THE OTHER MOTHERS

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Hi. My name is Debbi. My husband and I are the parents of three boys. Our youngest was born at 31.8 weeks. He had a Grade IV intraventricular and subdural brain hemorrhage at birth. Josh has multiple disabilities and complex medical needs.

I hear myself repeating this unlikely mantra for the hundredth time, and it comes as easily as though I were selling makeup or leggings or cookware. It is early morning, but the room is dark for its lack of windows. Dozens of employees slump into hard conference room chairs, clutching Styrofoam cups of hot coffee, hoping the session will end sooner rather than later. The room is warm and sticky, and the faces staring back at our small panel of parents are blank, bored, or sleep-deprived.

The event seeks to enliven the mission, a human resources innovation facilitated by a local hospital. New hires—doctors, clerks, housekeeping staff, and everyone in between—are introduced to the institution's mission and vision through the experiences of real live families. A well-versed facilitator launches a PowerPoint presentation extolling the virtues of family-centered care. From our perch behind the folding table, we three parents shift in our seats, scanning the crowd for signs of life.

We are the families of frequent flyers. Our children have been admitted to the hospital so often that, once stabilized, the rest of the stay becomes an odd sort of social event. We greet primary nurses like family and enjoy warm exchanges with our favorite medical assistants and support staff.

My name is Debbi, and I am a trach mom… I practice various opening lines in my head, searching for a new angle, a lead-in that might perk up this weary crowd.

Families are the experts, the constants in the child's life… The facilitator is listing the principles of family-centered care. We parents sit up straighter in our seats with each point, like star athletes. Some of the audience members drift further away, in a collective slump. It's awfully early for a lecture.

Hello there! I'm Debbi and I am so happy to be here today!

I continue the silent rehearsal of my introduction. This audience needs a jolt, a parent with lots of charisma, full of energy.

Not me. I'm too tired.

In the chaos that has become typical of our lives, I have spent much of the past two days at my husband's bedside, first in the ED, and then the critical care unit of the adjoining adult hospital. Our roller coaster never stops. A sick boy, and now an ailing husband…

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"Deb, something's wrong." Victor had awakened me late in the night, a couple of days before. His eyes reflected an eerie sheen, and his forehead was slick with sweat. I had never seen him so afraid. *Heart? Blood pressure? Glucose?* A career Marine, Victor is in superb physical condition for his age, but the effects of exposure to Agent Orange in Viet Nam continue to deliver worrisome health concerns.

"We're going to Emergency," I said. I had learned with Josh's many visits that I was treated more respectfully, taken more seriously, if I dressed professionally, slapped on some lipstick, and combed my hair. I repeated the routine, begged Josh's night shift nurse to keep an eye on the other two boys until I returned and led Victor to the car.

Hi, my name is Debbi! My husband and I are the parents of three boys. Well, my husband is in critical care right now, and I don't know what's wrong with him. Two nights ago, I sat worried and freezing by his bedside in Emergency in a stupid denim skirt—with lipstick on—as the staff administered test after test. I knew as soon as the nurse placed an IV with a Heparin lock that we weren't going home. I really hoped the daytime nurse would show up for my son at home. What day is this?

My imagined introduction is shaping up poorly. The man facing me in the front of the audience supports his head precariously on one arm. He holds his mouth in a boorish smirk, and both legs are spread carelessly into the aisle. Eyes half-shut, he makes no pretense of his desire to go to sleep. The facilitator's voice has devolved into a monotonous buzz as she moves mechanically from one PowerPoint slide to the next.

Hi, I'm Debbi, and I think the parent panel is doomed.

The first parent is finally introduced. The poor lighting in the room casts a gloomy half-shadow over his face, and the employees shift restlessly in their seats. The anxious father speaks enthusiastically about his child's medical journey, but the heavy mood does not lift. I think the crowd might just want us to die, so they can go to lunch.

Hi! My name is Debbi and I so happy to be here! My husband is upstairs in critical care, and our youngest boy—we have three sons, you know—is next door in the pediatric intensive care unit.

I don't know why I'm here, except that I promised the facilitator when she asked me some weeks before, during the rare twenty minutes that life was calm. Several hours after my husband was transferred to critical care—stable, but still awaiting diagnosis—we were discussing what to do with our two older boys during this emergency when my cell phone rang.

“Josh doesn’t seem right.” It was the new home care nurse. “His trach secretions are copious and thick. He’s febrile, and he can’t stop coughing.”

The new nurse is young and doesn’t know Josh yet, but I trust her assessment. It is viral season, and children with complex respiratory histories and exposed airways are at highest risk for illness. A call to the pulmonologist determines the course of our next few days. I am to return home immediately to pick up Josh and deliver him to the PICU as a direct admission. I arrange for an older church lady who lives nearby to care for our other boys. While home, I grab medication lists, back-up tracheostomy tubes, lullaby tapes, clothes, a curling iron, and a toothbrush. I spend days running the long hallways that connect the two hospitals to make certain that my husband and child receive proper assessment, reasonable diagnoses, and adequate treatment. I am exhausted.

