When the Window Closes

What I learned caring for my mom while she was   
alive and dying

(a memoir)

Jennifer Sullivan

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Names and identifying details of some of the people portrayed in this book have been changed.

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Dedication

This book is dedicated to my sweetest mom. She is the heart of this memoir.

It is also dedicated to my dearest dad. He was the person I turned to when I had questions about Mom and their life together. He passed away during the final edits of this book.

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Prologue

I KNEW THIS BOOK WOULD be a reality in 2014 when a deep sense of responsibility hit me. Though I tried to put it off or think, "It's not that bad," my mom's Alzheimer's progressed quickly in the early years. As I embraced my role as her caregiver, I came to accept myself for the service I was giving and not the burden I was carrying. I wrote short journal entries and social media posts about the journey my mom and I were on. This helped me cope and made me feel less alone in my journey as I interacted with others.

The ideas in this book were in my head, but to write them down and form them into a book, I had to have one thing—an ending. And the ending, in this case, was the death of my mother.

I carried that with me for over six years.

What I learned in those six years is immeasurable. I learned to love truly and completely. I learned the living definition of unconditional love. I learned that each of us has a soul, a true self inside us, and it is always present, even when the mind falls away. I came to believe that our humanness is not in our memories or our minds but in our souls.

I am grateful beyond words for this journey, for the blessing it was to walk by my mother's side as she died slowly, a little bit each day. Her loss gave me more than I ever thought possible.

Now that she is gone, and my heart is grieving, I realize that I love truer, I feel more deeply, and I appreciate little things I never paid attention to before. And most of all, I have learned to be grateful for each day, each hour, and each minute, because you never know when it will all be over.

I was blessed to see my mom at her worst and that she trusted me with her soul when she could not remember to take care of it.

Though I would not wish this Alzheimer's caregiver journey on anyone, I gained so much from it that I cannot imagine my life without it. This journey has changed me irrevocably so that I only have a vague recollection of my life before my mom was diagnosed with Alzheimer's.

I began writing this book six weeks after my mother passed away. It poured out of me in fourteen days, and I've been editing it for the last four years. Now, I share it with you.

This book would not be possible without my mother. It is her book; my mom lived with this disease. Without her, these words would not have been written. Without her, I wouldn't have had the experience.

This is the weight of her life, not a burden but a gift she gave me, and though I wanted to give it back many times, I'm so glad I learned to carry it.

My mom was brave and strong, and she fought, even when she forgot what she was fighting for. She will always be an inspiration to me.

Being by her side as her caregiver was an honor and a privilege.

How bad is dementia, anyway?

2013

THIS STORY STARTS ON A rainy November day in 2013 when I got a phone call from my sister. She and I hadn't spoken on the phone for two years.

Our mom had learned from her mom how to ignore someone when you were mad at them and would do that to my sister and me. My sister and I took this coping mechanism into our adult lives – our family way. And it was a helpful strategy to some extent.

Not speaking gave us time to think about what had happened and what we wanted to say to each other. Conversely, if we never talked about it, time marched on, and it would be years before we reconnected. Stubbornness? Determination? Self-reliance? Whatever it was, we learned it from our mom.

The current impasse occurred in 2011 when my then fiancé and I were driving home from California through Nevada and Utah. My sister got upset because we visited my dad in Nevada but didn’t drive nine extra hours to her house in Phoenix, Arizona. To make her point, she sent me a long message telling me she and her family were not coming to my wedding in Oregon later that summer.

So, we stopped speaking. The whole thing seemed silly, but it stung, of course. I didn't reach out to her and try to mend fences because I didn't think it would change anything. I’m not saying it made sense. It’s simply the way we did things.

By the fall of 2013, though, my sister and I had started texting and emailing again because we realized something was wrong with our mom. Mom had called me about a week before and told me she'd messed up. She told me she'd had to charge all her groceries on her Target card, and now it was maxed out, and she had no money because her bank was overdrawn.

"Mom, don't you have social security that comes in every month?" I asked.

"Yes, but my bank account is overdrawn, so when that money comes in, it goes to pay overdraft fees," she answered.

"Why is your bank account overdrawn by so much?" At this point, I was worried, but I didn't want to be too pushy or she would shut down.

"I'm not sure," she said. "I got a computer virus and had to pay for that."

In my mind, I was screaming.

My mom was given a PayPal charge account to make payments on a Walmart vacuum. She used her PayPal account to pay $40 a month for antivirus protection on her old computer. My mom had no clue how to cancel those payments, but rather than stop spending money from her PayPal, she used it to pay for anti-aging face cream. I remember thinking, *you’re over 70. There’s no need for a face cream that is that expensive – you can't erase those years!* But I also realized my mom was just like anyone else, worried about time, aging, and looking attractive. And my heart softened.

My mom and I talked for a few more minutes about her money problems. She'd gotten herself in quite a financial predicament. Her PayPal was linked to her bank account. When she didn't have enough funds in PayPal, they came for her bank balance to make those monthly payments. Things started bouncing when she had no money left in the bank, and those overdraft fees added up fast.

It didn't take more than a few months for my mom to be overdrawn by over $1000, and her monthly social security check was only about $1100. All her money was gone as soon as it went into the bank.

Hence, the Target card.

What blew my mind was that my mom had always been tight with money. She paid her bills, scrimped, and saved. Losing track of where her money was and how much was going out was completely out of character.

After I talked to my mom that day, I sent my sister an email with the subject line, "Please read: This is about mom!" If I had not included the subject, my sister would likely have deleted the email without reading it. My sister answered about an hour later with a text message that said, "It's worse than you think. I'll email when I get home."

And she did.

My sister and I put two and two together and realized what a money pickle my mom was in. But my sister also told me my mom had been pulled over by the police for circling her block a few times because she couldn't remember where she lived.

"Mom also lost her job at the mall because she wasn't performing well," my sister added.

"Oh, no," I said. "So, she really doesn't have any money."

I remember giggling as a family because she’d lost her car at the mall, and security had to drive around and help her find it.

It was much worse than I realized.

And so it was that I was in the parking lot of a Target store in Oregon, shopping for Thanksgiving when my sister called me with the dementia mic drop.

A few days before, our mom had been feeling bad, so she drove herself to the hospital and was checked in under observation. Mom was there for four days and was generally unwell, throwing up and having tests. The whole thing was a little confusing, and I wondered what the hell was going on when my sister called.

"I have something to tell you," she said. “The doctor told me that mom has dementia, and she cannot go home alone."

The blood started beating in my ears.

"Ok," I said. What else could I say? My mind started churning through little bits of knowledge right away.

What did I know about dementia? Not a whole lot. *Mom's going to forget things, she's going to forget me, she may need to live in a nursing home. But it’s fine. We’ll get her some help and move her somewhere where people can take care of her. We’ll throw some time and maybe some money at it, and she’ll be fine for a while. People forget things all the time.*

It wasn't going to be that bad. *How bad is dementia, anyway?*

I listened as my sister told me some of the things that had happened in the hospital. Mom would talk to the nurses, and they would tell her stories, and hours later, Mom would tell them back their stories as if they had happened to her. This was something Mom had already done to me—a sign of dementia. A sign I didn't recognize it.

The doctor came in every day and asked general questions, including, “Bobbie Lee, who is the president of the United States?” For days, Mom answered, “The Big Zero.” She was not a fan of Obama, but eventually, she must have realized they weren’t going to let her go unless she said his name.

"Fine,” she said. “The president is Obama."

But the damage was done.

The diagnosis was in.

The doctor and nurses observed my mom. They were aware of the signs, and she had dementia. Mom wasn't allowed to go home alone. My sister and her husband had to check her out, sign some papers, and agree to take her home with them. She had to surrender her driver's license and needed specialized care. She needed a doctor's appointment for a follow-up. She needed living arrangements. She needed things we could organize and plan. At least we had things to manage. I took some comfort in that.

It was a lot, but at the time, I simply went along with it, thinking it wouldn't be that bad. As long as I was able to do something and make some plans, we would make it through this, and everything would be fine.

*How bad is dementia, anyway?*

I was completely clueless.

One thing to realize about dementia is it forever changes the lives it touches. It has no cure, no miracle, no end but death, and once it starts, there is no going back.

We all die, right?

Yes.

And none of us truly knows when or how it will happen.

Once the dementia diagnosis is given, though, how it will happen is more certain. It's long, slow, awful to witness, and awful to live through, and it might be the absolute worst way for any human being to go.

When I first learned of my mom's dementia, I had no real understanding of what it was or how it would change my life.

My life before my mom's dementia seemed like a dream like someone else lived it. So, to understand how much it changed me, I'm going back to the past to bring my mom, as she was before, back to life.

The people that made her

1938

MY MOM, BOBBIE LEE, WAS BORN in 1938 in New York City. Her birth name was Bertha May Lee, and she hated it. She may come back and haunt me for writing that name in this book. Mom chose the nickname Bobbie early in life, and she changed it legally in the mid-80s.

My mom's mom, my grandmother, emigrated from Ireland when she was 18 years old, and based on what I know of my mom, my grandmother's life greatly shaped my mom's way of being in the world.

My grandma's name was Kate—at least, that's what is on her Irish baptism certificate. Her parents were Catholic in Ireland at the end of the civil war in 1921, and they had to flee the now mostly Protestant country. My great-grandparents had six kids at the time, and when they fled Ireland, they took only their oldest daughter with them and left their other five children with relatives.

I don't have any idea why.

My grandmother, who was left behind with an aunt and uncle, did not have the best upbringing. There was alcoholism – her uncle – and loneliness. My grandma told me she used to go outside at night, gaze up at the stars and the moon, and wonder if her mother in America was looking at the same stars.

My grandma worked during her teenage years, and right after she turned 18, she paid for passage to America on a ship. Can you imagine?

She arrived at Ellis Island in New York City, where she was given the name Kathryn Quinn because Kate was a nickname. Then, she went in search of her parents in the wilds of inland New York state. Armed with only a vague address in Glens Falls, New York—none of the children had heard much from their parents—she found them and then got a job in a hospital in New York City near Ft. Jay Army base. My grandma was working at that hospital when she met my grandpa, Richard Lee, a relatively fresh Army recruit. They fell in love, dated briefly, and got married, and within the first year of their marriage, my mom was born, the oldest of eight children.

I wish I'd been told more about my grandpa. He was born in Waco, Texas, and was the son of an insurance salesman. He had four other brothers and no sisters, and his mom died when he was young. His father remarried a few years later.

My grandparents had eight living children, but my grandma gave birth to eleven babies. The family joke was that my grandma got pregnant every time my grandpa came home on leave. My mom was 21 years old when her youngest brother was born. I like to think my grandparents loved each other truly to stay together through their trials and the Army moving my grandpa and his family around so much.

In their early married life, my grandparents lived in Florida and Georgia, and then they moved to Austria after World War II. Then, they moved to New York again, Virginia, and Illinois, adding children along the way. Eventually, they all moved to Honolulu, Hawaii, where my mom graduated from high school.

I think my grandpa's post in Austria with his wife and children made the biggest impact on him. They lived on the Von Trapp estate along with other officers' families. The family lore is my grandfather was involved in helping people who were found alive in Nazi internment camps. The other responsibility he had as an officer was to try and identify the dead at those camps and then tear down the structures and return them to the earth as if they'd never been there.

My grandpa saw so much, and it's what changed who he was.

I remember my grandpa as a funny old man who was always sitting in his recliner chair with a mixed drink next to him. He laughed a lot and loudly, and he wore thick, black-rimmed glasses. He wasn't tall, but my grandma was only four feet eleven inches, so my grandpa didn't have to be tall to be a character.

My fondest memory of him was a Christmas vacation when my mom took my sister and me to the Oakland Hills, where my grandparents had retired. Our cousin lived with them, and we stayed up all night on New Year's Eve, playing games and listening to the Top 100 countdown on the radio. We were tired, but we'd been so loud that no one else in the house slept, including my grandpa. He took his best revenge, piled us in his old car, and drove us around the city to "see the sights."

My grandpa drove into San Francisco and told us all about the city. We drove up Nob Hill road, passed the mission, and then he took us across the Golden Gate, but by the time we got to the other side, we had all fallen asleep.

My grandpa put on his Army voice and woke us up, chastising us for sleeping while we drove over the most wonderful bridge in the world. He turned the car around and drove us over the Golden Gate again, yelling at us to "stay awake!"

Mom described her young life as lonely. My mom's parents moved so much that she never made any long-term friends. She was only in Honolulu for her senior year of high school. She never went back for a high school reunion and didn't keep in touch with anyone from her school years.

What she learned was how to care for her younger siblings, make food for at least ten people, and live under the thumb of my grandma, who raised all eight kids practically by herself because my grandpa was always away serving a tour somewhere.

My grandma had this thing where she would physically ignore people and problems when they reared their ugly heads. She would refuse to talk to any of her kids if she was upset with them. My grandma would avoid eye contact and ignore their existence. I can only think this was something she learned in her upbringing in Ireland. Regardless, it is how she handled stress and strain in her family, and it carried over to her children.

In her house, it was OK for the kids to ignore each other for long stretches of time. The rumor among the family was that two of my aunts shared the same bedroom for years but didn't speak to each other. This makes sense, as these same aunts don't speak to each other now. They haven't since my grandma's funeral in 2001.

Looking back at my mom and how I experienced her as a child and a teenager, it's obvious where she got her independence, her stubbornness, her mean streak, and where she learned to cook enough food for an army.

I loved my grandma, and I always thought of her as a rockstar. Her Irish accent was so beautiful, and she would sing Irish folk songs to us girls when we were little. She was tiny and fierce, and her kids respected her – although it's possible they feared her. My grandma was probably harsh at times, and if she bottled up her problems and fled her childhood home to escape, perhaps she carried that dysfunction into her life with my grandpa and then put it on her kids.

This makes sense to me now because of how my mom raised me.

My grandma's children are scattered, and only a few of them spend time together. They all have their own lives and are equally stubborn and independent.

That upbringing made my mom who she was—a person I sometimes feared, a strong-willed, independent woman who ignored me when she was mad at me. I sought her love, but I also understood I didn't have it at times.

As a young girl, it was devastating to me when I lost her love, and she ignored me when I had no way of knowing what I did or how to convince her to open up her heart to me again.

This is the woman who raised me and how her life shaped her.

The Ogre and the Summer of Love

1967

AS A YOUNG PERSON, I OBSERVED Mom's struggle in her personal life. But despite this, she always had time for friends, and she was funny and outgoing. My mom was a contradiction.

Bobbie Lee met my dad, Gerald "Jerry" Lucas, in San Francisco in the 1960s. My parents were young adults trying to make their way in the world of the Vietnam War, drugs, free love, hippies, and a revolution.

Dad was born and raised in Long Beach, California, but moved up to San Francisco to go to college. Mom had traveled the world as an Army brat. Her parents finally retired to a house in the Oakland Hills, California, and my parents met when they both took jobs in their late 20s with American Airlines at the San Francisco airport.

My mom started at the reservations desk first, though I think she dreamt of being a flight attendant. However, she was such a meanie to customers her boss demoted her, and she was placed in charge of ordering passenger meals and drinks. Mom could be disagreeable with people, so she was put to work in an office by herself until American Airlines had to hire two people to help her prepare the food and drink carts for each flight, and one of those new employees was my dad.

To hear my mom tell it, my dad didn't like her because she was a stickler for the rules and protocol. That's probably why people booking airline tickets didn't like her either. To hear my dad tell it, my mom didn't talk to anyone; instead, she wrote notes about rules and operating procedures, and though she wasn't supposed to be his boss, she treated my dad like her personal manservant. A nickname for my mom sprung up in the little department – the Ogre. Even Dad used it.

I had never heard the story of how my parents met until I was taking a family history writing class at college, and one of the prompts was to ask your parents how they met. I was expecting love and romance, my dad sweeping my sweet mom off her feet.

Instead, I was told the story of how they didn't like each other. I find it hard to believe two people who disliked each other this much actually spent enough time together to become friends, much less decided to marry. But somehow, it worked.

My mom and dad eventually became such close friends that Dad found them both apartments in the same building closer to the airport. They moved in in the spring of 1965. My dad's practical reasons were they could commute together and help each other out, but after the move, they spent so much time together that their relationship blossomed into romance.

I'd like to think the apartment building itself helped them fall in love, after all, it was on the corner of Haight and Ashbury streets in San Francisco and only two years later the corner would be the epicenter of the Summer of Love.

My dad did not propose to my mom, though they eventually tied the knot. The story goes that since he and my mom spent their nights in only one of their two rented apartments, it made financial and practical sense to him that they marry. In late 1965, he said, “We're getting married,” and my mom replied, “OK.”

I hope by this time, he'd stopped calling her the Ogre.

Within days, my dad was enrolled in Catholic Catechism classes to join the Catholic church and marry my mom in a church wedding. Grandpa Richard wouldn't approve of their engagement any other way. During the last Catechism class, the priest started talking to my parents about birth control. They were adamantly in favor, so the priest said he would not marry them. After months in classes, Dad's plans were up in smoke. He never did join the Catholic Church.

My mom and dad talked to my grandpa, and he agreed to participate in a civil wedding service performed by a justice of the peace, so my parents moved up their wedding date and scheduled it at the San Francisco courthouse.

The family joked that my mom and dad moved up the wedding date because they had to, but at this time, I wasn't a glimmer in their eyes. They were married by Judge Lenore Underwood on March 25, 1966, in the San Francisco courthouse.

My dad and mom's families lived in the Bay area, and my mom had seven brothers and sisters. Altogether, 17 guests witnessed my parents' wedding, more than Judge Underwood had ever seen at one of her weddings. My mom was thrilled to be married by this particular judge because she was famous for putting the hundreds of war protesters milling around the streets of Berkeley in jail. Perhaps my mom thought Judge Underwood would crack down on the Haight and Ashbury crowd.

Right after the wedding, my parents consolidated their lives and settled into my dad’s apartment at the Haight and Ashbury building. They lived in that building for three more years while the neighborhood evolved from a quiet little place to the crossroads of the hippie movement, which culminated in the Summer of Love.

Those of you who learned a little bit about the hippie movement and the Vietnam War protests know about the Summer of Love in 1967 and the spirit of wild revolution that sprung up on the streets of Haight and Ashbury in San Francisco. However, my parents were not hippies; in fact, they were about as far from the hippie movement as two people could possibly be.

As newlyweds, they wanted to live in peace and quiet, but during that summer, it became obvious to my mom and dad that they wouldn't be able to stay in their little apartment. As the crowds grew, my mom became increasingly annoyed with the people sleeping on the sidewalk when she came home from work.

Mom told stories of people offering her drugs, offering to pay her for sex, and the throngs of people milling about so densely during the rallies that she had to push her way through hundreds of people merely to reach her front door. Dad was more upset at his effort to make it inside the building, only to still have the music, screaming, and chanting sounds coming in through his windows.

I would love to claim to be a child born out of the wildness of the Summer of Love, but sadly, I was not. My parents were not wild. In late 1967, they moved away from Haight and Ashbury and drove across the United States to Nashua, New Hampshire, where they settled in a quiet little farmhouse on the outskirts of town.

Their first winter in New Hampshire was cold, and where the Summer of Love failed, the bitterly cold winter brought my parents together. I was born in December 1968, and my sister came two and a half years later, in early 1971.

My parents got goats, chickens, bees, and some pigs the first spring in New Hampshire. They fixed up the barn, grew wheat, and a huge vegetable garden. For lack of a better word, they became part-time homesteaders. My parents both worked in town during the day and worked the farm in the evenings and on the weekends. I have pictures of me in my baby seat with my mom grinding wheat into flour and photos of tiny me and my dad outside with the goats.

I don't remember much about it, but when my mom and dad talked about this time in their lives, they sounded wistful, like it was a beautiful time for them.

My parents lived in Nashua for at least five years because I started kindergarten there. It was the longest time I lived anywhere until my dad left us.

Life after the divorce

1980

MY PARENTS GOT DIVORCED WHEN I was ten years old. We were on vacation in a small town in Montana, and my dad and mom were not getting along, so my dad went back to his job in Minnesota, and my mom, my sister, and I stayed behind.

Dad called a few days after he left. Mom cried on the phone, and all of a sudden, my sister and I were enrolled in the local school. And that's where we stayed, in a small town in Montana, unable to escape everyone knowing we’d been left behind.

I don’t remember any conversations about the situation. Mom told us she and Dad were getting divorced. All I remember is waking early one morning and seeing my dad drive away.

This made life for our little family a little telenovela-ish because everyone knew who we were after that. I had a difficult time making friends anyway because I was a bookish girl, and we'd moved so much in my first decade because of my dad's wanderlust. I didn't have much experience in keeping friends.

Mom loathed the spotlight Dad’s leaving had placed us under. She worked hard, took on a lot of different jobs, and kept her head down. But no matter where we went in a 50-mile radius, people had been told about our poor family and how we were left in that little town on vacation.

I'm not sure if my mom was embarrassed, but her anger grew after the divorce, remaining at the surface and always about to bubble over. I had no idea how to cope. I just understood she was quiet, fearsome, and independent. I had a sense of that even as a child.

My mom was also a stylish dresser and a loyal friend. In adulthood, Mom lived in towns long enough to make some lifelong friends, and though they were small in number, they became my aunts and uncles. We had fun gatherings where all of us kids ran around and played hide and seek, and my mom and her friends sat on the porch and talked and laughed.

Today, I only have faded memories of the warm sun, the lake water lapping up on the dock, and the sounds of dogs barking, but I do remember we had happy times.

I often recall that time and reconcile my life in two parts: before and after my dad left. Though I never talked to Mom about it because she didn't want to, I got the sense she probably reconciled her life much the same. Before my dad left, she was a wife, mother, friend, and sister, and perhaps she had a sense of control and acceptance of that.

After Dad left, she was an oddity. People whispered about us, and at church, people did a double-take when we first walked in. No matter what, though, Mom made sure we went to church every Sunday. Our little family was always dressed, pressed, and ready to sit in the front row. I think my mom did that for everyone else to see and not so much for God to see us obediently attending church.

None of Mom’s family lived near us in Montana. We had to travel for days and days to visit her parents. My mom wasn't a wife anymore, and in many ways, she couldn't be a mother because she was hardly home. She was a ball of rage, and she was scary. But she also persevered, and much of what I learned about surviving my life as an adult, I modeled after her. My mom was kind and caring and willing to help others in need. But she was also stubborn. Her hard edges were visible, and they hurt.

When I was 13, a few years after my dad left, my sister had a friend named Karen whose parents were melting down. Karen's mom and dad were fighting so severely that they left her alone way too much.

Mom volunteered for our house to be her new home, and Karen moved into my sister's room and lived with us for over a year. She became such a part of our family that after her parents finalized their divorce and she went back to live with her mom, she called us her sisters and our mom, “Mom.”

Karen had all the same rules and demands on her as my sister and I did. One of our favorite memories to talk about was one evening when we three girls had not done the dishes for days despite Mom telling us to. All the dirty plates, pots, and pans were piled up around the sink. Mom happened to be home for dinner that night and called us in to eat.

Karen, my sister, and I all sat at the table and waited. There were no plates or silverware set for us. Mom walked over with a bowl of mashed potatoes and spooned it right out on the table. She did the same with the meat and the veggies, and then she brought over plastic and wooden serving spoons that were way too gigantic to actually eat with and put them down on the table for us to use.

All three of us kids stared at her, but she sat down with her huge ladle and started eating dinner, taking a little spoonful of potatoes with her huge spoon and practically sucking the food into her mouth. Mom didn't say a word. She stared straight ahead and ate.

Silence.

Initially, I laughed, and my sister and Karen joined in, but my mom did not find it funny. One little flick of her eyes in my direction was enough for me to realize this was not a joke to her. This was her passive-aggressive way of making us aware we had not done the dishes.

This was her way of dealing with it.

And this was how things went through most of my teenage years. Mom ignored rather than spoke. She seethed. She abided. She took a lot of heavy sighs. She did almost anything other than talk.

These memories of my mom and the way she was after my dad left set the stage for our adult life as mother and daughter and for the stress and anxiety that filled our hearts as we navigated her early dementia diagnosis.

I didn't have much of a relationship with her, and she didn't with me. All I had were memories of how much anger she carried deep inside after my dad left.

The Christmas crochet debacle

1985

AFTER MY PARENTS’ DIVORCE, MOM got a newspaper delivery route. She woke up at 4:30 AM every morning for almost ten years and earlier on Sundays and holidays. After she delivered newspapers, she worked at the high school as a teacher's assistant. Afterward, she went uptown to a John Deere shop and worked as their secretary for a few hours. Then, my mom finished her day at the local hospital and worked as a nurse's aide.

Financially, things were tight. My father sent some maintenance money – Mom was clear on that – but they might have had some joint debt or some she’d accumulated after they went their separate ways.

More often than not, I was already in bed asleep when my mom got home from work at the hospital, and yet somehow, she dragged herself out of bed again at 4:30 AM the next day. In addition, at the weekends, the three of us cleaned office buildings together and sometimes worked for a caterer.

Getting through the day-to-day, there wasn't much laughter, and I had a lot of alone time. I babysat various kids, cleaned gutters, and pushed our lawnmower all over town. I also played in the high school pep band, sang in the choir, and did musical theater. My sister had various babysitting jobs, and she helped my mom when she could, but she was more social and was out with her friends a lot.

Most of the time, we were each busy doing our own thing and not doing much together. But one thing we did every year was the drive from Montana to Oregon and back again during a four-day break from school. My mom's sisters lived in Oregon, and I loved visiting them because they were hilarious.

We left at the crack of dawn on a Thursday and drove 15 hours straight to a little town south of Portland. The drive now would take about 12 hours because there are a lot more freeways, but Mom drove us fast and hard, and when I got my driver's license and then my sister, we pushed faster and harder.

My mom liked Roger Whittaker and John Denver, and my sister and I loved The Fresh Prince of Bel-Air and Journey. So, we had a family rule that whoever was driving got to pick the music. My mom didn't like it, but she was also glad for the help making such a long drive, so she tolerated our musical choices.

One year, my grandparents paid for us to fly to Oregon, and after our visit, we drove overnight to the Oakland hills in California with my aunt and my cousin in her VW bug. My mom and my aunt were in the two small front seats, and three of us kids were illegally lying in the trunk space over the engine. The sounds of the wheels going over the metal connectors on the bridges stayed with me, and I always knew when we were driving through a city because the back of the car would light up as we rushed by streetlights.

The visit itself was fun but uneventful. My cousin, who was an only child, probably loved having us come to visit, and my grandpa drove us around. My mom wasn't around much, which, as a teenager, was fine with me.

When it was time to fly home, my aunt took us to the San Francisco airport. This was a fall trip, and I remember it mostly because my mom was crafting Christmas gifts for everyone. Mom was a crochet fanatic at the time. She used plastic soda can holders, the kind that held a six-pack of soda or beer, as a mold to crochet around. I don’t remember why, but she was constantly making them.

And I do mean constantly.

Mom made more of these than seemed reasonable to me. She carried an oversized cloth bag filled with plastic can holders, yarn in various colors, and hooks to string them together. When we were visiting family on this trip, all her yarn colors were red, green, and white. She was celebrating Christmas through these damn coasters.

We'd made it to the airport, checked our one communal family suitcase, and gone through security. Back then, folks went through security without a boarding pass and waited with family at the gate to say goodbye, so my aunt Mary and cousin were waiting with us.

My mom and Aunt Mary sat down by the window, and my mom took out her crochet and began working furiously to finish another of whatever she was making. They were talking in hushed voices, and I’m sure my sister, my cousin, and I read or talked to each other.

At one point, my mom and aunt stood up and walked away from us. My cousin and I glanced at each other, and I whispered, "I guess they have grown-up things to talk about that they really don't want us to hear." We giggled and went back to whatever we were doing.

My mom and aunt walked around a little corner out of view. I didn't notice that my mom left her crochet bag behind, sitting by her chair in the waiting area. I was a typical teenager and only interested in my personal cassette player and the last moments I had with my cousin before we left for another year.

