

A true account of growing up with Cerebral Palsy.

The Unlikely Ballerina: A Daring Adventure with Cerebral Palsy

by Denise Lance

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DENISE LANCE

The Unlikely



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Denise Lance

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ISBN: 978-1-63491-876-3

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Published by BookLocker.com, Inc., St. Petersburg, Florida.

Printed on acid-free paper.

Booklocker.com, Inc. 2017

First Edition

Dedication

In loving memory of my parents.

Calvin L. Lance (1924-2003) and Dorothy Jean Lance (1930-2005)

This story is just as much theirs as it is mine.

I wish more than ever that these two mentors and friends were here to read this book. I miss your wisdom and guidance every day:

> Dr. Ann Marie Shannon and Dr. Myra C. Unger

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Chapter 1: Take Her Home and Love Her

I crossed the stage at the Leid Center at the University of Kansas, shook hands with the Chair of the Department of Special Education, and then turned around facing the audience to be "hooded." Dr. Tom Skrtic draped a heavy sash of bright blue and crimson velvet and black satin around my neck, pulled tightly in front and cascading down my back like a backward scarf.

I searched the audience for Mom, Dad, Sister, and best friend Heidi, giving them a huge smile. Just then, Mom leaned to Sister and whispered, tearyeyed, "And all we ever wanted was for her to be able to hold her head up."

I held my head high the day I became "Dr. Lance." It was the culmination of seven years of hard work and achievement of a dream, my dream. Thirty years earlier, my parents' dreams for me were much simpler than earning a Ph.D.

I was an unexpected addition to my family. My parents thought that they could not have more children because my Dad had the mumps and they went "down there," so his doctor considered it a natural vasectomy. My sister was 17 and not really thrilled to have a pregnant mother chaperone her senior year activities. My brother was 15 and bit more enthused, planning fishing trips and baseball lessons with his new baby brother. He later told Mom that he loved me anyway despite my being a girl. My parents were surprised but had considered having more children before the mumps, so they just settled into the idea. My mother was 38, and my father 43.

My mother thought she had the flu initially and was sick those first few months. Nothing differed from her previous two pregnancies. At eight months, she could not see her toes for the baby bulge jutting out from her thin frame.

On October 29, 1968, she had a doctor's appointment at which everything seemed fine. Though he thought she had several more days to go, but later that day, she went into labor.

As I was about to be born the next morning, the doctor discovered that I was in breach position—feet first, and the doctor used forceps to turn me around head first. Back then, the technology used to monitor fetal status was not available.

When I was born, the umbilical cord was wrapped around my neck and tied in knots, cutting off the oxygen. It was not clear whether the tangled cord resulted before, as I moved in the womb, when I was turned, or if some combination led to the result. I was not breathing, and the nurses had to blow air into my lungs through an intubation tube. My mother estimated that I was without oxygen for several minutes, but I have no specific details.

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In the days following, the doctors suggested that brain damage may have occurred, but that the extent was not determinable yet. I asked Mom many times over the years how she and Dad felt at this point, facing the possibility of raising a child with a disability. "Were you scared, angry, or what?"

She said they were afraid that I would die, but that the long-term implications did not occur to them. "You were our baby, and we knew we would do whatever we had to do for you," she explained.

The doctor and nurses came in and told Dad that Mom could go home, but that they wanted me to stay a few days for observation.

"You might as well keep both of them. Jean won't leave that baby," he told them. He was right. They may have left me physically two years apart on May 23, 2003 and May 27, 2005, but neither Mom nor Dad has really left me.

Wichita was the nearest large city to the small town of Neodesha. My parents took me to several doctors there, looking for an assessment of my condition and prognoses. The diagnosis was cerebral palsy, but my parents did not know what that meant. Most of the doctors were less than encouraging, emphasizing all the things I would never do: "She'll never walk." "She'll never talk."

One of these so-called experts, ironically named Dr. Lance, said, "She's too alert to be retarded. Her

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eyes are too bright." My parents' opinion of my ability matched that of this lone dissenter. They shrugged off the others' expert opinions.

As for how they should help me with my obviously delayed motor skills and other developmental delays, none had any suggestions. Most advised my parents to put me in an institution and forget me. One was a bit less harsh: "Take her home and love her because that's all you'll get to do."

Mom and dad opted to take me home and love me, alright. But placing limitations on what I could do never entered their minds. Having raised two children already, they decided to just do as they had done with Sister and Bub, adapting for what I couldn't do as needed.

I did not crawl as an infant because my legs were trapped in braces that did not allow me to bend. Instead, I rolled where I wanted to go. I also had a regular infant's walker (The kind they outlaw now for notoriously tipping over.) in which I scooted around the house.

When I was nine months old, Dad had to go to Texas for six months to work at another refinery. One night on his way home to our temporary apartment, he bought me a tiny wooden rocking chair. After dinner, he sat me in the rocker, and I sat for several minutes rocking and smiling. Dad was bent on one knee about two feet way, taking pictures, "Kodak Dad" in action. Suddenly, I stood up out of the chair, stood on my own for a minute, took

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three wobbly steps and fell into Dad's arms. Dad could not sleep that night. "She's gonna walk. I just know it!" He told Mom. The next day, he put me in the rocker again, stepped back, and waited. Nothing. I rocked and rocked, but never attempted to stand or take a step. I think he gave up trying after a few weeks. He was right. I would walk, but it was six years later.



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