to Nathanael (2 years)

I wish I'd known the stands would erupt with cheers when she got a hit in baseball, and that her classmates would circle around her with love and protection if anyone was mean to her. I wish I'd known that "being slow" would mean savoring every step, every puddle, every blossom.

—Michelle, mom to Ciarra (9 years)

I wish I'd known that children with Down syndrome are NOT happy all the time. Darah throws temper tantrums and needs time-outs just like every other three-year-old. I wish I'd known that when Darah was first born, she was MY baby. When she was in the NICU, I felt like the hospital owned her and was afraid to speak up with my concerns and questions.

—McKenna, mom to Darah (3 years)

I wish that I had known that my broken heart would one day heal, and the love that I felt for my son was the cure.

—Kristy, Mommy to Zachary John (3 years)

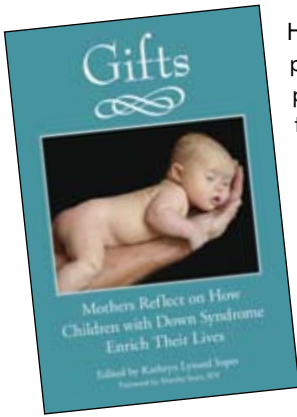
I wished I'd known we were going to be okay, that this one little chromosome was just a tiny piece of our lives. I wish I'd known that the dreams I had of the little girl with long dark hair were still going to come true! That while she may beg for a green Mohawk at times, she's still that little girl in my dreams.

—Leah, mom to Angela (12 years)

I wish I'd known that this would be such a marvelous journey, and that everything would turn out . . . JUST FINE.

—Jackie, mom to Emily (28 years)

Quotes gathered from members of three online forums for parents of children with Down syndrome: Downsyn ([www.downsyn.com](http://www.downsyn.com)), Uno Mas! ([unomas21.com](http://unomas21.com)), and T21 Online Community ([www.t21online.com](http://www.t21online.com)). For more insights about parenting a child with Down syndrome, visit the blog sampler at [www.giftsds.segullah.org](http://www.giftsds.segullah.org). Thanks to all the parents who shared their insights and photos in this booklet, to Woodbine House for the beautiful layout, and to the owners and administrators of the online forums which bring parents of children with Down syndrome together.



Having a baby with Down syndrome is not something most parents would willingly choose. Yet many who travel this path discover rich, unexpected rewards along the way. In this candid and poignant collection of personal stories, sixty-three mothers describe the gifts of respect, strength, delight, perspective, and love, which their child with Down syndrome has brought into their lives.

The contributors to this collection have diverse personalities and perspectives, and draw from a wide spectrum of ethnicity, world views, and religious beliefs. Some are parenting within a traditional family structure; some are not. Some never considered terminating their pregnancy; some struggled with the decision. Some were calm at the

time of diagnosis; some were traumatized. Some write about their pregnancy and the months after giving birth; some reflect on years of experience with their child.

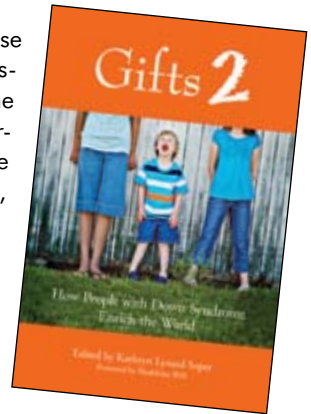
Their diverse experiences point to a common truth: The life of a child with Down syndrome is something to celebrate. These women have something to say—not just to other mothers but to all of us.



Acceptance, courage, friendship, awareness, and joy—these are the gifts recounted in more than seventy inspirational essays included in **Gifts 2**. Edited by Kathryn Lynard Soper, the follow-up to the bestselling **Gifts** presents a broader perspective on Down syndrome and life by including passionate stories by siblings, grandparents, cousins, aunts and uncles, as well as mothers of older children. Friends, teachers, medical professionals, and coaches also share the joys of knowing and caring for someone with Down syndrome.

Like the previous book, **Gifts 2** helps us see that the hopes and dreams family and friends have for a child with Down syndrome are similar to the ones we have for any child. And, more often than not, expectations are fulfilled—if not always the way we anticipated they would be. A grandparent, inspired by his grandson's strong will, discovers the ability to persevere and not give up on a job. A brother who assumed he would be the person helping his sibling with Down syndrome describes how often it is the other way around. A young teacher remembers her first student with Down syndrome and it gives her strength and clarity when she is faced with her own child's diagnosis.

This heartfelt collection is a source of comfort to other families, and offers insight to anyone who wonders how people with Down syndrome live today. Give the ultimate gift, share both volumes with family and friends, your child's teacher or pediatrician—help raise public awareness and provide others a point-of-view they might otherwise miss.



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