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Moments

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MOMENTS

By

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Abstract

Moments is a series of creative nonfiction essays depicting life with a child who is severely autistic. I compare events from my life prior to having children with life events after I became a mother. My goal is to present a side of autism that is not always seen – the meltdowns, the aggression, the injurious behavior. My desire is to show that, despite the obstacles this life has presented us with, I have been able to experience life with a beautiful, misunderstood human who has changed my life for the better.

Keywords: Autism; Life

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Chapter 1. Autism, Aggression, and Apathy

I leave the building, screaming three-year-old son in one arm, loads of paperwork in the other, look at him and ask,” What are we going to do?”

He hits me in the face.

“Yep, I get it. I’d want to hit someone in the face too if they had made me go through what I just put you through.”

A couple of weeks later the report arrives.

Bottom of page 8, I see it. No longer simply words floating in the air from their mouths to my ears, but in print, a formal document stating: *Impression #3: Autistic Disorder, moderate-severe, substantiated by Childhood Autism Rating Scale, developmental history, observed behaviors, and DSM-III R.*

Part of me kept the hope alive that they were wrong and I stated it to my mom and to myself daily, like a mantra: “They are wrong. It’s something else. His hearing, maybe. He doesn’t respond when I speak to him. I’ll prove they are wrong.”

They are the evaluation team at Arkansas Children’s Hospital. A group of individuals specializing in diagnosing developmental disorders in children, and I thought I was going to prove them wrong.

“He is my son. I know him. I can fix this. I’ll be known as the woman who defeated autism,” I told my mother.

This was 1993. It was supposed to be a great year. Bill Clinton had taken office in January as President. He’s from Arkansas. No longer will we, Arkansans, be forced to endure the mockery and ridicule of being backward hillbillies. Of course, I voted for him.

Change was coming, and it was going to rock the world. I expected changes in healthcare, gay rights, and an end to the never-ending threats to end abortion rights. He promised. He wouldn't lie, right.

Seven months later and I was feeling the world rock.

"You must enroll your son in an early intervention program. We will give you information and pamphlets before you leave. Also, we must test him for hearing disorders, possible genetic disorders, and get an MRI to rule out other causes for his lack of progress, but these are just formalities. We are confident in our assessment and diagnosis," says the social worker, a woman whom I suspect had been elected official group spokesperson. My grandmother always described Bob Dole as looking like he smelled a fart and I'm thinking this woman must be a relative. The slightly flared nostrils, the pursed lips, the accusing eyes asking the question, "Who let one rip?"

"If there is any chance at all of him speaking, you must begin speech therapy as soon as possible," notes the speech pathologist. As she says this I glance at my son, sitting on the floor, flapping his arms, and humming. I had to find a way to overcome the Globus hystericus[1] and speak.

I reply, "I don't know who to talk to, who to contact…I don't know what to do."

My brain is having a difficult time comprehending all the information they are tossing at me. Acronyms for medical and education terms are slamming me in the face like bugs splatting against a windshield.

I'm supposed to understand all of this.

I don't.

Fear, anger, resentment, sadness, and nausea congeal into a toxic JELL-O mold in my gut as I sit in the room designed to look as homey as possible with sofas, lamps, coffee table, throw rugs, and pictures. Now these words float around in the air wondering where to land. I can see them, bouncing off the walls, hovering over one person, then the next. The words follow me as I leave.

“No. He’s just ADHD,” was the response of my son’s primary care physician a few days later. “I’ll prescribe him Ritalin. It is like speed, but it slows hyperactive kids down. We’ll get him calmed down, he’ll start to talk, and you’ll wish for him to be quiet.”

My only concern was for my son and why he was not speaking. He was two. He should say something. Months earlier I had read an article in the newspaper – the Democrat or the Gazette, I can’t remember which one – about autism and the signs to watch for. I had never heard the word autism, but what was described in the article matched my son. In that moment I knew the truth, but I was not ready to accept it.

I discussed this with my son’s physician, who refused to consider autism seriously. His response was a joke, really a joke, about a kid who didn’t speak until he was five because he had no reason to speak any earlier. One of the nurses in his office, having overheard our conversation, called me one evening and told me where I needed to have my son seen, but I would need to be referred by a physician. I insisted on the referral.

“I told you all along he was ADHD, but I went ahead and made the referral you asked for and you’re stressing out because they told you he has this autism thing. ADHD doesn’t allow him to focus, which will prevent him from developing language skills, and that explains why he isn’t speaking. Now, let’s try and do things my way,” says the physician as he hands me the prescription for Ritalin and shoos me out the door. “There’s going to be a big change in the boy.”

“Do hyper children bite, pinch, and kick? All he wants to do is beat me up. Is that normal behavior for someone who is hyperactive? He no longer tries to speak, he has become fussy about what he eats and refuses to use silverware, and he will not sleep.”

“Don’t worry about it. I’m telling you, the boy is not autistic. He just has a little ADHD. We’ll take care of it and he’ll be fine.”

“Crying – he won’t stop crying. He sits in the floor, by the window, and cries for three solid hours,” I tell my mom on the phone. “The only thing different is the Ritalin. As soon as it wears off, he stops crying, but until that happens, nothing I do helps.”

Ritalin has a short half-life, which is a little confusing, but is used to explain how quickly half the dose of the drug works through your system. For me, it meant my son only cried for three hours instead of six. I was discovering a lot about drugs and most of it wasn’t good.

“He’ll get used to it and stop crying,” was the response my son’s physician gave me when I called him.

“This isn’t a normal reaction. It can’t be. I feel like I’m torturing him, and I know he feels that way,” I replied.

I seemed to be making my child miserable by continuing this drug. The alternative was spending my days with an aggressive little monster who liked to beat me up.

These are not great choices.

Doctors do not like it when your opinion differs from theirs. I would stand my ground and they would become aggressive in manner.

"I'm stopping the Ritalin."

"If you aren't going to follow my advice, why are you here," he questioned me, as he straightened his shoulders, huffed, stomped out of the room, and slammed the door.

Compromise seemed to have left the dictionary. My life was becoming one monumental argument. I was quickly becoming the difficult mother, not because of my cool logic and thinking things through, but rather because of my emotional reactions.

Emotions are the enemy in situations requiring detachment.

For the first two years of his life, my son slept soundly. There is a scene in *Terms of Endearment* when the baby is quiet and Shirley MacLaine's character climbs into the crib to make sure her baby isn't dead – that's how I felt as I watched how soundly my son slept. I would hold my hand over his chest and abdomen to make sure there was movement. Other times I would hold a mirror under his nose to see if it would fog up. Even though he was plagued with numerous ear and sinus infections, his disposition was unbelievably positive.

For two years, *Terms of Endearment* was the film that depicted what life was like with my son. Then, one day I looked up and the marquee listed a new featured film: *Gremlins*. Physically, my son looked like Gizmo, cute and adorable. You just want to hug and squeeze him, but don't—because behaviorally, he's Stripe. Unpredictable, moody, and able to stay awake forever – or at least that's how it felt. These were the changes, along with no speech, that prompted me to ask for a referral to specialists, and all his doctor can say is, “he’s just ADD with hyperactivity. Keep giving him the drugs and he’ll get over it.”

Meanwhile, in Washington, the Arkansas boy who grew up to be President was having his own issues. The Whitewater investigation was taking place and distracting him from presidential things. Politics isn’t my area of expertise and my attention was focused elsewhere, like trying to deal with education professionals who made me feel stupid. I’m sure most of them were not intentionally doing this, but throwing around all those random letters like I was supposed to know what they meant sure made me feel that way. It’s not like the Google app was on my smartphone and I could discreetly type in IEP or IDEA and then pretend like I knew all along what they were talking about. I didn’t use these terms daily. Not only was I being educated about autism, I was being educated about bureaucracy and its cost and the apathy that is prevalent in our society.

“No one cares,” I cried to my mother on numerous occasions. “They say they do, but they don’t. The programs that are supposedly designed to help individuals like him, the ones I never wanted to be a part of, make it almost impossible to get help. Yet, our government can waste millions of dollars investigating Clinton for something that happened years ago, and who cares!”

After a pause, I continued my tirade as my mother listened patiently. “The cost is out of this world. How can anyone afford to have an autistic child? Private insurance will not cover any of his therapies because his disability is ‘long-term.’ I must apply for Medicaid and that is a pain in the ass. How can the leaders of our country and state say they care about the welfare of children, when clearly they don’t?”

I wasn’t rich. I was the oldest child of a divorced mother who worked two jobs most of the time and we were still poor. For me, growing up, the term privileged meant moneyed and male – something I wasn’t. I was poor, white, and female, which meant it was almost impossible to be taken seriously, then, or now. To get the attention my son needed I had to get mad and then I was just the hysterical woman. My father always told me I wasn’t good enough because I was a girl, now I was receiving judgement from strangers who felt entitled to judge because I wasn’t perfect.

As First Lady of the United States, Hillary Clinton was also being criticized during this time. Her hair, her ankles, her clothes, and her overall state of being a villainess.

“Seriously, she is smarter than those men, she went to Yale, she can take care of herself and is a badass, and she still isn’t good enough. If Hillary is hated and ridiculed, I stand no chance,” I say.

Strong women are often subjected to harsh criticism, as I was finding out. Standing up for my child, making the decisions I felt best for him, made me difficult, a bitch, uncooperative. At times, possibly justified, such as when I had my first encounter with the Special Education Liaison.

Enrolling my son in school required a meeting. The honored guests included the superintendent, elementary principal, speech therapist, teacher, psychological examiner, and the LEA[2], aka the Special Education Liaison.

I prepared myself. I had a list of questions and a list of what I wanted for my son. I had read up on what the school was required to do, what my son’s rights were, what my rights were. I was terrified. My hands were shaking, my voice tight.

I was quickly schooled (I hate this phrase) on how things worked. The liaison gives her speech: “Yes, we are required by law to provide these things for your son, but the minimum. See, the school district has a budget and only so much of it, a small amount, is allotted for special education.”

“But,” I interject, “what you are telling me doesn’t match what I’ve been reading.”

“I’m telling you what we *will* provide regarding education for your son.”

“That isn’t enough,” I reply.

“Well, he should already be capable of some speech. *You* are not doing *your* job as a mother,” she snaps at me.

I replied, “Burn in hell,” and walked out the door. I was lacking skills.

Immediately after the school year begins: “He can’t be in my classroom, even for limited time, he is too disruptive,” teacher after teacher in the public school told me. “He tries to bite me, his aide, and the other children. He can’t be here.”