When my mom came back into view, she waved us over. My sister and I grabbed our stuff, and I slung my backpack over my shoulder while my cousin tagged along.

"Come on, girls. It's time for us to go," my mom said. I turned and hugged my cousin and my aunt goodbye. My sister did the same, and I was surprised when my mom got emotional when she said goodbye to her sister.

Once we were passed all the hugging, my mom sucked in a deep breath and wiped her eyes. When she glanced up, her eyes locked with mine. "Where's my crochet bag, Jenn?"

Oh crap.

I glanced over at my sister, hoping she had the bag. But she didn't. I shrugged my shoulders like a typical teen and said, "I don't know, Mom."

"You don't have it?" she asked, her voice getting louder.

I shook my head. "I don't."

Mom rushed back to search for her bag, and as she did so, it crossed my mind that I had never been put in charge of watching the bag of crafts. My mom didn't ask me to bring it. Why was it my responsibility and not my sister's? But, of course, I wasn't going to ask the question out loud. I don't even remember if I felt bad about it or not.

As a teenager and the oldest child, I typically had so much responsibility fall onto me that I didn't think should have. I always struggled with it, and it was one of the things that led my mom and me to have a distant relationship when I became an adult. The pressure, or what I perceived as the pressure she put on me, seemed unrealistic.

This was one of those times when I was put upon and responsible even though I wasn't, while Mom acted as if I was responsible, though she didn't ask me to take care of her crochet bag.

All of us waited while my mom ran to find her crochet bag, which I was sure would be there – because who in the world would want all that damn plastic and yarn? But when my mom came back around the corner, her face said it all.

Her bag was gone. Someone had taken it, and she didn’t have time to search for it. All my mom's hard work and craftiness were snatched away by a stranger who thought they were getting something great. I have often imagined their surprise when they opened her bag.

My sister and I joked about the "nana lips," and that day, I got the nana lips for sure. But, in truth, the nana lips were no joke. I didn’t call them that then, but when my mother pursed her lips in the perfect, flat, and pained way, I knew she had something to convey. On this occasion, that something was pure disappointment. Mom would also squint her eyes at us. This was her all-purpose upset, unhappy, annoyed expression.

When she did that in the airport, it was obvious we were in trouble with a capital T. This has stayed with me so vividly that I can still clearly remember the airport gate, how the chairs sat together, the windows opening up on the runway. The planes lined up next to the walkways, taking on and letting off passengers.

I stood still while she glared at me, weighted down from the pressure to have done something I didn't realize I was supposed to do. I was also astounded someone had taken my mom's crochet bag! I was sad for her, but there was absolutely nothing I could do about it.

All of us walked to the gate and got our boarding passes ready to show the agent. My aunt leaned in and grabbed me by the shoulders, squeezing tight. "Don't worry, dear. Your mom will get over it."

I smiled at her. "I hope so."

She tightened her grip a little more and said, "She will, you'll see."

But she didn't have to sit on the plane with my mom. I did.

My mom, sister, and I boarded the plane and settled in. Mom sat in her aisle chair, staring straight ahead. My sister was sitting next to her, and I had the window seat. I reached over my sister and asked, "Do you want a book to read, Mom? I've got plenty of them."

My mom shook her head and kept staring at the seat back in front of her.

"If I had my crochet, I'd have something to do, but I don't have it. Do I?"

This didn't feel like it was a question she actually wanted me to answer, so I wiggled in my seat and went back to looking out of the window. I was painfully aware I had a book to read the entire flight, and Mom had nothing to do.

Our plane landed in Salt Lake City about an hour and a half later, and my sister and I practically ran out into the terminal, taking it all in. It would be my last look at "big city" living for another year. I realize now Salt Lake isn't that substantial of a city compared to my tiny Montana hometown, but when I was a kid, it might as well have been New York or London.

As we sat and waited for our connecting flight to Montana, a winter storm closed in, and our plane was delayed.

My sister and I ran around the airport for another hour or two, but any airport loses its appeal when you’re stuck inside with no bed, pillow, and a cassette player with dead batteries and no money to buy any. Eventually, we settled on the floor by our gate and tried to sleep.

We were in the Salt Lake City airport for over eight hours that day, and I recall my mother repeatedly saying, “If I had my crochet, I’d have something to do right now.”

It was bad enough already, but she kept rubbing it in.

Every chance she got.

We finally arrived home to our little airport in Montana, but our one communal family suitcase didn't make it. Watching the suitcases go around and around at baggage claim, we patiently waited and eventually, another flight landed, and their luggage came out.

My mom approached an airline employee and said, "Where is my suitcase?" The woman asked for her ticket and returned a few minutes later.

"I'm so sorry, but your suitcase was put on a plane to Chicago," she explained. "The storm messed everything up."

"But what am I supposed to do?" My mom asked, spreading her arms out to show we had nothing but our clothes and carry-on bags.

"Go home."

My mom's face turned red, and her voice went up an octave as she yelled, "I'm supposed to go home?"

I waited for the screaming match, but the airline employee didn't seem to care that my mom was upset, which was good because I was upset and embarrassed and wondering how I would brush my teeth.

"Go home, and someone will deliver your bag to you when it gets back here," she said. Then turned and went to help someone else.

And that was that. I would be able to brush my teeth when our suitcase got back from its adventures.

The blessing to me was that the lost luggage overshadowed the stolen crochet bag. After over eight hours of listening to my mom whisper about her stolen crafts and watching her glare at me with the nana lips, I was off the hook, and my mom had something to really be mad about.

Everything my mom, sister, and I needed was in that overlarge, shared suitcase that had gone to Chicago. We got home, exhausted and travel-weary, with no toothbrushes, toothpaste, curling irons, or hairdryers—it went on and on. Because of all the delays in our flight, we arrived home a day late, the evening before school started, so it was too late to go shopping at the local grocery store. Everything but the bars were closed for the day.

The next morning, real life started up again. We had to wake up at 4:30 AM and deliver newspapers. The entire morning was an exercise in frustration. I needed my pink frosted eye shadow, it was in the suitcase. All of us had hair issues because, without a hairdryer, we had to wait for it to dry. But even worse, we had no hair spray, curling irons, or anything else. Our 80s hair was unachievable, our wall bangs flat, and our ends so much less than shiny and curled to perfection.

We were all standing around the bathroom mirror, wondering what to do, when my mom's face lit up. She ran out of the bathroom, down the stairs to the basement, and dragged something back up. I popped my head out of the bathroom door into the kitchen, and my mouth dropped open.

No way.

"We can iron our hair!" my mom said, setting up the ironing board. She reached over to plug in the clothes iron by the microwave.

"That is never going to work," my sister laughed.

"Yes, it will. If we turn the temperature on the iron down really low and put our wet hair on the ironing board, we can dry our hair *and* straighten it at the same time," my mom explained. The iron popped and fizzed as it heated up, and the water in the tank got warm. "At least this way, our hair will have some style."

Mom lifted the iron and motioned at me. "You do me first."

As I hesitantly took the iron, my mom put her head down by the side of the ironing board. Her hair was not too long, so I had to lay it out and make sure not to touch her head. I got started and did my best to iron her hair, telling her when to move and how to hold her head.

By the time I was done, Mom's hair was sticking out all over the place like Albert Einstein's. She seemed to like it, though. She grabbed the hand-held mirror and finger-combed her hair spikes to blend them all. "I like it, Jenn. Nice work."

Whew!

My hair was longer, so I volunteered to be next. Once my head was down and I was bent over the iron board, it was an exercise in trust. The whole time, I was worried my mom would burn my hair off as payback for forgetting her crochet bag. But she did try. When she was done, I checked her work in the mirror.

"What do you think?"

I didn't want to say anything because she was trying to make this work. My hair was frightful, but I gave her a little smile instead of saying it. "It's OK, Mom. It looks good."

My mom went back to the ironing board and pointed at my sister. "You're next."

What a mess we were heading out to school that day! We all had bumps and little steam holes in our hair where the iron did its work. I was wearing old eye shadow and no mascara. Our toothpaste was baking soda and lemon juice concentrate, and we used our fingers to scrub the mixture around. I didn't want to talk to anyone because I worried my breath would stink.

But thanks to the lost suitcase, the left-behind crochet bag remained forgotten. My mistake – which wasn’t actually MY mistake – was overshadowed.

Mom never crocheted again. I don’t remember her doing another crochet project of any kind. She stopped collecting plastic soda can rings, never bought another skein of yarn, and never sat down to work on Christmas gifts like that en masse ever again. Perhaps she was already bored with it, and she took me losing the bag as a sign she should be done, or perhaps it was so disheartening to lose all that work that she couldn’t bring herself to start again.

I couldn't tell you why it matters to me now, except I cannot ask my mom why she never picked up crocheting again. Thinking about it does make me smile, though, as I remember her surly face and her pinchy eyes when we were in Salt Lake City airport.

I suppose remembering it happened and that it makes me smile is worth the mistake. What I wouldn't give to see those nana lips and her surly face right now.

And so, it came to pass

1986-2013

FOR QUITE A FEW YEARS, it was my mom, sister, and me. I'd always struggled with my relationship with my mom. I was daddy’s girl, and when my parents divorced, I was more adrift in my family, circling on the outside of my mom and my sister. They were the nucleus of our family. I was the electron orbiting widely around them—not really necessary, but just there because that's how gravity works.

Three years after my parents divorced, my dad came to visit us for the first time in Montana. He was living in Nevada and drove about 1,000 miles by road. After leaving the Navy, my dad had become an air traffic controller for the FAA, later teaching for them. Having spent most of his career teaching air traffic control, he didn't trust other controllers and didn’t like to fly.

When my dad got out of the car, my mom walked up to him and kissed him on the cheek. "I'm glad you made it."

"Me, too, kiddo," he answered, pulling his cap off and tossing it in the open car window.

I was shocked that my mom showed any affection toward my dad. I didn’t have many memories of them being affectionate, so it stopped me in my tracks when they embraced. My parents' eyes locked briefly, and then my dad turned to me and my sister. I was frozen.

"Hey, you, kiddos." He walked to me and hugged me and then my sister.

My dad drove my sister and me to a state park, and we all went river rafting and sightseeing. We sat in restaurants and talked while my dad drank his coffee, and we devoured pancakes soaked in syrup. A couple of days later, Dad dropped us off at home, hugged us goodbye, and left.

Over the next few years, we either flew to visit my dad in Oklahoma, where the air traffic control school was, or he drove to visit us. He remarried when I was 15, so when we went to visit him after that, it was us and them, but not in a bad way. It was odd for me that he was with someone else, especially since my mom remained resolutely single.

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After my sister and I graduated from high school, we left home and started our own families. My mom mellowed some as her grandchildren were born, and her hard, sharp edges dissipated. She made a beautiful life for herself.

She had friends, worked the voting polls, and was a crossing guard at her grandson’s school in Arizona. She went country line dancing at a bar every week, seemed to enjoy her work more, and was more outgoing. She was a Red Hatter. If you don't understand what that means, Google it or go to your local mall at 7 a.m. while they are walking laps. You'll understand it.

The difference between how Mom was with me and how she was with her grandkids was interesting. When I didn't eat my dinner, I had to stay at the table until everything was gone.

"You can't leave the table until you eat all your peas," she'd say, crossing her arms and leaning back in her chair.

"But, Mom, I don't like peas, and there are so many," I’d whine, pushing the food on my plate into piles, hiding the peas in the potatoes.

But she didn’t relent. Instead, she acted like a prison warden, staring at me until all my food was gone. I hoped she'd leave the table to do the dishes so I could quickly dump some of the food on the floor for the dog, but she was determined to keep her eyes on me until I ate every bite.

But with my kids, she would let them eat whatever they wanted whenever they wanted, and if they didn't like it, she would whip up something else.

"Oh, you don't like that casserole, my dears! What do you like?" She’d spin around in the kitchen. "I can make whatever you like!"

They’d pound their little hands on the kitchen table. "We want peanut and jelly!"

"Ok, let me make you some." And that was that.

My mom softened as a "Nana." In so many ways.

We were a singing family, and we sang songs together. In the car, we made harmonies that would rival ABBA. We sang John Denver, Roger Whittaker, and Allan Sherman. He was the Weird Al Yankovich of my mom’s day, and she loved him, so we loved him, too.

Mom was also a huge fan of singing in grocery store aisles to embarrass my sister and me. I don't recall my mom singing to me a lot, but I'm sure she probably did before her life turned into a struggle and anger consumed her. But then she had grandkids. I loved listening to her sing to them.

"Nana, sing us a song."

"What do you want to hear?" she'd ask.

"Bush and peckel!” My son would say with a giggle as he said it wrong on purpose. He'd learned to say it correctly in school, but we loved it when he said it like he did when he was three.

"A bush and peckel? I don't know that song," my mom would tease, giving him a little tickle, but she'd start singing.

Then she'd put her arms around my kids' necks, hug them, kiss them on the cheek, and gently tell them it was time for bed. But if they didn't want to go to bed, she would stay in their room and sing to them some more.

*You are my sunshine.*

*She'll be coming round the mountain.*

*Twinkle, twinkle, little star.*

Being a nana appeared to me to be my mom's calling. She was more open and at peace, and her anger faded. I witnessed her gentler side through my children. I didn't realize she had a gentle side when I was a kid. She was all fierce and forceful, but knowing she had it in her to be sweet and loving was beautiful.

From my mom, I learned independence, stubbornness, and a strong work ethic and that I wanted to have beautiful, connected relationships with my own children. So, I got married when I was only 20 and moved away from my mom. I was driven, worked hard, and had three children who were my life as a young mother. I endured a difficult marriage for them because I wanted them to have the best.

As I embraced motherhood and created the best possible life for my kids, my relationship with my mom suffered. We talked less frequently, we didn't visit as often, and she didn't come to see us as much either, and things were strained. Our mother-daughter relationship was tense. But I took comfort in her relationship with my kids because she embraced being a nana with her whole heart.

We were able to visit my mom about once a year. When my kids were little, and my husband and I didn't have much money to travel, she would travel to stay with us wherever we lived.

Later, after my kids were teenagers with driver's licenses, we would pile in the car and make the 22-hour drive from Oregon to Phoenix to visit my mom. My kids loved their Nana, and we made that drive fast and hard down the West Coast and into the desert. We had the same rules in the car: whoever drove got to pick the music.

These sporadic trips were the way of things for a long time. I talked to my mom on the phone occasionally, but we didn't connect much as she moved into her later life, and I embraced my adult life as a mom. That was how we lived for almost 25 years, most of my adult life.

When she blows in

1995-2013

I OFTEN JOKED ABOUT HOW MY mom loved my sister more than she loved me.

"I am her least favorite daughter," I would say to friends.

With two daughters, Mom didn't have many choices about who she might have loved more, but I always thought I was the odd person out. When the normal mother-daughter tension hit our house, I usually took on the peacemaker role between my sister and mom. They would disagree, argue, and ignore each other, and I would be the person between them, trying to bridge the peace. Once the peace was brokered, my mom and sister were thick as thieves for a while, and I was the third wheel.

Life was always a little lonely for me, and I didn't understand why I was on the outside. Perhaps it was because I didn't choose a side, preferring to remain neutral, like Switzerland. More likely, it's because, during peacetime, no one needs the peacemaker. That loneliness stayed with me into adulthood as I went out on my own, married, and had kids. I spent time making new friends and welcoming new people into my life.

I took on motherhood with everything in my soul and wanted to spend a lot of time with my kids. I wanted to talk to them and include all of them in my life. I encouraged them to talk to each other and me when things went wrong. I didn't want any of them to feel left out, unloved, or ignored. I worked hard to have a relationship with my kids that was the opposite of my relationship with my mom when I was growing up.

When my kids were little, we lived near my mom in Oregon for a few years. But rather than growing closer, my mom and I grew farther apart. By then, my sister had moved out of state with her little family, and my mom visited her every few months.

I was jealous of their bond and wanted my mom to want to spend time with me and the kids. But at the same time, I was aware my relationship with my mom was not close. I didn't want to be jealous of my sister and mom, but it was familiar territory.

So, I held on to my little kids, played with them, stayed at home and put off going back to work, and did everything in my power to make up for their nana not being around as much.

Of course, when my mom came back from visiting my sister, she'd come to visit with my kids since we lived nearby, and she'd play with them and spoil them, and they loved it. And I was glad for it, even if my mom didn't spend as much time with me.

As my kids got a little older, my husband and I made the bold decision to go back to college to finish our degrees. We moved to Idaho, followed by Utah, which further strained my relationship with my mom. She flew to visit my sister every few months, and I supposed I thought she would do the same with me and my little family. But that wasn't how it happened.

After I moved away, my mom traveled to visit me four times in seven years – but I'm not keeping track or anything. In all the years my sister lived far away from my mom, no matter where she lived, my mom visited her for a whole week every three months like clockwork.

These visits were a running joke between my sister and me when we were talking.

"I've got to get my house cleaned up and the kids' beds moved around before Mom comes to visit," my sister would complain. Her voice echoed in the bathroom as she scrubbed the shower.

"When is she coming out again?" Mom would have told me this already—many times—but I asked anyway.

"Next week, and she'll be here for two weeks!" My sister added, "I better get going so I can clean my kitchen, too, because if I don't, you know Mom will, and then I won't be able to find anything for a month." She laughed, and she sounded happy even though she was complaining.

I wanted to be happy for her, but I still had a twinge of jealousy, so I didn't say much during these phone calls. I merely listened.

Though she said she needed to go, she kept talking. "Why doesn't she spend this much time visiting you?"

I lied, "Oh, I don't know." But I did. I don’t think my sister got it – most of the time, she only thought about herself.

In addition, things were tense for me at home. My marriage was crumbling, and though we were trying to hold it together, the cracks showed, and Mom had gotten to a point where she didn't like being around my husband and me.

When we moved to Utah, things got worse. I would leave my home in the morning after a tense talk with my husband and drive to campus, find the first bathroom in whichever building was closest, and cry and cry and cry. I tried to sob quietly, but it was building up inside me to the point where I was alone, abandoned, and depressed.

I decided to go to therapy, utilizing the free services on campus. This was my first real go at counseling, but I had to do something.

My therapist was a lovely man who believed in rational emotive behavior therapy. It was all new to me, but he told me it meant that what I told myself and the things I said out loud carried meaning in my body, and if I changed what I said, I could change my feelings.

One day, I walked in, and my therapist asked me how I was doing.

"I'm falling apart," I replied, tossing my backpack on the floor.

His eyes lit up, and he smiled. "Really, I'd like to see that. I've never seen anyone fall apart before."

I stared at him.

"Is your body going to literally come apart? Like your arms and legs, are they going to fall off? I want to see that."

I had no idea what to say. I didn't want my arms and legs to fall off, so I said, "It's just how I feel."

My therapist leaned forward in his chair, put his elbows on the armrest, and linked his fingers together under his chin like an evil scientist. "Tell me more." And that's how it went.

During my sessions with him, I started saying things like, "I feel like certain things in my life are becoming difficult to emotionally connect with, like my relationship with my husband and my ability to cope with stress." I had to be incredibly particular with him. This worked, though; changing what I said and the words I used changed how I felt.

My therapist also helped me cope with my mom's visits. I was complaining in a session about how she came into town with her judgments and her crazy and how she spoiled the kids, didn't talk to me, ostracized my husband, and destroyed everything.

He leaned in again, something I was getting used to. He was ready to use his rational emotive therapy to pick apart my thinking, but in a positive way, in a way that would help me. "You mean she breaks everything in your house? Does she use a hammer?"

"No, I mean, she just ruins everything?"

"How so?"

By this time, I was used to this and had to word it differently, but I couldn't put the sentence together in a way that made my feelings make sense. "I don't know," I huffed. This was my default when I was frustrated with rationally thinking through things.

"Ok," he said. "Maybe I can help."

"Yes, please!"

"You say, your mom comes in, and she destroys everything. She upends how things are in your house, your rules, your kids, and their bedtime, and she blasts through your boundaries, right?"

"Yes."

"A hurricane does the same thing. It blows in, it destroys everything, and what can you do about it?" My therapist was waiting for an answer. Holding his breath in anticipation.

The answer was obvious. "Nothing. You can't do anything about a hurricane," I said.

"So, what if you viewed your mom as a hurricane?"

I stared at him, the gears spinning in my head. It made sense.

"Do you get mad at a hurricane? Yell at a hurricane?"

"No," I said. This was the part of therapy I loved and also hated. "You just keep going and put things back together as best you can." I was practically grinding my teeth as I said it.

He laughed out loud and clapped his hands together. "Exactly. You can shake your fists at it, but it doesn't care. It's just nature. What if you looked at your mom's visits that way? You know when she's coming, which you don't know with a hurricane. You're pretty sure how she'll act, and you know that when she leaves, you have to put things back together."

It was amazing how much it changed my attitude during my visits with my mom. I didn't take the things she said to me so personally. I wasn't frustrated when she spoiled my kids or ignored my husband. When she was gone, I took a deep breath and returned to living my life how I wanted to.

Working with this therapist was life-altering.

Before one of my mom's last visits to us in Utah, before we moved back to Oregon, she had already been pre-complaining on the phone when we talked. But I was ready for the hurricane, and I was ready to take some control back. My mom got off the plane, and this was back before September 11, when you could meet someone at their gate. She started right in on me because I hadn't brought the kids, and my sister also told her I had another new tattoo.

I moved in front of her, standing between her and the walkway to baggage claim. My mom stopped in her tracks.

I took a deep, cleansing breath.

"Mom," I started, "I'm really glad you're here, and I know the kids want to see you, but if you are going to complain the whole time and just tell me what you don't like about me and my life, there is the plane headed back to Portland." I pointed to the plane sitting outside the window—the one she had gotten off of only minutes before. "You can turn right around and walk back on that plane and go home."

My mom was stunned; her jaw dropped, and she stared at me.

It seemed like an hour, but it was probably only 30 seconds. We stood looking at each other. My heart was pounding out of my chest. I'd said what I needed to say right in the eye of the hurricane, and she was not blowing back.

My mom finally closed her mouth, took a breath, and said, "No. I don't want to go back. I'll stay, and things will be fine."

And indeed, they were fine. She had an enjoyable time with my kids, was a tiny bit kinder to my husband, and was not harsh with her criticisms of me.

I moved back to Oregon in early 2001, and my family was back within a 30-minute drive from my mom, but things with my mom and I mainly stayed the same.

Then, in 2005, I separated from my husband. The kids were closing in on their teenage years, and my mom helped us through. She let me live with her and let the kids "camp" in her living room while my divorce moved forward. We talked a lot about the past, how much she struggled knowing I was in a bad marriage, and how hard it was for her to be around me. It hurt to listen to her say that, but I was working through all this with a new therapist who was more suited to what I was going through.

Mom and I mended some fences, and I was happy we were spending more time together. We had a year, and it was wonderful, but rather abruptly, in 2006, she quickly packed up her life in Oregon and moved to Arizona when my sister and her new husband had a late-in-life baby.

My mom sold her condo, packed up her things, and relocated to be their nanny. My mom loved her grandchildren, and she realized this would probably be her last one. Since she was retired, being an everyday Nana and helping out was something she wanted to do.

This added a new strain to my relationship with my mom. When Mom left for Arizona, I was left behind again, and because she was so far away, my kids and I would not have visits from her as often. Mom flew to Oregon a couple of times, and I visited her in Arizona, but things returned to being tense between us.

During those years, between 2006 and my mom's dementia diagnosis seven years later, my life settled. I met a wonderful man, and I kept going to therapy. The kids grew and graduated from high school. My middle son joined the Navy, and my other two kids lived nearby. My new husband and I joined forces and turned his eBay hobby into a full-on business. We traveled and built a loyal circle of friends. In the summer of 2013, we spent over three weeks in Hong Kong, China, and Thailand.

Through all my hard work, my life turned out to be rather amazing. Not without the usual ups and downs, which we all have, but quite great. So, of course, when my sister called that day in November 2013 to tell me our mom had dementia and couldn't be released from the hospital unless she went home with someone, I thought my sister would take care of my mom – end of story.

This was the obvious choice.

My mom and my sister had the closest relationship, and they were already together in Arizona. But it didn't work out that way at all.

That was only the beginning of this story.

She's going to Oregon to die

2013

ONCE MOM’S DEMENTIA DIAGNOSIS was in, we had to make quick decisions, and one thing both my sister and I knew was that Mom had been talking about moving back to Oregon. So, we decided to move her back.

The grandson she'd moved to Arizona for was older now and in school, and Mom’s day-to-day life was rather lonely. What we didn't realize was that she was already struggling with her memory and had isolated herself from her friend circle to hide what was happening. It seemed like the right thing to do because Mom had talked about selling her place in Arizona and moving back to Oregon.

Right after Thanksgiving that year, we picked her moving date, and I bought my mom a plane ticket. She needed a few weeks to go through her things, and my sister was going to help Mom wrap up some financial issues, so we decided to have her fly up the day after Christmas 2013. Luckily, my aunt and uncle (my mom's sister and her husband) were retired, had an extra room in their house and were willing to have Mom live with them.

My sister and I had been through the wringer by the time my mom flew up here to Oregon.

My mom had a garage sale where she opened her home to her church friends but told them to take anything they wanted. She didn't sell anything.

At one point, a man from church loaded Mom's TV, her stereo system, her subwoofer, her cords, cables, and any other electronic thing he could find. As he was getting ready to leave, someone from the church called my sister, and she came over to check out what was happening. She saw this man with all Mom's electronics loaded into his car. My sister asked him what he was doing, and the guy said Mom was giving it all away.

I don't think Mom intended to let people take things, but she had no idea what she was doing. She'd been sick in the hospital; dementia was kicking in, and she was confused. Some guy from church taking her things wasn't something she had the skills to handle with finesse.

My sister asked him to pay for the electronics, so he put some things back and paid for the rest. But the real kicker was when my sister walked into Mom's apartment. Mom had all her medicine on the table and was selling it to some people sitting there. She didn't have anything dangerous, no narcotics, but she was selling her Zoloft, her high blood pressure meds, her Tramadol, and her sleeping pills.

As my sister sat and listened and tried to stop what was happening, some lady asked my mom why she was leaving, and she said, "They are sending me to Oregon to die."

When my sister told me that, it was hard to take in, but still, we thought we were doing the right thing. In hindsight, I'm sure it was the right thing, but the good we were trying to do for my mom didn't seem helpful to her at the time. She had to leave her friends, church, and volunteer positions. She probably wouldn't be a Red Hatter again.

It took another couple of weeks to go through Mom's things and put the rest in storage. My sister went with my mom to the bank to close her overdrawn account and pay the difference. The next day, my mom yelled at the lady at the counter to reopen her account. She didn't remember closing it.

My sister's husband took my mom's car with the collateral loan to a salvage place, got as much as he could for it, and then paid that off, too.

I called Direct TV, PayPal, and the anti-virus place from Oregon and canceled as many of my mom's accounts as possible. With no power of attorney yet, I had to pretend to be my mom on the phone and cancel her accounts. Knowing her social security number sure came in handy.

So, when my mom was somewhat ready to board a plane to Oregon, my sister and I were exhausted.

But it wasn't quite over yet.

The Nana has landed

2013-2014

"I CAN’T GO ON ANYMORE!"

The concrete posts along the drop-off area at Phoenix Sky Harbour Airport look like little seats. In a last bid to stay in Arizona, my mom sat down on one and refused to move. Not content with that, she began breathing heavily and put her hand to her head. And that’s when she said she couldn’t go on.

So dramatic.

My sister and her family stood with the luggage, watching my mom, encouraging her to stand up, telling her she had a plane to catch. This took some doing, and it's a family story for the ages, but they did check her in, and my sister got a pass to escort my mom to the gate to make sure she boarded the plane.

And that was that for them.

I waited on the other end of that flight and picked my mom up at the airport. Now, it was my turn to go through the wringer. I was about to be dropped into the deep end of the dementia pool, and I had no idea what lay ahead.

