

The Story of Fred and Leroy: Our Mom Has Asperger's Syndrome

By Wendy Hamilton



For as long as I can remember, my mom has called me “Fred” and my big sister “Leroy.” We always knew our mom was different. We shared this magical, mysterious family secret that no one else could ever understand. “Who would want to?” I used to think.

It first occurred to me that people might be interested in our story in 2003. I was living outside the Washington, DC area working at Imagination Stage, a theatre arts center for children and families. There were a handful of theatre troupes for children with mixed abilities, and when they grew into adults and aged out of the mainstream school system, they were encouraged to continue participating in the troupes.

In my volunteer time, I was a mentor for the adult troupe *Wings!* The group was comprised of actors ranging in age from 21 to 50 with a variety of cognitive, physical, and/or developmental disabilities. Each year, through therapeutic and explorative theatre exercises and games, *Wings!* presented an original play based on their participants’ real-life experiences living with disabilities.

As I became comfortable with my fellow actors, I began to open up about my mom and her differences, still very cautious in my description of her challenges. I told them her behavior had characteristics of Tourette’s Syndrome, Attention Deficit Disorder, Obsessive Compulsive Disorder and a variety of learning disabilities. But these were all assumptions. Leroy and I had diagnosed our mom based on our own rudimentary research And we were coping without any kind of formal evaluation, diagnosis or treatment.

I was approached by the director and script-writer for *Wings!* about creating a scene between a mother with disabilities and her daughter. After we drafted a short monologue, affectionately called the *Momologue*, I asked the troupe if I could read it during rehearsal. For many of them, it was the first time they understood the complexity of my mom’s disabilities. My reading was met with tears, laughter, and acceptance. There were also many, many questions. “What was it like?” “How is she now?” “Are you like her?” “How can she have disabilities and be your mom?” “Is this a true story?” I realized that not only was it helpful for me to open up about my mom, people were really fascinated to hear our story.

While I found myself seeking every opportunity to talk about my mom with friends, family, colleagues, and anyone who was interested - which seemed to be everyone! - Leroy and I

became increasingly frustrated because we still didn't really know how to label our mom. With me living on the East Coast and Leroy working as a teacher in Nebraska, we didn't know where to begin. We read, researched, even went to family counseling for guidance. It wasn't like we could just go to the source and say, "Hey Mom, what do *you* think you have?"

Communicating with my mom is unique on a variety of levels, which is why Leroy and I consider ourselves bilingual. People who have learned to speak more than one language from an early age have the ability to connect in multiple worlds, almost instinctively. Such is the case for us. We can communicate in the "normal" world, and in our "mom" world – literally and figuratively.

Her vernacular is based in humor and almost always has an exaggerated East Coast accent. Everyone and everything has a nickname or an altered title, not because she's incompetent or doesn't know the given names of people and things. It's just more comfortable for her to use her own words, as in calling us "Fred" and "Leroy." She never says "soap opera" - it's called a "soapie." Fish are referred to as "pftleleh." When she is scared, she says, "skin!" which is accompanied by an animated hand flapping gesture. She's never *excited*, she's "*recited*." One of my personal favorites is how she refers to herself: "Moppy" instead of "Mommy."

When we were growing up, our Moppy provided us with basic needs like food, shelter and clothing. She performed regularly scheduled duties such as taking out the garbage, driving the carpool, and occasionally attended our dance recitals and concerts. When we were young children, she went grocery shopping and did the laundry. She was incredibly attentive to our pets and always greeted them with endless kisses and hugs. More than anything, she never took herself too seriously. Whatever her insecurities may have been as a wife and mother, she always presented herself honestly. But the silent question remained: *why* was she so different?

The list of things she didn't do while raising us goes on and on. Thankfully, Leroy and I were acutely self-sufficient and independent. Our Moppy didn't cook for us or clean the house. She didn't help us with homework, teach us how to wear makeup, or tell us about the birds and the bees. She was more comfortable being affectionate with us when we were small children. She required hours upon hours of "me time," during which she would obsessively watch TV and read her magazines, which to me was interpreted as a painful rejection. Was she abusive? Certainly not! Were drugs or alcohol a factor? Never. So what caused her to be so seemingly *indifferent* to us?

Our mom's mom, Granny, has always been supportive and very involved with Leroy and me. In fact, our relationship with her feels more like mother-to-daughters than *grandmother-to-granddaughters*. But she also didn't have any answers. Describing my mom's childhood is hard for our Granny. It was the 1950's and society placed a terrible stigma on children who were less than perfect or damaged in some way. My Granny suffered years of personal torment, asking herself if her daughter's oddities were *her* fault. Did she harm her baby girl by allowing the doctor to deliver her via forceps? Was it the Phenobarbital she gave her for colic? Her fears morphed into anger and denial, causing a tumultuous relationship with her only daughter. "Oh, just try harder. Apply yourself!" Granny would shout at my mom. Even now, my mom instantly regresses into an enraged child around her mother.

My mom was destined to slip under the radar. She seemed to develop normally through kindergarten. Around age six, she first exhibited symptoms of social and developmental difficulties and was labeled a “problem child.” As my Granny explains it, she simply stopped accelerating, without rhyme or reason. Did something happen? Was there a trauma? Was something there since birth but remained dormant until this time? What was *wrong* with her?

