

# She Taught Me Love Without Words: Growing Up Alongside a Sibling with Disabilities

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My sister and I are different flowers from the same garden. Together, we've grown to make a beautiful bouquet that represents our unique sisterhood impacted by disabilities. I want to describe the bond my sister and I share as well as the experience growing up alongside a sibling with disabilities. This narrative is intended to better understand the feelings commonly experienced by the sibling without disabilities.

## The Backstory of My Sibling and I's Relationship

I was two years old when my sister, Celeste, was born. To my family's surprise, Celeste was born with an orthopedic condition that resulted in multiple joint contractures. Though I cannot remember these moments from my early childhood, my parents relayed the mixed feelings they experienced, including shock, joy, worry, hope, and numbness. All I knew was "I'm going to have a little sister" and that's all that mattered to me. My mother jokes that I tried to be helpful from the moment I met Celeste because I attempted to feed her a banana at a few days old. From that point forward, I proudly proclaimed the title of "Celeste's sister."

As months and years passed, it became clear that Celeste may never communicate through spoken words or develop the cognitive and motor skills to live life independently. Celeste received occupational (OT), physical (PT), and speech therapy (ST) services her entire childhood. As her sister, I often accompanied

her to appointments and sometimes her therapists would let me play with Celeste during sessions. I was fortunate to witness the progression Celeste made in her therapy goals and see how it impacted her life at home and in the community. Therapy taught Celeste how to feed herself with utensils, propel her hot pink wheelchair with light-up casters, and use an augmentative and alternative communication (AAC) device, among other useful skills. With practice and patience, Celeste learned to independently navigate her environment, eat meals, and communicate her preferences. Although Celeste continues to need assistance in all other areas of self-care; including transfers to and from her wheelchair, toileting, dressing, bathing, and grooming; my family and I are grateful for all that she *can* do.



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Reflecting on my childhood and adolescence, my favorite memories involve spending time with Celeste within the community. My family and I were strong advocates for the inclusion of individuals with disabilities and often spent time with local organizations that offered a welcoming environment for Celeste.



Celeste enjoyed playing soccer, basketball, and softball with a local inclusive sports team for individuals with disabilities. I would attend many games to propel Celeste across the field or court with the team to score points or cheer her on from the sidelines.

As Girl Scouts, Celeste and I enjoyed volunteering, camping, as well as selling (and eating) cookies together.

When I was 14 years old, Celeste and I joined Ainsely's Angels of America, an empowering organization that offers opportunities to celebrate inclusion and unity through community races. Using a specialized racing wheelchair, I pushed my sister over 100 miles and across at least 30 finish lines. Every stride is an opportunity to see each other's life through the other's shoes.

Celeste spent many summers at the Louisiana Lions Camp, an organization that provides a summer camp experience to children with cognitive and physical disabilities as well as diabetes. Wanting to join the fun, I became a camp counselor. Celeste and I spent a week together away from home and enjoyed activities such as swimming, archery, fishing, paddle boating, as well as arts and crafts. In addition to the memories I made with my sister, I also learned the importance of accessibility, inclusion, and enthusiasm through "LC Love" as well as met lifelong friends and my husband-to-be.

## Common Feelings Growing Up Alongside a Sibling with Disabilities

Growing up as a sibling to someone with disabilities led me to experience a vast range of feelings. I reminisce about my happy childhood and recall many wonderful memories spent with my sister, Celeste. However, there were moments when I was conscious of the reality of having a sibling who is dependent on others for living, especially as I grew older. I often harbored my feelings and masked negative emotions, not wanting to display the full truth of how I felt about Celeste. With age, I realized the importance and need to process these feelings to enhance my overall mental and emotional well-being. To encapsulate these feelings, the following section depicts how I felt growing up alongside a sibling with disabilities.

### Hopeful "*Maybe tomorrow she can.*"

As a child, each day was filled with hope that Celeste would make progress toward being more independent. As a family, we celebrated each milestone Celeste achieved and hoped she would continue building her motor, cognitive, and language skills. I often prayed that Celeste would miraculously wake up and be able to talk, run, and play alongside me. I dreamed of standing beside Celeste on her wedding day and being an aunt to her children. I live with the hope that my little sister is living a happy life. As an adult, my hopes for Celeste

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have changed. I now hope she lives a long and healthy life that is free of suffering, I hope that she shares her belly laughs with my future children, and I hope that I will always be around to take care of her...