I had arranged a wheelchair to pick up my mom at her gate when she landed, not because she needed it, but because she was a slow walker, and I thought the wheelchair would help her reach the airport waiting area faster.

Boy, was I wrong! My mom told the man with the wheelchair that no one was waiting for her and that they should go straight to baggage claim. I'm not sure how, but my mom convinced this man to take her down a service elevator, completely skipping the waiting area where I was standing.

As people walked past security, I caught sight of the folks from Arizona. They are easy to spot in Oregon. They wear tank tops, shorts, and flip-flops and are generally tan. They don't look at all like they've been stuck in the rain and fog for months. As the flood of passengers thinned out and fewer and fewer people came by the waiting area, I thought perhaps Mom had forgotten something on the plane. She may have had to go to the bathroom. She might be talking someone's ear off.

I started sending my mom text messages, and then I started calling. My calls went straight to her voicemail, so I picked up the white courtesy phone and gave them my mom's name. I listened as it was announced over the airport speaker system.

“Bobbie Lee. Bobbie Lee. Please come to a white courtesy phone for an important message from your party.”

I waited. My hands in my lap, taking heavy sighs.

Finally, I decided to head down to baggage claim. By this time, my mom's plane had been on the ground for over 40 minutes. I rounded the corner and walked to the carousel where my mom's luggage would have come from. There, a man with a name tag stood by an empty wheelchair.

I went over and asked him if he had brought Bobbie Lee here. The man nodded.

"I didn't see you come by the waiting area with her. I must have missed you."

He reached down and put his hands on the wheelchair. "Um, she told me that no one was here to pick her up, so I just brought her here on the back elevator."

"Well, I'm her daughter, and I'm here. Where did she go?" I asked, looking around for her by the baggage carousel.

The man pointed over toward the MAX ticket machines. "She's over there." I followed his pointed finger. Mom was standing in front of the kiosk, staring at it. The MAX is our local commuter light rail, and Mom traveled the trains for years to and from work.

I walked up behind her. "Hi, Mom."

She glanced my way and glared. "Well, hello, Jenn. I didn't think you were coming."

A sign of so much to come.

"Of course, I was coming, Mom. Where's your suitcase?"

She waved her arm around the area, "I don't know," and I turned my head to the baggage claim carousel. An agent was lifting an overstuffed green suitcase off the circle and getting ready to tag it as lost luggage.

"Mom, is that your suitcase?"

Mom moved her head in that direction and said, "I think so, but I wanted to leave it behind. I told them not to send it."

I claimed Mom’s suitcase, convinced my mom to let me drive her, and we left the airport. I was beyond irritated. All my best airport plans to make the transition as smooth as possible had failed. We drove for an hour to my aunt's house in silence. The only noise was the radio. Mom had only been in Oregon for a few hours, and I was exhausted and ready to give her to someone else. I dropped her at my aunt’s and got back on the road to my own house, about an hour away. In a foul mood, I was already starting to think of myself as a terrible caregiver.

A few days after she arrived, I drove back to my aunt's house, collected my mom, and took her to the local Department of Human Services (DHS) office to help her apply for services. A Place for Mom and Home Instead Senior Care – referral companies who help find places for seniors to live – told me that because my mom had no retirement income besides Social Security, she didn't qualify for their help.

She was only able to apply for state assistance through Medicaid. So that was my first step. I had the application, I filled it out, Mom signed it, and we drove to the local office.

When we arrived for our intake interview, the woman sat behind her desk, studied the application, and asked my mom questions. "Do you walk with a cane?"

"No," my mom said. And I glanced down at her chair. She'd left her cane in the car.

The lady turned to me, and my mom yelled, "Don't look at her!"

"She left her cane in the car. Do you want me to go get it?" I was already rifling in my purse for the keys.

"No," the lady said. "That's not necessary." After that, she made sure to always make eye contact with my mom.

Another question was, "Do you take any medications?"

“No,” said my mom again. I had written paperwork showing the medications she took, but I didn’t have it with me.

And this was how it went.

I tried telling the woman about my mom's diagnosis in Arizona. "She was in the hospital for four days, and they diagnosed her with dementia and said that she cannot live alone."

My mom pounded her hands on her thighs and yelled, "That's not what happened!" And I didn't have any of the papers from Arizona to offer as proof.

It was my word against my mom's.

The lady was confused by the end and said she would talk to her supervisor. If they decided to move forward with my mom's application, they would have someone come out and do a home visit with my mom. As my mom was leaving, I stayed behind to talk privately with the intake lady. "She has dementia. You have to believe me."

The woman said, "I understand what you're saying, but your mom seems fine to me." She started to talk away and turned back. "I will speak to my supervisor, but I don’t have very much to go on. Your mom says she doesn't take medications. She doesn't need a cane, even though you said she has one. She's been living alone for years. She may need rent assistance or food stamps, but she doesn't seem to need the kinds of medical help you're applying for."

I started pleading, "My mom doesn't know she has dementia. She doesn't understand. Please, please, can you call my sister in Arizona? My mom was there for years. She can tell you so much more than I can. I am helping out here with my mom until my sister and her family move up here to take care of her. Please. She has to get this help."

I was begging and didn't care because I needed them to approve her application. The confused caseworker lady must have seen my desperation because she called my sister, and they eventually scheduled a home visit. After that visit, we waited for their decision on Mom's Medicaid application.

As the months wore on, I was the person who helped put my mom's finances in order. I helped when DHS approved her medical coverage. I was with her at interviews with case managers and looking at rooms in assisted living homes, hoping her housing application would be approved. As I did these things, I realized more and more that, though I didn't feel like it, I was a caregiver. If only in the sense that I was the person who was actually taking care of her. Though it was still a title that I struggled against.

While we waited, my mom continued living with my aunt. But during that time, I witnessed more and more how far Mom's dementia progressed when we weren't paying attention. A few days after we visited DHS, my aunt called me. "Your mom is out of her medication, dear. She needs refills."

I had no idea how that happened. My sister told me my mom had gotten a 90-day supply before moving here. And then I remembered my sister telling me that my mom sold her meds at the so-called garage sale. I had to call the doctor in Arizona and tell her what happened to have the refills approved and moved up to a pharmacy near my mom. Thinking I was only going to pick the prescriptions up and drop them off, I was surprised when my aunt pulled me aside when I got to her house. "Your mom has a personal issue, and I think she needs to go to urgent care."

"What kind of issue?"

"She has an itchy infection between her legs," she whispered.

Oh boy.

I called the local urgent care to ask how busy they were. I told them about my mom, and they said anyone with dementia had to go to the hospital emergency room, no matter the issue. So, we drove straight to the ER. When the triage nurse called my mom's name, I walked back with her, and as my mom started answering questions, she turned to me and said, "What are you doing here? This is personal."

"Sorry, Mom," I said as I backed away and went to sit down in the waiting area.

The nurse took my mom through the emergency room doors, but within 15 minutes, another nurse came out for me. "We have questions. Would you please come back?"

My mom wasn't making a lot of sense to them. When I walked into her little room, my mom smiled at me and was so happy. "There you are. I wondered what happened to you."

That made me smile. My mom had kicked me out of the room only to forget and wonder where I was.

As it turned out, my mom had traveled to Oregon with a yeast infection. She wasn't unaware of what it was and kept forgetting she had it. For more than a month, this infection had been brewing (such a terrible word choice), and she'd put hydrocortisone cream on it, which only made it worse.

I studied her lying in the emergency room, uncomfortable with all the itching and embarrassed that people had to see her like that, but also not able to remember why she was in the hospital. I was touched by how quickly dementia had taken not only her memories but also her ability to socialize and be herself.

My mom and I picked up some prescription cream at the pharmacy, and when I took her back to my aunt's house, I told her what was going on and asked her to help remind my mom to use this cream.

About a month after Mom arrived in Oregon, her Medicaid application for housing was approved, and we began officially looking at places for Mom to live.

Early on in her disease, mom was feisty, and because she was so far gone in her dementia before she was diagnosed, she never realized that she had it. This meant that whenever her dementia diagnosis came up in conversation with caseworkers, doctors, med aids, or anyone, Mom would become pissed off. Specifically, she got pissed off at me for talking about it. But I had to talk about it as we visited assisted living homes and talked to new doctors and case managers.

That was what led me to my caregiver title. I was the focus of my mom's anger and confusion, and I was the only face she saw consistently. No matter what she said or did or how much she ranted, I was her person. I was the daughter beside her, helping her navigate the care she needed because she couldn't do it for herself.

In March 2014, I found Mom a place to live. This was an immense relief for me, my aunt, and, at the time, my mom. I thought I'd found a place she would stay for years, meet people, be her social self, and they would keep an eye on her. I'd done my caregiver best, for now, and I would be able to take a step back.

As she settled into her first assisted living facility, I was confident. By this stage, she’d lived in 55+ communities for quite some time. Mom was social, said hello to people, and settled into assisted living with surprisingly little fuss.

I got used to my new routine. I got used to the drives to her assisted living, the sanitized odor and her being upset with me over various things. It was not a routine I wanted, and it was certainly a immense change from how my life had been – I had much less freedom and time to do what I wanted, like catching up with friends. But I had to do it for my mom because if I didn't do it, no one else was going to.

But I also believed that being the person Mom relied on was temporary because my sister and her family were moving to Oregon that summer. My sister and I talked about that when we decided to move Mom to Oregon, and they were due to relocate within months. Because my sister was my mom's favorite child, she would take over the primary caregiving, and I would be her backup if she needed me.

I hung on to that to make it through those first months. Soon, I wouldn't be doing this alone. My sister would be here to take over, and I would be able to help her, so my mom's care wouldn't be entirely my responsibility. I clung to that.

Learning to be a caregiver

2014

AT THE BEGINNING OF MY MOM’S diagnosis, I had so much to do, so much to learn, and so much to accept. As I started helping her and making phone calls, people would ask me if I was her primary caregiver. I wasn't sure what to say. I certainly didn't feel like a caregiver; I was just a daughter trying to help her mom. Caregiver was a word that came up a lot during the crazy beginning of her dementia journey, especially as I took over the planning.

Taking care of Mom and getting her settled in Oregon was nearly a full-time job. And yet, I still didn't believe that I was a caregiver.

Why?

Mainly because she didn't live with me, I wasn't helping her in the bathroom, and I wasn't the person taking care of her every need 24 hours a day. I thought that disqualified me from being a caregiver. I believed that unless I was the one she relied on every second of every day, it wasn't right to call myself a caregiver.

Real caregivers deserved that honor. I did not.

When I first told people that Mom had dementia, they would make *the* face. Everyone who has a loved one with Alzheimer's or dementia has seen that face. People frown just a little and squint their eyes. These people are sad for you. They also make a slight "ah" sound. And then the relief passes across their face. They’re glad it’s you and not them.

What I didn't realize was how quickly my mom's dementia would become the central focus of my life. When my mom was first diagnosed, I had so many things to do, and as a result, I ended up talking about my mom and her dementia quite a lot. I spoke to people who set me up with her various accounts and services. I also spent time talking to her care team and her doctor.

My life got more busy, so I had to explain to my friends why I missed events. They cared about what I was going through, of course, and asked a lot of questions. Some of my friends asked me where my mom was living, and when I told them she was in assisted living, I imagined them thinking, *what is she going on about? It can't be that bad if her mom doesn't live with her*. But mostly, I think I leaped to that assumption.

I was so hard on myself. I was sure that was what they were thinking of me – that I wasn't doing enough for my mother. That she should be living with me. Jokingly, I told people that if my mom lived with me, we would be a news story on CNN.

"What happened in this small Oregon town? Where did it go so wrong between this mother and her daughter?"

I would laugh, and they would laugh, and I would hope that explained to everyone why my mom didn't live with me. I didn't tell them anything specific; I only hoped they got the message.

As those first months wore on, it became draining to make excuses for my mom not living with me, and I had plenty of reasons why she should not.

*I travel too much.*

*I have stairs in my apartment.*

*I'm not home during the day.*

*My mom would hate living with me.*

*She would hate being a burden.*

*She and I have had a distant relationship most of my life, and I'm not her favorite daughter.*

I didn't often arrive at that last one because I already felt judged by everyone, as well as myself, and I didn't want to admit that though my mom had dementia and needed help, I was not emotionally equipped to do it.

Feeling like I needed excuses drove me crazy. So, even though I didn't feel like I was her caregiver, I had to accept that I was giving my mom the care that she needed. So, I started asking myself questions.

Am I helping my mother? Yes.

Is it stressful? Yes.

Am I making major life decisions for my mom, like where she will live, who her doctor is, helping her refill prescriptions, and speaking for her at the doctor's office or emergency room? Yes to all of those.

Am I the voice of my mom to family members who call to ask me how she’s doing? Yes.

Am I handling her money? Yes. She hated that. Did I do it anyway? Yes.

Was I filling out paperwork for her? Was I her medical power of attorney? Yes, and yes.

Was I the person she turned to when she was talking for validation that what she was saying was still true? Yes.

As I thought over all these questions and more, I realized that though I wasn't a caregiver in the traditional sense of the word, I was most definitely taking care of my mom and helping her with her life when she was starting to forget things. At first, it was small things, like where she put the keys to her apartment or how to turn her television on. Eventually, it became bigger things, like remembering passwords, taking over her finances, and making sure the food in her refrigerator wasn't spoiled.

That's important.

Because it was a chicken that started it all.

Chicken soup for the caregiver's soul

2009-2013

MY MOM SUFFERED A FALL IN 2009, and it was severe enough that she developed bleeding on her brain. This is an important distinction. The bleeding was on her brain, not in her brain. The pressure this bleeding put on her head was immense, and she complained of a headache for weeks before she finally went to the hospital.

My mom ended up having brain surgery and was in the neuro-intensive care unit for six days. She was kept at the hospital for another week and finally released to go home. I spent those 13 days with her in the hospital. This was the last time I would spend time with my mom before her dementia started. But I didn't appreciate that then.

Mom lived in Arizona in 2009, and what’s interesting in retrospect is that though my sister lived minutes away from the hospital, I flew 1,200 miles from Oregon and stayed the whole time. My kids were 19, 17, and 15, so the youngest two stayed home with their dad – the oldest had moved out for a while. But despite the children being older, being away from home was quite difficult.

I was working remotely as a web developer for a small database shop. But my sister told me she was busy working and didn't have the time, and I couldn’t let Mom sit in a hospital on her own. I guess it was like the crochet debacle – I just absorbed and responded to expectations.

My sister did come to visit my mom in the evening, but it was a sign of what was to come. Not that I regret that time with my mom. It was incredibly fulfilling. At first, I read books while she slept, but as she perked up, she became quite entertaining, cracking jokes and making the nurses laugh.

A couple of days after my mom’s surgery, one nurse came in to check on my mom, telling her, “Let me check your incision area.”

The nurse pulled back the sheet to expose my mom’s thighs and stomach. The surgeon went into her brain through a blood vessel in her upper thigh.

“That’s a surprise,” my mom said as they glanced down.

“What’s that, dear?” the nurse said, confused.

Witty as can be, my mom answered, “I didn’t realize you were going to give me a *bit and a shave* down there!”

The nurse cracked up laughing. Of course, to enter a blood vessel, they had to sterilize the area, and that included a complete shave.

The nurse told me later that my mom was a cherished patient because most of their intensive care brain patients don’t talk, much less tell jokes.

In the years after her surgery, it was obvious to me that my mom was changing, but she was such an eccentric woman, and I thought she was becoming more eccentric in her older age. My mom told odd stories and embellished events that happened. These were all signs that we didn't pay attention to.

Around this time, my sister and I had fallen out over my wedding. To work through that, I did a lot of journaling, wrote my Morning Pages, and let my sister go, focusing instead on my husband, kids, and friends. My sister and I started speaking again when my mom's dementia was diagnosed, but we skipped over everything that had happened. We didn't talk about the past or resolve anything.

My sister and I picked up our sisterhood as best we could to help my mom. But we did talk about how much Mom had changed – how oddly she acted, and we both wondered what the hell was going on. That’s one regret I have: not reaching out to my sister when I realized certain things were off things about my mom. Perhaps we would have found out sooner and gotten my mom on some early intervention medicines.

But what does this all have to do with chicken?

By the latter part of 2013, my mom had spent all of her retirement money. She'd collaterally leveraged her vehicle to pay bills, overdrawn her bank account significantly, and maxed out a Target card to buy food. She'd told me all that on the phone, and I'd already emailed my sister about it.

To help make her meager ends meet, my mom portioned out her food to last her as long as possible. In November 2013, she put some chicken breasts out on the counter to thaw. Mom most likely forgot about them and how long they'd been out. She cooked them, portioned them into small servings, and put them in the refrigerator.

Mom always warned me to be careful with chicken. "You don't want Old Sal coming to visit," she would tell me.

She always had funny one-liners – warning me in a memorable way to be careful of Salmonella poisoning.

She didn't remember her own advice. Mom ate the chicken and got awfully ill, and that is how she ended up in the hospital that day in November 2013, blaming Target for selling bad chicken, which made me laugh. She was held in observation for four days, and at the end of that stay, she was diagnosed with dementia, which was when my sister called.

That was the day everything changed for me. Things had already changed beyond repair for my mom.

My caregiver journey began that day. It began quietly and without me even knowing.

I didn't want all the responsibility, and I didn't want to be the person my mom depended on. I didn't want my life to change. But I also didn't understand the gravity of what was coming my way. At that time in 2013, if someone had popped into my life and said, "*Whoa there, Jennifer. This will change you and your relationships with everyone in your life, and it will be hard. Harder than anything you've ever been through before, you're going to begrudge your mom and your sister, and you'll be miserable for a few years, but it will all work out.*" I have no idea what I would have done. I might have run for the hills.

No one said that to me, and I thought I could shoulder it. Also, I thought it wouldn't be that bad.

What I understand now is that the caregiving I did at the beginning of my mom's diagnosis was so-called easy compared to what came later. The responsibilities and emotions pressed in on me, and fighting against them took up all my energy. Being a caregiver became a role to accept, though I did not embrace it easily. It took time, but eventually, I had to accept that my life would never be the same.

To say our overall relationship was strained once Mom moved to Oregon was putting it mildly. Of course, I always loved her, but in the years before her diagnosis, we didn't communicate well, and we went months without speaking to each other. I would send her a card for her birthday, and she would do the same, but neither of us picked up the phone and called to chat. We were not *chatters*.

It wasn't what we did.

Mom had a busy life, and so did I.

Another aspect of my caregiving journey was based on my family dynamics. It was the three of us for about half of my young life. I didn't have any other siblings to worry about, and my parents got divorced when I was 10. My sister and I didn't have a lot of choices for who would be with Mom, care for her, or help her if she needed it. My mom had my sister and me to choose from. This was something I didn't think about.

When the diagnosis first came in, I thought my sister would be the one to take on the caregiver role for my mom. That was the obvious choice for me. They lived in the same town, were together almost every day, and *they* were the nucleus—the bonded pair.

I was circling on the outside.

The grief cycle

2014-2015

THE THING ABOUT GRIEF THAT anyone will tell you, even if they've never experienced it, is that grief takes time.

What a trite and annoying statement.

The other thing about grief that no one can explain to you is how hard it hurts.

I had moments early in my mom's diagnosis where her confused face left me shaken and so incredibly sad for her that grief slammed into me. She was a powerhouse of a woman, and watching her fade away was awful. She got mixed up over little things and had a wounded expression on her face, and tears would spring to my eyes.

My mom would stand in her little kitchen with a dirty cup and stare at the sink. She would reach out to touch the handles but pulled her hand back as if she didn’t remember how to turn the water on. If I stepped in to help, she got cranky with me. So, I learned to do nothing to keep her mood more stable. Eventually, she would eventually set the cup down, shrug her shoulders, and walk away.

My mom's memory loss especially affected me with things she used to be skilled at, like computers. Though they came around in her later life, she was a whiz with computers. But when she returned to Oregon, she used my computer and my aunt's and got viruses on both.

For the first few years Mom was in Oregon, early in her Alzheimer's, and I had her over to my place about once a week. We would shop at the store, buy food for dinner, and then go to my place. This gave my mom a break from her assisted living and gave me a chance to do something else besides sitting with her in her room watching television.

On one of her first visits to my home, she walked up to me while I was cooking dinner. Mom acted shy and said, "Jenn, there's something wrong with your computer."

The confusion on her face was devastating. She was fully aware she'd done something she shouldn't have, but she also didn't understand what she had done.

Those were the moments when I truly saw her leaving – the woman she was fading away – and oh-so-slowly, my grief slipped in. So much of it was unexpected, like taking her shopping at her favorite store, walking her to the checkout lane, and seeing that she couldn't count money anymore. Those experiences gave me a window into what was to come, but I tucked most of it away in my heart. Instead of worrying about the future, I was focused on learning how to balance my life with taking care of my mom and all my new responsibilities, like helping her find a place to live, going to doctor’s appointments, and meeting with her care team.

In the summer of 2014, I talked to my mom's doctor on the phone. She explained some changes to Mom's care.

“With your mom’s Alzheimer's diagnosis, we’re going to put her in palliative care,” she explained.

I had to Google that.

Palliative care is a fancy word for the first stage of hospice. Essentially, in acknowledging palliative care, everyone has a general agreement that the patient is going to die. Perhaps not soon, but the illness is terminal, so palliative care was about making my mom comfortable while she slowly died. The doctor was going to put my mom on general meds for depression and Alzheimer's, but the goal was to ease the time she had left medically.

But my mind didn't go to the hospice part. My mind was stuck on the doctor using the word Alzheimer's. For some reason, dementia seemed less terrible, and Alzheimer's seemed awful. To me, Alzheimer's was an illness that could be inherited, and dementia was something that happened to people who got old.

I was worried that I might get Alzheimer's.

I finally asked the doctor, "You keep using the word Alzheimer's. Does my mom have Alzheimer's or dementia?"

The doctor took a beat and explained to me that Mom had Alzheimer's and that it is the most common type of dementia.

I asked the next logical question that came to my mind. "Do my sister and I have to worry that we are going to get Alzheimer's?"

The doctor went on to explain that mom had Alzheimer's from a traumatic brain injury. She'd fallen a few times and had a few concussions as a result. The doctor told me that my mom's Alzheimer's was the result of her falls and the damage to her brain and that it probably started after her brain surgery in 2009.

Was it a relief to me? Yes. My sister and I didn't have to worry.

Was it terrible news for my mom? Yes. Devastating.

I was even more worried after I spoke with the doctor. First, my mom was in palliative care, and that meant she was dying, and second, Alzheimer's was bad.

Extremely bad.

I sat on the couch that day, crying and looking up Alzheimer's on my phone to learn more about what was going to happen. There are online forms where you can enter your person's symptoms, and they will estimate how many more years your person *may* live.

And that didn't help me at all. My mom might live for ten to 20 *more* years.

2024.

2034.

The next few years were a blur. I spent them going through the motions with my mother and my family. Eventually, my family members realized that I was changing, and when they brought it up, I said, "I'm busy. I have a lot on my plate." But what I didn't realize was that I was going through a cycle of feelings about death and grief over and over. I'd probably started going through that cycle right then during that call with my mom's doctor. Right when I first learned that she had Alzheimer's. Right when I knew beyond a doubt that my mom was going to die from Alzheimer's.

In traditional terms, grief has five stages of emotions people move through and around when someone is dying. These stages were originally proposed by Dr. Elisabeth Kubler-Ross in her book *On Death and Dying*, written in 1969, in relation to people who were diagnosed with a terminal illness and the emotions they would go through in reconciling their impending death.

Over time, though, those five stages also came to include the grief that individuals struggle with when they love someone who is dying.

The first stage is denial, the next is anger, and then comes bargaining, depression, and eventually acceptance. However, these stages are not to be experienced in any particular order or over any set period of time. I don't think I ever came around to acceptance in the early years, but I did run through these emotions from denial to depression and back again. Over and over.

The traditional death and grief cycle is helpful to learn, but it's also crap. The popular idea became that a person moved through these stages and their grief would be better, or they’d stop grieving so much. But that isn't what happens.

Grief is forever. Death is for always.

It never goes away.

Putting it into stages is an okay idea so that people understand the feelings of grief, but it's crucial that people understand that it never goes away and people don't experience the stages in order. My grief cycle is ongoing every day, and mostly, I still go from denial to bargaining and back again, and it started that day in 2014.

Denial. *Mom's doing well, and she remembers a lot. Her dementia isn't that bad, right?*

Anger. *Why is she always pissed off at me? She ran away again. Dammit. I'm wasting my time. I'm just going to ignore her because she isn't doing what she's supposed to do. Doesn't she realize she has Alzheimer's?*

Bargaining. *She's doing so well that I don't need to worry about her right now. If she needs something from me, she'll call me, right?*

Depression. *What the hell am I doing? I'm not equipped for this. I hate hospitals. I don't want to go to the movies. I just want to stay at home. Mom never really gave a hoot about me anyway, so why should I drop everything and take care of her?*

All these questions rolled around and around in my head. At times, I bounced through these feelings in the grief cycle in a few days or over a few weeks. It depended on whether my mom was sick, whether she'd been in the hospital, whether she was mad at me, or if some other drama was going on.

Also, it didn't help that my mom would call family members and tell them that I shoved her away to a nursing home, had taken all her money, and paid the doctors to diagnose her with Alzheimer's so I could take everything from her. Though my family understood the truth, some people believed my mom’s stories and asked me about them.

One Thanksgiving, a couple of years after moving back to Oregon, my mom went around to all my mother-in-law's relatives and told them she needed a lawyer. My mom told everyone she needed to sue me because I stole all her money, lied to her doctors, and stuffed her in a nursing home.

I was standing in the kitchen washing my hands when my mother-in-law walked up beside me. “Your mom said that you took all her money and won’t let her move.”

“Ugh. Yeah, I don’t know what to tell you. She didn’t have any money to take …” I started to say.

“But you have to give her the money that social security gives her,” she interrupted.

“That’s the thing, though, all that money goes to the state of Oregon now to pay for her care and her place to live.”

“So, she doesn’t have any money left over,” my mother-in-law pressed.

“She gets a personal allowance each month that they give her in cash. She has that money.”

“Are you sure? Because she says that you took that.”

By then, I was done with the conversation and being second-guessed, but my mother-in-law still didn’t let it go.

I bit down hard on my tongue and took a deep breath. “I did NOT take her money. She has it,” I said firmly and studied my hands, scrubbing away to make sure they were clean.

“But Jennifer, if she wants to move to another place, shouldn’t she be able to do that?”

“Sure, but it has to be a place that takes her Medicaid where the state can pay for her room. Not all places take government Medicaid money …”

My mother-in-law interrupted me again. “But you shouldn’t make her stay somewhere if they are taking her money.”

I quickly turned to my mother-in-law and said, “I get it. My mom is saying a lot of stuff right now. But I am doing the best I can to make sure she is taken care of, and let’s remember that she has Alzheimer’s!” I tried not to yell that last part, but I was done with the conversation, so I walked away.

That Thanksgiving, I experienced denial, anger, bargaining, and depression all in one day. What an uncomfortable dinner.

This grief cycle happened over and over again for many years, and I almost always landed in sadness. A deep and abiding darkness that filled every corner of my life. On the outside, that grief started to seem a lot like depression. Though I didn't ever think I was depressed, it appeared that way to the people in my life.

My husband occasionally got frustrated with me for not wanting to do the things we used to do. He loves movies. I used to tag along with him despite not being interested in many of the movies he enjoyed. I went anyway because he wanted to go, and I liked being with him.

Eventually, something changed in me. Movies with action scenes where tons of people died started to bother me. Cities crumbled, and instead of accepting that it was a story in a movie, I was worried about all the millions of people dying inside those buildings, and all of a sudden, I wouldn't go to a lot of movies anymore.