Though my mom was able to finish high school, it was extremely difficult because she never received the special attention she needed. She was teased and didn't fit in socially, though she did have a handful of girl friends. She repeated eleventh grade because of her academic challenges, and transferred schools in order to graduate with a clean slate. Sadly, she didn't have peace at home either. Her father was verbally abusive and neglectful; they never mended their broken relationship. In the late 1960's, he was stricken with dementia, leaving my Granny as the sole provider for the family. Fortunately, my mom had a special connection to her youngest brother. He was a dedicated source of support for her – never judging, never pushing; always accepting.



Surviving life's challenges with a non-traditional mother was like watching a movie. When I spent the night at a friend's house, I eagerly anticipated watching their *normal* mom doing *normal* things like making dinner, or bringing a neatly folded blanket out of the laundry room, or engaging in important adult conversations with neighbors. I knew my mom wasn't like the other moms, but I couldn't explain why. She dressed strangely, made funny noises with her nose and throat, and she didn't have friendships with our friends' moms, or participate in other *normal* activities like the PTA or bake sales.

In our minds we knew she loved us. After all, she was our mother...she *had* to love us. But in our hearts, we knew it was a different kind of love; one not expressed by typical “how was your day today, Honey?” inquiries nor random acts of kindness, like a kiss on the forehead as she passed through the room. Did we *know* she loved us? Yes. But *feeling* love from a parent with Asperger's was – and remains - a constant work in progress.

As a child, I was anxious and depressed, and I needed a mommy to make it all better. And what *did* I have? A woman I called “Moppy” who didn't relate to me or know how to support me. She used to call me “Daddy's little clone” because he and I had a healthy relationship. Her distance toward me made me wonder if I was a selfish, ungrateful child who didn't love her mother the right way. Was something wrong with *me*? Did *I* do something wrong? Why didn't she like me? Was it all in *my* head?

I felt isolated and defective during these lonely years. I didn't want to burden anyone with my insecurities, especially Leroy. So vibrant and ever living life to the fullest, she seemed to thrive in her new world of independence. From my perspective, she didn't *need* our mom the way I *needed* her. To me, my pretty and talented big sister was going to grow up untarnished by our weird mom. She learned how to cook, how to dress in trendy fashions, and she went on dates

with boys. Her life was sure to be full of color and shine (maybe it was all that Aqua Net?) and mine was dull and gray.

And where was our father during this most unconventional of childhoods? Loving, feisty and fiercely intelligent, our dad was the foundation of our stability. A gentle Daddy, his love for us was – and still is – unconditional. But his personal struggle with our mom’s situation became all but unbearable. He was impatient and intolerant with her, and lashed out verbally. He distanced himself from her and took up hobbies to keep himself distracted. Make no mistake: she knew just how to push his buttons. There is a part of her excited by rebellion, and she was fully aware of the consequences of her negative actions. Their 22-year marriage was anything but ideal, and the only solution was to separate. Their decision came as a welcome relief to Leroy and me. “Thank goodness!” we shouted, reassuring them they needn’t stay together for our benefit.

Their divorce was final in 1993 and my dad was granted full custody of me. The day my mom moved out of the house, I snuck a letter into her suitcase with the lyrics to Dolly Parton’s song, “I Will Always Love You.” It must have been my last ditch effort to break down her stone-cold emotional wall. To this day, I don’t know if she ever found the letter or read it.

My Moppy and I became estranged for almost four years. We had no interaction of any kind. Occasionally, she would come to visit the pets but my dad would make sure I wasn’t home. It was just too painful for me to try to have a relationship with her. I think subconsciously I knew our separation wouldn’t last forever, but shutting her out was my only way to cope.

It’s hard for all of us to recall those years of transition and loneliness. My cool big sister had moved out, trying to prove herself to the world and make it on her own. She felt detached from both parents. Meanwhile, I did my best to make it through adolescence without a mother in my life.

When I was preparing to leave for college, my mom approached Leroy about reconciling with me. Reluctantly, I agreed on the condition that Leroy would mediate. We all met for lunch and shared awkward small talk. My mom asked if I would call her once a month, which I agreed to do thinking she’d never remember that she asked me. I started calling her on the 27th day of every month and surprisingly, she was quick to remind me if I missed our phone date. We slowly began to reconnect and even spent a few holidays together when I came home from school. As I matured, I eventually found forgiveness. Even though I still didn’t understand at the time why she was the way she was, I knew I had to stop blaming her. It wasn’t her fault. *It’s just the way she was.*

In the late 2000’s, my mom’s symptoms became even more confusing and complex. Her behavior simply didn’t fit the normal aging process. For instance, during Leroy’s baby shower, my mom behaved strangely child-like. She had written a poem for the baby, and Leroy read it aloud for her guests. During the reading, my mom was sitting on the floor, rocking back and forth, moving her mouth and making sounds (but not saying any words), and flailing her wrists up and down very rapidly. At the end of the poem, she jumped up, raised her arms in victory and shouted, “Go Grandma Moppy!!”