“Hi, I’m Debbi. My husband and I have three boys. The youngest has Muscular Dystrophy—”

They have introduced me and I am caught off guard. I have heard myself repeat this practiced introduction countless times—for conferences, panel discussions, committee meetings—and Joshua’s medical history and assorted diagnoses usually roll off the tip of my tongue. But I think I hear myself say Muscular Dystrophy, and that’s not on the list.

“Oh, wait! Did I say that our youngest has Muscular Dystrophy? No, he doesn’t!” I throw my head back and let out a hearty laugh. The audience remains quiet, uncomfortable. I muffle my roar to a soft giggle, and explain.

“I don’t mean to make light of anything, but I am just so tired. My husband is very sick, upstairs in the Critical Care Unit, and my toddler, who has complex medical needs and multiple disabilities, is next door, in the PICU. I have been living in the hospital for days, and I’ve come here to you from the adult hospital upstairs. Two of our boys have been in the NICU, so we know everyone there. And our oldest has had Scarlet Fever, meningeal encephalitis, and a strange immune deficiency reaction. The cashier in the cafeteria keeps giving me the employee discount, no matter how often I tell her that I don’t work here. I can barely remember where I have left our other two boys, and talking so much about this frantic, ridiculous, joyful life has done nothing to make it normal to other people.”

But we’re alive and together, and that’s everything.

Much of the audience comes alive then, likely thankful for a bit of levity and appreciative of the candor. The stretched out, sleeping man remains unresponsive, but I decide it doesn’t matter. I let the employees know how important their roles are to families like mine, and the facilitator introduces the next speaker, a striking, curly-haired blonde who reminds me of Barbie.

I catch significant parts of her extraordinary story between the animated sighs and gasps of the now lively group of employees.

“Hi, my name is….My husband and I have six children…

Six children? How does she do it and still manage to look absolutely marvelous!

“One of our children has a major heart defect and has had countless surgeries. The other has a neuroblastoma.”

No!

“The doctors could do nothing about the tumor, so we decided to treat our child through an extremely disciplined diet. Both are doing very well.”

I should have stayed upstairs.

“Everyone here knows us. One day, I was coming down the hill from the parking lot, and the baby threw up on me. In shock, I accidentally let go of the stroller, and the other kid began to roll down the hill!”

The impeccably dressed mother laughs and the audience roars.

“But two nurses rescued the stroller, grabbed the vomiting baby, took me inside, cleaned me up, and wiped my tears away. This is such a wonderful place!”

Hi, I’m Debbi and my son has a trach and a feeding tube, and a wheelchair, and an oxygen concentrator, and an oximeter, and a feeding pump, and a ventilator, an occasional PICC line, and a cough assist machine, and…

We are all considered the *uber* parents. We devote ourselves to our children and their seemingly impossible medical conditions and demonstrate our gratitude for their lives by volunteering every spare moment to the hospital that saved them. We want to nurture understanding—if that will help heal them, or simply ease their pain and ours—and inject the hearts of anyone who will listen with a bit of empathy, understanding of our realities, and compassion.

Hi, my name is Debbi. My husband and I have three boys…

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Early on, I resolved to make this new, unanticipated life worth living, to normalize this roller-coaster world for my precious family, and to tell our story the only way I knew how. The sacrifices have assured that money is in short supply. Vacations are few—and those we do set about require the organizational skills of a career Marine, three months of strategic planning, and the additional financial expense to carry along two home care nurses. I find myself peering into the mirror from time to time, wondering how the thin skin around my eyes has become so dark, forgetting the exhaustion of too many open nursing shifts, almost three cumulative years of my husband's active-duty deployment as the boys entered their teenage years, and the profound sadness of a difficult diagnosis of a beloved parent and becoming part of the sandwiched generation of caregivers. Friends easily fall by the wayside, unable to keep pace with what they see as a life defined by despair, and unprepared to celebrate the new, minuscule things we've chosen to define our joy. But I find that faith and hope often emerge in a stronger way when at first pressed down by adversity. I learned that from my mother.

I see my mother now only in my dreams. This time, we sit together in a large stadium. My weary head rests on her shoulder. The silkiness of her black hair brushes against my forehead, and I feel safe. We pay little mind to the grand antics taking place on the wide field far below us. The participants there are like dolls, or puppets, their performance of little consequence to us here.

"Would you like to stand, Mama?" I ask. "I don't mind standing, if you'd like." My mother is grand, elegant, and profoundly articulate. In this moment, she is funny.