I had always loved Disney theme parks, but they were the happiest place on earth, and as my mom's disease progressed, I wasn't happy. Being around happy people did not do anything but aggravate my grief. So, instead of our yearly trip to Orlando to spend a week blowing through Disneyworld, I wanted to go to Mexico and sit on a beach and read a book, or I didn't want to go on a vacation at all. I wanted to sit at home and power-watch all nine seasons of One Tree Hill on Netflix.

The holidays stopped being important because they'd become a marker of how much things would be different when my mom died and how much things had already changed. And the holidays were stressful because of the way my mom acted.

This part of my life lasted about four years. This was the long middle, and it was a time filled with grief, sadness, abrupt changes in my life routine, resentment, and some laughs. Thank goodness for those laughs. I don't think I would have made it through if I didn't have those enjoyable times.

As my normal routine disappeared and I was more overcome with the caregiving responsibility, I fought against the grief. Alzheimer's was too enormous and too scary, and imagining my mom dying was too painful, so I railed against it. Every time my mom acted up, I fought back against her and her Alzheimer's. And I also fought the guilt that came over me.

That Thanksgiving day, my mom asked everyone for money. I went around to every person there, though they were all strangers to me, and I told them all my mom had Alzheimer's and that her delusion was not true. I did not steal her money; I did not lock her away in a nursing home. This wasn't something I had to do, but I wanted everyone to believe that it wasn't me. It was her. My mom was the one who had Alzheimer's, and she didn't realize it. This was not a part of her reality. It was my reality. I was the one who carried that through every day with her, even as she treated me like her jailor.

I thought Mom should understand what I was doing for her and not be mad at me. Despite the days I utterly failed at being her caregiver, I thought she should be grateful. Those days, the grief plowed into me like a freight train, and I realized that almost everything I was doing was making things worse, and I also realized that I was losing her.

I remember one day, my mom came home from her doctor's office and had these papers with her. She was always organized. Most of her jobs were in reception and office administration, so she found this innate joy in keeping her personal paperwork and filing it away.

Mom showed me these medical papers, and at the top, it said her name and diagnosis.

“Alzheimer's disease from a traumatic brain injury.”

My mom pointed to those words and said, "I don't have Alzheimer's. This is wrong. We need to get this changed."

When I met her eyes, instead of offering support, love, or a hug, I was a deer in the headlights.

I blurted out, "Mom, but you do have Alzheimer's." And to this very day, I have no idea what I was thinking or why I said that.

Instantly, she was horrified as her face fell. Looking back, I believe my mom was fully aware at that moment that she did have Alzheimer's. Something was wrong, and she wanted me to help her; she wanted me to say that those papers were wrong because she wanted them to be wrong. My mom realized the truth, and she needed me to lie to her. But because I was so overcome with grief anger or grief depression or even probably grief denial, I ended up hurting her instead of accepting her.

I pushed her away instead of comforting her.

This moment and its memory are still close to me. Whenever I think about it, I am right there in her living room, and I can experience that moment all over again. The tears fall, and my heart aches for the pain I caused her. I am reminded of how much a few words can hurt and how I couldn't accept my mom for who she was and how she was. I couldn't accept where she was in her progression. At that moment, my mom wanted me to tell her that everything was going to be OK, and I let her down because I was all wrapped up in my own anger and sadness.

I didn't want her to be dying, and I didn't want the responsibility, and that moment was a clash of pain, guilt, grief, and fear for both of us. I don't think, even now, that I can ever forgive myself for letting her down when she needed me, but I have no doubt that wherever her soul is, she has already forgiven me.

Caregiving is heavy. It is all-consuming, and when you add grief on top of it, it's a hard load to shoulder. I had to accept that I was grieving and that I would be grieving for quite a long time. Looking back, I should have loved the long middle for the calm before the storm that it was. I should have cherished that time, but instead, I endured it, I suffered through it, and getting through it was work.

Hard griefy work.

The long middle is where I held on to all my anger, resentment, and irritation at so many things – chiefly the responsibility of being my mom's caregiver. Because I was doing so much of it by myself, waiting for my sister to come help.

So, in true over-achiever fashion, I went online to learn all about grief so that I would be the absolute best at experiencing it, and that's when I realized there is a particular kind of nasty grief for people who love someone with dementia or Alzheimer's.

It's called ambiguous loss, and let me tell you, I was not ambiguous about my feelings about it.

This is a special kind of griefy hell reserved for those of us who are anticipating the long, slow death of our person.

Anticipating the loss

2016

WHEN I FIRST HEARD ABOUT ambiguous loss, I was furious. First, I don't think loss is ambiguous. Loss is loss, it's sad and it's painful. I wanted to fight against it. I'm ambiguous about whether I want to go to the grocery store today – I'm not ambiguous about my mom's Alzheimer's and knowing she's going to die.

And then I read about anticipatory grief. Those two words didn't go together at all. I anticipate going to the mall to buy new jeans. I don't anticipate grief. This all seemed like a cruel joke and a poor combination of words.

But I was always one to try and look at the bright side; everyone is going to experience grief in their life, and I was getting a considerable head start on it. Knowing that weirdly helped me.

I also struggled with the not-so-bright side. Different types of grieving make regular grief even more griefy. Anticipatory grief is one of those. This type of grief applies specifically to grieving for someone who is going to die, eventually ... someday, like grieving for someone with terminal cancer, Alzheimer's, dementia, Parkinson's, etc.

So, what I'm saying is there is more grief.

I know.

This is not what I wanted someone to tell me either, but it is the truth, and knowing that I was going to have all this grief to go through did help in an odd way. At least it wasn't a complete surprise.

Anticipatory grief "refers to a feeling of grief occurring before an impending loss." And it is important to realize that this kind of early grief is not simply normal grieving begun earlier.¹ It is not pre-grief. And it's not a *grieve a lot now, don't feel as much later step either*.

Anticipatory grief came around with the idea of ambiguous loss, which was first used in the 1970s by Pauline Boss, a researcher who studied the families of soldiers who went missing in action during the war. Ambiguous loss occurs without closure or a clear understanding. It's a loss where a person is left searching for answers. This searching complicates and delays the grieving process and can result in a lot of unresolved grief.

Some common examples of this type of ambiguous loss are women experiencing infertility, the disappearance of a family  
member or a family member being physically alive but in a state of cognitive decline due to Alzheimer's or dementia.

That was me.

The emotions of ambiguous loss take over, and the regular grief process is in limbo, making it hard to cope. In the regular grieving process, after some time has passed, people experience a general sense of grief lessening. The grief is still around, and it can be heavy and present on occasions like birthdays or holidays, but usually, a person can integrate it into their lives, and the deep emotion eases off.

But in ambiguous loss, that easing, that integration does not happen. That closure, for lack of a better word, is far away and cannot be experienced in the same way. The journey to the eventual death of our loved one is so long and so difficult that we can anticipate it, but we don't experience the closure. Ambiguous loss is an open-ended, griefy hell.

We KNOW our person is going to die.

It was in her eyes as my mom forgot a little each day. I witnessed it happening as she lost her words and waited for breakfast at 5 o'clock in the afternoon. I saw it in my mom in unexpected ways, and each time, it left me with more grief to work my way through.

My mom loved the holidays, and though she celebrated all of them, her favorites were Halloween, Thanksgiving, and Christmas. She wore socks, scarves, sweaters, leggings, and earrings to celebrate each holiday, and in the weeks leading up to each one, she loved dressing for the occasion.

One evening in early November 2016, I visited with a drive-through dinner, and when I brought the food in, Mom was dressed up for Halloween. She wore a scarf, earrings, and socks and was ready. I told her how great her outfit was, but the Thanksgiving advertisements came on later that evening as we were eating and watching television.

Mom glanced at me and flicked her earring with her finger.

She said, "I missed it, didn't I? Halloween's over."

I nodded.

It was in those little moments that I realized my mom was slowly exiting this world. She was dying, and I was mourning that little part of her that left that night. I wanted to cry right then and there because my mom forgot Halloween, something she loved so much, but I couldn't cry in front of her because it would upset her. I had to hold it in, save it for later, and let the emotion go.

To me, it was another thing that reminded me that she was dying. And another thing that I experienced that prepped me for the eventual end.

When I first learned about anticipatory grief, I hated it. I hated the idea of it. I hated everything about it. I hated acknowledging it, and I thought it was a load of shit. Isn't it enough that our loved one has a terminal illness with no cure? We have to experience the grief of losing them while they are still alive and anticipate it like it was a freight train headed straight for us.

I anticipate a vacation, a bonus check, or a package in the mail. The act of anticipation to me was a positive thing, like something to look forward to, but to anticipate grief felt like a mind fuck.

Pardon my swear!

So, I did all this work to accept this grief and death cycle, and then I experienced this pressure to accept anticipatory grief all over again.

Fighting against it wasn't getting me anywhere, though. All I could do was press forward. I'd learned that from Mom. So I reached deep down inside and tried to find that wellspring of acceptance and got ready to ride the waves of whatever life and Alzheimer's and grief had to throw my way.

I'll say it again: grief is hard. Grief is going to hit you over and over again. At the most random times, in random ways, and when you least expect it. For example, when your mom is wearing her Halloween outfit in November. Grief is a pain that pierces your heart like no other.

And for me, anyway, what pierced me the most was the worry in my mom's eyes. She was a vibrant woman, full of life and laughter. When my mom was confused, sad, or embarrassed when she got something mixed up, it was painful to witness. I wanted her to be who she was. In a way, I missed who she was, and I also caught a small glimpse of what was coming and anticipated just how challenging it was going to become.

Rather than fighting that, I had to accept it. My mom would only need me more, and I needed to be ready.

Never laugh at a gift your mom gives you

1983

WHEN I WAS ABOUT TWELVE, my mom went on a trip with a few friends while my sister and I stayed with some folks in town. Mom worked hard, and it was rare that she left and went anywhere without us. The divorce changed her in ways that changed our whole lives. Mom didn't move on, she didn't date, she rarely laughed, and we were poor. However, poor is a poor word to describe how much the lack of money affected our lives.

So, when my mom returned from that short trip, I was surprised to find that she had brought small gifts for my sister and me.

Mom handed me a little box, and I opened it to find a hair comb with a soft peach-colored fake flower attached to it and a couple of ribbons and beads hanging off the side.

I took one peek at it and laughed out loud.

How in the world did my mom think I would ever wear something like this? The comb was silly, like something a grandma would stick in her hair before going out for tea.

I gaped at my mom as I laughed, and her face fell.

My mom loved what she had gotten me and had put a lot of thought into this gift. She wanted me to like it, and I realized she was crushed. She turned away.

“It's nice, Mom,” I said. “It'll look good with my church dress.”

But the damage was done. I have no idea if she even cared when my sister opened her gift, which was also a hair comb with a different colored flower. But sister had the luxury of being prepared, and she was ready with her thanks.

My mom walked away. I walked into my bedroom, sat down on my bed, and stared at the flower comb. Why did I laugh? Why didn't I like it? The truth is that it wasn’t me, and I thought Mom knew my style. Perhaps she bought something she liked and would have worn herself, but instead, she gave me this little hairpiece that was the opposite of me. Now I wonder if possibly it was all she was able to afford.

I hurt my mom’s feelings, but I learned something I have never forgotten – never laugh at a gift someone gives you.

Ever!

I saw the hurt in my mom's face so rarely that I was shocked and felt terrible. The next Sunday, I wore the comb to church, and when I came out of my room with it in my hair, my mom said, "You don't have to wear that, Jenn. I know you don't like it."

But I smiled and said, "Mom, you gave it to me and so I love it because you gave it to me."

I'd practiced the words because I needed to say something to make up for my careless behavior. Mom smiled, and we got in the car and went to church.

After Mom was diagnosed with Alzheimer's, she gave me some odd gifts. I smiled and thanked her every time and made sure to wear or use the gift so she saw that I cared. Any gift is from the heart and was picked out with care and love. My mom picked that flower because she loved it for me.

The flower comb is still in my jewelry box – a reminder that my mom had a heart and a soul long before I ever realized she did.

To love someone who is alive and dying

2016-2017

WHEN I WAS IN COLLEGE, I learned about Schrodinger's cat.

Erwin Schrodinger was an Austrian physicist who created the thought experiment that if you put a hypothetical cat in a box with some poison and a radioactive source and sealed up the box, the cat is both dead and alive at the same time.

If you open the box, you can see if the cat is dead or alive, so it is one or the other, but not both. When the box is closed, you have no idea if the cat is dead or alive. The basic idea in this thought experiment was that when the lid was closed, the cat existed at the same time as both dead AND alive.

I often thought of my mom as Schrodinger's cat. She was alive, but she was dying, and at times, she was so completely different from the woman she used to be that, to me, it seemed like her soul was gone, and all that was left was her body. Though she was not tucked in a box, there were times when she appeared both dead and alive at the same time.

She resembled my mom, but she was not my mom.

She acted like my mom but was so different from the woman who raised me.

The cat analogy didn't quite work all the time, but I guess the point that I had to wrap my head around was that my mom was going to die. There was no other end for her. My mom had Alzheimer's. Her disease was terminal. And so, while she lived, she was dying, and she was dying while she was alive.

From my perspective, this time between her initial diagnosis and her eventual move to memory care was the long middle in which I lived my days, which ran into weeks, that poured into months and years taking care of my mom as she *ever-so-slowly* died right before my eyes. We had enjoyable times during the long middle and a lot of bad times, but one of my favorite memories of the long middle was my mom's feistiness at her first assisted living facility.

The day Mom moved in in April 2014, she glanced around the room and said, “How long am I staying here?”

“As long as you need to, Mom,” I answered.

She was only there for one year.

My mom acclimated to assisted living quickly. She was always social and liked to be involved in her community. She also did what she did best: speak her mind. Mom jumped right into the fray at that facility, and people either loved her or didn't like her at all. She yelled at the nurse’s aides. She refused to sit with certain ladies at the dining room table she was assigned. When she asked to take her food into her room, they said no, and she refused to eat. My mom walked around and talked to people, and she made some friends. She loved doing chair aerobics. And she got involved in community leadership (because, seriously, folks, the idea of government never goes away, not even in an assisted living facility).

But it all came to a head when she led the charge of residents for change in her community, and the change my mom spearheaded did not amuse the facility director.

As part of the facility's goodwill, they had these cards called “WOW” cards. The residents, visitors, and family members could grab a WOW card, fill out the name of the employee who did a stellar job, and write about how they went above and beyond.

What amazes me is that Mom thought this through in her early dementia, but she was a smart, creative woman. She went around the building and grabbed every WOW card she found. Mom took them all. Once she was in her room, she crossed off WOW and wrote BOO at the top, then took the cards to the resident meeting and handed them out to anyone who would take them so that they could write everything they disliked about any employee at the assisted living.

Those BOO cards got a lot of attention, and soon, residents on every floor were writing about how rude some of the nurses were and how terrible the food was, and how the guy who cleaned the bathrooms was mean and needed to bathe more.

The BOO cards were everywhere, being put in every dropbox and left on every table, but when it came down to who started it, the other residents spilled the beans on the mastermind.

“Bobbie did it,” they all said when questioned. And that’s when I got the call.

This facility had been through a corporate buy-out. There were all new managers. They had high turnover, like most assisted living facilities do, and those BOO cards were hurtful. I think they were the straw that broke the place. Some of these old folks, like my mom, had no filter anymore, and they said what was on their mind. And a lot of what they said was not kind. A lot of what my mom wrote on those BOO cards was not kind. And my mom had been causing other problems.

Mom had walked out of the assisted living facility twice without signing out, and one of those times, she’d gotten on a city bus and ended up about an hour away with no way to return home. I had to drive to her and bring her back.

The second time, she got caught in a rainstorm, slipped and fell on some leaves, went headfirst into a mailbox, and landed in a ditch. A teenage boy drove by, picked her up, and took her back, but my mom was injured and ended up in the hospital.

The staff was sick of her, and those BOO cards threw them over the edge.

I don't think I helped my mom out any, though, because when the manager of the facility told me about the BOO cards, I laughed out loud.

There was complete silence on the other end of the phone line and then a quick inhale. The manager did not think it was funny.

“We think it would be a good idea for your mom to find another place to live,” the manager sternly said.

And that was that.

Mom's BOO cards were a flop, and when they asked me to find her another place to live, it turned out they were darn serious about that. The facility gave me one month's notice.

One year after finding her that little apartment, I was hunting for another. Luckily, I found a beautiful, small assisted living facility closer to my home and to places in town that Mom remembered. The building had only 64 residents, and the staff was much smaller. My mom had fewer names to remember, and they had fewer community politics for her to become embroiled in. She was moved in a month later and stayed until she had to go into memory care.

Mom spent about three and a half years at this facility, which had vaulted ceilings running down the entire length of the building. My mom's front door opened onto a beautiful second-story indoor walkway. Through the open-concept glass ceiling, she could lean down and talk to people and gaze up at the clouds, the sun, or the blue sky. The best part about this place was the freedom she had.

Mom had the choice to eat in the dining room or go out with someone from her church. She could walk out front and catch the bus to the grocery store or her favorite restaurant. She made friends with the other residents, people who did not have Alzheimer's or dementia, and they weren't aware Mom did, so she had more normal friendships with them. Mom and her friends went shopping together and went on walks in the park. Eventually, they all figured out what was going on with her, but she was stable for a couple of years.

I visited her once a week or so during her first year. I was still in the mindset that my mom wanted her life alone with her friends and that she wasn't too interested in a relationship with me.

Mom was aware that I was the person her doctor or case manager called when they had questions, and she also begrudgingly accepted that I was the person they called if she had to go to the hospital. She hated that, and I took that as a sign that she wanted me to stay away more, so I did.

My mom and I continued our weekly-ish visits, and I did my best to stay out of her daily life.

During the Christmas season of 2015, I was into making jewelry. I dove into the hobby like my mom had gone crazy Christmas crocheting so many years before. I went to the local craft store and bought an immense amount of earring wire, necklace chains, colorful stones, beads, and clasps. I set about making every female member of my family a pair of earrings and a matching necklace. I picked stones in their favorite colors and got busy.

My mom loved the color red, so I made her a pair of red dangling earrings and a necklace with a hanging red stone.

But after all my hard work, not a single member of my family ever wore the jewelry I made them. This reminded me of the flower hair comb my mom gave me years before and my reaction to it. Since no one in my family wore the jewelry I made, I'm glad I didn't see their faces as they opened up their gifts. My idea of home-crafted jewelry was not less is more. My craftiness leaned toward the more bits and baubles, the better.

A few months later, my mom came over for Easter. My son was in town, and he picked her up and drove her over. When she walked in, she walked straight up to me and put her face right in mine. This was a new thing with her and not something she'd ever done before Alzheimer's, but there she was, her nose practically touching mine.

Mom flicked her fingers on her earrings and said, "What do you think?"

I sighed. "They're nice, Mom."

And she flicked them again and again. "What do you think?"

"Yea, Mom. They're great."

She had a sharp expression on her face. She was concerned. "Do you know where I got these earrings, Jennifer?"

I leaned in to get a closer view. "I don't think so, Mom. Where'd you get them?"

Mom paused and stared at me.

"Didn't YOU make these for me?" She asked this tentatively, like she'd possibly gotten it wrong. Mom really wanted to be right, to have remembered it correctly.

And it hit me. These WERE the earrings I made her. I made so much jewelry in such a short amount of time rushing to finish my Christmas presents that I'd completely forgotten what bits and baubles I'd used in the earrings I'd made her. My mom was worried that she'd misremembered.

"Oh my gosh, Mom. Those are the earrings I made for you, " I said with as much lightness in my voice as I could muster. "I forgot."

"Well, at least YOU forgot something," she said. And that made us both laugh.

My mom was the only person who wore the earrings and necklace that I made that Christmas. I imagine that my crafty jewelry was over the top for most of my family, though I thought everything I made was beautiful. My mom made the effort, and she wore them. I have no idea if she liked them or not. That doesn't matter now. What matters is that she was happy, and she'd remembered something correctly.

I also remember my frustration with her at that moment. My mom often frustrated me. She was chatty and remembered stories wrong (who was I to decide that her memories were wrong?). When I was with her and she started repeating herself and eventually got angry with me for not understanding her story, I would easily become frustrated. As much as I tried not to show it, she sensed I was upset and irritated. As her memory worsened, her emotions were more attuned.

On this earring day – as soon as I got a little irritated with her for flipping those earrings in my face – her worry bubbled in.

When this memory sprung into my mind while writing this, I felt so silly for getting irritated. What was that worth? Why didn't I go along with her silliness? Why did her face right in my face bother me so much?

This memory brought me sadness for a long time, but now I can smile. I judged myself harshly for my reaction that day, and I added it to the rest of my caregiver mishaps on that journey with my mom.

Planning for the end before the end

2016

ONE IMPORTANT BUT DREADED TASK I had to do with my mom in the early stages of the long middle was to plan for the end.

Mom's care was fully paid for and sustained by the state of Oregon and government Medicaid. She was part of this beautiful program called Elder Place. Mom had a doctor who specialized in geriatrics and a case manager who checked in with her in person almost weekly. She had a nurse, a physical therapist, a speech therapist, and a counselor. My mom had complete access to everything she needed, and they included me in everything. Everyone at Elder Place was truly wonderful.

If I had taken care of Mom all by myself and had her live with me, I would have been tasked with putting all these services together on my own, but Elder Place already did that. It was a beautiful program and exactly what my mom and I needed.

One day, her case manager, Suzie, called me and said, "We need you to talk to your mom and put together an end-of-life plan."

"Why?" was my first question, and my mind started racing to all the other things I wanted to say but couldn't.

*Yuck.*

*What in the world do we need to do that for?*

*She will die, but I don't want to think about that right now.*

Suzie pushed and said it was part of their program so that family members were prepared and that, as a program managed by the government, they had her end-of-life plan in her file. Another crucial part of this was that I would also sign paperwork to officially become my mom's healthcare power of attorney so that if she were in a place where a medical decision needed to be made, I would honor my mom's wishes and make the best decision for her.

When I filled out her Medicaid forms with her initially, I was listed as a person who would make medical decisions for her if she was unable to do so. This power of attorney paperwork made it officially official.

I begrudgingly took on the task. Elder Place had given me a workbook with questions and things to consider in end-of-life planning.

I called my sister to discuss it. We chatted about basic life stuff for a few minutes, and I quickly jumped right in.

“Mom’s Elder Place program needs her end-of-life plan. They gave me a workbook,” I explained.

“Well, I’m glad it’s you and not me because I don’t want anything to do with that,” she answered.

“Do you think she wants to be cremated? Buried? You were the one who spent a lot of time with her,” I asked.

“We didn’t talk about that stuff. At all. I just don’t want a ring.”

Confused by that, I asked, “What do you mean?”

“Mom was gonna have her ashes made into two gems so we could each have rings and carry her around with us ALL the time. I do NOT want that.”

“Ok, so no ring. But does that mean she talked to you about being cremated?” I tried again.

Silence hung on the line. “I really don’t want to be involved in this part. I gotta go.” And that was that. I was on my own.

So, one day, I popped over to my mom's place and tried to play it cool. I asked her about her day, what she had for lunch and just general life stuff. And then I casually slipped in, "So, Mom. We have to talk about what happens when you die and kind of ... plan it out."

She glanced away from the television, turned her eyes to me, and squinted. "Okay. So, what do *we* want?"

I smiled. Mom didn't want to do this either.

"Well, Mom, we need to decide on a funeral home and things like whether you want to be buried or cremated and stuff like that."

She instantly huffed and slapped her hands on her knees, and blurted out, "I don't care, Jenn. Why don't you just flush me down the toilet!"

Not to be distracted, I took this as a positive sign. Perhaps my sister was right. "So you want to be cremated?"

And that is when I got the stare-down—the nana lips.

"I do not want to talk about this," she whispered.

So, I put it away for a week or so, but Mom's case manager called again and asked about her end-of-life plan. After hearing about my struggles, Suzie suggested that I come up with a few ideas on my own, present them to Mom, and try to figure out if she liked one idea more than another.

At first, I wanted to think of Mom's case manager as someone who took on the hard stuff I didn't want to or wasn't ready to do, but over time, Suzie became a person I turned to for sound advice. She loved Mom, and her wisdom and ideas often came from previous experience. So, this time, I listened to her. I wrote a few ideas based on what Mom had said over the years. I was not a fan of the ashes-to-rings idea, but she’d talked to my sister about it, so I wrote it down, hoping I would be able to steer her away from it.

Mom had also talked about planting a tree using her ashes and calling it the Nana Tree, so her family could come to sit by her tree and talk to her. I wrote that one down, too.

I also wrote down a casket burial, wondering where she would want to be buried. My mom's parents were buried near Oakland, California. Perhaps that's where she'd want to go? I wrote it down.

As far as a service, I always thought she would want a church service and a fancy dinner afterward, where people might gather and tell stories about her, and laugh, hug, and cry together.

Since bagpipes are a thing at American-Irish funerals and every member of the family on Mom’s side who has died has had bagpipes at their funeral, I imagined a bagpipe player blasting Amazing Grace as we let balloons go floating to the sky covered in messages we'd written to her.

I wrote both ideas down.

When I finally talked to Mom again about her end-of-life plan, she was in a better mood. But even then, she led with sarcasm.

"I thought we talked about this Jenn. You're going to flush me down the toilet and say good riddance."

"No, Mom, that's not what we're going to do. I don't want to do that."

I paused for the full effect and pulled out my notes. "I did jot some ideas down, though. Do you want to hear them?"

Mom nodded, and so I pressed on.

I gave her the choices and told her about my ideas for a funeral service.

"Do you like any of those, Mom?"

"I like the Nana Tree idea, but you have to donate my body to science first."

My jaw dropped to the floor. This was the first time she'd ever talked about this. I was aware people donated their bodies to science because I used to work in the biology department when I was in college, and they had donated bodies. The cadaver room. I remembered it, and the idea of my mom laying on a cold metal slab for months on end while medical students worked on her tore me up inside. My brain was not able to handle the thought.

I forced myself to nod at my mom, and I jotted it down on my list so it appeared like I was taking it seriously, but I could not take it seriously. I told my sister about it, too.

“No way!” my sister said. “I do not want her body donated. I just couldn’t handle that.”

“Good. 'Cause I agree. It’s too much.” At least on this one thing, I’d had a little help, and my sister and I had agreed.

I also did my due diligence and asked a friend about it because she'd mentioned her mom had donated her body to science. My friend said they had her mom at the local teaching hospital for about a year. When they were done, they invited all the families to a beautiful service at the hospital, where they honored each person. She explained that a few weeks after that, she got her mom's ashes in the mail. But for me, the idea that my mom's body would be up on the hill for some amount of time before she was cremated was too much. Mom wouldn't care, but I could not do it.

At this point in our end-of-life plan negotiations, my mom got stuck on the idea of donating her body to science. She was exceptionally attuned to emotions, so she might have sensed my hesitancy and pressed harder on the idea.

"You can plant a tree with my ashes once the hospital is done with me."

My mom said this every time I talked to her about it.

I agreed to her request in what was a therapeutic lie. I told my mom I would do it. I told her I'd made the arrangements, and we talked about memorial trees, how they worked, and where the tree would be planted. My mom and I talked about the Irish wake she wanted and the bagpipes. But when it came time to write down the end-of-life plan, I left out the part about her donating her body to science.

Mom had a funeral home picked out. A man from her church owned it. I wrote that down. I wrote down the family gathering, the bagpipe player, and the songs she wanted to be played: *Take Me Home Country Roads*, *God Be With You Till We Meet Again,* and, of course, *Amazing Grace*.

I also told her we would use her ashes to help fertilize a tree planted at my sister's house – the Nana tree. By this time, my sister and her husband hadn’t found a place to move to, but they told me wherever they went, it would be their forever home. So, they wanted the tree planted there. This sounded like the best option, given that I lived in a rental home then.

I wrote it all down and gave it to my mom’s case manager at Elder Place. Suzie glanced at it, took about 30 seconds, and turned to me and said, "No donation to science?"