At this point, the counselor asked to hold a meeting that would include her, the special education liaison, and me. I was the first to arrive and she was prepared: “Your son is a menace. If his aggressive behavior continues then the school will be forced to call the prosecuting attorney and have charges filed against him.”

“What? Aren’t you supposed to be helping me, working with me to figure out a plan?”

“That is not our job. Our only requirement is to educate your child. You are responsible for controlling his behavior.”

“What do you think I’ve been doing?”

“Well, *you* haven’t been doing *your* job as a mother.”

“I do not think we should be discussing this until the liaison arrives,” I said as I get up to leave.

“Sit down! I am not finished speaking to you.”

“Do not speak to me that way. I am not a child,” is my retort as I walk out the door.

I slam the door and burst into tears.

Two times in as many months I have been told I wasn’t doing my job as a mother. I did not realize at the time that they would say this to make me doubt myself. As if I didn’t already.

All of this led up to the placement of my son in a self-contained classroom, the most depressing room I’ve ever entered.

Funny thing, this is the same classroom that held my second-grade class. The year I was jump rope champion. Walking into the same room now was like leaving a children’s book where rays shoot from the sun like arrows of happiness and the flowers and butterflies are all drawn in primary colors and adorned with smiles and long eyelashes and entering an Edgar Allan Poe story, dreary and comprised of grayscale imagery.

I hated it.

He would never make progress in that room. I knew it. I felt it. There were students in wrist constraints so they would keep their hands to themselves. It was a nightmare world and I felt there was no escape.

Clinton may have felt he was in a nightmare world after his moral transgressions with Monica Lewinsky took place. “I did not have sexual relations with that woman, Miss Lewinsky,” stated President Clinton on January 26, 1998.[3]

It was a lie.

He did.

Add this to the ongoing Whitewater investigation and the money spent keeps adding up – tens of millions of dollars. The attempt to remove him from office was becoming more aggressive.

“Who cares,” I wanted to know. “He lied. He wasn’t the first, he won’t be the last. Reagan got off on the whole Iran-Contra Affair and that involved war and military stuff.”

Wasting money made me ill and there seemed to be a never-ending supply to spend on this endeavor. Meanwhile, a communication device was a possible answer for my son, but for this, there was no money. I’d already spent plenty of my own money. Mostly on overpriced books. One of these was a book of social stories that would help my son understand his schedule. It was wasted money. So much wasted money on products and books purchased from people willing to leech money off parents desperate to help their child become “normal.”

“If we can purchase a communication device then your son will be able to hear pre-programmed phrases and eventually be able to type in his own words and phrases. This will help him develop speech. There will be less pressure on him to speak with the pre-programmed phrases, thus making it more likely for him to develop speech on his own,” explained the speech therapist. Finally, someone who wants to help.

“Okay. This sounds great,” I replied. “What do we need to do to make this happen?”

“We will put in a request with the insurance company first, but they will turn us down because they will not cover a device for a long-term disability. Once we have their rejection, we will request the device from Medicaid, which will pay for it.”

I was excited. It would be the first step, in a long line of steps, in the right direction. This speech therapist was the first person to give me hope that progress could, and would, take place.

By this time, my son was becoming a subject of conversation around the school.

As I walked down the hallways people would suddenly become quiet and watch as I passed by. Some of the parents of children in my oldest daughter’s class suddenly refused to let their children have anything to do with my daughter.

“I wasn’t invited to the sleepover, but all the other girls were,” my daughter told me.

“Why?”

“Because her mom thinks my brother is dangerous.”

“Well, he wouldn’t be going.”

Nothing I said or did made any difference. My son freaked people out with his humming and flapping and his funny way of walking, always on his toes. Certain parents took an aggressive stance in keeping their children away from mine. Many times, I would watch as other parents would pull their children behind their back to get them away from my son. Sometimes a parent would yank their child so hard I thought they would pull the poor child’s shoulder out of socket. Fear and ignorance was winning.

Two years later, still no communication device.

Once again, on the phone with my mother, I was explaining why. “Insurance wouldn’t pay citing long-term disability. Medicaid wouldn’t pay stating it was the school district’s responsibility. The school wouldn’t pay stating it would be for personal use, as well as school use, therefore Medicaid should pay. Back and forth for two long years and nothing. I’m telling you. They don’t care. It’s all about money. I don’t understand any of this. Don’t people matter?”

Twenty-five hundred dollars was the cost of this device. Twenty-five hundred dollars was going to break the bank. Our fearless leaders in Washington kept spending money on the investigation, the defendants kept racking up millions of dollars in legal fees, and no one could cover the cost of a $2500 communication device for a little, nonverbal, autistic boy in Arkansas.

“Go ahead and tell me how much our country cares about the welfare of our children. Tell me how much the state cares, how much the school cares, tell me,” I ranted to my family. “I never want to hear how much they care about children again. There’s all kinds of money available to spend on investigating a president getting blown in the oval office, but not to help a child develop speaking skills.”

“Tiffany,” my mother said, “that was a tacky way to phrase that.”

“It’s a tacky world, mom.”

Bill was like the boys I knew in high school. The smooth talkers who have cars, let you wear their Letterman jacket, all in an attempt to get in your pants. Even as President, he was like the boy who never grew up. My son’s doctor was the same way. At a meeting with him where my son and I were in his office, not an exam room, my son was playing with what looked like clear stress balls. I finally realized they were breast implants.

"Sorry," I said as the doctor walked into his office, "he really likes playing with these."

Sitting down he replies, "So do I, so do I."

"Yeah, I walked right into that one."

Autism brings a lot with it. I was afraid every day of what could possibly happen and when I heard the word autism, my fears became greater. I was attempting to overcome my fears, and it was not easy. As I learned to deal with my son's aggressive behavior, I was finding how aggressive others were. There were the educators refusing to think creatively; physicians rejecting the existence of developmental or mental disorders and believing the right pill solves everything; other parents thinking my son was a freak and by default my daughters and myself; and those who represent us in Washington who aggressively fight for their party rather than the people. I was smothering under a blanket of aggression I had no idea how to deal with.

Worse was the apathy, the platitudes, the lack of empathy that existed. It was difficult to convince others of this because everybody already thinks they are empathetic, except they always add "but…" there are certain groups of people.[4] We fell into the "but" category.

Notes

[1] Globus hystericus. Outdated term for the feeling of having a lump in your throat.

[2] LEA. Local Education Agency. For students in Special Education a representative from the school district is part of the education planning process. This individual is commonly referred to as the LEA. Also, in my experience, this individual was also referred to as the Special Education Liaison.

[3] From a speech Clinton gave after his affair with Monica Lewinsky was made public. There are several YouTube videos of this speech, which is the easiest way to search for and listen to what he had to say.

[4] Clair, Erin. Line borrowed from a Facebook status, with her permission.

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Chapter 2. 1:30 a.m. and Carpet

I was sitting on the floor, crying, scrubbing human feces out of the carpet and off the walls. No sleep for two days. I hate carpet. I still hate carpet. Carpet is a haven for miniscule particles of stuff. Stuff you carry in on the bottom of your shoes, stuff that is dropped or spilled, that works its way to the bottom. Vacuum and steam clean all you want, but you will never get rid of all the stuff. Then mites take up residence. It is a whole different world underneath the carpet. Mite housing tracts and condominiums where they go to restaurants and feast on delicacies made from bits of feces and insect remains carried in from outside, along with the tasty human food tidbits dropped into the carpet by toddlers.

Yep, there I sat; awake for 48 hours, scrubbing shit off the walls, out of the carpet, and off my son. I had been rudely awakened, having dozed off for maybe ten minutes, by my husband (now ex) screaming at me, "This is your responsibility. I have a job. I have to be up in five hours. I live in the real world. You *cannot* sleep. You must monitor this freak. Shut him up, now!"

The "freak" in question, who is not a freak at all, was my son.

Three years old.

Autistic.

Nonverbal.

I simply sat, silently seething, on the floor, scrubbing shit out of the carpet, having a mental conversation with myself.

"Tiffany, why did you marry this asshole?"

"I didn't know he was an asshole."

"Get real. The signs were there. You know, how he never accepts blame. It is ALWAYS someone else's fault. He is overly concerned about appearances. He always has a reason why you cannot attend company functions – you might embarrass him by saying the wrong thing. He belittles you constantly. He drinks all the time. He always did. What, did you think you could change him with love?"

"I did not see them – the signs. And, isn't that what happens in romance novels? The wild untamed man always changes for the woman he loves."

"You were blind and foolish. You need to leave."

"Shut up. I know. Do you think you are telling me something I don't already know? I have no money, no skills, no degree. I have three young children. I love my children. I don't want them to grow up with a single mother who always has to struggle and remain poor the way I did. I hate myself. I hate him. I want to leave, but, how can I?"

I will eventually leave, but it will take me six years. Six years during which time I hear phrases like, "You will never find another swinging dick that makes as much as I do."

I did not marry for money. It was always about money with him. I married because I was an idiot, an introvert who was shy and socially awkward, and someone who had never dated – ever. I guess I wanted to feel loved. I was loved, but it was not the romantic kind of love, which I was obsessed with. I have four amazing women in my life: my mother, my sisters, and my grandmother who all love me dearly, but I have a dickhead for a father. A wife-beating, child-beating man who one time slapped me so hard my contact lenses popped out and said things like "women are useless and aren't capable of raising children.” I wanted a marriage that was like the ones present in storybooks. I thought I found that. I was wrong. Sure, I thought love was the reason I married this man, but I realized I had no clue what it meant to be in love, and he was not capable of such a thing.

The whole experience humiliates me now. I became someone else. I outwardly adopted his way of thinking, but inwardly I cringed at the words I would speak…his words. I was an enabler, constantly driving to Scranton to buy beer, even when he ran out at 10 p.m. on Saturday night. At those times, I would drive across the bridge connecting Johnson County to Logan County chanting, “Please do not let me die tonight.”

In my mind, I never live it down. I don’t let myself.

I changed myself into someone I hated and kept telling myself “you are doing this because you love this man.”

No love existed. Why me? Why did he marry me? The answer: I was almost a decade younger, inexperienced, and easy to control.

But, as I looked at the man I married, my mind wanders, as it so often does, and I ask myself the more important question: “What is a swinging dick?” I picture a clock with a phallic pendulum hanging on the wall. The phallus swings back and forth and behind it, hanging slightly lower than the head of the phallus, are the testicles, which resemble clackers. I had a set as a child. Two hard balls on a string. The object of the game is to swing the strings and bang the balls together creating a clacking sound, all the while trying not to hit your head. “You kids do not need to be playing with those things--they are dangerous,” my grandma would tell us. The clacker testicles would clack once on the half-hour and then clack together on the hour the number of times necessary to announce the hour, two times for two o’clock, four times for four o’clock, and so on. In real life, those would be some seriously bruised balls.

