

We Used to Dance

Loving Judy, My Disabled Twin

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Prologue

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The more time I spend on this earth, the more I see the impossibility of going through life without experiencing some sort of life-altering event—be it the death of a loved one, the diagnosis of serious illness, or a tragic accident. For my parents, it was the birth of their daughters.

We had spent nearly nine months together, my sister and I, cramped within that small space. And when the time finally arrived for us to enter the world, after positioning ourselves for our arrival, she dropped down in front of me and emerged feet-first, the cord wrapped around her tiny neck. That only added insult to the already existing injury; there was evidence that her cord had not been healthy, and she may have been deprived of oxygen even before that moment. Whisked away to intensive care and remaining there even after I was taken home, it wasn't clear if she would live to join me and our two brothers. But she did survive and, once she had stabilized, the doctors sent her home, knowing there was damage but unsure of the extent. Only time would reveal the answer to that question. And time, as it turned out, was not our friend.

We used to dance, my sister and I. There we'd go, swirling around the room, both of us laughing with glee. Of course, we were younger then; she, more relaxed and I, more able to hold her in my arms. Oh, how we dipped and glided, so comfortable was she in my arms. Those were happy days when we used to dance.

Introduction

Judy

My earliest memory is from when I was about two years old. I am cheerfully saying good night to my sister, standing at the head of my crib peering out over the top. Judy is lying on her stomach looking up at me from her own crib. Our cribs are perpendicular to each other, with a small night table between. Is it then or in later years that Raggedy Ann and Avis sit silently watching? Ann, which was not only the given name of the doll but also, coincidentally, my middle name, is my doll; Avis, Judy's middle name, is hers. Judy laughs as I say good night. In a few minutes, my father will sit in a chair between our beds and sing us lullabies. It is really for Judy, who does not fall asleep as easily as I, but I, of course, also reap the benefits. In later years, my father managed to slowly remove himself from this nightly task, first shifting his seat to the other side of the room near the door, then just outside the room, then down the long hallway in our apartment, until finally he was relieved of his duty. For many years, though, I benefited from my sister's need to have him nearby.

Another looming memory is not of an event or circumstance but of a photograph. We are younger than in my true memory—only about a year old or so. As in the true memory, I am standing, and Judy is lying on her stomach, looking up. We are in our playpen, both smiling happily at the camera. When I discovered the photo years later, though, it did not bring a smile to my face but rather a sadness that this is how it was and how it would always be: me, able and ready to meet the world; Judy, forever bound by her disability.

It took nine months until Judy was officially diagnosed with cerebral palsy (CP), which Merriam-Webster defines as “a disability resulting from damage to the brain before, during, or shortly after birth and outwardly manifested by muscular incoordination and speech disturbances.” As Judy made her way from infancy to toddlerhood, it became apparent that she was going to have physical limitations, but in the beginning it was unclear how severe those limitations would be. At that time, infants were often placed on their stomachs, and it was from there that we learned how to roll over. Judy began lifting herself up with her hands before I did, and that was seen as a good sign. However, as it turned out, it was due to her muscle rigidity and did not indicate an ability to control her body. Long into our childhood, we played a game in which Judy would lie on her bed and lift herself up and up and up on her hands, until, ultimately, she tipped over. Depending on how she landed, she might pull her arm out from under her and be back on her stomach (and repeat the process), or she may have tipped over too far and now be in jeopardy of falling off her bed. That would cause her to laugh aloud, and someone would come running to her room to save her as she dangled precariously above the floor. But Judy always thought it was so funny!

Judy never had control of her hands or leg muscles, and, when she was young, she had limited control of one of her arms. When attempting to move the arm forward, she would first pull it back before extending it forward, although she was never able to extend it very far. Over the years, her increasing spasticity prevented even that. Never fully able to hold her head up on her own, she eventually needed one and then two head supports added to her wheelchair, and, for a while, she was able to move her head from side to side with that support.

Though she was severely disabled, Judy was able to do many things. She could breathe on her own. She could laugh, and she could cry. She was considered cognitively impaired, but she understood a lot of what went on around her. When she was ten months old, she ran a high

fever and was hospitalized for about ten days. The cause of the fever was never found, but when it finally subsided, she was sent home. For years afterward, whenever we happened to pass by that hospital, Judy, looking out the car window, would start to cry. She clearly remembered it was a place she didn't like. In addition to her phenomenal memory, Judy understood when people spoke to her and responded through particular mouth motions: an opening and lowering of the jaw was "yes"; a sidelong grimace meant "no." She laughed when someone said something that amused her and made guttural noises indicating that she disagreed if she didn't like what you were saying or was unhappy about her routine being disrupted. Judy enjoyed listening to rock and roll music on the radio and to songs from Broadway shows on tape. Her favorite tapes were ones our family made for her, detailing a trip we had taken or a family story.

Her daily routine also included watching TV sitcoms and family dramas. She would scream when anyone yelled on *I Love Lucy* and cry when Lassie was lost, but she wouldn't miss an episode.

Every year, once a year, the Cerebral Palsy Telethon was on TV. We watched together from morning till night, with host Dennis James. Even after we grew older, and I no longer lived at home, Judy continued to watch. We also watched the Jerry Lewis Muscular Dystrophy Telethon—which, to my great frustration, always collected so much more money—but the CP telethon was by far our favorite. I don't know what she loved about it, but for me, for a long time, it signified hope. I watched as they brought out the children, and I ached—with joy for the child and with longing for Judy and me—when one of the children would throw away her crutches and walk, some, they said, for the very first time. And the special telethon song would be sung . . .

Look at us, we're walking.

Look at us, we're talking.

We who never walked or talked before.

*Look at us, we're laughing.
 We're happy and we're laughing.
 Thank you from our hearts, forever more.*

*But there are so many other children,
 Who only speak with a silent prayer.
 For those who haven't been so lucky,
 We hope and pray you will always care.*

*And someday they'll be walking.
 Someday they'll be talking.
 Imagine walking to the candy store.*

*But the fight has just begun.
 Get behind us, everyone.
 Your dollars make our dreams come true.
 Thanks to you, thanks to you.*

I knew that Judy was one of those *other children*, and I would sit and dream about us walking together to the candy store. For years, I imagined the two of us laughing as we headed down the street to Featherbed Lane to buy some candy. And I prayed. I prayed and I prayed and I prayed.

Sadly, there was no walking and no candy in Judy's future. Judy was never able to even *use* crutches, never mind throw them away. She also wasn't able to chew. She *tongued* the soft foods that my mother or grandmother—or I—fed her. She was able to swallow soft or pureed food, but even that often ended in bouts of coughing, with food spraying everywhere, much of it landing on the bib she always had to wear (to catch her drool as well as her food). Growing up, we had a parakeet we named Pee Wee. Pee Wee was the happy recipient of Judy's inability to keep food in her mouth until it was swallowed. He loved to fly around the kitchen, his favorite landing spot being Judy's bib. Pee Wee would alight onto Judy's shoulder or head and then walk down onto

her bib, strolling up and down, pecking at the food bits that had fallen there. Judy loved Pee Wee and would laugh every time he visited her, clearly enjoying his foraging attempts.