"No," I answered. "I just couldn't do it, and I think she'll eventually forgive me for it."

Suzie smiled at me, wrapped her hand tightly around my arm, and squeezed. "I'm sure she will," she said.

The last time my mom and dad saw each other

2017

AS I GREW TO ADULTHOOD AND had kids, my dad and I still connected. He moved a lot, especially after he remarried, so I didn't visit him too much, but we got together whenever we were able. When he lived close to us, I would pack up the kids and visit for a few days. And when he drove through town close to me, he'd call, and we'd have lunch at a diner along the freeway.

I relied on my dad for memories as my mom's Alzheimer's progressed. My dad's side of the story may not be the exact truth either, but from him, I could usually put one of my mom's crazy stories in perspective.

The ogre story is true. When I asked Dad about it, he smiled and shook his head. "I'd forgotten about that."

"So, people really did call her the ogre?"

"Yeah, we did."

"You did, too?" I was shocked.

"Never to her face, but I guess she knew anyway." He seemed a little embarrassed that this nickname had come to light after all these years.

"It's crazy the little things she remembers, Dad. I never know if they are real memories."

He grinned, "Well, that one is real."

And that was that.

The last time my mom and dad were together was in the winter of 2017. I had one of my best mom experiences when all my kids were together as adults. My middle son, his new wife, and new son, my first grandson, had come to visit, and we all had time together to laugh and play cards.

My heart was full.

Dad decided to come into town to visit his new great-grandson, and the weekend he visited also happened to be his birthday.

I told Mom that Dad was coming, and she glared right at me and said, "I've never been married, so how could he be your dad?"

What a mix-up of memories! But I smiled my huge I'm-not-going-to-talk-her-out-of-this smile. Lots of teeth, wide eyes, deep breaths. "I don't know, Mom. Maybe I was a child like Jesus in the Bible."

She laughed, but she had a puzzled expression on her face. Mom had an inkling something wasn't right, but couldn't figure it out.

I found a photographer to take photos of our whole family together. I drove my dad over to my mom's assisted living place, nervous most of the way about what crazy things my mom would say to him or if she would recognize him and how he would take it if she didn’t. These things were not my responsibility, but I still carried them anyway. I still worried about how my mom's Alzheimer's would reflect on me, and I was ready to apologize for it. It was aggravating, but I had no idea what else to do.

My dad and I walked in, and my mom was waiting in the lobby. My kids and the photographer were also waiting.

My mom walked up to my dad, gave him a quick hug, and said, "Hi, Jerry. It's good to see you." It was like watching them the first time they saw each other after the divorce.

My dad smiled. "Hey, kiddo. You're looking good."

I listened but soon realized there wasn't anything to worry about, so I herded my family outside and down a narrow walking path to the little park behind my mom's assisted living. It was a walkable distance for my mom and a cute park. The day wasn't the warmest, but we let that photographer place us in family groups, kid groups, and a one-big-happy-family group and take as many photos as needed to document the day.

This is one of my best memories. For the first time since I was nine years old, I had photos taken with my mom and dad, and my kids got photos of themselves with their grandparents.

During the photography session, my mom came over to me and whispered, "I remember him. He is your dad."

I smiled at her, and as I opened my mouth to reply, she added, "But I was never married."

I laughed and let her have the moment because, though I was a slow learner, I had learned that trying to tell her how it was was harder than letting her tell me how it was. These were her memories, after all.

After our chilly photo shoot, we all walked back to Mom's place and went to their facility conference room. Our family group had pizza, and I'd made cupcakes for my dad's birthday. As we were sitting at the table eating, I glanced at my dad sitting next to me, his head leaning toward my mom's. They were talking in quiet voices.

"I remember the house with the white barn," my mom said.

My dad nodded.

"Was that the house with the red kitchen?"

He shook his head. "No. The red kitchen house was in Minnesota. The house with the loft."

"Oh," and my mom scrunched her face, trying to remember. She gazed off to the side and then back at my dad. "Ok."

My mom was quiet for a moment. She moved her plate aside and put her hands on the table. After a moment, she lowered her voice and asked, "Can we go through them again? I don't want to forget."

"Sure," he smiled and set his plate aside, too.

My mom and dad started again with their apartment in San Francisco, and my dad patiently walked through every place they'd lived together, helping my mom piece together her memories. This was a beautiful moment. It was like I was a kid again, watching my parents at the kitchen table as they made plans for their little homestead, planning where they would put the goats, the chickens, and everything else.

"Where will we put the bees?" my mom asked.

My dad laughed, "Farther from the house than last time."

I don't remember much about my young childhood except running through the farm, driving a tractor with my dad, and hiding in the lilac trees until there were too many bees and I had to run out before I got stung. Our family always had goats, rabbits, dogs, pigs, and much to do.

As I remember it, it was a wonderful life. But my mom and dad were not meant to be together. And my life changed.

As I sat at that table in that assisted living, watching my mom and dad talking and laughing and him gently helping her through her ragged memories, I was touched by their closeness after so many years apart. My dad's memories are still crystal clear. And my mom needed that.

I needed that.

Even now, when I have questions about my mom, he is the one I turn to.

Adventures in running away

2017

ONCE I SETTLED MOM IN HER new assisted living community in the spring of 2015, she lived there for most of the long middle—about three years. Most of the people were sweet and eventually understood, to some degree, that my mom had memory issues. She would introduce me to people I'd already met, and they'd smile at me, and I'd smile at them, and they would give the knowing nod, silently saying, "We've done this before, but it's okay."

Many times, during the long middle, Mom would end up lost somewhere in the city. While living in the Portland area during her working years, she took the light rail or the buses to go almost anywhere. Mom loved the freedom and independence and that she didn't need to drive her own car.

One time, soon after she'd moved into her assisted living, Mom decided she wanted to go to her favorite store. It was one of those super stores, like Target, that's local to Oregon, and it has clothes, food, garden supplies, and so much more. She had missed the community bus to the store and decided to go alone. Mom got on the city bus and headed down the road, but it didn't take long to forget where she was and where she was going.

Eventually, she must have decided to exit the bus and ride on another bus, and she did this a few times until she finally recognized a hospital a few towns over. Mom got off the bus in front of the hospital and called me.

This whole experience was sprinkled with a little magic dust because, somehow, my mom had her cell phone with her and remembered how to use it. This is one of those looking back moments because when she called me, I about lost my mind.

Her call came through, and I answered. Mom said, "Jenn, I'm at Meridian Park Hospital, and I need to get home."

"What in the world are you doing there, Mom?" I practically yelled.

"I was trying to go to Freddie's," she huffed.

I asked a few questions and got the story out of her that she got lost on the bus. I had to call her place, tell her where she was, and drive out to pick her up. Mom was sitting at the bus stop on a busy road in front of the hospital. Oddly enough, it was the hospital she was rushed to in an ambulance during her first head injury fall.

Perhaps she knew.

Perhaps she remembered.

I only remember being highly irritated that I had to drive out to her and that my day was interrupted. That was the general undercurrent of emotion I carried during the long middle.

In another bus-related incident, my mom snuck out of her facility without signing out because she wanted to go shopping at the mall. She got on the bus that came by her place and rode around for hours, and the driver, who acknowledged her, didn't say anything to her. What harm would a little old lady with grey hair and a cane do anyway? So, the bus driver let her be.

As his day ended, he drove his bus into the last transit center and told everyone it was time to exit. The bus driver put on the "out of service" light, and I can only imagine that my mom was cagey enough to duck down in her seat so he didn't spot her. He drove his bus a few miles to the city bus parking lot, and as he was walking through and doing his end-of-day checks, he found my mom.

This is a funny story now, and it also makes me cry a little because I missed these moments then. I missed the humor and the lightness and how absolutely crazy the human mind is. My mom, even with advancing Alzheimer's, managed to recall enough NOT to sign out of her residence, step on a bus, ride all over town, and hide and scare the crap out of a bus driver.

What an experience!

But I missed it. It's another event that irritated me at the time. I was at home, and I got a call on my cell phone from a number I didn't recognize. I didn't answer, but the same number called me back again. I answered, and it was the driver telling me he'd driven my mom to the bus garage, and I needed to come to pick her up!

PLEASE AND THANK YOU.

And I did. But I also seethed with quiet anger as I drove her back to her place, walked her in the door, and got her up to her room. The workers at the assisted living were worried but my mom was fond of the disappearing act.

One of the final memorable events from the long middle came a few months before she moved into memory care. Mom was a faithful member of her church, and a kind man took her to church and helped her home. Most people at church thought she was an odd, eccentric old lady.

My mom's pastor was not aware she had Alzheimer's, and he asked her to take on a volunteer position helping people at another church building. This wasn't just another building on the same property; this was an entirely different building in another part of the city, about 25 minutes from where Mom went to church.

Of course, she said yes.

That is how she ended up on a dark and rainy Friday evening, giving a taxi driver all the cash she had and would have for another month. Mom got out of the cab, walked into the building, and told the man at the door that she had no way back home. I would have loved to see some of those people's faces.

Again, I got a phone call from a number I didn't recognize. Repeat. Once I answered, a man told me my mom was at the church and she needed a ride home.

This was my experience with my mom's long middle. Being frustrated and put out by her adventures.

My mom lived at that assisted living facility for three years. She had friends, went to dinners, participated in chair aerobics and craft time, and had people who loved her and loved talking to her.

I spent most of my time getting annoyed with her during the long middle. Annoyed that I was taking care of my mom by myself, annoyed that my sister hadn’t moved to Oregon yet, and generally frustrated by Mom’s adventures and larger-than-life stories.

The one thing Mom loved to do was tell a story. This was, in fact, this particular thing she loved to do that began tipping people off that something was wrong. Mom would listen to a story someone told her, and the next day or the day after, she would tell that story back to that person (with some embellishments, of course), and they would say something like, "Yeah, Bobbie, I told you this the other day."

Mom would purse her lips and say, "No, I'm telling you this now."

"No, but I told you this the other day."

Mom would sigh and say something like, "Fine, whatever. I didn't want to talk to you anyway, " and then walk away.

I think at first, people were put off by her abruptness, but as the people at the assisted living started to realize she had Alzheimer's, they understood that she didn't NOT like them. My mom wasn't being mean on purpose; she just didn't have a filter for her thoughts anymore.

My mom had one story that she told everyone a lot. She spent about two years as a child in Austria at the end of World War II. The Army stationed my grandpa there, so my mom went with her parents, younger brother, and sister. She was eight years old when her family moved to Austria. My mom had no idea then, but as an adult, she realized that she lived on the Von Trapp property and played on the grounds at the Von Trapp estate as a child.

If you're wondering, the Von Trapps are the real-life family that lived out The Sound of Music movie. They escaped Nazi-controlled Austria and fled to the United States. The Von Trapps liked to sing and dance as a family, and my mom carried those memories of being in the place where this family lived. She experienced watching The Sound of Music as if she lived in it.

This became problematic as her Alzheimer's progressed. One day, I walked into her assisted living facility, and one of her friends waved me over to her, quietly whispering, "Did your mom live in Germany?"

I shook my head, "No. She did live in Austria, though, at the end of World War II."

The lady made a face like she was starting to understand, and she asked, "Was your grandfather a Nazi prisoner of war?"

"Ah... no."

This friend appeared surprised and told me my mom had been telling some crazy stories.

As Mom's Alzheimer's progressed, her story of being a child in Austria while her father was stationed there morphed into her family living in Nazi Germany during World War II. My grandfather became a spy for the US Army. As the Nazis closed in on him, my mother, who in her delusion spoke fluent German because she'd lived there all her life, was a translator between her father and the Nazis and helped her family escape to the United States.

If this sounds like the storyline of The Sound of Music, that's because Mom started mixing them up.

I'd recently had Mom over for dinner, and we watched The Sound of Music on the television because she loved it. However, I had no idea how much it would add to her delusion. Near the end of the film, when the Von Trapp family escaped through the cemetery, Mom started crying about how scared she was that her dad was going to be killed. It was like it was real to her.

Because it WAS real to her.

But I thought she was being overly dramatic.

This story of my mom's about living in Germany and saving her father from the Nazis only got crazier as time went on. Eventually, it involved a cave system, gunfire, and mushrooms. I can't explain that part.

Mom's case manager called me one day and said, "Jennifer, I'm confused. Was your mom born in Germany?"

I smiled. She had a computer right in front of her to pull up Mom's medical records and read that she was born in New York City, but as the story of Mom surviving Nazi Germany got wilder, people started to second-guess themselves. Even an experienced case manager like Suzie.

This was one of those things that I tried to fight against. "Mom, you lived in Austria, remember?"

That was back before I'd learned that asking a person with Alzheimer's to remember something was a lot like asking a deaf person if they heard you.

As the long middle went on and on, the Germany story got wilder with each telling. Luckily, I learned to go with it and not tell Mom she was wrong. Perhaps the mushrooms were psychedelic. I have no idea.

I think back on the long middle now and I learned so much. Though I was struggling with grief and trying to figure out how to accept my mom as she was alive and dying, I learned to juggle a crazy schedule, how to smile when I wanted to cry, and I learned how to advocate for my mom without belittling her.

I still had a lot of learning to do, and I judged myself harshly for my mistakes with her. I judged myself for trying to plan things and getting frustrated and resentful when things didn't go as expected. I judged myself most harshly for not wanting to visit my mom and not understanding that how she was and how she acted was not *who* she was.

These years during the long middle were when I hit the wall that forced me to change.

But life marches on, as it does, and all things end. If I squinted long enough, it would be easy to spot the end of the long middle on the horizon in the summer of 2018.

That July, I was visiting my dad and my stepmom, and I got a phone call from my mom's assisted living facility. This wasn't uncommon for them to call me, but it was always stressful for those calls to come in when I was out of town.

"Hi, Jennifer. Your mom fell, but I know you're out of town, so please don't worry."

I hated those calls.

A fun favorite was when a doctor would call me from a hospital ER and say, "We have your mom here. I know you're in China right now, but I wanted to talk to you about your mom."

Mom hated that I was the person her doctors called. She hated that I was "in control" of her life, and she did everything she in her limited power to keep me out of it.

“I’m not in China," I would answer. “I’m at home now, and I can be there in a few minutes.”

But my mom was yelling in the background. “Don’t call her! She doesn’t need to be here.”

The doctor replied, “Yes, it would be *really* great if you could come down. I have some questions.”

Inevitably, my mom would still be yelling, “I don’t want her to answer your questions!”

Unfortunately for her, no matter how much she wanted me out of her life, I had to take a giant step right into the middle of her path.

In this particular summer in 2018, Mom fell a few times. She'd also disappeared from the facility several times in recent months. She'd been pushing the boundaries of their care at the assisted living. Mom's Alzheimer's was taking over, and her needs were becoming too substantial for them. The stress of it all was on their faces each time I walked through the door. Almost everyone who worked there watched me frantically, and though they would smile, the smile didn't reach their eyes.

Their eyes said, "We love your mom, but we really can't wait until she doesn't live here anymore."

This call was about that.

Mom had waited at the door to the facility until it was jammed with people, and she used it as a distraction and disappeared. It always amazed me that she had Alzheimer's and couldn't turn on a television or answer her cordless phone but still had the ability to calculate her escape so perfectly.

Eventually, someone realized Mom was gone, but by then, she had pushed her walker up to the street and was scooting down the sidewalk as fast as her legs could carry her. A med aide headed out to find her and try to help her walk back, but by the time the aide found her, Mom had forgotten her goal. She didn't remember the med aide, where she was, or where she lived when they brought her back.

It was a fiasco.

Mom was yelling at the med aide. She wanted to leave and go home. She wanted to call a lawyer because they'd kidnapped her, and no, she did NOT want them to call her daughter.

THANK YOU VERY MUCH.

As I listened to the executive director of Mom's facility tell me the details of her escape, I could tell she was upset, frustrated, and on the verge of tears. I had a few guesses as to why.

It would be stressful to have an Alzheimer's patient escape onto a busy street, and she told me Mom had yelled at her, and when my mom yelled, it wasn't a pleasant experience. Mom was fierce when she was angry.

The executive director told me that it was time to put my mom in memory care. And I was in Idaho. I couldn't do anything about it then, and I'm sure it was frustrating for them that I couldn't come right in and meet with them.

I made an appointment to talk to them when I got back, but by the time I got to the appointment the next week, Mom had spent a few days being calm and kind, and everyone's anxiety had eased, so she was allowed to stay.

The facility director pushed it off, in part because the high anxiety of the situation had faded, but also because they genuinely cared for my mom. She was fierce, but she was also so lovable, and for a short time, at least, the love won out.

The trouble with the F word

1985

AS I’VE ALREADY MENTIONED, MOM could be fierce when she was angry. And over the years, I had a few choice words for my mom.

I grew up in a small town in Montana. When I was about 15, I liked a boy and thought he liked me too. He flirted with me and smiled, and when we would cruise in groups of cars up and down Main Street, he made sure that he was in the car I was in. This boy was so handsome and my first real crush. His parents moved to town recently, and he played basketball. His blond hair was always perfect, even when he was sweaty and running up and down the basketball court, carrying the team.

He was so beautiful.

I believed he liked me, and for the first time since we'd moved to that tiny town, I was included with the cool kids.

All this teenage romance blossomed into us holding hands and kissing one Saturday evening. Even though it was the best night, but I had an early curfew, so he and his friends dropped me off at home. I had to wake up before sunrise, but I was so happy and couldn't sleep, so I grabbed my journal and wrote about the entire night, right down to everything we said.

When I went to school the next Monday, none of my new friends would talk to me, and some even laughed at me. I had no idea why, but I found out later that day that this boy told all his basketball buddies that he was using me, that he didn't like me, and that I was a terrible kisser.

I was mortified. And so angry.

I had to be around him at school every day and brave the whispers until some other gossip took over. To add insult to injury, I played in the pep band and was required to be at the basketball games.

This was torture. I kept to myself for a few weeks. I went home from school, studied, played the piano, and read a lot of books. The only time I went out in the evenings was when I had to return to school for musical rehearsal. Our theater department performed The Sound of Music that fall, and I was playing Leisl. I was singing the song, *I Am Sixteen Going on Seventeen*, and I turned sixteen that December. It was all supposed to be so magical, except it wasn't, and I hated this boy so much.

I wrote a lot in my journal about this boy, and I blasted him with every horrible thing I wanted to say to him. Then, I started writing lots of swear words. Swearing was not something my mom allowed, but I was brave enough to write out all the mean things I wanted to say to him.

And here come the swears.

*"Fuck him!"*

*"I'd like to fucking punch him in the face."*

And it went on and on.

Once I wrote *that* word, it became the best word in the whole entire world to express my intense anger at this stupid boy. I kept writing it over and over, though I would never say it to his face. I didn't want any trouble. My mom worked at the high school as a secretary. This boy and all his friends were among the popular kids, AND he went to the same church as I did. I had so many reasons I would never say these things to him.

I was hiding out at home when my mom yelled down the hallway, "You girls better clean your rooms, or you know what will happen?"

I got right to it and cleaned my room because when we didn't clean our rooms to my mom's standards, she would come through with a heavy-duty garbage bag and throw away anything *she* thought was out of place.

I came home from school that day and found my room "brown bagged" by my mom. When I went to write in my journal about how upset I was, I couldn't find it, and I started to worry. I tore my room apart, and when I didn't find it, I tore everything apart again. Finally, I went to bed, wondering where I'd left it.

I found out the next morning. I was getting my schoolbooks ready when the doorbell rang, and as I opened it, my mom moved in behind me. Standing on the front doorstep was our pastor, holding my journal.

I realized what had happened in a single, quick moment that ticked by like an eternity. My mom took my journal when she was cleaning my room. She'd read all the terrible things I'd written about this boy, all the swearing in my journal, and gave it to my pastor. The person I trusted most in the world—my mom—had violated my privacy by taking my journal. I was standing between her and my pastor, and my brain exploded with shame and unreal anger.

Hate and embarrassment took over.

My pastor opened his mouth to say something, and I cut him off. "Fuck you both!" I yelled. I glared at my mom, pushed past my pastor, and rushed down the stairs and off to school.

I could not believe those words came out of my mouth to real people. To living people. I'd only ever written them. But as I was running down the sidewalk toward school, burning with anger, I was terrified because my mom would be at school, and I had no doubt I was in so much trouble.

But it was much worse than that.

When I got home that day, I stepped into the house and realized what my mom had done with her rage and her shame at my outburst.

My mom had used her red lipstick and written "Fuck you" on every picture of me hanging up around the house. She'd printed it on the glass right over my face. Horrified and frozen, I clutched my books tightly in the doorway.

My mom's face was stern and evil. She pointed to my eighth-grade portrait, now with FUCK YOU written in all caps over my face and my dress, and said, "That's all I can see when I look at your face."

My mom turned her back to me and walked into the kitchen. "Oh, and you're grounded until further notice."

I didn't say a word. I walked down the hall and into my bedroom and noticed my journal now sat on my desk. I set down my schoolbooks and tucked my journal under my pillow. I sat down to do my homework, except I could only stare at the pages, blood pounding in my head. My hands were shaking.

This was the moment that changed my relationship with my mom. My trust in her was gone. She'd gone to our pastor instead of talking to me. My mom had shamed me and then piled on by writing all over my pictures. My sister would see them. These photos would be on display to anyone who came to the house. I was utterly devasted. Alone. Abandoned by her. Like I didn't matter, and she'd stopped loving me. I had so much HATE for her, and it consumed me, but I had nowhere to put all those feelings welling up inside of me.

My head was spinning.

*"It was wrong for my mom to take my journal and give it to my pastor, so why was I in trouble?"*

I wrote those things in private, and she violated that privacy.

*"None of this would have happened if my mom hadn't gone into my bedroom and read my journal!"*

*"Why didn't my pastor chastise her for reading my journal?"*

The whole thing was unfair.

I tried to be brave, but swearing at my mom and pastor was not brave. It had gotten me grounded right before my sixteenth birthday. It was impulsive and driven by shame, and it was stupid to write down all that stuff about a dumb boy. He certainly wasn't worth the trouble and anguish I was in now.

I stayed in my room until I had to leave for rehearsal. I put on my coat and quietly snuck out the back door and walked down the alley toward the high school.

For the next two weeks, my pictures at home were covered with red lipstick and those two words. My mom and I didn't speak. She didn't leave me any notes about the dishes, laundry, or anything. It was like I didn't exist ... at all. My mom and I were in a standoff.

I was sure my mom thought I would wipe the swear words off my photos, but I stubbornly dug in my heels. I didn't write those words, so why should I clean them off? Granted, I was the one who wrote it all down and swore at my mom and my pastor, but still. I wouldn't have gotten so angry and swore at her if she hadn't invaded my privacy. At that moment, I was so ashamed and just exploded.

Overall, though, I had the most difficult time reconciling that my mom chose to embarrass me instead of showing me some understanding and love. How she treated me did not seem motherly. Every day, I noticed the photos of me around the house. Every day, she ignored me. Every day, I was in my home with my family yet abandoned and alone.

My mom, sister, and I stayed out of the living room for those two weeks. No one went in to play the piano. We didn't talk; we shuffled around each other in stifled silence. We didn't sit in front of the television as a family or share any meals.

Eventually, my mom had to have her friends over for a church gathering, so she took the pictures down, sprayed them with glass cleaner, and wiped away the swears. At least she hung them back up.

I never agreed with my mom's punishment, and I never again left my journals out where she would be able to find them. I found a hiding place for them and only wrote in them at night after my mom had gone to bed.

My mom also never "brown bagged" my room again.

This experience changed me, and it had a deep and lasting impact on my relationship with my mom. We were not the same. Our family was not the same, and my heart hardened against her. Though my hatred for how she acted did fade, I couldn't trust her. I stopped sharing my teenage worries and woes with her.

That December, I was Leisl in The Sound of Music, and my mom did not come when I performed on stage. She sold tickets for the show at the door because she worked at the high school, but my mom went home when she was done selling tickets. And she didn't come to my sixteenth birthday celebration.

I left home when I graduated high school and didn't return to visit my mom often during the holidays. I got married and had kids, and things between my mom and me were always difficult. If I'm honest, it was because of what happened during these few weeks when my face was covered by red lipstick.

Before my mom was diagnosed with dementia, she apologized for throwing away my things over the years. We were at her house cooking one night, and she glanced over at me and said, "Jenn, do you remember how I used to go through your bedroom when you were a kid and throw your things away?"

"Yeah, Mom, I sure do," I said.

"Well, I wanted to say I'm sorry for doing that. The thing I regret the most was throwing out that doll house that you made."

"Oh, I remember that. I worked so hard on that thing."

Mom smiled, "You did. You made your own carpet with yarn and glue. I knew you loved it, and I shouldn't have thrown it away. I'm sorry."

I put my arm around her shoulder and gave her a little squeeze. "Thanks, Mom. I appreciate that."

Judgment, fear, and resentment, oh my!

2016

FROM THE MOMENT MY MOM was diagnosed with dementia, my struggle with judgment, fear, and resentment began. Perhaps it all came from my strained relationship with my mom, or perhaps it was a struggle because I didn't want to be a caregiver, and I was thrust into the role without a choice.

During the long middle years of my mom's Alzheimer's, there was no end to the barrage of emotions and grief. As my mom progressed and I realized she was getting worse, I had a lot of internal struggles come up and started to judge my own reactions and feelings.

One day, my father-in-law said, "How's your mom?"

Without thinking about it, I said, "She's stubbornly clinging to life."

He stared at me, and his jaw hit the floor. But it was true. My mom was alive and dying. The lid on her box was closed, and she was clinging to life with that poison right inside. I wasn't going to open the lid and find out whether she was living or dead.

Though I thought what I said to my father-in-law was kind of funny, his face told me he was not amused. I started to judge myself and my own reactions and fears.

I was fearful of all kinds of things, like saying the wrong thing or doing the wrong thing. I was worrying about when my mom would die. I also wanted some measure of control over everything that was happening, though that was an impossible request. And then the resentment started to creep in. Wasn't my mom aware that her Alzheimer's and her being alive and dying were interrupting my actual life?

All this grief and all these feelings were at war inside me, and all of a sudden, it was turning against me. I'd made peace, right? I'd done all the accepting I could while she was alive and dying. I felt better for a little while. So why was it all a mess inside me? Why was I doubting myself and judging myself, and why did I have so much resentment?

My mom was suffering from Alzheimer's. She would never have wanted to live like this, pooping her pants and rambling to strangers in the grocery store and going out to dinner in her pajamas and a construction hat. If she'd been given the choice, she would have ended her own life before getting this far into Alzheimer's. Mom would have been mortified by where she was and how little control she had over everything, yet I didn't want her to die.

I wasn't ready.

My internal struggle was that I didn't want her to suffer. I didn't want her to be embarrassed. I didn't want her to have so much confusion, and I didn't want her to be like this. I certainly didn't want the responsibility and stress. If she were gone, I wouldn't have to deal with it anymore, but in my heart, I didn't want her to be gone.

I didn't want her to die, but I didn't want her to suffer.

These two opposite feelings existed in my heart at the same time. If I loved her truly, I would want her suffering to end. But I loved her truly and didn't want to live in a world without her in it.

As a result, I started to feel deeply depressed and sad that I was upset with Mom for being alive, but I was also not ready for her to die. Looking back at it now, it was such a heavy emotion. I thought I was depressed, but I truly think it was grief circling in my brain and my heart. Wanting someone to live with such a disease is difficult to rationalize, but I didn't want her to die, so therefore I wanted her to suffer. I judged myself and my weaknesses harshly. This seemed like depression, and it appeared like depression on the outside, but it was very heavy grief.

I also had all the fear. Was I doing enough for her? When she was upset with me one day, I wouldn’t visit her the next day because I was worried she would still be angry with me. When I was a kid and she was mad at me, she was scary. That's a fear I carried into the long middle. But I was making my mom suffer for something she most likely wouldn't remember.

So many times, her confusion was clear in her eyes, and she would turn to me and say, "Something is wrong with me, but I don't know what it is."