As I sat on the floor, crying and scrubbing shit out of the carpet, I watched my son. He never stops moving – until he does, but that can be days. It is like watching the Tasmanian Devil sans tornado feet.

“Why? What did I do that was so terrible I deserve this? What did my son do to deserve this?” I asked God.

These talks once took place frequently as I attempted to deal and bargain, “I’ll never ask for anything again if my son can be normal” and “I’m willing to die and not watch my children grow up if you will make him okay.” God didn’t answer. These talks stopped by the time my son was five.

I do not think there is a God – the God people talk about, the one they pray to, the one whose hands the world is in. I want to think there is. Once upon a time, I did, but I think I must never really have believed if it is so easy for me to question.

I think of all the people I encounter who proclaim, “God does not give you more than you can handle.” These people quickly made their escape, feeling grateful they weren’t the ones who sat on the floor, at 1:30 a.m. scrubbing shit out of the carpet, off the walls, and off their son.

The truth is I wasn’t sure they knew to be grateful. I would never talk about what autism brings with it. This shame. Yes, shame. It is not normal for your child to spread feces on himself, graffiti the walls with excrement, and rub it into the carpet. What I did not know at the time was that this is a common behavior among severely autistic children, but for now, I was just ashamed. “I can handle this. I don’t need help. I am superwoman. I am a Virgo, a perfectionist, and I do not admit failure,” I said to myself.

It felt like failure though.

He told me I was a failure, the (now) ex.

“The house is never clean, the pool table is covered in laundry that needs folding, your son plays in feces,” he said to me in a voice I can only describe as filled with hate.

My son, not his. *His* son would never do anything as disgusting as smearing feces on his face, a smelly war paint. *His* son would not try to recreate a Dali painting, where instead of melting clocks there are melting commodes, on the wall using body waste instead of oil paints. *His* son would be perfect, as I am supposed to be perfect, a Stepford Wife. Perfect hair, perfect body, not one ounce of fat anywhere, and perfect makeup. After all, appearance is everything according to the man who says, “If I were a woman, my hair would be long and styled every day. I would use hot curlers every morning. It is important to train your hair.”

I wasn’t supposed to think, just do. Make his life beautiful by taking care of everything unpleasant. After all, he lived in the real world and the real world had no room for error. *My* son was an error. I hate perfect.

I continued sitting on the floor, angry, crying, scrubbing shit out of the carpet, off the walls, and soothing my son who wanted me to leave him covered in his own waste. There is a sense of pride in his accomplishment. There were times I had seen him undo his diaper, let it drop to the floor, pick up the bodily waste in his hands, and use his body as a palette. He seemed to be telling me, “Look. This is dark Sienna. I think the walls would look better this color.”

Later, while educating myself about autism, I read theories regarding why this is. Most likely written by individuals without profoundly autistic children. It goes something like this. The fecal matter is theirs. They do not understand it is waste, they think they are losing part of their body, and they fear losing it and need to find a way to keep it. I do not buy into this theory, not then, and not now. I think it has more to do with senses. Specifically, in this case, tactile and olfactory. First, he smells, and then he smears. He smiles and seems to derive the same pleasure a child gets playing in a mud puddle. I studied my son and I noticed how his senses are different. His hearing is overly sensitive and even the slightest noise can cause him to clasp his hands over his ears and cry in pain. He likes to smell strong pungent odors, but it may be possible these are the only smells he recognizes. His sense of touch and feeling is off, for example, covered from scalp to soles with the worst case of chickenpox imaginable he never feels it, but touch his head with a comb and he screams in agony.

"Ms. ____," said the developmental pediatrician, "the autistic brain is full of short circuits. It simply is not wired correctly." I envisioned a complex interstate and railway system with curvy mountainous terrain full of gaps in the highway and railroad, spots where the engineer did not complete the creation. A design flaw. No repair was possible as this tangled system was now encapsulated inside a skull; the chief engineer was dead, and his plans nowhere to be found. So, what happened when my son encountered one of these gaps? Everything came to a crashing halt - picture a hundred-car pileup, during rush hour, in a large city. He does not know what to do. Meltdowns occurred. Redirection was recommended. The idea was to help him attempt to re-route incoming information so he can learn and function in the world as we know it, but taking the alternate or flood route does not always work. The brain is a complicated piece of machinery. If top neurologists cannot figure it out, I stand no chance. Science fiction would be beneficial in this instance. I could be shrunken down in size and injected into my son's body, navigating the microscopic blood vessel submarine to his brain.[1] Upon arriving I could make the necessary repairs, plug in the proper USB connectors, and leave. Not a real world possibility, but I can imagine. I wonder what my son's imagination is like, especially when he focuses so intently on images in movies and in books. Does he see himself swimming under the sea with Ariel or dancing with enchanted household objects with Belle?[2] Will I ever know?

After 2 a.m. I was still sitting on the floor, scrubbing shit out of the carpet, off the walls, and watching my now clean son who was walking around and flapping his arms. Another common trait of autism I would learn about in the coming months. It is a world of tactility and stimming that I do not fully understand. Then, a smile. His smile is a truly, capital T, astonishing thing. It is phenomenal. Joy and happiness are visible in this smile that reaches his eyes. Purity radiates from him. He is not capable of presenting an emotion that is not true, even now. I watched this child, my son, with the flapping arms, beauteous smile, and long blonde curly hair, and I smiled back at him, but my smile didn't reach my eyes. I thought of things that would never be. I looked at that golden hair, the hair women stopped us in the street to get a closer look at and say, "I would kill to have that hair. Look at how beautiful it is. It is not fair for a boy to have this hair. God, that hair is gorgeous. You are so lucky." I would just smile and say, "thank you" like the good southern girl I am supposed to be, but I was not her. I thought to myself, "We paid a price for this hair lady. You do not want to pay the price, it is steep." I see this physical beauty my son possesses, but I do not take pride in it. I know women who would, but that is not what is important to me about my children. Do I deny I want them to be attractive? No, but healthy and happy are far more important. What was I supposed to say? “He does not speak, he plays with his poop, but he is fucking beautiful and that is what matters.”

It was now 2:30 a.m. I was still sitting on the floor. Shit was no longer visible on my son, on the walls, or in the carpet. Of course, it was not really completely gone as there had been a certain amount forced down into the carpet where the mites live and play. There had also been a certain amount that had permeated into my skin and into my nose. The odor was trapped on the hairs inside my nostrils, stuck there for eternity. I leaned forward and rested my elbows on my knees. I placed my chin on my palms and used my middle fingers to massage my temples. I smelled it, a field of rotting animal carcasses mingled with one of the floral Lysol scents, the funky foulness of feces. It never leaves. Whenever my son walks into the room I am in, I smell it. I must consciously remind myself that shit is not present. I feel guilt and shame as I look at him and wonder if he is aware of this. I hate that I look at him and I am overcome with this smell. I love him. I never want him to suffer, but he does. He has my heart. I never want him to know that I still wake up at 2 a.m. and smell the aroma of human waste. I hate shit. It is a reminder of autism and how much it has stolen from our lives.

Notes

[1] Reference to Innerspace, 1987. Film starring Martin Short as a hypochondriac and Dennis Quaid as a screw up military guy who is miniaturized and injected into Martin Short's body. Of course, chaos ensues.

[2] *The Little Mermaid* and *Beauty and the Beast.* Disney movies that my son is fascinated with. He seems to like the princess movies the best, especially Ariel and her red hair.

Chapter 3. First Christmas

"I figured it out! I can't believe it! It's one of the only times I've managed to figure out what is going on when he is upset," I said to my mom. I had picked up the phone and called her as soon I had made the connection. To this day, it is still one of my favorite stories involving my son. Every Christmas I remember the event, along with the laughter and tears that accompanied it.

It was our first "single mom and her three kids" Christmas and I wanted it to be memorable. Funny thing is, I don't remember that much about it other than the incident involving my son. I took all the Christmas decorations after the divorce. They were mine. I spent those "married" years collecting them. They were not specifically listed in the divorce agreement as being mine, like the guns and tools noted "his." Gifts to me were on my list. One of the gifts had been a cement mixer and the molds for making stepping stones, but since *he* considered them tools, he refused to let me remove it from the premises. "I'm still pissed about that," I tell my daughters any time we talk about the divorce.

"You'll get another one someday," they reply in unison.

"Yeah, but I don't need one. It's the idea. It was a gift. Does *he* not understand the concept?"

They look at me and roll their eyes. We all know the answer to that question.

I had put off getting the tree out and decorating. My daughters had been asking me to since Thanksgiving. I used as every delay tactic I could think of: "I'm tired" to "Your brother isn't having a good day," but, if I'm being honest, and in telling this I am trying my best to be honest, here is the truth, I really dislike the whole process of getting the tree out, putting it together, and decorating it. For me it is always a reminder of what I can't afford. I cannot afford Christmas, at least not the Christmas I want. I'm not necessarily talking about expensive gifts. I mean the type of Christmas I want, if only one time in my life, where I am at peace with myself and I feel the joy of the season naturally without having to "fake it."

In my mind, I picture living in a Victorian house with lots of rooms. Not as many as there originally were because renovations had to be done. After all, closets, bathrooms, and kitchens are far too small in Victorian homes. The entire house is decorated for Christmas – every room. The house smells like Christmas: Gingerbread, apples, spices, and cedar. The smell of cedar is okay, but not the actual tree itself, because I'll spend the entire holiday season sneezing. It takes time. Decorating, baking, gaining weight. All of this doesn't happen overnight, or even in week. Success requires two months. Even then, there needs to be one room that is the designated *Christmas Room*. The tree, the decorations, the miniature village strategically laid out to perfection on the huge oak table with the train that runs through the middle and the waterfall on the west end, remaining in place all year long. When the new year has come and gone, simply cover everything with sheets and close the room off until next Thanksgiving when once again, upon removal of the sheets, the Norman Rockwell Christmas I imagined is present, just a sheet tug away.

I don't operate that way. I thrive on getting it all done at the last minute – decorating, wrapping, and baking – running on adrenaline the entire day of Christmas before collapsing and sleeping until noon the next day. These days, I can, if I want, snap a picture with my phone, Instagram it along with the caption: *Whew, done just in time for kids to wake up! #gotitdone #unwrappingsoon #smellslikeXmas.* Scrolling down the list of replies, I would see comments like, “Beautiful <3” and “How Very Christmas-y!”, all sharing my enthusiasm for a job well done. My ego would get a boost. Positive social media responses provide an affirmation that is needed. Is there another reason so many people put these aspects of their private life out there for followers to see?