**Responsible** *"I know what to do, I'll help."*

Growing up, I would know exactly what Celeste needed to be taken care of properly. I was able to decipher Celeste's vocalizations and body language to understand how she was feeling and problem-solve to find a solution to address her needs. I proudly took on the role of "a helper" in my family and was often described as "mature for my age" by other adults. I often saw how tired my parents were from taking care of Celeste and tried to relieve them of their stress by helping with Celeste's morning or bedtime routines, preparation of meals, and times of wakefulness during the night. My parents and I didn't realize it at the time, but assuming this significant role led me to experience fatigue and affected my ability to set boundaries for myself.

**Independent** *"I don't want my parents to have to worry about me."*

Celeste's dependent nature led me to crave independence for the sake of not burdening my parents with additional worries. As a child, my outstanding behavior and achievements were influenced by my perceived need to fill a gap in my parents' lives. However, when I needed help, I hesitated to tell my family and tried to handle my problems on my own. I felt like my needs were not as important as Celeste's needs and, therefore, didn't deserve attention. As an adult, I realize this couldn't be further from the truth.

**Jealous** *"Why does she get so much more attention?"*

As a young child, it was hard to understand why I was not afforded the same amount of attention as my sister. I believed it was unfair that Celeste's caretaking required most of my parents' time and attention. There were times I wished I could spend time with my parents, together or individually, without my sister.

**Embarrassed** *"Why is everyone staring?"*

I sometimes felt embarrassed in public settings when Celeste made loud or repetitive noises or when she rocked in her wheelchair. I wanted her to act "normal," which was an unfair and unrealistic standard, to try and fit in with peers. It was common for people in public to stare at Celeste or our family, which felt uncomfortable. I was afraid of Celeste being judged for her differences and became incredibly defensive against people who would mock her.

**Guilty** *"I feel bad for getting mad because it's not her fault."*

It's typical for siblings to have arguments and get into fights. However, I often felt guilty for being frustrated with Celeste. I would feel frustrated when Celeste's vocalizations were loud and repetitive, when she would run into my legs with her wheelchair, or when she would pull my hair, which was often actions she could not necessarily control. This led me to feel guilty because Celeste could not defend herself against me.

**Fearful** *"What's the future going to look like?"*

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As I grew older, the more I realized how much uncertainty lies within the future. Anxiety festered within me as my mind went down a rabbit hole of thoughts wondering what would happen when my parents were no longer here or able to take care of Celeste. It scared me to imagine that one day I would be solely responsible for the caretaking of my sister. Beginning as a teenager, I found it stressful to consider how my life and future family would be affected by being Celeste's primary caretaker. Through conversations with my parents about plans for Celeste's care, these fears are alleviated, but still not completely resolved simply because it's difficult to predict what the future is going to look like years from now.

## **Joyful** *"You are my best friend."*

I felt genuine joy being Celeste's big sister. A fun memory I cherish is placing Celeste on top of a blanket on the floor and sliding her around the living room. I loved seeing Celeste smile and hearing her giggles radiate throughout our childhood.

## **Loving** *"I love you for who you are."*

Celeste and I share an unconditional love. Without saying a single word, Celeste taught me love in its most genuine form. Through this love, I learned to accept other's differences as well as be empathetic and kind to all.



## **Who I am today**

I sincerely believe my experience being Celeste's sister molded me into the person I am today. Celeste motivates me to be courageous and pursue my dreams. I am about to graduate with my doctorate in occupational therapy and become a clinician in a profession I've aspired to be in since I was nine years old. I am inspired by Celeste to be a lifelong learner and an advocate for individuals with disabilities. Celeste has taught me invaluable lessons about humanity and myself. I wonder, who would I be without Celeste? I've come to peace with never knowing this answer because of how great life is because of her.

This is my unique experience growing up alongside a sibling with disabilities. Other siblings of those with disabilities may share many of these common feelings in their own lives. To conclude this narrative, I want to emphasize the importance of addressing the many feelings that accompany experience. I encourage siblings of those with disabilities as well as parents raising both children with and without disabilities to seek resources to process their feelings. The strongest gardens are those that are well tended to and watered with love.

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