I would take her hand and say, "I know, Mom. It's ok. We'll get through it together."

But afterward, I wondered if I said the right things. Did I make it worse? Was I helping? What was I supposed to say? Something *was* wrong with her. Mom had Alzheimer's. She was dying. Her brain was stealing all her precious memories and ability to function, and I couldn't do anything about it. I was also aware that I couldn't just blurt out, "You have Alzheimer's, Mom," because she did not realize that. I’d already done that once, and it hurt her so badly. My mom hopefully didn’t remember, but still.

I also wondered why she would act a certain way. Mom focused a lot on me and technology. I'd made some mistakes up to this point, for sure. I bought her a smartphone when she first moved to Oregon because I didn't understand dementia at all. I compounded that problem by buying her an iPad, thinking that if a small child could use an iPad, my mom, with Alzheimer's, could learn to use it.

What a mistake!

On many occasions, my mom yelled at me about her TV remote. In all my wisdom, I put tape and paper over the buttons on her TV remote, hoping she wouldn’t mess up her television settings. But inevitably, those things backfired.

“Jenn, this remote isn’t working?” she would complain.

“What’s going on with it, Mom?” I would ask.

“I can’t find Netflix, and my friend wants to watch her favorite show.”

“But I covered up the Netflix button because you don’t have Netflix,” I tried to explain. I’d taped over almost every button on her television remote, so she wouldn’t try to use them. Only the power button and the volume and channel buttons were showing.

“My friend pulled that paper off.” And on and on it went. Almost everything I tried to make things “easier” only made life difficult. I would offer to help my mom, but she would be so upset with me that she turned to my husband like he was the best thing since sliced bread.

My husband would step in and be the buffer, and I appreciated him for that. But it was also frustrating that my mom treated me like I wasn't helping her on purpose.

I got so irritated and later worried that she would still be upset with me. My fear of her was astounding. My mom was a force to be reckoned with in her life before Alzheimer's, and she was scary to be around and sometimes mean. Even after her Alzheimer's, when she was mean, all my old feelings of fear came back, and I didn't want to be around her. This took me a long time to work through all that.

My only outlet was playing loud rock music in my car while I drove home from visiting my mom. The loud music thumped my heart and pounded over the screaming voice in my head.

Nothing worked out the way I wanted it to, and I kept on with the frustrated feelings, the loud music, and trying to control my mom's death from dementia.

I had a friend named Becki who always listened when I needed to vent. She and I met for lunch every couple of months. I'd told her about many things that had happened with my mom when I was a kid, how things were now, and that my sister hadn't yet moved to Oregon. It was lovely that I didn't have to do a full recap of everything when we met for lunch.

One day, I talked about how upset my mom would be with me.

"I shouldn't be so afraid of her and how she acts,” I explained.

Becki simply smiled. “Says who?"

"Me,” I laughed. It sounded silly, even as I said it. “I know, I know. I get all wound up about it, and she forgets how awful she acts."

"Which is a blessing for her, but what about you?"

I knew what she was getting at, but self-reflection was hard for me when I was still working through my fear.

Becki understood I was dealing with a lot. She added, "Holding in your feelings isn't helping you."

"I know, but it's hard to let it all go. I’ll work on it, though,” I sighed. “It’s my only option because she needs me.”

Becki was such a positive cheerleader when I needed it. "Well, I think you're doing amazing! Your mom is lucky to have you."

“If only she knew,” I chimed in. It helped to share and to have a friend who would listen without judgment.

Finally, there was resentment. This came on slowly. When my mom was in assisted living near the beginning of the long middle, she made friends. The assisted living facility bus took her to the grocery store, and she had company and people to talk to. Mom had chair aerobics and walks in the park. The Boy Scouts visited, and her friends walked in and out of her room. But later, when she needed more from me, and it started impacting my real-life activities, work, and sleep, the resentment started to creep in.

My sister had not done what she said she would do, and while I imagined some reasons why that might be, I was upset that she and her husband could have been here by now helping me and weren’t. I felt put upon.

Someone would call to tell me that mom was being taken to the hospital, and as I was driving in, I would think, *if my sister were here, maybe she would take this one.* And it would sit in me like a rot, and I would hold on to that resentment that I had no help.

Becki also had some words of wisdom about resentment: "I don't want to give you advice or tell you what to do. I'm your friend, and I'm here to listen."

This was one of the best parts about being friends with Becki. We listened to each other, and we rarely gave each other advice. So, I understood that what she wanted to say to me was important.

I put down my fork. "But if you have any thoughts, I'm all ears."

"Okay,” she started. “I will say that you are doing an amazing job taking care of your mom, and I can’t even imagine what you’re going through.” Becki leaned forward and said, “But you have to make time to take care of yourself, or all your resentment is just going to wear you out."

She was right. I was resentful, and I wasn’t doing much for myself.

Becki continued, “What does Jennifer need? What will help you?”

I sat, taking in her words. What did I need to work through all my resentment? I didn’t have much history with my mom, and what I did have was from my tumultuous teenage years. My mom and I had struggled in our relationship and spent plenty of time not keeping in touch. There was also my sister and how I was now shouldered with this responsibility. I didn’t have a reserve of love and wonderful memories with my mom to pull me through. So, I had to find a way to move through it for myself. I had a lot of work to do.

As I sat silently wondering what I needed, one of the most resounding things Becki said that day was, "You are doing so much for your mom, mostly by yourself. And you have reasons to be resentful, but it's hurting you."

It was hurting me. Everything my mom needed in her day-to-day caregiving was on me, which caused me to be resentful when I was with my mom. And it showed.

One thing I realized about people with Alzheimer's is that they are very astute at reading emotions. They are losing memories and their own thought patterns, but their other senses kick into overdrive, and my mom sensed when I was upset.

Mom would tell me feebly from the hospital bed, "Go home. You don't want to be here."

I didn't want to be, but I was because it was what I had to do for her. She was my mother. She raised me, and none of what was happening to her was her fault. But I did begrudge it sometimes, and I was irritated at my sister for not being there. The anger, sadness, and bargaining I was going through made everything worse.

I was stuck in the clouds, the rain, and the grey, and all I could think was, "Why couldn't my sister be doing this?"

The better question was, why was I doing such a poor job of it?

I had to turn my judgment and resentment around somehow, but I had no idea how. My feelings were valid, I recognized that. Mom and I didn’t have a lot of shared history as adults, so I didn’t have a huge bank of warmth and happy times to draw on when my reserves were meager.

I think my sister realized I had resentment, though, in reality, I didn't care if she did because I was angry with her for not moving to Oregon yet. I covered my feelings well when she and her family came to visit, but that deep resentment hung around for a long while.

I was walking a tightrope, especially with my sister. If I said anything about my resentment, she might stop coming to visit Mom altogether, and I didn’t want that for her. Also, I was uncomfortable speaking up to my sister because it seemed confrontational, and that scared me. I needed to believe that my sister and her family would help more when they finally moved to Oregon. If I told my sister what was truly on my mind, it might drive them away completely. Then I would never have help, AND my mom would suffer, too.

No matter how hard I tried to make things normal and plow through, the people around me were not me and could not understand what I was going through.

I couldn't manage everyone, and I had to figure out a way to let go. So, I decided to do what I thought was best for me and my caregiving journey.

Which was helpful because things were about to change.

The best/worst thing that never happened

2018

IN THE FIRST FEW MONTHS OF my mom's move to Oregon, in the winter of 2014, my sister called one day and said, "Jenn, I have to be honest. I've been watching the weather in Oregon, and it's raining a lot. I don't think we can do it."

"What do you mean?" I asked.

"I talked to John about it, and we just don't think we can live in such a rainy place." My sister explained that she hated the rain when she lived in Oregon and couldn't imagine coming back.

She also told me that her daughter, who was heading into her senior year, didn't want to move for her last year of high school. I understood that part.

“But next summer, after she’s graduated, we’ll look at moving closer,” she said. “Maybe to, like, Hood River or The Dalles”

Both of those towns were in Oregon but not in the Portland area. Depending on which one my sister and her husband chose, they would be over an hour away.

I took a deep breath and said, "Ok, well, next summer it is."

One more year.

I could do it. I could make it one more year, and then I would have help caring for my mom. Perhaps not all the time, but they could drive in to handle some weekends. If Mom needed to go to the emergency room, they might drive in and sit with her. And perhaps they would take her for Christmas or Thanksgiving. I would have a break.

I could make that work.

As the following winter of 2015 rolled around, about six months before their support arrived, my sister started messaging me about how much it rained in The Dalles and Hood River.

“What about Camas, Washington, or Battle Ground?” I suggested.

“No, they are too close to Portland. Too many clouds!”

“How about the Tri-Cities?” I tried desperately. The Tri-Cities were about three hours away, but it was better than nothing.

“No, still too cloudy and not enough snow.”

"Snow?" I asked. When did they start looking for snow as criteria to move? Snow was rare in the Portland area.

"Yeah, John wants to be somewhere with snow in the winter," my sister said matter-of-factly.

It went on and on. Each city they settled on didn't work for some reason, and the summer of 2015 came and went. The following year also came and went. In 2017, my sister and her husband rented an RV and went on a road trip. Mom and I were a stop along the way. And finally, in the summer of 2018, they settled in a quiet little town in northern Idaho. A whole six-and-a-half-hour drive from me and Mom.

By this time, I was worn to the bone, frustrated, struggling with my own life, and angry with my sister. I wondered if I'd been played.

My sister agreed to move Mom to Oregon. She agreed to help, and she told me they were going to move, but as soon as Mom was here in Oregon *with me*, the responsibility was off my sister, and she didn't follow through.

As I reflect on it now, I have to tell myself that she did her best. This is the only way I can make it through the emotional turmoil.

My sister and I decided to move my mom to Oregon. My sister was supposed to come help take care of Mom, and after years of doing it myself and hoping and awaiting her arrival, it didn’t happen. It was like a million pounds had been put on my shoulders, and I was forced to carry it.

I believed I was lied to and betrayed – like my sister knew from the beginning, she was never moving to Oregon. Even now, I can be overwhelmed by those feelings, so I have to tell myself that my sister did her best with what she had. My sister wasn't ready or able, for whatever reason, to be Mom's everyday person under the conditions of dementia.

My mom and sister were like peas in a pod before dementia, so it might have been too much for her to witness. I have no idea because she and I never talked about it.

In some of her family's visits to Oregon, I had to grit my teeth and plow through it. They saw the vacation, relaxed side of Mom. She was happy they came to visit. The teenagers distracted her, and her favorite youngest grandson was there, so everything was right with the world. But I begrudged all the time I spent caring for Mom and was irritated at my sister for popping in for a few days in the summer or a holiday to make an appearance.

I was around for the day-to-day, and she wasn't. So, when we did talk about Mom, we didn't relate. My sister was around for the fun-time mom on her best behavior, and I cared for dementia mom as her least favorite daughter.

Ultimately, though, I do believe my sister's not moving to Oregon was the best thing that never happened. Though it was terrible and gut-wrenching, and sometimes, my deep-seated anger and resentment were next level, as time went on and my life changed and my heart changed, what seemed like the worst thing turned out to be a blessing.

Those long middle years changed my heart and opened up my soul. They helped me accept that I was, in fact, an honest-to-goodness caregiver, and they helped me accept Mom and the path we were on together. And that path was going to be rough, and it was going to end.

I met this lady at the one and only dementia caregiver support meeting I ever attended, and she said, "Welcome to the club."

I smiled and said, "Thanks."

This is 100 percent a club no one wants to join because – let's be real – right now, there is no cure for dementia or Alzheimer's. It is a death sentence. In accepting my role as my mom's sole caregiver, I had to prepare for the long road ahead of me. And ultimately, I had to accept that my mom was going to die. That is the club I was thrust into against my will.

That was the end I had to be ready for.

As it turned out, it was not dementia that took my mom's life, and I wasn't ready for that either.

That wasn't what I planned. But the ups and downs that I went through from the beginning of my mom's diagnosis were profound.

Get ready.

Because here comes the grief.

The forgetting

2018

FOR THE FIRST TIME, IN THE fall of 2018, right at the start of the big decline and our hunt for a memory care facility, Mom forgot who I was. My husband and I took her out for our regular Wednesday night dinner. We’d started those in 2017 to give Mom some consistency in her schedule. We went to the same restaurant each week, so the layout and the food were routine for her. Our nephew, my sister’s son, had recently moved to the Portland, Oregon, area, and he went with us every Wednesday. My mom had familiar faces and familiar food every week.

By this time, though, it was clear to me that Mom was in a rapid decline. She’d started forgetting a lot, and the Wednesday dinners didn’t always end well. What I noticed first was that while we were eating and talking, Mom would become quiet. She’d study me and her nephew and then glance around the restaurant like she was seeing it and us for the first time.

“How are you doing, Mom?” I would ask.

This would give her pause, and she’d take a breath and stare hard at me.

“I’m OK, but where are we?”

“We’re at Pietro’s. Your favorite pizza place.”

“And you are?” And then we were silent. I sensed my nephew and my husband looking at me. My mom didn’t have a clue who I was. She didn’t remember any of us, and she had no idea where she was.

“I’m Jennifer,” I would explain with my happiest voice.

“And you’re my daughter?” The uplift in her voice told me this was a question.

“Yes. I’m your daughter.”

“And I guess I know these people, too,” she would say, looking around the table. So, I would introduce her to her nephew and my husband. This started to happen more often on those Wednesday dinners.

Soon, Mom started forgetting where she lived. When we brought her home to her assisted living, she appeared confused. As we pulled up to her building, she stared out the window, her lips pursed together in a straight line. The nana lips, but this time not for me. They were for the building. Mom turned to me, then back to the building, and then back to me, and I had no doubt I was a stranger to her at that moment. She’d forgotten me again, even after talking about it at the restaurant. We walked in the door, got in the elevator, and turned the corner toward her room. The entire time, my mom looked scared.

When I opened the door to her room, her eyes landed right on the old black-and-white photo of her dad taken after World War II. That was where she found comfort.

I pointed out the photo of her father on her wall, and I said, "That's your dad, and this is your home."

Mom glanced at me, smiled, and said, "Well, that is my daddy, and you seem like a nice lady, so I'll believe you."

She sounded so childlike.

My husband glanced at me, and I gave him a quick nod. Each time, it was a relief that she recognized that photo of her father.

I asked Mom if she was OK or if she wanted us to find a med aide for her, and she said she was fine. She wanted to sit in her chair, look at her dad, and listen to the TV. I leaned in to give her a hug, something I always did, but she backed away from me. The expression on her face said it all. My mom did not recognize me, and though she thought I was a kind lady and I took her home, she wasn't comfortable enough with me to give me a hug.

This was something I'd tried to prepare for. I’d read about it in Alzheimer’s books and online, so I learned from them what it felt like when their parent or loved ones forgot them. How did they cope? How did they process those emotions? I thought, if I can study this and plan for it and over-achieve the hell out of preparing for it, it won't hurt as bad when it happens to me. But that didn't work.

It hurt. It hurt badly.

This was a huge milestone in my Alzheimer's anticipatory grief process.

When I told people my mom had Alzheimer's, the inevitable first question was always, "Does she know who you are?"

If anything, I hope reading this changes someone's mind about asking that question. This is a loaded question, and the answers are abounding. And they vary depending on the day.

I experienced an incredible sadness in my heart that first time my mom completely forgot who I was. And it wasn't any easier as it continued to happen more and more often. As I stood reaching in to hug her and watching her pull back from me, it was like a knife in my caregiving heart. It also gutted me as her daughter.

When people first started asking me, "Does your mom know who you are?" I would say yes.

I would also say, "Most of the time, she knows I'm her daughter."

But after this experience, I started to answer with, "She knows I'm a nice lady who comes to visit, though sometimes she knows who I am."

Later, I would say things like, "She doesn't know me, but that's OK. I know who she is."

This experience and many more in the fall of 2018 were part of a big decline in my mom's cognitive function. It was like she was barreling downhill in a runaway train car, and I couldn't stop it. This was the end of the long middle. And though my mom was still alive and dying, this big decline pushed the dying part of her Alzheimer's journey to the forefront. There was no denying it.

Mom fell a few times in late 2018, and she was taken to the emergency room twice in one week for injuries. I noticed that her head started falling to the left when she was sitting in her reclining chair as if she was having trouble holding it up. She stared at a fork and didn't have any idea what to do with it. Her food sat getting cold on her plate as she stared at it and her fork, moving it around like it was something she'd never seen before. Mom lost her words and would stare off into space. She would also be speaking and, as normal as anything, say a completely made-up word and giggle at me and say, "You know what I mean?"

I didn't have any idea what she meant at all, but I nodded and said yes anyway.

It was a scary decline, and as it was happening, I plowed through all the death and grief emotions in about a month.

At first, I was in denial that it was that bad. Mom was still in her assisted living facility, and the thought of my mom in a locked memory care facility crushed me. She would hate it and hate me for putting her there. That made me angry that any of this was happening. Why did my mom have to get Alzheimer's? I was irritated when the directors of different memory care facilities told me that they didn't have an open bed for my mom. Why did they schedule a showing if they didn't have a bed?

I started talking to the staff at mom's current assisted living and asking why mom couldn't stay. Soon, I started bargaining with her case manager, Suzie, asking where she might be able to live instead of memory care. Why couldn't she live in an adult foster care home? Why couldn't she have a room by herself?

And finally came the depression of knowing my mom had to move. It was obvious that she was getting worse, with no end in sight to her decline. I worried that my mom could rush into the end of life at any moment. I called my kids and told them to come to visit because their nana might die any day. I thought she was going to go into memory care and die soon after. It was awful.

The big decline rollercoaster

2018

THE BIG DECLINE STARTED FAST. It was as if we'd slowly rode up to the top of a rollercoaster, and now we were at the top. As soon as we crested that hill, the coaster let go, and we started flying down and around corners and loops. I couldn't deny the big decline was here, and we were flying fast into the wildlands of advanced Alzheimer's.

Mom locked herself in a public bathroom in her assisted living because she'd had an accident at dinner and was embarrassed. By the time the staff realized she was missing, it had been about two hours.

I was looking over a mountain of apples at the grocery store when I got the call that they'd lost Mom.

“Hi, Jennifer. I really didn’t want to have to call you, but too much time has gone by. We can’t find your mom.” The strain of the situation straining the med aide's voice.

My mind had to catch up. “How long has she been missing?”

“Well, we think it’s been about an hour.”

“Oh, my goodness!” An hour for my mom was enough time to leave the building, hop on a bus, and be halfway across the city.

By this time, they had a location necklace on my mom. “What about the tracker you have on her? Can you find her that way?”

“That’s the thing. Her tracking necklace says she’s in the building, but we can’t find her.”

I was confused. “So she’s there?”

“Yes, we just don’t know exactly where.”

By this time, I’d put down the apples and walked away from my shopping cart. Heading toward the toy aisle to find my husband, I said, “I can be there in about 15 minutes.”

All of a sudden, I heard talking in the background, and someone yelled, “We found her!”

One of the med aids eventually thought to check the public restroom, and the door was locked. My mom had been inside for almost three hours. She was sitting in her poop, with her dirty pants around her ankles, crying and red with shame. Mom didn't remember how she ended up in the bathroom, but each time she thought she wanted to leave, she realized she was covered in poop and started crying all over again.

This time, the staff was overwhelmed by the responsibility. The anxiety of looking for her and worrying that they'd lost her was too much. Even if they wanted her to stay, it was time to find her a memory care home. It was obvious to everyone that Mom was going through a cognitive decline, and her assisted living was not equipped to care for her anymore.

I was approaching the thing I feared the most: putting my mom in a locked facility. I imagined the moment when I walked out the door, and it locked behind me, and then turned back to my mom, watching me walk away.

I had to do it, but I also dreaded it. This was the end of my mom's independence. She would reach for that door handle and find the door locked with no way out and she was going to be furious.

Mom moved to memory care in the fall of 2018. Moving someone with dementia or Alzheimer's from one place to another is not easy. The entire move was challenging for my mom. Mom did not remember from day to day that she had to move, so every day when it came up, she got frustrated and confused, like it was the first time someone told her she had to pack and be ready to move.

I tried to consider things from her point of view, though, and empathize with her. Imagine if you couldn't remember day-to-day and abruptly someone told you you had to move somewhere else.

I would take my mom to view a room in memory care, and she wouldn't like it too much, so we would leave. She had the energy for one viewing at a time, and I had the patience for only one viewing at a time, too, so that worked out. But the next day, when I would visit her, Mom wouldn't have a clue who I was, and she didn't remember that she'd gone somewhere yesterday and didn't like it. Her only option was to try and trust my sort-of-familiar face. The ordeal was frustrating, and my mom was so confused by the entire situation.

So, I decided to start looking at places on my own. My mom had spent as much time as possible in assisted living, and she needed to move. Suzie where to go and who to talk to, and I made appointment after appointment until the rooms started to run together in my mind.

I was focused on the odors, the number of people working, whether visiting family members appeared at ease, and whether I saw fear or discontent in the residents' eyes.

But I was mostly focused on the building's overall aroma. If it was bad, it was a hard no.

Finally, I'd visited enough places and was comfortable inside myself that I'd done everything in my power to pick the best possible place for Mom to go. Deep down, my gut told me this would most likely be where she would die, so I wanted it to be a good place.

This was the task.

Finding a good place for my mom to die.

But no matter how many places I visited and how quickly I tried to make the decision, my mom was frustrated with the changes in her life and what she couldn't remember.

My mom's last days in assisted living were rough. She was getting lost in the building, walking out the front door when no one was looking. She didn't remember anyone, and she was sundowning a lot.

In the Alzheimer's world, sundowning occurs when a person has a clearer mind in the morning, but as the long, long day wears on, they become tired and can't remember much of anything. Memories they had in the morning are gone, and people they remembered are strangers now. Overall, it happens most frequently at night in Alzheimer's patients, hence the name sundowning.

The most significant change in Mom during this time was that she started sundowning almost every evening, and the accomplishments of the day preparing for her move were lost. I would come over to her assisted living to go through more things, and all the boxes I'd packed the day before were unpacked, their contents lying all over the floor.

"What's going on, Mom," I'd ask. "Why are all these boxes open?"

Hands on her hips, she'd answer, "I don't know why these boxes are even in my apartment! Are you giving away my stuff?"

The weeks before her move were challenging. A week or so before moving day, I got a call from one of the med aides at assisted living. Mom had woken up not knowing where or who she was, and she was scared. The chaos of her little apartment probably didn't help. The med aide put Mom on the phone with me, and she was crying that she didn't remember her name. ⠀⠀

“Your name is Bobbie,” I said. ⠀⠀

“Ok. If you say so,” she answered. ⠀⠀

“Who are all these people in the pictures? I don’t know who they are.” Mom must have been standing by her front door. I'd covered the inside door to her apartment with photos of her whole family: me and my sister, our husbands, her parents, all her grandchildren, and cards that people had sent her over the years.

“Every one of those people loves you,” I said with a smile. ⠀

“Do you love me?” ⠀⠀

Barely holding it together, I answered, “Of course I do, Mom. I love you very much. ”⠀⠀

“I’m your mom? I didn’t know that.” ⠀

It was heartbreaking.

The med aides settled Mom in for breakfast, and I spent some of the day with her, helping her pack up more stuff and organizing her living space so it wasn't so messy.

Eventually, I found a room in a small memory care facility for my mom and moved her in, and though it wasn't without its hurdles, it made a huge difference for me. I was comforted that she couldn't escape, that she was fed, that she had people with specialized training for Alzheimer's, and how to handle her.

I had no doubt she would be mad, but it gave me a measure of peace.

My sister and her family came over and helped me pack up Mom’s place and move her to memory care. This was an unbelievable relief, if only for a few days.

What surprised me most about this move was that though Mom couldn't remember why or how she ended up in memory care, she remembered that she used to live somewhere else and had more belongings. Perhaps it was because she shared a room with someone in her new memory care. Or perhaps it was simply a long-held memory that refused to fade in her mind, but she remembered she had more clothes, a kitchen, papers filed away, necklaces, earrings, and scarves. She had boxes of things.

For the first six months that she was in memory care, Mom asked me each time I visited where her stuff was.

"Those people went through my room without me and took my things," she would complain. This conversation was something she circled back to almost every visit I had with her during that first long winter.

I would gently tell her that I had been the one to clean up her room. I told her I'd gone through everything carefully. I reassured her that almost everything that didn't make it to her new room was in my garage in storage. So, she focused on my garage. Mom wanted to come over and sort through her things. She started calling it my "magic garage," where I kept everything from her.

It got to the point where I dreaded these conversations, and I would do almost anything to change the subject when Mom focused on it. Truth be told, I gave away a lot of her clothes. I had some of her wall hangings, her jewelry, some of her papers, and some knickknacks. The rest of it—the furniture, the DVDs, most of the books, the tables, the desk, the bed, and the dresser—I gave it all away. I had nowhere to keep it, and Mom would never be in a room with enough space to have it all with her.

I made the decision, but I also did not expect that my mom would so deeply remember those things. This was a struggle for me because I thought my mom would move into memory care and the big decline would take her quickly.

My kids traveled to town to visit their nana after she went into memory care. I talked to them often about how she was doing, and they understood what I was going through, so when I told them I was worried she might die any day, they came out to spend some time with her.

But she didn't die.

My mom hated memory care too much to die. It was almost like her hatred of the place and of me for putting her there jump-started her brain, and as abruptly as her decline started, it was over, and she leveled out.

Mom had gone downhill for sure, and so much had changed, but at least she wasn't on the big drop of the roller coaster anymore.

My grief emotions started anew.

Let's move to another motel

1975

DAD HAD WHAT HE CALLED “the wanderlust," and right after I started kindergarten in Nashua, New Hampshire, we started moving. I have many memories of many moves. I have vague recollections of farmhouses, yards, and some schools, but many of them run together now, and I mix them up. Each time we moved, my parents would try again in a new place.

My strongest childhood memories before my parents divorced are of watching my mom as she busied herself around the house, but more so, tagging along behind my dad as he worked outside. He was where I wanted to be. He was quiet and patient, and my childhood memories of my mom were not memories of her patience.

I also remember that in our own little family, my mom and my dad didn't speak much, so in my little childlike way, I experienced the tension. Mom would ignore us if we did something she didn't like, and she often ignored my dad. Once she got into that hard, silent mode, it wasn't easy to open her up again.

I remember a farmhouse by the lilac bushes and the bees always trying to sting me. I remember a different farmhouse by the corner and the barn near our pigs. I remember an apple orchard and the caterpillars we would follow back to their trees. I remember the playground on the hill in Colorado Springs and the boy who was so tiny that when he put his arms out with his jacket on, the wind would fill up the sides of his jacket and almost lift him off the ground. I remember the grove of trees near one house and how it was the only place in the world where I felt peaceful.

I would pack up all my stuffed animals and wrap them in a blanket, take them out into the middle of those trees, lay myself and all my toys out on the blanket, and pretend that we were adrift at sea. None of us was allowed to leave the confines of the blanket, or we would be tossed overboard. I would, on occasion, chuck one of my stuffed animals into the trees and pretend to cry because it was lost forever. But I made sure to gather them up again when I was called inside for dinner.

One house I remember well was the last one we lived in as a family, the four of us. It was our little farmhouse in Park Rapids, Minnesota. When we first moved into the house, it was a small, one-story building with a long attic split into two little rooms.

My mom and dad set out to remodel it right away because that would be their forever home. The house and the buildings on the property were so old that we only had an outhouse. During the remodel, the plumbing was turned off, and we used that outhouse for an entire summer and into my fourth-grade school year. I didn't realize it was crazy and weird at the time. This was how we did it.

My parents had a large barn across the driveway from the house and an alfalfa field my dad rode the tractor through. I don't think he actually farmed that; I just remember him letting me handle the steering wheel and teaching me how to turn it. We had goats, bunnies, our huge dog Tanoose, and a little poodle I named Curly.