Financial insecurity causes the holiday season to be a stressful time of year, but autism also takes some of the joy away from Christmas. Christmas is a break from the norm – a time for gatherings and surprises. It is stressful for me because I want everything to be perfect and I know it isn’t. It isn’t only that I fail in my attempt to make the tree, the food, the house, and the wrapped gifts beautiful or that I cannot afford to do the things I want to do, it is always a reminder that I failed my son. True or not isn’t the point, it is the way I feel.

Christmas disrupts routines. Structure is no longer possible, regardless of my efforts to keep it. Increased chances of meltdowns exist. There is nothing like the knowledge that lurking around the Christmas corner an autism meltdown is waiting to be unwrapped on Christmas morning. This is a gift no one wants to open.

Why should my daughters, and now my granddaughter, be expected to minimalize their excitement, their shrieks of happiness at unwrapping the new set of 36 *Copic* markers or *Puppy Dog Pals* playset. Why should my son have added anxiety to his day because we are celebrating a day that culture tells us should be different than other days?

“What did he do? Tell me. Don’t keep me in suspense,” asked my mother, anxious to learn the news concerning my 8-year-old son.

“Let me start at the beginning,” I tell her. “I decided to go ahead and decorate the tree tonight. The first thing I do is string the lights because you know it is easier if the lights are on the tree before putting on the other decorations. As soon as I got the lights on, I plugged them up and they began to twinkle, and you know how he feels about flashing lights. He is waving his hands and humming his happy hum and then, suddenly, he stops and begins to cry. Hard. He is standing there, looking at the tree, and crying as if his heart is broken. I try to calm him down and I’m not being successful. After I make certain, as certain as I can, that he isn’t hurting somewhere, I begin to look around to see what is making him cry. I don’t see anything out of the ordinary. He hasn’t taken his eyes off the tree. He is just staring at it and sobbing. So, I begin inspecting the tree. It looks okay. All the branches seem to be evening spaced, so do the strings of lights. I’m spinning around frantically scanning the room to see what I’ve missed, when out of the corner of my eye, on the side of the tree closest to the wall, I see a light that is burned out and wonder, ‘could this be it? This is the direction he is staring in, so maybe the light is the culprit.’ I run to the Rubbermaid container with all the Christmas stuff and furiously search for a replacement bulb. Finding one I get my butt back over to the tree, yank out the nonworking bulb, put in the new one, and hope like heck it works. And, guess what? It did. As soon as the new bulb started flashing, his tears dried up, and he returned to flapping his arms and doing his happy hum.”

"No one else was here to see this. The girls were in the other room and missed it, but once I solved the mystery I yelled for them to 'come here,' of course, not too loudly because I didn't want to upset him again now that he is finally calm and laughing. The girls were excited too, and we all grabbed hands and jumped around in happy circle. It's crazy to get so excited over this, but I can't help it. I figured it out. You know how difficult it is to make the connection and this time I did it. Next time I probably won't, but tonight I did it," I told her as I began to cry.

Yep, I cried. I cry a lot. Sad cries, happy cries, depressed cries, someone hurt my feelings cries, and autism cries. There are a lot of autism cries. My mom understands this, but most people I encounter in my life don't and can't possibly fathom why Christmas has become a season of merriment mixed with misery.

Every year we receive a letter from the wife of a family friend. Most years I do not even open it until February. I can't bear to read about another perfect year in the life of her perfect family, described on perfect stationary, and then gaze upon the accompanying picture showing them smiling in their perfectness.

Dread. This is how I feel when the Christmas letter arrives. I know that what is presented in the letter is only a part of their lives, but still, I can't bear to read it. I know it will be filled with perkiness and "how perfect" their family is. I know they are not perfect…no one is, but reading this yearly description of their life causes me to throw up in my mouth just a little bit. It is that sickeningly syrupy sweet. The most recent letter I read on December 29th, four days after Christmas. I should have waited.

Every year a letter arrives in the mail. Yes, actual snail mail, no cute blog post or email or Facebook message. Maybe mail that you pick up from your mailbox is more personal. Anyhow, like I said, every year I know this letter is coming and every year I dread seeing it. Now, IRL, which means in real life and not I ride llamas, this family is not perfect, but seeing them presented on paper, they appear to be. Am I the only person who wants to read a little more reality and a little less fiction when it comes to the lives of other families? What is this need to present only the perfectly positive proficiencies (I needed a p-word for accomplishments) of their life that some people have? Okay, true, no one wants to hear whining all the time, but I am not talking about whining, I am talking about a small dose of reality, so you do not make other people feel like losers, when you are writing these disgustingly delightful documents. My marriage is perfect, my husband has the perfect job, I have the perfect hobby job, my children are perfect in their careers and relationships, and we have had another perfectly, fabulous year darling. Oh, and by the way, we really need to get together next year…it has been far too long. Umm…hell, no. My life is far from perfect and I do not pretend it is…ever. I do not want to. And, I do not want to get together. Ever!

Warning: What comes next does not reflect anyone real, it is simply the author's imagination at work.

How about a year-end letter something like this?

"Well, another year has come to a close and here is hoping next year is better. Junior (our oldest) got three DUI's this year, and he has just been admitted to rehab (again) and

we are praying it works this time. Thankfully, we can afford a good lawyer who has managed to keep all of this from becoming public, so he has managed to keep his job. Of course, the biggest thing to be thankful for is that he managed never to hurt anyone or himself. Our youngest has decided he needs to find himself, has dropped out of college, and is attempting to become a YouTube star. I have gained 50 pounds over the past six months with all the stress these kids have caused me, but hubby still tells me I am hot, but I have noticed he is working longer and longer hours and he has a new assistant named Bianca. Do you think I have anything to worry about? No, I did not think so; I am being silly because he is as faithful as the day is long. Well, write soon. I would love to hear from you."

Okay, now I am being ridiculous, but you get the point. Right? A year-end letter from me would go something like this:

"I am afraid to say anything for fear of jinxing next year. Let me just say…well, nothing, because I do not want to jinx next year. Hope you all have a Wonderful New Year!"

Presenting the best of her life is what this woman attempts to do, I know this. My children tell me all the time, "do not compare your life to anyone else's." I am becoming better about this, but when Christmas rolls around all bets are off. I cannot help it. I feel like a failure. Every. Single. Year. I listen to people talk about hoverboards (am I the only one who thinks of Back to the Future and says to myself, "these are not hoverboards"), and other expensive gifts and thinking to myself, “fuck, they are already at two grand a kid.” I am thankful that I have children who like books.

You know, even if I could afford it I would not buy these gifts for my children because I want to give gifts that mean something, that have some personal connection. It is from me to them, I thought about this gift, and that is the message I want to send. I know you, you are my child, we have been through all kinds of ~~shit~~ stuff together and I recognize that…I remember. At least until senility enters the picture. Maybe, if I am very lucky, this will not be the case.

But seriously, I really am glad things are going well for the letter writer and her family. I would not wish for anything else. I would just like the yearly letter to feel a little more like an actual human people person wrote it.

While I am at it, let me add to this the stress Christmas movies add to my life. The beauty, the perfection, the freaking miracles.

“I thought you liked Christmas movies,” daughter #2 says.

“Me too,” says daughter #3.

“I do like Christmas movies. I do not like them 24/7 for two months. It’s overkill. Jesus, is Hallmark intentionally trying to point out my inadequacies?”

I hear daughter #2 say, “I really think you are being a bit dramatic.”

“I’m going to write about what my life would be like as a Hallmark movie.”

“I want to read it when you are done,” daughter #3 tells me.

“Sure. I’m calling it ‘If my life was a Christmas movie, what would happen?’”

What is it about Christmas movies? Every year the Hallmark channels begin playing Christmas movies the day after Halloween. Are not there thirty days of Thanksgiving movies out there somewhere? I suppose not. Occasionally we will see a Christmas movie that is "outside the (Christmas) box," but normally these movies follow the same format. Down on their luck (male or female) protagonist who does not believe in: a) love or b) miracles, and by the end of the film all issues have been resolved. Luck changed, love is in the air, miracle(s) occurred, and our protagonist is now financially viable and believes.

Hold on! I'm making it sound as if I do not like Christmas movies, I do, but not the overkill we are presented nowadays. Plus, with very few exceptions, these movies have become unrealistic. Everyone in the cast is now beautiful. Even when people are supposed to be "poor" or out of work, the women carry $600 handbags. Couldn't they at least mention at some point in the film this handbag came from a consignment store or was a hand-me-down from a well-off relative? Am I the only one bothered by this? Right, the film is about the holidays and not handbag. It seems we always have the fantasy that everything will work out and Christmas is the perfect time to indulge in those fantasies. For two months of the year, Hallmark gives us the equivalent of a Netflix binge…with commercials.

I wonder. What if my life was like a Christmas movie. How would it play out? Here goes:

Middle-aged mom played by someone at least ten years younger than I actually am, with a fabulous body, who possesses the ability of witty comebacks, attending college in order to better life for her and her children, one of whom is a non-verbal autistic son. Given these circumstances, I will drive a new Prius, carry a Michael Kors handbag, and wear $400 boots. In the movie my son will be much younger than he is in real life, because, after all, a young child around the age of 5 or 6 tugs at the heartstrings more than a 25-year-old, non-verbal autistic young man. Heartstring tugging is extremely important in these films. My daughters will be selfless children, with the occasional momentary flash of jealously due to having a brother with autism. At some point during this movie, I will have: a) purchased a lottery ticket with the last remaining dollar or two I find at the bottom of my $400 handbag and then win, or b) find out I am related to some incredibly wealthy person who has been spent most of their life alone and is longing for a family. By the end of the movie I will have met my guardian angel who is in disguise as: a) a professor with literary contacts, b) a wealthy philanthropist (the rich person wanting a family), or c) a publisher who sees my writing by accident, and my dream of writing a novel will be on its way to becoming a reality. Last, but certainly not least, let us not forget the most important part of this movie…the miracle. My son, who has never spoken a word, on Christmas morning, will begin speaking. All accomplished in a two-hour timeframe (including commercial breaks). I will now have a benefactor, be financially stable and able to accomplish my dream, and a miracle will occur. I will believe and will never again doubt. Goal accomplished. People will finish watching the movie, teary-eyed, because the beautiful little boy finally spoke, and his mother finally believes in *miracles. It is a glossy, colorful, version of a Christmas miracle where everyone is beautiful and nothing too horrific (like a dying child) occurs.*

There you have it…my life as a Christmas movie.