"Oh, no," she replies. "Where I am now, we stand all of the time. Part of that whole dominion thing." I snuggle in and we talk. I tell her about my life. The boys. I don't tell her about Papa, how sad he is, and how his deep well of grief leaves no room for ours.

A song I love says that heaven is real, life is a dream, and I am caught somewhere in between. The day after my mother died, I felt the soreness of a thick dagger, straight through, from the front of my heart to the back. I could not move without the heaviness and sharpness of the imaginary blade announcing its presence. My spirit wept unceasingly, and the sorrow took my breath away. I wanted to find her, this woman who had given so much of herself to me, to assure her happiness and well-being in this new realm, an unknown world just a heartbeat away, but still so far from my mine.

But my mother is eternally and immutably mindful, even in death. She enters my life in profound ways, other than my dreams, through sweet, caressing messages left in the books, cards, and notes she so carefully scripted while she still could, her beautiful handwriting stretched across each page like priceless works of art. Mama was my cheerleader, a nurturer, the Great Encourager. She believed in me and in my writing. She quietly knew it would make my life, save my life.

"We kept everything you wrote," she told me once, her voice soft and full. "When you were little, we were so amazed with what you could create at such a young age."

Sometimes I am drowning in my fishbowl. I am crushed by the tenuous nature of my life, and I cannot breathe. Creativity becomes an elusive foe, and I cannot write. I begin to clear the *cluttered physical spaces of added responsibilities—substitute matriarch, hostess, and facilitator—to make a place for a writing life among the busyness of my motherless world.*

I straighten stacks of old books, sort through tangled strands of jewelry, and fold brightly colored summer dresses into a cardboard box to make way for the coldness of winter, and room to hone my craft. I think about Mama, and what she might say to me now, how she would smile, her dark brown eyes twinkling at sight of Josh's progress. He's twenty-one, Mama. Imagine that! He cried out when you left us, against the physics of his tiny tracheotomy tube, he called for you as your spirit flew.

My hands run across an old calendar: Baby's First Year: Your Guide to a Happy and Healthy First Year with Baby*. I remember how sad I was so many years before as I set aside the dubious gift, devastated that the richly colored stickers to mark typical milestones would likely never be used. Two decades years later, I pull it closer, examine its pages. I smile now at the parenting* tips—finger foods, stranger anxiety, ear infections*—and warm at the sight of fading scribbles on the cover, love notes from the family, welcoming its tiny new member whose head swells with an abundance of fluid, and whose skin hangs from malleable, barely formed bones, like crinkled parchment paper.*

Mama has facilitated the intervention against a life of pity and despair. She has set the tone for inclusion of this strange, fragile person. Her note hangs prettily in the upper left corner of the otherwise unmarked calendar, surrounded by autographs from siblings and cousins who had just learned how to write, and others who followed her lead, etching polite introductions, hopes, and blessings.

I read Mama's note and weep tears of gratitude for yet another prophetic gift:

1/11/93

Hi Joshua,

You won't remember our conversation, but you and I had a long talk with God and each other. You're going to be a real blessing to our family. We love you very much.
Oma

Fresh with the renewal brought by the deluge of tears, the gift of this unexpected emotional release, I take my place in the corner of my newly organized, lovingly dedicated creative space, and begin to write.

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I'm Debbi and I'm a trach mom. This is my whole life. Is it enough?

The new employees are all ears now. They are captivated by the courage and vigor of the other mother. I watch her grace, and strength, contemplating my own frailties, and I am ashamed at the need for comparison. We are a rare element, a unique category of families, and we share the same kind of pain. But the stress of our lives often makes that too easy to forget, and the isolation leaves us hungry for attention—and validation.

The presentation comes to a natural pause as the other mother bends delicately and searches for something in her tote bag. The audience hesitates, their anticipation is palpable. They are fully invested.

What more could there be?

The other mother emerges from her search with a kittenish smile and a glossy covered paperback.

“If you’d like to know more about my life,” she says at once proudly yet humbly, “you can purchase the book I’ve written at any local bookstore.”

At the end of the other mother’s presentation, the crowd gathers around her, eager to greet such an extraordinary woman. I take a few steps back to give her more room. A copy of the book lays on the table, its shiny back cover glimmering under the subdued lights. A photo of the happy family shows eight smiling faces amid a yard of perfectly manicured greenery. They wear matching outfits.

Hi, I’m Debbi and I’m a trach mom. I contemplate the soothing sound of familiar words, grab my shabby mismatched purse and head upstairs, first to critical care, then to the PICU. Feeling just as blessed as every other mother.

Halfway between heaven, and the uncertainty of earth,
A child hangs in limbo for the promise of its birth.
A veil holds back the darkness, the certainty of death
As a mother cries for nothing more than to feel the baby’s breath.

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