This house sticks out the most in my memory because so much happened here right before my parents divorced. This is the one place I vividly remember my parents touching hands and giggling and talking in hushed tones. They were so distant most of the time, and I remember being shocked that they touched each other and laughed. I was almost ten years old and starting to pay attention to that sort of thing.

Perhaps my parents had an inkling it was the end, so they were making one last effort to work on their marriage by trying to go back to the playful time they might have had at the beginning. All I remember is that when we lived on this farm, and my parents were remodeling the old house, it was the happiest I ever remember my mom being.

One thing we did a lot when I was a kid was play a game called “Move to another motel.” This is the family tradition I remember most from my childhood.

Whenever both my parents were home – so probably on the weekends and holidays – my parents would sneak into my room and wake me up by getting on my bed and prodding me awake.

My mom would say something like, “There’s too much light in here, Jerry. We need to get another room.”

My dad would answer, “Yeah, and this bed is lumpy and smells funny. I don’t like it.”

By this time, I was awake and giggling, and I would sit up in bed and say to them, “Let’s move to another motel.”

Mom's eyes would pop open, and she would drop her jaw and turne to my dad. “Wow! I didn’t know there was some kid in our room with us, how did that happen?” she would say.

“I don't know," Dad would reply, "but this kid’s got some smarts. Let’s do it. Let’s take her with us and move to another motel.”

I would laugh and jump out of bed, and we would quietly make our way to my sister’s room, tip-toeing down the hall in a fake, sneaky way and crawling into her bed, all the while trying not to giggle.

I would tickle my sister, and my mom would laugh. My mom's laughter was such a rare gift that I would do anything to hear it.

“Well, now that we’re in a new motel, let’s try and get some sleep,” my dad would say. And we would all lie down and pretend to sleep, making so much noise that my sister couldn’t help but wake up. I would pretend to snore extra loud, and by this time, Tanoose, our huge Newfoundland dog, was in bed with us.

Giggling ensued. We would all be awake pretending to sleep.

“I don’t like this hotel, Jerry,” my mom would whisper. “It’s so noisy in here and there’s another kid in this bed. I don’t remember her from the other motel.”

“Mom, it’s me,” my sister would giggle. “You moved into MY motel.”

By this time, the dog was licking at us like mad, and we were all laughing.

“Oh, my gosh, this motel allows pets! We need to move to another motel,” my mom would say.

“You’re right, Bobbie. Let’s go,” Dad would say, and they would hop up and start back for my bedroom. Of course, my sister and I followed them, and Tanoose followed us. Mom and Dad would lie down in my bed and pretend to be asleep while my sister and I crawled in, and the dog jumped on top of us.

“It’s even noisier in this new motel, Bobbie! What are we going to do?” my dad would say, his eyes closed, his face buried in a pillow.

“I know!” either my sister or I would yell. “Let’s move to another motel!”

And back and forth we went until my parents decided they were tired of the “noisy” motel, and we would go downstairs to their bedroom, and all climb into their extra high king-size bed.

By this time, we were hungry, and the dog was barking.

No matter how many times we did this as a family, it was always fun, and it always seemed like love, like a warm blanket wrapped around us, holding us together.

It was our tradition.

And it always ended in pancakes and eggs and bacon for breakfast.

I think back on this now, and these are the happiest memories I have of my mom and dad, especially of my mom. I have never been a morning person in my adult life, so my kids were always awake before me. I never played “move to another motel” with them. This was something that I only did with my parents for the few short years we were a family.

A month!

2018

MY MOM’S CASE MANAGER, SUZIE, told me that when I moved my mom into memory care, I should stay away for at least a month.

I was shocked. “A MONTH!” I couldn't do that.

“Even though it seems like too long,” she explained, “it gives them time to settle and, honestly, to forget where they were before.”

“That just seems so cruel,” I replied.

I thought about it and wrestled with the emotions. I could not stay away for a month. That meant I didn't love my mom enough, that I wasn't a loving daughter, and that I certainly wasn't a satisfactory caregiver. I told Suzie, “I just can't do that.”

I sensed the trepidation in her voice.

Suzie knew what I was in for.

I did not.

She gently said, “I understand, and no matter what you decide, I’m here for you. She’s your mom, and you have to do what you think is best.”

The day after my mom moved in, I went to visit. As soon as my mom saw me, she jumped up from her seat at the lunch table, practically ran to me, and grabbed me in the tightest hug. I couldn't breathe.

"You have to get me out of here," she whispered. "Thank you for coming back."

I smiled, and we sat down and talked about her day so far. Eventually, she was brought to the community room, and they sang. Mom forgot she wanted to leave, and I was able to say goodbye and sneak around the corner to the door. I continued to visit her every day, and her reaction was much the same. She wanted out!

A week after I moved my mom to memory care, she was refusing to eat and told me that they were starving her. The staff gave her muddy water to drink and no meat, and the food was terrible. They never fed her breakfast. My mom said all this while she was at the table eating her lunch right in front of me.

Two weeks after I moved her into memory care, I went to visit my mom in the evening. I was by myself, and my intuition told me to go see how she was adjusting. I'd been checking in on her every few days, and she appeared to me to be doing well. My mom persevered. It was her thing.

When I walked in that night, one of the aides told me Mom was in a mood. She was sitting on her bed in her room, and she had the nana lips. She glared at me. All she wanted to do was talk about where her things from her old apartment were. I tried to change the subject, but she was wise to my diversions. I finally asked her if she wanted to go out into the hallway and walk the courtyard.

The building was built around a courtyard, and that made it easy to walk the square through the hallways by all the rooms. Mom and I would talk to people and say "Hi" as we walked. Each time we came around it to the beginning of the square, my mom forgot she'd said "Hi" already, so we would do it all over again. For me, it was something to do. And I was hoping it would take her mind off being so upset at being moved into a new place with new people and routines. So, we walked, and the turns of each corner and the people waiting and its repetitiveness wore on my mom and only made things worse. She started pounding her fists on the bar of her walker.

"You dumped me here," she spit.

"Oh, Mom. I'm so sorry you feel that way. I didn't mean for that to happen," I replied.

"I hate it here and I want to leave, and they won't let me leave," she spit back.

"I know, and I'm sorry, but I think this is the best place for you right now."

"It is not! I want to be with my friends and my things."

And on it went. My mom got more spun up the more we walked that courtyard square. It was like the walking around and around was winding her up like a jack-in-the-box, and she was ready to blow her top. I wanted to say so many things to her that evening that are things you can't say to someone with Alzheimer's. I mean, you can say them, but every bit of advice I read online about Alzheimer's said not to say things like "remember when," "don't you remember," or "remember that day." Lord, help me; that was all I thought of saying.

As my mom was pounding on her walker and yelling at me that I dumped her there, all that came to my mind was, “*Don't you remember getting lost at your old place? They were so worried about you.*"

"*Remember when you went out onto the street and forgot where you were and fell in the ditch?*"

But I didn't say any of that.

It crossed my mind to tell her we moved to another motel, but I didn't want to confuse her more if she didn't remember that, and I also didn't want her to think I was taking her anywhere.

Eventually, I bit my tongue and recognized deep in my soul that my mom was where she should be. She was safe. I didn't have to worry that she would walk on a city bus and become lost, hop off miles away, and try to walk home. No matter how mad at me she was, I had done what was best for her.

On our last turn around the building, Mom got red in the face as she yelled louder. She was drawing attention to herself. A woman following us at a distance started to cry. I had to leave. One more time, Mom pounded on her walker and stomped her foot.

"You just dumped me here to forget about me," she yelled.

I was right next to her, so obviously, I hadn’t forgotten about her, but I couldn't say anything right at that moment. Letting go was difficult, and I hadn't mastered that yet, but I put my arm around my mom and said, "I'm so sorry you're upset. I love you, Mom. I'll come back tomorrow."

I walked to the front door, punched in the code, and left. The next day, I called Suzie again, and she *again* told me to stay away for at least a month.

“The goal is to let your mom adjust to her new routine and her new place and new people and in a way, forget about you. It’s difficult, I know, but it will help so much,” she explained to me again.

“Ok, I’ll try,” I said through my tears.

This was beyond what my heart could comprehend, but at that point, what I was doing was not working.

So, instead of staying away for a month, I didn't visit my mom for two weeks. I split the time down the middle.

Two weeks

2018

THOSE TWO WEEKS ALLEVIATED SOME of the stress for me, and they made a difference in my mom's emotions about her new place. She forgot the name of her previous home and started to replace those memories with new ones. Ultimately, though, as happens with Alzheimer's and also with my mom, she blamed me, and many of the things I thought might happen did happen. I had no doubt she would hate being locked in, and she would be angry with the nurses and med aides, and that would test everyone's patience.

About three months after she moved into memory care, Mom snuck out the door during a busy moment when they were getting someone out via an ambulance gurney. My mom got down those stairs and walked like a bat out of hell into the parking lot. She got halfway down the long driveway, which led to a busy four-lane city road before an aid caught up with her. A staff member turned her around, but not before my mom started yelling that she was a prisoner and that if she'd known this was going to be her life, she would run out in traffic and end it all.

The aide was able to wrangle Mom back into the building, and they tried to settle her in her room. But when they left her, thinking things were OK, my mom tied her scarf around her neck and attempted, as much as she was able, to end her life. She was found a few minutes later, twisting the scarf tighter around her neck and yelling about how she wanted to die. She was taken to the hospital on a psych hold.

When I got the call, I grabbed my purse and cell phone and put on my coat when the director of Mom's facility said, "Your mom doesn't want you to see her. Let the hospital call you."

I took my coat off, and I sat on the couch and turned on the TV, and I waited.

But they didn't call me soon enough, so I called them. The nurse on the phone calmly told me that my mom didn't want me with her and that they thought, given her level of agitation, that it would be better if I didn't come to visit. The hospital would call me if they needed me.

My mom was kept on a psych hold, but that night, I had to go over to her little room and remove all her scarves, her necklaces, and her shoelaces. Anything that might be used as a hanging implement.

It was awful.

Mom was returned to her memory care the next day, quite drugged. I snuck into her room when she was sleeping, and her sixth sense must have kicked in because she opened her eyes and glared at me. She lifted herself in bed enough to say, "You don't love me. You can't love me if you abandoned me here."

I tried to smile, and I told her that I did love her, and I was sorry she was so upset. Then I left because I didn't want her to become upset again. Mom was crying as I walked down the hall. And I cried in my car the entire way home and blasted the music, so the beat of the songs shook my heart.

Mom spent months and months in this mental space where she recognized my face and would frown when I came in, but often, she didn't recall my name. Mom would forget how to move one foot in front of the other, how to eat, and how to speak. Some days, she was fine; others, she was almost catatonic. She was an empty shell kept alive by a beating heart and Alzheimer's medicine. I tried puzzles, but she simply stared at them. I would turn on the Hallmark channel in her room, but she couldn't understand what anyone said.

One day I was walking the courtyard circle with her and as we rounded the corner to the dining room her roommate, Shirley, was sitting at a table. Mom smiled and said, "What's new?"

Shirley answered, "What?" Because she was practically deaf.

Mom would yell, "What's new?" and Shirley would answer, "Nothing, what's new with you?"

And Mom gave her standard memorized answers, "New Jersey, New Caledonia, New Brunswick," and they both laughed.

Each time we circled that courtyard loop and mom pushed her walker around the corner, it was like she'd never seen Shirley, and the entire conversation started all over again.

“New Zealand.”

“New Hampshire.”

Day after day, week after week, I kept walking around the courtyard and going through all the complex grief emotions. No amount of fighting against it could stop it from happening.

I wrote in my journal one day that I was going to be with Mom to the end and give her the grace and dignity that she deserved as she left this world. I experienced an ending, almost final feeling as I wrote those words, but nothing was final about the days ahead. It didn't help that every day with my mom was painfully sad. Sometimes we laughed. I sang to her, painted her nails, and cut her hair, but no matter what I did, she was still alive and dying, and I couldn't do anything about it.

I tried the next thing that came to my mind, and that was to detach from the pressure of her dying. I thought if I were able to view visiting her and taking care of her as a volunteer position at a memory care facility, it would take some emotion out. This would make it easier for me to be around her, as she declined. It didn't take away the grief, but it did help ease my stress. Especially when she was mad at me, and she was mad at me a lot of the time.

Mom spewed a lot of hateful words about me dumping her in the memory care. More often than not, I would leave and cry in my car all the way home, sit down to eat a bag of potato chips, and turn on mindless TV to forget about how dreadful I felt.

But the detaching helped.

When I was with Mom and she was in a pleasant mood, I was with her as her daughter. I let all the love in and held on tight to the rollercoaster, but if things were rocky, if she was mad, I clung to my detached belief that I was volunteering with an Alzheimer's patient.

When mom yelled at me, I could let it go and recognize that she couldn't help being mad because she didn't recall who I was. I got in my car to go home and told myself I'd done a fine job volunteering and would do just as fine a job tomorrow.

If my husband was with me, it usually made things a little better because he would make her laugh, and oftentimes it deflected her irritation with me. And I continued my “volunteer” work and talked to him about it on the car ride home. That mindset helped so much with my mom and it made it easier for me to be with her when she was alive and dying.

Incorporating grief into my life and learning to carry it with me made it easier to handle, and detaching from the experience helped me cope.

Little did I realize that I would need all this practice of loving and detaching.

My mom eventually transitioned into memory care, though it was not without some major challenges.

After my mom snuck out of the building and ended up at the hospital on a psych hold, her brand-new memory care wanted to kick her out. The facility owner called me into a meeting, and my sister was going to be visiting that week, so I told her what happened and that we may have to move Mom to another memory care.

“Well, that would suck because it was a lot of work to move her in,” my sister replied.

She didn’t comprehend half of what it took me to find Mom a memory care place.

The day came for our meeting, and the tension in the room was thick. I had asked Suzie to be in the meeting, too, because I had no doubt she would help us through this.

Tina, the memory care owner, started the meeting, “So we are here to talk about Bobbie and what happened the other day.”

I glanced at Suzie, and she met my eyes with an expression that said she wanted me to wait. We’d talked in the parking lot, and she’d already told me and my sister to let her do most of the talking.

“This is a delicate situation,” she explained.

I listened to Tina as she continued. “As you know, your mom had an issue and left the building, and it caused a lot of chaos. She has been physical with the nurses and rammed her walker into our charge nurse while she was giving out medication. My nurses and med aids here have a lot of experience, but we just can’t have that kind of behavior.”

My mom’s case manager took in a breath, “I understand. I love Bobbie, and I know she can be a spirited woman, but I hope we can take into account that she only recently moved in, and she’s having a difficult time adjusting.”

“Yes,” Tina replied. “I understand that, but if we can't get her more calm, she won't be able to stay here.”

“What about adjusting her medication?” Suzie asked.

She'd talked to my sister and me about this ahead of time, so we were expecting it.

Tina glanced at me and then at my sister. “That’s something we could do. She’d have to see her doctor and have some meds added.”

“I can get that set up,” Suzie said. “I’ll make sure and do that first thing tomorrow so she can see her doctor right away.”

I let out a sigh.

“So she can stay?” I asked, looking back and forth between Tina and Suzie.

Tina was the one who answered, “Yes, for now. And we’ll see how it goes.”

In the end, we agreed to start my mom on some new antipsychotic medication. She would receive a dose in the morning, again in the evening, and another one during the day if her emotions got amped up and out of control.

By this time, my mom had leveled out in her decline, but it had left her with more cognitive deficits, and one thing she was fully aware of was that she was locked inside a building, and she hated it. This new medicine would help with that. Though I wasn't thrilled about the idea of medicating my mom more, I couldn't fathom the idea of moving her anywhere else.

And so we did our best, week after week.

My sister came to visit during the warmer months and stayed for a week at a time, and we visited Mom every day. Overall, my sister and I got along well enough, and our visits were comfortable. She stayed in a hotel at first and later at our house. We drove to visit with Mom for an hour or two, and a few times, we took Mom shopping with us or out for lunch.

But much of our time was spent around a table in the dining room at her memory care. One of Mom's cognitive deficits, though, especially on the new medication, was not knowing when she had to go to the bathroom. Be it poop or pee. This started to happen. A lot. And at the worst times.

But it was never worse than when we had to take a photo.

Poop hugs and poop pictures

2019

NUMBER TWO. POOP. DROPPING YOUR kids off at the pool. It's not something everyone talks about, and it's definitely not something I was used to talking about.

As a young mother, I had to deal with poop, lots and lots of it. I cleaned up poopy diapers and made up fun ways to make my kids giggle and quit squirming so I could wipe their butts and clean them up and put on dry diapers. This was a thing I did. It's not a thing I ever thought I would do with my mom. But when you're taking care of someone who is alive and dying, poop becomes a thing that you deal with.

My first poop experience with my mom happened during the long middle when she was still in her assisted living. My husband and I had taken Mom to a new place we loved called Cafe Yumm. The restaurant served rice and meat and a yummy sauce full of milk and cheese. My mom was extremely lactose intolerant, but on this day, when we stood in line to order our food, she forgot that.

During the long middle, I learned not to argue with her about it. If she believed that she was able to eat all the cheese in the world and not poop, who was I to argue? Mom would eat all the cheese, and when I dropped her off at her assisted living, she would realize she needed to poop and then eventually forget again. I didn't have to worry about it. But as with all things Alzheimer's, those things I pushed aside eventually became things I had to worry about.

That day at Cafe Yumm, we ordered the food and paid for it at the counter. We found a table by the window and sat down, waiting for them to bring out our food. We were eating and talking when I peeked over at my husband and sniffed. He was already looking at me, his eyes wide and his nose scrunched. My mom was scooting around in her seat, and at about the same time, the stench of poop hit our noses. Mom said she had to go to the bathroom.

"Sure, Mom. We're not going anywhere." However, I wished we could at least move to a table on the other side of the restaurant.

Mom got up and walked away. My husband and I gave each other a knowing glance, and we continued talking about whatever it was we were talking about, and as we chatted, we lost track of time.

Finally, we paused, and I glanced at my wristwatch.

"How long has she been in the bathroom?" I wondered, and my husband shrugged.

We guessed it had been about 15 minutes, and we decided to wait five more minutes. If my mom wasn't out by then, I would go in. I was dreading it.

At exactly the five-minute mark, I was walking over to the bathroom door when the lock clicked, and Mom peeked out and spotted me.

"Jenn," she waved me over, "I need you to walk behind me, OK?"

The aroma coming out of that bathroom was otherworldly terrible. Thankfully, it was a single bathroom, not a full-on women's restroom with lots of stalls. No one else could come in while she was blocking the door.

My mom was a tiny woman, and if I haven't already mentioned it, she was always very well put together. She loved fancy outfits, skinny jeans and scarves, and necklaces. She always liked to dress well.

On this particular day, my mom wore a pair of skinny jeggings and a cute little tank top with a sweater. I spotted the mess all over her pants as she stepped outside the bathroom door. Mom had probably lost her bowels (that's something I never thought I would write) on the way to the bathroom and spent the last 20 minutes trying to clean it all up.

Bless the cafe worker who had to clean up the bathroom after her.

I didn't even glance in to check what it was like inside the restroom, but with those jeggings and their skinniness, it was hard to miss the dark stains all down her legs and up the back of her shirt leaking through her sweater.

Like a little fish in a dirty fishbowl, I took a shallow breath and got ready to walk behind her. It was obvious to me that she was terrified.

"I got you, Mom. Let's go," I said, and we started walking.

I don't remember how many people were in that restaurant, and I don't remember getting any sideways glances from anyone. During the long middle, I was often self-conscious about what people must have thought of me and my mom, how she acted, and how she would walk up to anyone and tell stories or start talking their ear off.

At that moment, I didn't care about anything. I only wanted to get out of that restaurant.

That is all I remember thinking.

As we walked to the table, I walked right behind my mom, trying to hide her backside from view. We didn't even stop at the table. I kept Mom moving, and we did a "fly-by." Tapping my husband on the shoulder, I said, "Gotta go, dear," and I put my hand up in the air and circled it around like I was rounding up a herd of sheep or something.

"We gotta GO!"

I've said it before, and I'll say it over and over again – being an Alzheimer's husband is not an easy job, and by this time, my husband followed along when I was in caregiver mode with my mom. He jumped up from his seat, noticed me standing so closely behind my mom, and his eyes went down to her poop-soaked pants. He grabbed coats and purses and stood ready for action.

"Walk in front of us," I whispered. "I'm going to follow BEHIND her." My husband put all the pieces together and started walking.

We got my mom out of that little cafe and into the car and drove her straight back to her assisted living. My husband and I tried to have a normal conversation in the car like there was no poop and no odor, but it was difficult to do that.

I was probably rambling about the latest road construction on the way back to her place or how busy the freeway was as we drove underneath it. Anything to fill the time and not bring attention to the stinky elephant in the car. We had cracked the windows, and my husband was taking snorkeling breaths for some fresh air.

My mom was so quiet in the back, and finally, as we got closer, she said, "I'm sorry, Jenn."

I turned my body in the passenger seat to see my mom's embarrassed face. "It's OK, Mom," I answered.

She gazed at the seat and scooted up a little bit, "Your car," she whispered.

Tears sprang to her eyes, and I tried to keep it together, "It's just a car."

As we walked into the building, I waved over a med aide on the evening shift. I whispered as I told her what happened. We walked my mom up to her room, and the med aide took her back to her bathroom. My husband and I waited outside until Mom was cleaned up and changed, and then we said goodbye and left.

As a first poop experience, it was quite memorable. After that, I put a towel in the car, grabbed some of Mom's incontinence underwear, and had a full change of clothes at the ready. I created a Go Bag that I stowed away in the back of the car.

A poop go-bag.

I also started carrying lactose intolerance pills with me wherever we went. If Mom forgot she was lactose intolerant and refused a pill, I made her take one anyway and put up with her being angry at me.

As things progressed, and we entered the big decline, poop happened more often. And more publicly.

One thing I decided was to take Mom to the same restaurant for our Wednesday night dinners. This provided consistency for her regarding place, time, and day of the week. It also helped that we could order the same food week-to-week, and I wouldn't have to worry about her fighting me to get something with cheese in it. Before we left for our Wednesday night dinners, I would make sure my mom's diaper (something I never thought I'd have to deal with) was changed and that she was dry and comfortable.

On our drive to dinner, we often talked about how she wanted to find a job or a new place to live. Mom would ask about house prices and how she could buy a bus pass to travel to work. Sometimes, she even talked about going back to college to finish her teaching degree.

We would eat and head back to her place. But as Mom declined, her ability to hold her bladder and bowels got worse. Often, she didn't remember that she needed to go to the bathroom and would have an accident at the table. The stinky odor was generally our queue to leave.

Regardless, I always took a family photo to capture the memory of my mom at that moment. Poop pictures became a thing. I cannot tell you how many photos I have of Mom and me or a group at a restaurant, and we all have these smiles on our faces, but to the trained Alzheimer's caregiver eye, they are actually grimaces.

We're holding our breath and hoping we don't pass out while the photo is taken.

After the weekly photo, it was time for the long, slow walk out of the restaurant. Mom loved to talk to people anytime, anywhere. She would stop by tables and talk to the kids as we walked out. She loved that, and kids generally loved her because she was so social.

Once, as I tried to scoot Mom out of the restaurant quickly, she stopped to talk with a little boy. As she stood at the table, the boy's mother grabbed her younger child and sniffed his butt, and then she peeked down his pants to check if he'd pooped. That mother's eyes flashed up to mine, then she glanced at my mom, and she figured it out. It was a moment.

I spent many long, slow walks out of that restaurant, trying to move Mom along and spare people the lingering odor, and my mom usually got upset with me for "rushing" her. This was another caregiver task I had to adjust to during the big decline.

One of the last times I took Mom out for our Wednesday night dinner, my oldest son was with us. Our nephew always met us, so five of us were at dinner this week. My mom announced that she needed to go to the bathroom, and I panicked.

"We can leave right now, Mom. Can you wait until we get back to your place?" I asked.

"No. I need to go now," she said, and she hopped up from the table and quickly pushed her walker down the little hallway to the bathroom.

I marked the time on my wristwatch and told my husband we'd give her about 10 minutes. "If she's not out by then, I'm going in."

And so, we chatted with the boys about life, college, and work, and 10 minutes came and went, and my mom wasn't out yet.

I walked into the bathroom and peeked at her through the stall door. "Mom, how are you doing? Do you need help?"

"Yes," she huffed. "Jennifer, I've been waiting for you. I can't get this thing off of me."

Mom leaned forward and unlocked the bathroom stall door. As I opened it, she was sitting on the toilet, her pants around her ankles, and she was holding her sweatshirt. Her industrial-strength diaper was still on her. She'd had an accident but wasn't able to take the diaper off in time. Mom had been sitting in the toilet trying to rip at the sides of the thing near the perforation to tear it away, but it was not working. A factory defect diaper that didn't easily rip away. What were the odds?

I went out and got my son and asked him to stand at the bathroom door and I grabbed a knife from the salad bar. That's right, a knife. When I returned to the bathroom, a little girl with long blond hair in braids was staring at my mom as she sat on the toilet. I cut the diaper away from my mom with the knife and wrapped it up, poop and all, and put it in the garbage can.

The trouble was that I didn't have a replacement diaper with me. I'd had my car cleaned, and I'd forgotten to put the poop go-bag back. The only thing I had were incontinence pads in my glove box.

I was so unprepared for this, but since we couldn't wait for me to drive back to her place and grab her a new diaper and pants, all we could do was pull up the pants she had and walk her out commando. I hoped she didn't have another accident on the way out.

I told my son the plan and had my husband and nephew ready to escort us out.

I leveraged myself in the stall door, grabbed my mom's arms, and helped her stand up. I pulled up her soiled sweatpants and started that long, slow walk out of the restaurant...again. I told my son to walk behind us and had my nephew and my husband walk in front of us. We got out with a little bit of a mess left behind, and only a few people made faces as we wafted by.

All of us stopped long enough after we got mom in my car to take a selfie poop photo by the vehicle door. This is another photo I look at now and recall the story behind those poop smiles. The hugs we gave her were not quite as tight but still lovingly given.

After that incident, I grabbed a handful of her diapers and put them in the poop go-bag, along with a few pairs of mom's underwear.

I wonder what my mom would think about me writing about this. At the time, she wasn't aware enough anymore to be embarrassed about it, but I wonder if she would be embarrassed now, wherever she is in the cosmos, knowing I'm writing about her poop and her diapers and her accidents. I'm hoping that she'll be happy that perhaps she and I are helping people.

When my mom was diagnosed with Alzheimer's, poop was not something I thought about. When I questioned how bad dementia would be, poop did not even make the list of worries. I had so many other concerns, but as time went on and mom's memory declined, poop became a worrying thing. A nasty, smelly thing. Poop became a scary, ever-present part of our experience. I had never changed an adult diaper before. Poop was not something I wanted to deal with. That's what med aids are for. THEY do that.

I wondered how they could do that and why it was something I avoided at all costs. I thought I SHOULD be better at dealing with it.

But as it turns out, I wasn't. When it was clear I couldn't take her out anymore, I switched up our schedule. I ordered pizza and had it delivered to her memory care, and I never changed a diaper. I also never beat myself up over that.

What I have now are a lot of poop photos. I said goodbye to my mom on countless occasions and waved down a med aid to change her and gave my mom a poop hug, and left.

I miss poop hugs and poop pictures.

Inhospitable

2019

ONCE POOP HUGS AND POOP PICTURES were a normal part of our routine, my husband and I came up with a code word—something to say when the whiff of poop hit us. And believe me, it hit us.

Mom had always had belly troubles, she was lactose intolerant, she loved chocolate, but it made her gassy, and I've always heard, "Never trust a fart over 40." I don't think my mom ever heard that one. She tooted a lot during her last few years, and many of them turned against her in the worst way.

One day, my husband and I were visiting my mom in the dining room of her memory care, and a terrible stench accosted us. It was poop, for sure, but poop mixed with old pee and perhaps some steamed broccoli on top. It was so terrible that it seemed like the stench of it stuck to my tongue, and I could taste it.