While imagining my life as a Christmas movie, my real life autistic son knocks over his drink and while I am blotting the liquid from the rug, he holds up his cup, with the remainder of the liquid left in it, and lets it drop to the floor. I am not sure why he does this. Does he like to see me on my hands and knees cleaning up the mess? When he spills his drink, it tends to piss him off, so why would he purposefully do this? Autism…the mystery I will never solve.

Christmas, for me, isn't a season of miracles. It's a yearly season I wonder if I will survive.

"I never have enough money to buy you kids the things I want."

"We don't need it. Don't worry about it. You stress out way too much," daughter #1 says to me.

"You make a good point. No, you don't *need* stuff. It's what I want to do, but can't afford. Your aunt can afford to get her kid oodles and oodles of gifts. Your in-laws can afford to buy you things I always wanted to."

"Stop it. Stop comparing yourself to other people. My aunt has one child, you have *four*. Of course, you can't afford what she can. My in-laws have both worked a long time and are at a different place financially than you are. You haven’t been able to do all the things they have. Just stop it. We love you and we don’t need stuff.”

“I know,” I sniffle.

“Good. Now quit being a drama queen and get over yourself.”

There have been Merry Christmases and Un-Merry Christmases over the years and I’ve survived them all. But, that first Christmas as a single mom is one that will stick out in my mind because of the discovery I made.

Chapter 4. Tire Swings and Broken Fingers

“Help me! Get him off of me!” I screamed.

Daughter #2 ran out of her room – the room I told her and daughter #3 to stay in during the epic autism meltdown that was occurring. I did not want them hurt by their brother, but now I was the one being hurt and, this time, he was winning.

Moments earlier I had been sitting in my office, aka my dining room. I worked from home as a transcriptionist, and I wanted to finish typing the final report so I would be done for the day. I knew I needed to stop working when the high-pitched whining started, but I keep repeating, “One more minute, baby boy, this is the last one. I promise. Then I will give you all the attention you want.” But, it was too late. He lunged for me, hands and mouth open – in attack mode. My desk was a straight shot from the living room, which made access to me easy. The direct path from my desk to the back door was stacked with boxes because I had been cleaning and packing away unused stuff to make more room and because of this my escape route was closed. I stared into my rage-filled, 20-year-old, son’s face and knew his sole purpose for existence at that moment was to hurt me. Because he hurts. The world of silence that traps him becomes too much at times. Nonverbal, with no ability to ask questions, explain needs, vent his anger, would lead to lashing out. This was one of those times.

It was my fault. After all these years it seemed I would have learned not to push it, but I pushed it that Saturday morning and I was stuck in a fight I couldn’t win.

What had caused this autism meltdown? His DVD of *Beauty and the Beast* froze. He was already in a testy frame of mind as he had been awake for 36 hours, but the DVD glitch led to all out warfare. He now used his body to keep me blocked in the hallway.

There was no escape. I attempted to get into the bedroom with my daughters. I failed. I could not manage to get inside without my son following me. “Lock yourselves inside and call L at work. Tell him it’s an emergency.” Daughter #2 was already on the phone by this time and yelled through the closed door, “He is on his way!”

I refused to remain a prisoner in the hallway. Our hands were clasped, my son and I, as this was always the only way I had to keep his mouth away from me. I began to perform this weird dance with my body, a cross between a salsa and a wresting maneuver, so that I was back in the living room, but I continued holding his hands. My hands are all that protected me from his wrath. He forcefully kicked my shins. I was terrified. The adrenaline produced as a result of fear was the only thing that gave me the strength to hold him away from me. He wanted to bite my face, but since he could not make it my face he pulled my hands to his mouth and bit. Left hand index finger first, I saw bone. Right hand index finger, my knuckle was exposed and only a skin flap remained. Right hand pinky, top joint snapped by his teeth. I screamed for help.

“What do I do?” asks Daughter #2 as she exits her bedroom, making sure the door locks behind her.

“I don’t care. Get him off me! Pick up the chair, hit his back, and when he lets go, run like hell!”

She did. He did.

She ran. I ran.

She locked herself in my bathroom. He jumped up and down, full weight, and I heard the floor groan under his anger.

I ran across the kitchen, bare feet sliding on the vinyl floor, out the back door and rounded the corner of the house as L pulled in the drive. I collapsed and jerked my head towards the house indicating he needed to get inside – fast!

I sat on the snow-covered ground and I shoved my blood-covered hands into the snow. I watched the blood from my hands begin to form a pattern that spread over the snow. The contrast was vivid – beauty and pain meeting. Bloody trees emerged, centimeter by centimeter, as I sat transfixed.

I looked up and saw the naked, black tree branches.

I looked down and saw the naked, red tree branches.

The iciness of the snow froze the remaining adrenaline that coursed through my body and I remembered…

*****

Fear.

As a small child, I lived in fear of my father. I never knew when he would lose his temper and hit me. I don't remember wanting him to die, or even hating him, but I do remember not wanting him to return when he left. When he was around, I always felt like throwing up.

The summer I was six was the first time he hit me in a place on my body that everyone could see. "Hit" is a kind word for what he did. Having become enraged over something he assumed I did, he beat me with a stick about five feet long and an inch in diameter. His anger was something I was familiar with. I did not eat my eggs – hit. I was watching *Scooby-Doo* – yell and demand I turn it to *The Pink Panther*. I wanted to talk to my mom – mocking voice telling me I was a useless little girl, as were all girls, and then tell me to get the hell out. That particular summer evening remains seared into my memory.

It was an early evening in June, after supper, and my sisters and I were outside playing. We lived in the middle of Lamar, population 350, on about half an acre, but our yard had trees galore: Magnolia trees in the front with huge white flowers and the fruit cone center that I always referred to as the “pine cone thingy,” a small grove of pecan trees, and several huge American Elm trees. The biggest Elm tree, the favorite backyard tree of my sisters and me, had a large, low-lying branch and we decided to make a tire swing. We had everything we needed. Being the oldest, and at that time the tallest, it was my job to throw the rope over the branch.

“Come on, Tiffany, you can do it,” my sisters yelled in their excited voices.

“Let’s get the tire,” I told them when the rope was finally in place. Together we picked up the tire that was leaning against the concrete shed and carried it to the rope. The tire had not been there earlier in the day, but had magically appeared, most likely another piece of junk brought into the yard by Him.

As we were pulling the rope through the tire, we heard: “What in the hell do you girls think you’re doing?” as we looked up to see Him storming towards us.

Shaking, I managed to answer, “Making a swing.”

“Stop it! Girls can’t make a swing. If I see you doing this again, I’ll hurt you,” He yelled as he walked back into the house.

We knew what He meant. It did not matter what my sisters and I did, it was never good enough or it was wrong. Our neighbor had sons. We saw how He treated those boys and it was different. These boys spent a lot of time at our house and He talked to them like they were people, but he would tell us, “girls talk too much. You need to learn *when* to speak.” They boys could talk anytime they wanted. He showed the boys how to use tools, but when we would ask, He replied, “girls don’t use tools.”

“We gotta stop,” I told my sisters.

My middle sister insisted we keep on. “Let’s do it anyway.”

“No, no, no. He’ll hurt us if we do.”

Not one to listen, she picked up the rope and threw it back over the branch. Immediately the back door opened and out He came, yelling at the top of his lungs that I’d had it and now I was going to get it.

To this day I’m not sure how he knew we were still working on the swing. I think he was simply hoping to catch me in the act of continuing my previous endeavor. I have always felt he derived pleasure from beating me.

I wish I could say I was brave and attempted to protect my little sisters, but I wasn’t and I didn’t.

“She did it. Not me.”

“Stop lying and trying to blame her. I said if you did it again I’d hurt you.”

He grabbed me at the top of the arm and dragged me along with him as he searched for his weapon. He grabbed the biggest stick he could find. It was not a switch like the thin, flexible ones from willow trees, but a small limb from a tree that was about an inch in diameter with pointed spots leaves had been ripped away. He swung this at my legs, repeatedly, until they were a bloody mess. I felt my flesh tear open and felt the blood running down my legs. From my ankles to my upper thighs – no spot was left unblemished. The blood was warm and sticky. It trickled from my legs, across my feet, to between my toes. I felt sick.

“No, no, no, stop. I didn’t do it. Mama, help me!” I cried.

Finally, my mama yanked open the back door, dishtowel on her shoulder, and ran down the seven concrete steps, and rescued me. I vomited.

My father meant to hurt me. It was deliberate and intentional. He had a choice and he chose abuse. My son did not mean to hurt me. He reacted to emotions he cannot understand and an inability to express himself.

Slowly, I pick myself up and walk up the wheelchair ramp, built by the previous owner, open the back door, and enter my house. My body felt rubbery, as if I lacked a skeletal structure. I felt like *SpongeBob SquarePants* when his legs wobble and he flails his arms. I walked through the kitchen and stepped into the living room where my son sat, on the couch, next to his stepfather who spoke softly to my son, “it’s all right now, buddy. It’s all over. You are okay. We all love you.” *I am jealous at times of this man’s ability to soothe my son in ways I cannot, and, at the same time, grateful he is able to do this.*

My son was crying the fat teardrops of a small child, as he always does after this type of colossal meltdown. He looked at me and held out his left hand, all the fingers curled under except his index finger. This was an indication that this finger must have been sprained or twisted during our “skirmish.” He wanted me to kiss it and make it better. It was also his way of offering an apology.

I returned his gaze, burst into tears, held my bloody broken hands out and say, “Look at my hands, baby boy. Do you see what you did to me?”

He stands up and moves towards me. I want to back away, but I remain and wait until my son is directly in front of me. He then lifts his hand to my face and wipes away my tears. One corner of my mouth turns into a tired smile.

“I know. I love you, too.”

*****

Minutes later, I stood in the bathroom, sink full of peroxide, coaxing myself to stick my hands in and clean the wounds. Pulling my bottom lip between my teeth I plunged my hands in and watched bubbles fill the sink. I looked in the mirror and saw the reflection of my 6 year-old self, standing under the Elm tree, legs covered in blood, and she spoke to me:

“Our son loves us.”

Chapter 5. Seizures, Memories, and (possible) Miracles

“I need an ambulance. My son is having a seizure.”

“I’m connecting you to the emergency room,” the 9-1-1 operator tells me. I hear the click and the phone in the ER begins to ring, and ring, and ring. Finally, after fifteen rings, someone answers the phone.

“Emergency Room,” a disinterested female voice says.

“My son is having a seizure,” I reply.

“Does he have a history of seizures?” she asks.