Over the next few months, my Granny, Leroy, and I became concerned for my mom's well-being, but felt lost for direction. We were fairly certain she had OCD in addition to a learning disability. But we just knew there was *more*. We had to find the answer. After several phone calls to social workers, mental health professionals, and her insurance company, the three of us decided to embark upon an intervention.

Personally, I was fraught with anxiety that my mom would feel betrayed, defensive, and that her intense paranoia would cause a downward spiral of erratic behavior. Imagine being a middle-aged woman and having your most trusted family members tell you your safety and well-being could be at risk and that you might actually have a disorder?

Because my Granny, Leroy and I lived in different parts of the country at the time, our intervention was planned as a three-way phone call. Fearing the worst, I listened as Leroy made the call and presented our Moppy with some of the benefits of seeking a medical opinion. To our amazement, our mom simply said, "Okay, if you think it will help."

The process started in the summer of 2006. When we got an appointment with a psychologist who was recommended by her general practitioner, I flew back to Nebraska to support my mom and Leroy, and also to satisfy my own curiosity. Our first session ended with the following diagnosis: "She's just eccentric, have her take some anti-anxiety meds." Obviously that accomplished less than a band-aid would on a gaping wound, so we moved on to the next psychologist who was recommended by a family friend. This doctor gave us our second diagnosis: "She has ADHD and she should consider taking Ritalin." While that seemed more thorough than the first diagnosis, it clearly wasn't enough. Feeling defeated by the system, we put things on hold for a few months.

And that's when fate stepped in. On my way back from DC to Nebraska for the holidays, I had a chance encounter with a psychiatrist when I fainted mid-flight between DC and Chicago. He escorted me on the second leg of the trip from Chicago to Omaha, monitoring my vitals. He and I talked non-stop during the flight, and he took a special interest in helping my family's quest for a diagnosis. He put me in touch with mental health professionals at The Nebraska Medical Center. In the spring of 2007, we were granted a full psychiatric evaluation for my mom, on the eve of her 58th birthday. She bravely answered each question, completed each test, and allowed a medical professional some insight to her way of life. On a five-page memo, the diagnosis included Obsessive Compulsive Disorder (OCD), Tic Disorder, and Non-Verbal Learning Disorder (NVLD) with characteristics of Asperger's Syndrome, in addition to Attention Deficit/Hyperactive Disorder (AD/HD), severe anxiety and paranoia. FINALLY! A label! Many, many labels! A real diagnosis for my Moppy!

But now what?

The diagnosis didn't *change* anything. It wasn't a quick fix. There was no crystal ball full of answers. We were suddenly thrust into a new world of questions, frustrations, terminology, legal options and mountains of paperwork. It was hard to measure the urgency of our mom's situation. Nothing was immediately changing in her life, but now there was so much more to consider, and we didn't want *it* to get worse. Leroy and I have always been

a team, but I found myself having a much more intense reaction to “officially” having a mom with disabilities. I assumed much of the responsibility of her treatment and in turn, my own mental health suffered from the overwhelming feelings of obligation. I wanted to make up for lost time and be a dutiful daughter who spared no expense to help care for her special needs parent. With the support of my family and friends, I eventually resurfaced with a healthier approach to assisting my mom.

My family is keenly aware that my mom’s diagnosis isn’t a cure. She is today who she has always been, yet we finally know what that means. The diagnosis became the key that unlocked the mystery of her life. After more than 50 years of being pushed aside as “eccentric,” “different,” and “troubled,” my mom is finally getting the treatment she deserves. She attends regular cognitive therapy sessions that provide her with useful remedies to better cope with life. She doesn’t always do her homework, but she isn’t ashamed to talk about her challenges, and can more easily identify her accomplishments. She is employed, and lives and drives independently. She is the mother of two successful, grown daughters, and the grandmother of a remarkable little boy.

I believe that everyone is damaged *and* perfected by their parents. Our story is fundamentally no different from yours, or your friend’s, or your friend’s friends. We had good times, we had hard times. We went through phases of idolizing our mom, and sometimes wishing we were adopted. As we age, every child faces the possibility of having the roles reversed, when we must become the caregiver to our parents. For Fred and Leroy, the roles will never reverse. We have always instinctively known we must care for our Aspie mom, even before her condition had a name.

The greatest and most profound result of my mom’s diagnosis is watching her accept herself and understand that *it’s not her fault*. During a casual conversation, the topic of being on the spectrum came up and she got confused about her diagnosis. I said, “Mom, you have Asperger’s, which is on the Autism spectrum, remember?” With a touch of enlightenment shining through her deep brown eyes, she said, “Is that why I’ve always felt like I don’t get it?” I simply nodded, feeling a mixture of pity and relief. This was her moment of clarity. And, true to form, using her gift for unconventional language, she says she’s okay having Asperger’s... because she likes asparagus and burgers.

BIO

Wendy “Fred” Hamilton lives in Omaha, NE. She and her sister, Becky (“Leroy”), are active in their mother’s treatment and maintaining her quality of life. They are hopeful that with more exposure will come more avenues for support for adults living on the autism/Asperger’s spectrum.

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