“No. He has *never* had a seizure before,” I answer.

“Okay,” she murmurs. “Tell me what is happening.”

“I was sitting at my desk and I heard a sound, like someone hitting a table with their fist. I looked at my son, asleep on the couch, and noticed his hand was hitting the coffee table next to him. I got up and realized he was asleep, but his entire body was jerking. I yelled for help. My husband and oldest daughter got him onto the floor and on his side. The jerking has slowed down now,” I tell her.

“An ambulance is on the way,” she tells me. Then, possibly because she remembers she works in an Emergency Room and should at least pretend to be concerned, or maybe because she hears in my voice the fear she would feel if it was her child, she asks, “Are you okay?”

Was I okay? During my son’s lifetime, he has been hospitalized four times: Twice with pneumonia, once when he was injured, and once when he found and took the entire bottle of his anxiety medication. Twice he has had anaphylactic shock caused by allergic reactions. Those times I had maintained control, handled the situation, and then broke down. This time, I heard the hysteria in my voice. I wasn’t the one who was handling this situation, it was his stepfather and his “big” sister. I was standing on the sidelines this time – watching, paralyzed, terrified.

Minutes later, it is over. The seizure has subsided.

He isn’t himself. He is still, quiet, calm. Not characteristics usually associated with my son.

I sit with him, on the top step of the front deck, and wait for the ambulance to arrive. It is 3 a.m. I listen, but I hear no siren. The silence is startling, I haven’t been able to stop my body from quivering with fear, but my son is like a slow-motion version of himself, leaning his head against my shoulder – something he *never* does unless he is ill. It feels like hours have passed, but it has been only minutes. Finally, I notice an intrusive light disrupting our dark solitude. I look up and see flashing lights as the ambulance tops the hill. They pass my driveway. They turn around. They pass my driveway again. They turn around. They pass my driveway a third time. My son’s stepfather walks to the highway and flags them down.

“Is this the patient?” asks the female EMT as she walks towards us. We are still sitting on the step.

I watch as she meanders towards us. The ambulance driver, also an EMT, hasn’t even removed his butt from the driver’s seat. It is obvious my son is no longer in active seizure mode, but this lackadaisical approach is bothersome. Is it real or is it an affected attitude meant to put those on the receiving end of emergency situations at ease?

“Yes, this is the patient,” I answered. “The seizure is over, but he is still not himself.”

“Well, he wouldn’t be. Does he have a history of seizures?”

“No, he does not,” I told her as I wondered the same thing I had wondered so many times before when dealing with any type of medical personnel: “Do these people ever actually communicate with each other?” But, I did not ask this question. Instead, I answered all the questions that were asked of me, relayed medical history, and agreed since the seizure was over, and all vital signs were normal, that we would forego the trip to the ER and call his physician in the morning to discuss what steps needed to be taken.

I learned a long time ago to hide the irritation from my voice. Bite my tongue. Be nice. If I don’t act like an asshole, there is less of a chance they will act like assholes. Occasionally this trick works.

Years ago, my mother bestowed a truth upon me. “Tiffany,” she said as she looked in my eyes, “you do not hide your feelings. Ever. Whatever you are feeling or thinking is written all over your face, it can be heard in your voice, and it is seen in your body language.”

“And you couldn’t have shared this information earlier, say, when I was a teenager,” I asked her.

“Why? You wouldn’t have believed me. You may not have thought you knew everything, but you sure thought I didn’t know anything,” she responded.

Reminder to self: Apologize to mother for being a selfish little shit and thank her for putting up with me.

Talking about the alarming medical emergencies that have occurred over the years is not my favorite topic. It reminds me of how life can be altered in milliseconds. With a nonverbal autistic child, there is the additional disadvantage that he cannot answer any “after” questions when the scary part is over. I think about this a lot. Body language only conveys so much and I’m left playing the guessing game.

Pets present the same type of problem when they become ill. Pet parents make due with noticing changes in behavior. Our pets can’t say, “I feel a migraine coming on”, “my stomach hurts”, or “I can’t feel my leg”, so observation is key.

I know it may seem as if I am comparing my son to an animal and I worry about the possible criticism I may receive, “Oh my god, she is comparing her son to an animal.” What if I am? Pet parents love and try to protect their pet children, the same way I love and try to protect my son. And, here is the point I am making – the key word is nonverbal.

Nonverbal takes on a significance I never imagined possible since my son is the person who cannot speak to me. My pets don’t speak to me, but I never expected them to. I expected my son would speak eventually, but, to date, he hasn’t. Before realizing my son would likely never speak, I never really thought about what it means to live with someone who is unable to form words. Now, I know.

We never know what, or who, is going to impact our lives. For instance, I love a pig named Esther. I’ve never met Esther. She lives in Canada with her dads: Steve and

Derek. She is a Rockstar Pig on Facebook and Instagram. She’s incredibly famous and millions of people love her. I am one of those people.

Growing up my television viewing consisted of three channels, two CBS stations and an NBC station. The CBS stations played mostly the same content, except in the early morning when one showed reruns of *Our Gang* and the other showed *Bewitched,* and in the afternoon when the choices were *The Brady Bunch* or *Petticoat Junction.* The broadcasting tower for the ABC station must have been too far away because we rarely got reception. However, if the TV gods felt truly magnanimous then ABC would come in long enough to watch 15 minutes of *Happy Days* before the snow began falling once again on Channel 7, leaving you wondering or not if Fonzie had been kidnapped by Mork from Ork. There were also the occasional times when adjusting the antenna on a clear night when the stars were at their brightest, holding your arms at a 45-degree angle, with one leg lifted at a 90-degree angle, while humming the *Pink Panther Theme* would bring AETN into view on the 25-inch console with the fake oak veneer.

Bewtiched, I Dream of Jeannie, The Brady Bunch, and *I Love Lucy.* I watched on weekdays, either before or after school. They were all okay, but *Green Acres* was my favorite. Not because of the dimwitted farm hand, the “farmer” who wore a three-piece suit while driving a tractor, or his ultra-glamorous wife with the exotic accent, but because of the smartest character on the show – Arnold the Pig. Arnold did everything humans did, in fact, the town thought of him as a person. He could write, he was well-informed on world events, and had a paper route. There was also Wilbur in *Charlotte’s Web,* but let’s face it, while loveable, Wilbur wasn’t too bright. He had no idea he was meant to be food for the Zuckerman family, and, if not for Charlotte, he would have been.

Arnold was brilliant, but aloof, whereas Wilbur was sweet and loyal and a great friend. As a child, I knew I wanted a pet pig, but I never told anyone this. My mom would have told me our house was too small and we could not afford to feed a pig. Everyone else would have thought I was crazy. Where I was from, pigs weren't pets – they were food.

Our small town entered the twentieth century when I was eighteen – about eighty-five years too late – when cable moved in. No longer were we limited to only three channels, but would have an amazing fifteen channels and HBO (no extra charge). Finally, I could watch movies that only those in our rural area who could afford a satellite dish or a VCR were always bragging about watching.

Thirty years later cable or satellite is no big thing, now it's social media, streaming services, and YouTube keeping me updated on everything I never knew I wanted to know – and some things I do. One lovely lady I am always ready for news about is Esther the Wonder Pig. A diva darling with a love of cupcakes and a turkey companion named Cornelius, Esther possesses a smile full of crooked teeth that makes my days a little brighter.

"I want a pig," I told my family.

"We would have a lot of bacon," replied my husband.

"We aren't going to eat the pig. I don't eat pigs. She would be a pet," I told him.

"I know what you meant," he said laughing, "I just wanted to see your reaction."

"Asshole," I mouthed back, smiling. I knew what he would say as soon as I made the announcement. He is a lover of bacon and I do not try to convert him to vegetarianism.

“I’ve read Esther’s book,” daughter #2 tells me, “and having a pet pig isn’t easy.”

“I know,” I tell her, “but, I have your brother and I’m used to challenges.”

“Yes, yes, yes! Let’s get a pig,” daughter #3 pipes in, “of course, we will have to get a bigger house with a sturdier floor.”

“Yes, we will,” I lament, “but, one day we will have that house and I will have my pig!”

Esther had a seizure a few days ago and is currently a patient at a Veterinary Hospital. I learned of this as soon as it posted to Facebook, my phone alerting me there was a notification that needed my attention. The seizure scared the crap out of her dads, which is why they’ll remain at the hospital as long as it takes to get an answer. They want to know the cause and some of the best vets in Canada are working with them to help figure out what is going on with Esther. Reading about Esther’s seizure reminds me of the seizure my son suffered a few years ago. I wanted to know the cause and it was finally determined that the seizure was most likely caused from a hit he sustained to his head a few days earlier. He had been at my mom’s house, was jumping up and down as he frequently does, and hit his head on a 2x4 located along the ceiling in her hallway. It is suspected Esther has a back injury and needs rest to heal. Seizures are weird like that – some people have one after a severe injury and others have one with no known cause, for no apparent reason. I hope Esther never has another seizure, but I am certain her dads will always be worried that another one could occur. I never want to experience another occurrence with my son. It scared me shitless.

I don’t sit around and think about it all the time, but the knowledge that my son could have another seizure is always there, lurking in the dimly lit corner of my mind. The corner I place current worries, the ones I don’t want to think about all the time, but need to keep close by and can take quickly remove from the shelf and deal with it. This corner is not to be confused with the basement of my mind. The place I keep events in my life that I never want to think about again. It is a place where the memories are covered in sheets, like furniture in an empty house, and the corners are littered with cobwebs. The windows are covered with heavy drapes attempting to keep the sunlight out, but occasionally, a sliver of sunlight breaks through and exposes one of the suppressed memories that I was certain I had long ago forgotten and I am forced to remember.

Funny thing though, all the forbidden memories I keep in this haunted house portion of my mind are not bad ones. Some of them are happy, but somehow these happy memories became tainted, associated with something unpleasant, ensnared with barbed wire to such an extent it is dangerous for me to try to retrieve them. I must wait for a slice of sunlight to break through and allow the memory to reveal itself, and little by little, as I make my way through the dust particles that have been released from their imprisonment, I can see the good and the associated pain has become dulled – not gone – but no longer that ice pick sharpness that hurts so badly it is impossible to breathe.

Memories of my son do not belong in this place. These memories must be kept within grabbing distance so that I can grab on quickly and deal with the situation at hand.

No forgetting.

Always vigilant.

It’s exhausting.

“But, Tiffany,” I can hear people ask, “isn’t this required of every parent?”

“Well, yes and no,” I know I will reply, “these memories also serve as reminders of what not to do so that I do not get a hunk of flesh bitten out of some part of my body.”

Autism parenting 101 should require the teaching of basic ninja skills. The ability to move around without being seen with your child. Or possibly, the lightning quick skills of The Waco Kid from *Blazing Saddles* who could draw his gun, fire, and re-holster it before anyone realized he had fired off a shot.

Like a Ninja or The Waco Kid, as an autism parent I develop a skill set for dealing with situations as they arise. No two situations are alike and the best I can do is pull that memory off the shelf and adapt it for whatever the current situation requires.

Pet parents must do the same thing. Neither of us get to hear any descriptive words forewarning us of what is to come – we rely on observing behavior and sometimes that fails us or we fail to observe. Like I said, it’s exhausting, but we can’t spend all our time worrying about *what may* happen, so, my solution is to put those memories on a shelf within easy reach and pull it off when needed, like a much-needed reference book.

“Tell me if this makes sense,” I say to my three daughters a few years ago, “or if I sound like I’ve totally lost it.”

“Well, we all know you totally lost it years ago,” replies daughter #1, “but go ahead and we’ll let you know if what you are about to say makes sense.”

“That’s exactly what I was going to say,” daughter #2 says laughing.

“Yep,” chimes in #3, “same here.”

“Smartass children,” I retort, “I don’t know where you all get it from.”

All three in unison, “You!”

“Guilty,” I admit.

“Okay, here goes,” I begin. “You all know how your brother is. He is hard-headed, determined, stubborn, resistant to change, blah, blah, blah. But, what if this is the best way for him to be? Let me finish. If he wasn’t autistic, he would still be these things and it would still be almost impossible to reason with him, at least until he decided he wanted to listen, which he almost never does, and then I would deal with a whole different set of problems. What if he drank? Or did drugs? Or liked guns? Or liked to shoot guns while drinking and taking drugs and driving? Okay, maybe I’m being a little extreme, but, do you all understand what I am saying? Plus, a certain person would want more to do with him and would mess with his mind, and so I would have a stubborn-I-know-everything-no-one-can-tell-me-what-do son with a fucked-up mind. Know what I mean? Okay, I’m still working this whole thing out in my head and I know it may sound looney, but, what if the life I always thought I wanted for him would have been worse than the one he has? What if autism is the best life for him?”

“I understand,” daughters #1, #2, and #3 all reply, one right after the other.

“We know what you mean,” says daughter #1.

“I didn’t think about the alternative in this way for a long time. Whenever I allowed myself to think about what life might be like if your brother wasn’t autistic it was always in positive ways. We would all have an amazing relationship and I would have the kind of son I created for myself in my mind, but that is ideal and not real. And, what if the real was a nightmare and this is more like the dream?"

"Yeah," says daughter #2. "I think his life would be worse if he wasn't autistic. He Who Must Not Be Named would pressure him in ways he does not pressure us, because we are girls and in his mind not as important as boys, but he who shall not be named would also tell him what a bad son he is, the same way he tells my big sister what a bad daughter she is. The only reason he does not tell me this is because I refuse to speak to him. So, yeah, I get it and I've wondered about the same thing before, but I didn't want to say anything and make you feel bad because I know you already feel bad because you can't fix this."

"I love you all. I'm not sure there are any other people in my life who get me the way you three do," I tell them.

If someone says to me "it was a miracle" I will tell them "I don't believe in miracles." That is safe. It protects me from anger. If I look at life as "shit happens and we deal with it" then I have an easier time dealing with it. If I become mired down in wondering why my son is autistic and why I have never heard him say, "I love you" or "leave me alone" or tell his sisters "get out of my room," then I begin to think in terms of how unfair life is. This does no one any good.

I ask myself, "What if autism is the miracle and I'm too stupid to realize it?"

Esther's dads say she came into their life for a reason. They also admit that Esther handles the emergency situations better than they do, remaining calm even when they are in panic mode. I can say the same about my son. He remains calm when he is seriously ill or hurt. On what level did Esther understand the severity of her situation? On what level does my son understand situations that present danger or how close he has been to death on more than one occasion? Is this a miracle? That Esther and my son can accept things in stride where we cannot? We fight for their acceptance, for them to be seen as something than “other.” Esther isn’t food, she is a living creature capable of love, and my son is a young man with an inability to speak and behaviors seen as odd, who too is capable of love. I know my son is aware when someone hurts him, as no doubt Esther also is, but there is also a lack of awareness of how intense certain situations can be. Is this level of unawareness a way of protecting them in situations where panic would turn a stressful situation into a dangerous situation? I am coming to terms with the fact there will always be questions I will never have an answer for. However, I will continue to educate myself about my son and fight for him to be recognized as an individual. Esther’s dads also fight for her.

Steve and Derek, Esther’s dads, seem to always be positive, at least via Facebook, Instagram, and their YouTube videos, but having read their book, *Esther the Wonder Pig: Changing the World One Heart at a Time*, I know it hasn’t been easy, and it still isn’t. I haven’t been successful at radiating positivity, but, and I believe this, I am getting better. For me, the change in attitude that is slowly taking place is the result of letting go of anger and accepting the love others choose to bestow on me. The anger still rears its ugly head, but it is no longer a suit I constantly wear, instead it’s more like one I try on occasionally and find it no longer fits quite right.

I like my life better this way.

Chapter 6. Tattoos, Fear, and Zoloft

"Look at all the skulls," I say.

"Well, it's a tattoo parlor. What did you expect?" replies my 14-year-old daughter.

"Yes, I know, I just didn't expect so many. Why are people so fascinated with skulls?" I asked.

"Really," she mouths, looking at me incredulously. "This from a woman who wants a full skeleton in her house that she can decorate."

"True, but I don't want flames shooting out of Dante's head. I want to wrap twinkling lights and boas around his neck. He'll also need a top hat that I'll need to cut from the back to the center so that it will fit around the hook he hangs from," I tell her.

"Since when is his name Dante?" she wants to know.

"Since a couple of minutes ago. It just popped into my head. It's perfect. A skeleton, fresh from Hades, named after the man who wrote about the nine circles of hell," I explained.

"I'm glad you're my mom. You are so weird," she laughingly says.

"I'm glad you're my kid," I say back to her.

"I love you," she says.

"I love you, too," I reply.

"A lot."

"I love you a lot, too."

"I really do."

"I really do, too."

“I mean it,” she says.

“I also mean my love for you is true,” I tell her.

She smiles, puts her earbuds back in, and turns her attention back to her iPhone, leaving me alone with my thoughts. Well, as alone as one can possibly be in a tattoo parlor.

I pick up my notebook, grab my pencil, and begin writing.

It’s two days before my 51st birthday and we’re sitting in the waiting room of a tattoo parlor. Is it called a waiting room? Would foyer be appropriate? A foyer covered in skulls – some with snakes, some representative of Dia de los Muertos, some with flames sprouting through the top splintering bone in all directions. The point is, one way or another, they all represent death – killing skin, injecting a poison underneath the skin so that an image will emerge. Often, an image of death. Yet, here I sit willing to do the same to myself, pay someone for their ability to prick my skin with a tattoo needle and create the image I want displayed on my body for the rest of my life. A needle that pricks the skin 50 to 3,000 times per minute.

I’m not a fan of needles. In my experience with needles, I’ve never been the person in charge of when they pierce my skin. Someone giving me an injection, pricking myself with a needle while sewing, or stepping on a needle that has been dropped, are all unpleasant surprises. My children unintentionally helped me overcome my fear of injections. I had no choice; Rh-negative blood made it impossible to avoid the RhoGAM shots necessary to prevent my blood from developing antibodies against itself during pregnancy. It was just my luck that the first time I received one of these was from a

Nurse Ratched wannabe who held the syringe the way a small child holds a fat crayon. To use a phrase I dislike, I had to suck it up and get the shot.

As I continue looking at the photographs of skull tattoos adorning the walls, I am reminded of *The Hearse Song*: “The worms crawl in, the worms crawl out. The worms play pinochle on your snout.” The song is about what occurs during decomposition. Skull tattoos are symbols of the final stage of decomposition. This become especially true if the tattoo is all black.

“That is gross,” my daughters voice announces. “Is that really a song?”

“Yes, it is. I first heard it when I watched *Porky’s II,*” I tell her.

“What?” she asks with a quizzical look on her face.

“One of the “horny teenager movies” from when I was a teenager,” I tell her. “And yes, it was bad. Here watch.”

I open the YouTube app on my phone, type a few words in the search box, and show her the video.

“I really don’t like that song,” she replies as she turns her attention back to reading fanfiction.

“What is the fascination with skulls?” I silently ask myself. I’m determined to come up with some theory.

Are skulls a reminder that death is ever present? To be able to look at the body art that adorns your flesh and know that at any time you could be a corpse, joining the legions of the six-feet under club soon to become worm food… “they eat your eyes. They eat your nose. They eat the jelly between your toes.”

So, here I sit waiting to get my third tattoo in two months. Killing the little bit of skin that so readily accepts the ink, while at the same time freeing my soul.

How did it take me so long to let me be me? Fear. Of what others would think, of what I would think of myself. Here I sit, closer to death than not, and I finally feel liberated enough to show others who I am.

“Are you depressed yet?” Is the question I would ask my readers at this point.

I’m jolted out of my reverie by a voice above me.

“What are you writing?” asks the tattoo artist, on his way to the vending machine.

“Ideas for a paper,” I respond.

“Hey,” he says, “sorry you are having to wait again, but my friend from Texas showed up unexpectedly and I had to work him in. You understand.”

“No. Really I do not. He should have called and made an appointment. I walked in and made an appointment *and* paid a deposit at the same time. I’m really tired of being jerked around.” This is what I want to say, but knowing I had already paid a deposit, money I would not get back if I left, I cowardly smile, nod, and mumble, “sure.”

“Thanks for being cool with it,” he says. “So, tell me why you want this particular tattoo.”

“It’s a tree, which reminds me to stay rooted. The color of the leaves represents the colors of autism…”

He cuts me off and tells me, “I know all about autism. I’m autistic. Well, Asperger’s, but it’s all the same thing.”

If autism had not entered my life, who would I have become? My voice catches in my throat when I imagine my life void of autism. As I am wondering about this question, I recall a conversation with my mother that took place eighteen years ago. It was a few months after my divorce and we were in her backyard pushing the swings holding my two youngest children. What I said to her is a mystery, but she blurted out, with tears in her eyes, “My daughter is back.” Until that moment, I never knew I was gone. I now realize if I had not made that escape, I would be a prisoner in a marriage in which I lacked a voice, and would allow myself to be little more than the hired help.

Autism saved my life.

How could I explain this to a person who so cavalierly says, “it’s all the same?” It isn’t the same. He, the tattooist, is a high-functioning, verbal, business owner. My son is nonverbal and requires someone monitor him 24-hours a day. It is not the same.

I knew in that moment that, once my tattoo was completed, I would never return to this place again.

I left my marriage with the only items of importance: my children. No house, a ten-year-old car, and no money. If I’m being honest, in a moment of fear, I did ask *him* a day before the court date if he wanted to try counseling and work things out, but, thankfully, he said no. I certainly did not ask out of love and most certainly not because I truly thought I would ever be happy with this person. In a moment of weakness, I was willing to sacrifice a chance at happiness and freedom for a lifetime of misery and a house. I’m grateful every single day that I was turned down.

Autism forces me out of my comfort zone and requires me to face fears head-on. From the moment I received the diagnosis, I have lived in fear of what may happen to my son. From the basic fear of “what if he can never care for himself” to the fear of “what if he has a meltdown and seriously injures someone” and now the fear of him having a meltdown in public, some bystander calling the police and my son being shot. Yes, I fear this. All that adrenaline pumping, combined with a refusal to listen, causes some police officers to be trigger happy. Shoot first and ask questions later is the mindset of so many people, and not just police officers. Add this to the fear I felt being near *him*, the fear of my father when I was young, my fear of speaking to anyone, my fear of making a mistake and people discovering I’m not perfect. Still afraid, I walked out the door, and except for that moment of weakness, I have never looked back.

Getting a tattoo, for me, is a step to overcoming fear. Not simply fear of needles, but fear of wearing part of my life on my body for everyone to see.

Imperfection.

Fear.

Vulnerability.

“How long are we going to be here? It was your turn. These people are pissing me off. Want me to go back there and tell them you were next?” My 14-year-old daughter is not happy. Neither am I.

“I can’t believe they are doing this to me again,” I say back to her. “I was certain after the time management fiasco of last time, I would be treated better this time.”

She rolls her eyes and tells me, “We should just leave. Tell them to eff off.”

“I’ve already paid a deposit. If I leave, I’ll lose it. Even if the screw up is their fault, I will be the one who pays for it,” I say to her.

"Demand they give your money back. When you got your tiny tattoos, we had to wait over two hours, then reschedule for another day, and still wait that day. You made an appointment the first time and you made an appointment this time, and it's already past your appointment time, but he calls back the guy who just shows up to do his tattoo before yours. What a douche," my child rants.

She is angry at the way I am being treated. So am I. The first appointment she is referring to was in June. I showed up at my appointment a little ahead of time to fill out the paperwork. Then I waited and waited. Finally, I was informed that the woman ahead of me had changed her mind and wanted a *much* larger tattoo than she originally asked for. In my opinion, she should have been the one to reschedule, after all, she was the one throwing off the balance of *my* universe. Here I was, a tattoo virgin, and the longer I waited the more nervous I became. But, after waiting for two hours, I was asked if *I* would mind coming in another day, so I did. I was then rescheduled for July 3rd to receive my two tiny tattoos and when I showed up that day, I waited again. Now, here I am again, waiting for tattoo number three, and some dude from Texas takes priority over me. It's been more than two hours since my scheduled appointment and I'm mad. Patience is not my virtue. I own that, but, come on, being made to wait for hours both times I've scheduled appointment is unacceptable.

"I don't really know what to do without making a scene and I don't want to make a scene. All the other people in here are male. I don't handle myself well in a group of all guys. I wish there was an "all-female" tattoo styling salon where you came in, had a consultation, designed the tattoo, chose an aromatherapy scent, selected music, scheduled the appointment, came back at the designated time where, on arrival, you are immediately swept away to a sterile, yet cozy, room smelling of lavender with the sounds of sitar music radiating from unseen speakers. Then begins the ritual of body ink embellishment, which is part of the spiritual journey of self-discovery," I dreamily convey to her.

"I still think you should demand your money back and go somewhere else," she replies. "And, I'm ready to go home."

"Me too," I concur.

"That's creepy," my middle daughter tells me.

This was a couple of years earlier, when I was explaining my fascination with birds of prey.

"Why?" I asked. "It's true. There is something equal parts beautiful and gruesome about vultures feasting on carrion."

"I'm not really seeing that," my youngest daughter pipes up from the back seat.

"Maybe. I think I know what you mean, but it's still gross," says my middle daughter.

"Come on, it's like the circle of life. You know, the animal met a premature death by automobile and rather than letting the roadkill go to waste, the vultures have lunch. Maybe it was a daddy raccoon on his way home with food for his family and while crossing the road, out of nowhere, comes a four-wheel drive, driven by a 17-year-old on his way home from a middle-of-the-woods-my-parents-will-never-find-out-where-I-was-keg-party, who hit the raccoon and never knew it. The hot dogs the raccoon had foraged, from the garbage cans at the party the teenager had just left, were immediately snatched up by other animals, who, while sympathetic to the plight of the raccoon, found free food for the taking. By midmorning vultures surround the body and fight over the white meat. By this time the raccoon wife and children have realized daddy is dead. The nearby animals arrange a wake and bring leftovers for the family to eat. The widower raccoons in the community are drawing pine needles to see who gets first dibs at dating the widow. Circle of life stuff."

'You've given this too much thought," my middle daughter tells me.

"Not really. Spontaneous nonsense on my part. It's what I do, it's what I live for. To share my nonsensical ramblings with my children," I inform her.

"I worry about you."

"Somebody needs to. Seriously though, I wish I wasn't always driving when I see this sight. I can't get pictures while I'm driving."

"*Do not* attempt to take pictures while driving. It's dangerous.

"I'm not going to. I don't want to become vulture food."

Full-size skeletons, the habits of birds of prey, and skulls may fascinate me, but this doesn't mean I want them on my body. Since the first time I read "The Raven" I've wanted a model of a skull and raven sculpture sitting on my desk, or possibly atop a bookshelf looking down, to remind me that life can be morbid at times. This doesn't mean I want these images on my body; I don't. The art displayed on my body must speak to me. It is personal. Does everyone who gets a tattoo feel this way? My youngest daughter Googled tattoos and found an image of a woman with a cluster of penises tattooed on the top of her head.

“Why?” I asked aloud. “No one can possibly be that fond of a penis, much less a gaggle of them. Please God, let those be temporary tattoos.”

“It doesn’t say they are temporary. They’re probably real,” my daughter says.

“Does she want people to call her a dickhead? I promise you, at some point, someone has told her she is “a dickhead.” I’m all for people expressing themselves, but really, a cluster of penises on the head. I think multiple penises should be referred to as “peni.” It sounds better that way. Do you think she was under the influence of something? Drugs, alcohol, a controlling boyfriend?”

“I think she’s stupid.”

And that is 14-year-old logic. I’m having a hard time arguing with it.

I’m sticking with the tree.

Twisted trunk, puzzle pieces for leaves, seven sections of color, a little boy swinging on one side of the tree, a mama bird and her three daughters on the other side. This tattoo represents my world: My four children, autism, and a reminder to stay grounded.

Hours later, and on my birthday because I was also forced to reschedule this appointment, the tattoo is on my body. I want to cry. Not because I am overcome with emotion at having my life emblazoned on my arm for everyone to see, but because it hurts. The tattoo is on the inside of my arm, right below my elbow, where the skin is tender. The tree image was tolerable, but when he began putting the colored ink on the tree branches it felt like he was moving an electric sander across the worst sunburn imaginable. I didn’t cry, because I chose this pain and I wasn’t about to cry in front of the burly tattooist, but I squeezed my daughter’s hand so hard she thought I was going to break it.

“What do you think?” asks the tattoo guy.

“It looks good. I love it,” I say looking at my variegated, extremely swollen, arm.

“Hold on, don’t leave. I need to get a picture,” he says pulling out his iPhone and clicking away. I now know my arm will end up on his Facebook page.

“The two small ones did not hurt this bad,” I say to my daughters as I am backing the car out of the parking lot.

“This one is a lot bigger and it has color,” my middle daughter answers back. She slept in the car while I was undergoing the procedure.

“That was the part that hurt. Going over the tree branches with color. Tattooing the fresh tattoo. How can people have these *all* over their body? Whatever, I did it. It’s over. What do you think? Did I make a mistake? Am I too old to get a tattoo?” I am bombarding her with questions.

“I don’t know. Yes, it’s over. I love it and I’m glad you got it. No, you didn’t. No, you aren’t.”

“Thanks! Now, let’s go home.”

My youngest daughter looks at her sister and says, “She almost broke my hand. You should have been in there and we could have taken turns having our hand squeezed by her.”

“Sorry,” I tell her.

“It’s okay,” she replies. “Hey, can we stop by Wendy’s before we go home. I want some chicken nuggies.”

"I hate it when you say that word."

"I know. Why do you think I say it?"

"To torment me."

"Yeah," she says and smiles.

Finally, home. I marvel at what I have done to my body. I've joked about getting a tattoo for a long time, but that is all it was – joking, but now, within two months, I have three. Fifty. That number allowed for a shift in my attitude. Okay, I admit it, it wasn't just that. Zoloft helped, and by helped, I mean I didn't quit taking it when I felt less anxiety, less stress, less panic, less depression. The previous three times I took it, I quit when the symptoms were manageable. I was always certain I had reached a point where I could manage without the assistance of a medication. I was wrong. Previously I was ashamed to admit I needed the help it provided. I shouldn't have been. Anxiety, stress, panic, and depression will always be part of my life, of this I am certain. They are still there, but now instead of ruling my life, they lurk behind a gossamer curtain in my mind. I see them there, waving their arms, wanting to come out and play, and frequently they do, but it's easier for me these days to say, "playtime is over – go away." Fifty said to me, "Tiffany, it's time to overcome your fears and live life. There isn't that much time left and you've wasted a lot of it by being too damn afraid to speak, to do." I'm listening. Hence, three tattoos.

A 36-inch skeleton resides in my house, his name is Jingle Bob, as does a raven skeleton. Compliments of Target. I try to take as many pictures as I can of birds of prey because there is a beauty and gruesomeness in their actions that pleases me. I try to relax when my son is on the verge of losing his cool. I’m certainly not always winning at this, but I did say try. I feel I possess an awareness of self that I never had before, or more likely, I didn’t see it because it was hiding behind anxiety, stress, panic, and depression. I want to spend the rest of my life kicking fear’s ass. I’m tired of missing out, of not knowing what might have been because I refused to take a chance. It’s not easy, but I don’t want to quit.

My name is Tiffany and I want to enjoy life.