I glanced around to see who else was near us besides my mom. Occasionally people would walk by, and their odor would follow them out of the room, but no one was around, and I couldn't remember if anyone had walked by us recently enough to leave a walking fart behind in their wake.

My husband turned to me, and said, "That is inhospitable." And my goodness, it was hard for me not to bust up laughing. I didn't want to hurt my mom's feelings, but he hit the nail on the head.

The smell was inhospitable.

I smiled at my husband, held it together, and asked my mom if she needed to go to the bathroom. She smirked and said, "Sorry, I had to go."

"It's OK, Mom," I answered. "Let's get someone to help you to the bathroom."

I got up and walked around the facility until I found a med aide, and I mentioned that my mom had had an accident and needed to go to the bathroom. She huffed, "Can you take her?"

I practically backed away as I held up my hands and said, "I don't do poop."

I probably apologized for saying that, which, at the time, I was still prone to do, but I realized later I didn't need to. I never wanted to be a nurse, a doctor, or a med aide at a nursing home. I did poop when I had babies, and that was all the poop I was ever going to do in my life.

I DON'T DO POOP.

I love my mom, and not wanting to change her poop-filled diaper did not in any way lessen how much I loved her. I loved her enough to accept that I couldn't do it. The med aide smiled despite the inconvenience – they were all wonderful and understanding, and as she walked down the hall to retrieve my mom said, "It's alright. I'll take care of it."

"Thank you," I called to her. And I meant it.

I got back to my mom behind the med aide, and she put her hand on my mom's shoulder and took her to the bathroom. My husband and I waited, but we talked about the word inhospitable while we waited. What a perfect word to describe the stinky situation! It was not inviting, beautiful, touching, or something I wanted in my nose. Hell is inhospitable, I imagine.

This was like an extremely smelly hell.

So, the word stuck.

Whenever we were visiting or at a restaurant or sitting doing a puzzle with my mom and the poop odor drifted to us, whoever got a whiff of it first would say, "It's inhospitable." And then, it was time to take Mom home or ask a med aide to take her to the bathroom.

On the next visit, I shared that with my sister, and it became a thing, a real code word thing. Anyone in our family could say it quickly, under our breath, or sometimes text each other "inhospitable," and we understood, without embarrassing Mom or hurting her feelings, that it was time for her to go to the bathroom. It was like our own little Alzheimer's secret spy tradecraft.

This is a word that will always have a different meaning to me. It makes me laugh out loud when I think about the first time my husband blurted it out, but I will never be able to say it or write it without thinking of my mom and our last year of visits.

Inhospitable.

Trips canceled

2019

AS TIME WENT ON, MOM’S hospital and emergency room visits started to impact more than just my feelings. A few times, I was supposed to leave the next day for a work trip or vacation, but I was in the emergency room instead of getting ready at home. My husband was at home wondering if or when we would be leaving because I wasn't packing with him, and he couldn't reach me on my cellphone.

Other times, he would come to the hospital, and while my mom was off getting a CT scan, he would start asking questions about if we were going to go and when we were going to leave. This was immensely stressful.

It is hard to be an Alzheimer's husband. I appreciated this. The changes in our married life and my time commitments wore on him as much as they did on me. Our marriage was tested in those emergency room moments and so many other times when I needed him to be there for me, and instead, it seemed to me like he was selfishly thinking about himself.

Then, I simply started canceling things. That seemed easier than sitting in an emergency room judging myself, resenting where I was, and defending my mom.

The first trip I canceled was in the spring of 2019. I had made reservations at two resorts in New Zealand a year in advance. One resort is on the north island, and the other is on the south island. I had lists of things we would do, and my husband and I would be gone for two and a half weeks. Part of that was the long journey across the Pacific Ocean, but we were so excited about the trip that the long flights didn't matter.

When I made the reservations, my mom was in assisted living, and she was doing all right. I had no reason to think that she would hit a big decline or that things would be different next year. But as the New Zealand trip loomed closer, I considered the cost of plane tickets and realized truly how far away we would be.

My mom had started to mentally decline more quickly, and she'd moved into memory care a few months before our trip. A part of me had no doubt she would be safe, she would not be able to sneak out, and she would be well-fed and cared for. The doctor had adjusted her medication, and she had great people looking after her. I had no reason not to go and take a much-needed vacation from caregiving. Even Suzie told me she would check in on my mom more frequently while I was gone.

But I also saw my mom slowly getting worse and worse as the trip time neared. She was more listless. She had days where she didn’t speak at all and other days where her words made no sense. And many times when I visited her, she had no idea who I was.

I got stressed. My husband and I would be in a time zone 18 hours ahead of her, and should something go wrong, we would have more than 24 hours of flight time to return home. It didn’t occur to me to ask my sister to help.

As the trip approached, I put off buying the plane tickets. I procrastinated. I called my friend Becki and had her travel agent plan the airfare, but I still didn't say yes when she gave me prices. I could not buy those tickets. Soon, it was three weeks before we were supposed to go, and I had not purchased our airfare.

The death knell for a trip like that.

The hotels would be easy to cancel, but if I didn't buy the tickets, they would double in price the closer we got to flying. When that 21-day mark came and went, I decided I could not go. I had to cancel the entire trip.

New Zealand wasn't going anywhere, right?

My husband was disappointed but understanding.

I was resigned that this was how my life was going to be as long as my mom was alive and dying. I would not be able to travel far in case she needed me. I had to be with her at the end. This was non-negotiable.

I took some of the money we had set aside for New Zealand and purchased airfare to Los Angeles instead. I even upgraded our seats. I got us a sweet hotel room near Disneyland, and we went for five days. It was close enough to hop a quick flight back, but still a little vacation at the happiest place on earth.

The day before I was supposed to fly to Los Angeles, my mom got into an argument with a resident at her memory care. They yelled. She poked him with her cane, and he shoved her down. Mom smacked her head against a door frame, cut the back of her head open, and was taken to the emergency room. I was in a hospital room the evening before I was supposed to board a plane for Los Angeles, which would have been the evening before our trip to New Zealand if I hadn't canceled that trip.

Mom's expression was worried as she remembered I was leaving the next day. I had been mentioning it for days, hoping it would stick in what was left of her short-term memory.

"You're supposed to be going on a vacation,” she said.

I smiled and replied, "I'll still be able to go. Don't worry, Mom."

That evening ended up being terribly bad because Mom didn't want to return to her memory care, which was all new to her. Mostly, though, she didn't want to be around the man who shoved her. She sat on the edge of the hospital bed and refused to move.

I focused my eyes on the nurse, hoping for some assistance, but instead of helping, she scowled at me and said, "I've given you her discharge papers. You have to take care of this. We need the bed, and she has to go."

It took some work and some kindness from my nephew, who showed up at the emergency room to help me, but we eventually got my mom in my car with the false promise that I would call the police about the man who had shoved her.

Another therapeutic lie. I didn't like doing this, but sometimes, it was the only way to help my mom and help myself.

Mom sat in the car the entire way back to her memory care. She was quiet and sullen. She kept reaching for the door handle and gently touching it, almost like she was thinking of pulling it and wondering what would happen. I'd belted her in so she wouldn't be able to jump out of the car without me knowing, but she sat quietly, running her fingers along the window to the door handle and back again.

When we finally got to her memory care, Mom refused to go in, so I had a med aide come out the back door and help sneak her in. My nephew went with me to walk her in, and she said goodnight to him and kissed him on the cheek. Mom didn't want to talk to me at all, but I was so glad that my nephew came to offer her the love she needed.

That evening, a huge chunk of resentment and judgment washed away. Though the situation was terrible, I relied on my nephew to help. He was still coming to Wednesday night dinners, and since this was a Wednesday, he was free to help. I canceled dinner, of course. The blessing for me was that I could accept my nephew's help openly and not judge him for doing "better" than me or judge myself for not being able to do enough. I didn't resent the time I'd spent with my mom or her unexpected trip to the emergency room.

From somewhere deep in the depths of my soul, and because I loved my mom, I was able to find some acceptance. She was hurt, angry, and scared, and ultimately, she had no control over what was happening to her. This memory care was her "home." All I could do was be there for her and love her. This was a tremendous first step toward acceptance without realizing I'd taken it.

I checked on my mom the next morning, but I was up packing late into the night and kept taking deep breaths and thinking that I would be on vacation tomorrow and be able to de-stress and catch up on much-needed sleep.

Instead, I ended up crying most of the trip. I'd put too much pressure on the trip as a means of resetting. And my husband was so excited that I wanted to be excited for him. But Disneyland was not the happiest place on earth for me anymore because I was so sad and carrying so much grief. The traffic in Los Angeles was terrible, and I got tired of being in the car. We went to escape the rain, and it rained every day, and I kept breaking down.

In the middle of our trip, we decided to take a break from Disney and drive to Universal Studios. The 35-mile drive took us almost two hours, and by the time we got inside the theme park, the skies opened, and it started to pour.

My husband and I had gone on one theme park ride, The Mummy, because it was an indoor ride. Afterward, we walked in the rain to Hogsmeade in the Harry Potter part of the park and waited to make it inside the Three Broomsticks restaurant to order some lunch. The line was long.

We waited outside in the rain for over an hour. Shivering, I held it together, but by the time we got our food and sat down at the table, my emotional bucket spilled over, and I started sobbing.

Right at the table.

The little kids at the table next to me stared. My husband reached out and took my hand, then put his head down and stared at his food. Eventually, he pushed a pile of napkins over my way, and I blew my nose and wiped my eyes. He understood instinctively that I didn’t want to make a scene.

We'd paid the daily park rate to go into Universal Studios Hollywood, but after my tear-filled lunch, we left. My husband reached for my hand as we left the restaurant, “We can go back to the hotel. I know you’ve got a lot on your mind.”

“Really?” I asked.

He nodded and put his hand out to catch some raindrops. “This weather is terrible. Let’s go back to the hotel and watch Netflix.”

So, we drove almost two hours to Universal Studios, and we only lasted two hours at the park. The car ride home was even longer, and when we got to the hotel right next to Disneyland, I crawled into bed, cried, and fell asleep.

After that trip, nothing sounded like a good time to me anymore. I was pulled by my responsibility to care for my mom, and I kept thinking I had to be with her to the end. She was my person, and I had to make sure she saw my face as much as possible so she didn't forget me.

The irony was that as my mom’s Alzheimer's progressed, I was aware I was her least favorite daughter, but she’d forgotten that. To her, I was the nice lady who came to visit. Sometimes, she recalled I was her daughter, but even when she didn't, she smiled at me when I walked in and was happy to see me.

That moved something in my heart deeply. I didn’t hold on to that second-place daughter ranking anymore. I was my mom’s person, her family caregiver, and I was working to accept that role with grace for her and me.

When family members visited town, I organized gatherings so my mom could visit them. When my two oldest kids from out of state visited, we went to the memory care to visit my mom. This was not easy for them, but they loved their Nana.

My mom deserved to have family come to visit with her in her memory care.

Life became an enormous balancing act for me. I had this responsibility to my mom, and at the same time, I carried a tremendous amount of grief, knowing that my mom was alive and dying. And I had to be with her when she died.

After the Los Angeles trip, I started to stress out about not being close by if my mom suddenly went into end-of-life.

I was so melancholy and confused by all my grief, my fear of losing my mom, but also the fear and resentment of my mom living for years longer and taking up more time in my life. I didn't want to cry at theme parks for years, but I also didn't want to give up what I loved doing.

But I wondered if I loved those things anymore.

My husband told me that I had to take care of myself, but I secretly wondered if all he wanted was for me to want to go on trips, take time off, or go to the beach and not be a caregiver. My thoughts were spiraling. I was unfair to him and unfair to me.

This became my daily battle to try and remind myself that what was happening in my mind and my heart was part of grief and death. I was grieving my mom, who was alive and dying, and I was grieving the life I had before she had Alzheimer’s, and yet it was now my responsibility to take care of her until she died.

I worried I was letting everyone down, though I was trying my best, but mostly I was tired.

I was suffering, but I was ignoring that because my mom was suffering, and I had to find a way to let go of all my fear and resentment so that I was able to truly be present for her.

I couldn't be with her and be resentful because that wasn't fair to her or me. I had to be with her and content with the journey.

For now.

My mom would not be alive and dying forever, but it might be years longer, and somehow, I had to be able to accept knowing that.

Letting go of lots of things

2019

ONE DAY, SITTING IN MY therapist's office, I told her how tired I was of going to my mom's place.

I flopped back on the couch. "I'm just so exhausted all the time. I get up, I work, then I drive to my mom's and sit with her. It's wearing me out."

"That's understandable," she answered. My therapist tilted her head to the side a little but didn’t say anything more. She patiently waited for me to keep talking.

I crossed my legs and sat up a little bit. "And I'm so sick of people smiling all the time. All around me, people are happy, and I don't get it."

"You don't get why people are happy?" She asked with a smile.

"All I can think about is that my mom is going to die, and I look around, and people are happy, and it drives me crazy."

"Why?"

I leaned forward, put my elbows on my knees, and cupped my chin in my hands. "Because I'm so exhausted and worn out! My mom is dying so I’m not very happy. And I have to go see my mom and be there, you know?"

"No, I don't know. Why do you have to go if you're wearing yourself out?"

"Because if I don't go see her every day, she'll forget who I am."

And there it was, hanging in the room. I believed I needed to be with my mom more and spend more time talking to her so she would have no doubt how much I loved her and how much I cared that she was alive and dying. I also believed I had to visit her so that she would remember my face. If I stayed away for too long, she might forget me forever.

My therapist leaned in as I started crying and said, “Does your mom remember each of your visits?"

I wiped away the tears spilling down my cheeks and shook my head. "No, she rarely remembers my visits, so each day it's like starting over.”

I saw my mom practically every day at this point, but when I walked into the building each day, my mom was typically upset with me for being away for so long. She didn't remember the previous visit, the puzzle we tried to do, the TV show we watched, the cookies I brought her, or the haircut I gave her. My mom was mad at me for leaving her alone for so long. So, each day, I'd done so much and tried so hard, and it didn't matter.

I wanted her to care.

I wanted her to remember.

On my worst days, I wanted to go in and tell her how hard my day was, and I wanted her to reach out to me and tell me it was going to be ok. Because that’s what Moms did, right? Mine really never had, but that didn’t stop me from wanting it. I wanted her to be how she used to be, and I usually got an irritated woman who didn't give a hoot about anything except what I wasn't doing for her.

That's harsh. But my mom was a stubborn, eccentric woman before her Alzheimer's, and the only thing Alzheimer's did was remove her filter. All her emotions and her personality were more true and more real after her diagnosis. It's not that she didn't love me before her diagnosis. It was that she couldn't remember that she loved me.

What I experienced of her in the long middle, especially after she went to live in memory care during the big decline, was that she was an angry woman who didn't understand why her life was the way it was.

My mom wanted out of memory care. Was I going to help move her? Where were the rest of her clothes? Did I steal them? I hadn't taken her shopping. When was I going to do that?

As I was crying in my therapist’s office, working through all these emotions, she said something wise.

She usually did.

My therapist said, "If your mom doesn't remember that you visit every day, do you need to go every day? Wouldn't you feel better with some time away to recoup?"

I reached for another tissue as she continued. “Your mom is in good hands. She is secure in the building and can’t run away. She is being fed healthy food. She has good care. She has help in the bathroom. She has a television and people to talk to. If you don’t go every single day, she’ll be fine, and if she isn’t fine, they’ll call you.”

This was true, but my heart and guilt didn't want it to be true. I wanted my mom to give me more acknowledgment. I wanted her to appreciate that I was trying so I could feel better about how much I was doing.

“You’re right. That’s all true, and they will call me if they need me,” I answered, leaning back again on the couch and trying to ease the tightness out of my shoulders and my heart. I didn’t want her to be right, but she was.

Instead of shaking off the worry, I started crying again. I was acting quite a bit like a martyr. “I’m making myself miserable, aren’t I?”

My therapist had tears in her eyes, too, and she nodded. “But you are learning.” And then she added, “And that’s important.”

That was an eye-opening therapy appointment.

Once I realized that truth, I had no other choice. I started letting go. I had to let go of my desire to be the person who was always there for my mom. I had to let go of my desire to be an overachieving caregiver. I had to let go of who I wanted my mom to be because I couldn't stop what was happening to her.

I also had more work to do to let go of my need for people to understand precisely how hard it was for me to be my mom's PERSON. The one person who was around for all the bad stuff, and no matter what happened, I had to keep being that person.

I thought that if people truly got it then it would validate my hard work. I'm not sure why that was so important, but it was.

I wanted to talk about my mom all the time. I found ways to bring it up in conversation, sometimes with strangers, so that I could talk about it and how hard being a caregiver was. I think I wanted to observe their faces, and I wanted them to have a look of concern or compassion. I was so overwhelmed by taking care of my mom. I spent so much time with her, and not only that, but the time involved in driving to her memory care and back.

Everything got to me.

I persisted in visiting her even when she was upset with me, and when I drove home, I processed it all and how it affected me, and usually, I cried *a lot*. I wanted people to understand what I was going through. I believed that if people realized how hard it was for ME, I would receive the empathy from them that I really wanted from my mom. These people would understand, even if my mom didn't, and that would make what I was doing more validating.

This was all part of this martyr complex I was developing. If people had sympathy for me, it somehow made all my hard work worth it.

As much as I needed to accept my mom for who she was, not who I wanted her to be, I had to accept myself for what I was doing, not what people thought of what I was doing. Because, ultimately, those people were not with me doing it. I was. And no matter how much I talked about it or cried about it or complained about it, and no matter how much external support I got, I was still going to take care of my mom. Whether people had compassion for me or not, it didn't change the path in front of me.

This was my path, and I had to accept that most of the time I would be walking it alone. Just me and my mom.

My overachieving, martyring, and crazy thinking only made things harder FOR ME. And because I thought I was more like a martyr than a daughter, I was holding out on accepting myself as a caregiver, and I was holding myself back from truly being present in my best caregiving because I was judging ME.

Though I was with my mom, I wasn't truly WITH her. And when I think back to it now, I think she figured that out.

She forgave me, but she knew.

She sensed I was begrudging.

When she would complain about her missing clothes or how someone stole her money, I would take a deep breath and sigh and try and say something like, "I'm sure your money is in your room. We can look for it later."

But that wasn't what she wanted me to say.

My mom wanted me to tell her, "That's terrible, Mom. I'll do everything I can to get it back for you."

Because in her reality, she believed beyond all doubt that someone had stolen her money. And I was her caregiver, so why wouldn't she turn to me for help?

I had a lot left to learn.

The long middle taught me about grief and death and that all those feelings were going to be with me for as long as my mom was alive and dying. The big decline taught me that my fears and my guilt were holding me back from being present in the moments with my mom. Thank goodness for the long middle and the big decline because without them, I wouldn't have realized I was being a martyr, and that was my biggest realization.

I had no idea, but my therapist recognized it, and she helped me face it without adding to my guilt.

This was my season of letting go. Though it was hard, and it took longer than I thought it should, I had to let go of expectations, fear, and judgment, and most importantly, I had to let go of my resentments because those were wrecking me.

My mom's Alzheimer's affected every single aspect of my life. I taught part-time at a community college, and my husband and I owned a business together, and I was working with him, too.

I had trouble teaching. I had difficulties understanding my students' needs because to me, they would complain about the little things, and inside my mind, I was screaming, “*But my mom is dying!*" "*Can't you tell that I'm dealing with so much, and your problems are NOT that bad?*"

I would also create social media content for my husband's business, and I would rush to finish it so I could drive to my mom's place. I misspelled things. I forgot things. I forgot coupon codes, and I made excuses. My husband understood I was buried under my stress and strain.

By this point, I was working so hard to be ready for my mom to die that I was plowing through life but not actually living it. I was afraid I would miss it or that she would die in her sleep, and someone would find her and call me in the morning.

I was afraid of her being mad at me. My mom was upset with me quite a lot, which is normal for a caregiver. I was her person, and because I was the face she saw day-to-day, she fixated a lot of anger and upset on me.

I would leave her place, holding on to her upset and stressing about what I might have said differently, what I could have done differently, and if I should do or say anything the next time that would keep her from getting mad at me. If I determined that I had done something wrong, I overthought the hell out of that, but most of the time, it didn't change the next day or the next or the next.

Every day was different; what worked with my mom one day did not work the next. And something that I thought would never work worked like a charm. I had so many expectations, and they were dragging me down more than knowing that my mom was slowly dying a little bit every single day.

As she disappeared from me, I had to let go of so much.

I let go of thinking I was her least favorite daughter.

I let go of fear.

I was often nervous about visiting my mom, especially after a particularly bad visit the day before. I feared her yelling at me more, not knowing what to say, or being in the spotlight, and I let go of that. My mom didn't remember being upset most of the time, so it didn't make sense to put myself through the turmoil of worrying about her being mad at me. Also, I realized that it didn't matter if my mom was upset with me. I was her caregiver. I was showing up for her, so she didn't have a choice even if she didn't want me around.

I opened myself up to the grief and let the feelings happen. I had to accept them to let go of my attempt to control what was happening. My grief emotions had always been denial, anger, bargaining, and depression, but accepting that those feelings were going to be with me for a while allowed me to let go.

I let grief into my heart to hold on to and cherish, not to fight against. That kind of grief meant she was still alive and dying. My mom was not dead yet.

It's odd how letting go of grief actually brought it closer and made it softer, like something I learned to love and hold close.

Finally, somewhere in all this, I was able to let go of the resentment.

I resented my sister for not being there for the day-to-day caregiving. I felt put upon by the responsibility. I thought she stuck me with the responsibility of caregiving for my mom and put out this carrot in front of me, saying that she would move to Oregon, and I blindly followed the carrot and believed her.

Was she lying the entire time? Perhaps not. It is possible my sister didn't do it intentionally, but ultimately, it didn't matter. She didn't move to Oregon. And while waiting for help and needing help from her, I grew more resentful. It was eye-opening to accept that I had been misled.

I was resentful of all the time I had to spend taking care of my mom, and during my season of letting go, somehow, I was able to let go of my resentment toward my sister.

One day, it hit me that I was the one taking care of Mom. She needed me, and I was there. I also realized that whether my sister was helping or not, I would still care for my mom. It just so happened that I was doing it alone. That was my path, and I made peace with that.

I also realized during this time that when my sister and I did walk into my mom’s memory care together, it was me my mom turned to. It was my face she recognized. My mom talked to my sister, and we enjoyed the visits, but it was during this time that I realized I went from being my mom’s least favorite daughter to the only person she knew.

I accepted that my sister would visit when she could, and the rest of the time, it was only me. Also, I also realized that in the reverse, it might be hard for my sister to learn news about my mom from so far away. What I ultimately realized is that I didn't want that for myself.

I wouldn't want to be far away from mom. I wouldn't want someone to tell me the news from a distance and not be involved in the day-to-day. That also helped me realize that the choice I made to be my mom's caregiver was the right one for me. I couldn't change what my sister did, and it didn't help me to focus on what might have been. This change of thinking helped me to let go of the idea that having help would have made taking care of my mom while she was alive and dying easier somehow.

It wouldn't have.

In the end, all this letting go brought my mother's heart closer to me, and it opened my heart in ways I never expected. I was able to accept my caregiving role in her life and to love her as she was, not as I wanted her to be.

I discovered the woman underneath my mom's hard exterior. I got a glimpse of her soul, which made our relationship something to cherish. And that allowed me to be present for her and also to be there for myself.

What a realization!

I come first

2019

I SHED SO MUCH RESENTMENT, anger, and fear during the big decline. So much. This helped me and my relationship with my mom, but the last weighty pressure I still put on myself was to be with her when she died. I had to be there for that.

I was able to let go of so many things, but I was still holding on to controlling the outcome. My mom's death. I had to be with my mom, in the fight with her every step of the way, no matter what, and I started to suffer from what is commonly called caregiver burnout.

This makes sense, right?

I was teaching. I was caregiving, and in a misguided effort to stay busy and keep grief at bay, I took on too much for my husband's business. AND I was pushing myself to spend more time with Mom than ever.

But deep down inside me, something had to give.

I had to take care of my mom because no one else was near who would or could. Though it took some time, for the most part, I'd accepted that I was a caregiver. I'd stopped being so judgmental about my role in her care, and I had put my feelings about my mom in a mental place where I tried to separate the woman from the disease. I realized that inside her soul, she wasn't mad at me, though she yelled at me or blamed me for where she was in her life.

I also stopped oversharing with strangers to receive some validation that I was doing the right thing, though that was a difficult adjustment.

I was also continually grateful for the beautiful friends in my life who asked about my mom and listened when I spoke about her and how things were going. Those folks were my grace.

Naturally, though, with Alzheimer's and dementia, things become more difficult. The memory loss gets worse, the grief gets deeper, and the declines are more frequent. Medicines change. The doctors report more bad news than good news.

By the time my mom was in memory care, I had been through a couple of rapid declines with her, and I'd already canceled a couple of vacations. But as I went on and pressured myself to visit Mom almost every day, one more massive change was around the corner for me. That was deciding whether to stay for the winter in Oregon.

I struggle with Seasonal Affective Disorder. This general gloom comes over some people as the skies turn grey and the rain rolls into the Pacific Northwest. Once the fall season rains hit and winter comes around, there can be months of daily gloom where the sun is hidden behind dense clouds and fog.

It's a difficult time for me. I was built for the sunshine.

I'd been living in Oregon for almost thirteen years by the time Mom was in memory care. In previous winters, I'd left Oregon for a few weeks at a time and escaped to sunnier locations like Phoenix, Orlando, Las Vegas, and Denver. Those weeks away from the Oregon gloom in the sunshine were restorative. But as mom's first winter in memory care came around, I had to choose between leaving Oregon for the sunshine or staying near her because I was her caregiver.

This was late 2018. I remember thinking it would only be this winter because Mom likely wouldn't make it another year. I could do one winter.

And so, I did.

I barreled into that winter, keeping myself as busy as possible. I was on the go almost all the time. I was even on the go at night when I was trying to relax on the couch. I would obsess over something my mom said, grab my phone, and try to plan my Instagram story for the next day. I'd write about the latest difficult thing that happened with my mom. I would write out all the hurt and add a picture, and I'd always end with how I loved her anyway and that I would take care of her no matter what.

While I was enduring that winter, I learned my oldest son was going through a difficult time and hadn’t called to talk to me about it. So, I called him.

“Mom, the reason I didn’t tell you is because your emotional sponge is full, and I didn’t want to load you down with my problems.”

Pulling together my words, I was silent. And though I was slightly offended, it dawned on me that he was right. “I get it, Bud, but if you need me, I don’t want you to worry about my *emotional sponge*. It helps me to get out of my own head.”

And he agreed. However, he still leaned more on his dad and sister because my emotional sponge was overflowing.

I thought that 2018 would be my darkest winter, but as it turned out, it wasn't. It was only my first one. I spent those dark months drowning in my emotional baggage, and I wasn't that great at being available to anyone who added more. Any drama or high emotion went in one ear and out the other, and while I cared, I couldn't take it on. I'm sure people thought I was callous or depressed or both, but those weren't worries I spent too much time on.

My husband suffered the most from this. I was so focused on getting through the winter and being the best caregiver I could be that I detached from him, his struggles, and his business. I pulled away when he needed my help and assumed he would understand.

“I’m sorry, honey, but I just can’t do that today. I’ll add it to my list, though, and try and help later in the week. You know I’ve got a lot on my plate, right?”

And he would nod.

My husband understood, but it wasn't easy for us. I was convinced that all my time and attention had to go into my mom and her care first, and what was left would go to everyone else in my life. Despite this, my husband went with me often when I visited my mom, so he understood what I was up against. He was at dinner almost every Wednesday night. He realized it was hard for me.

For over a year, we were in our separate bubbles, unable to connect on anything other than my mom's Alzheimer's.

I was burning out brightly, and everyone around me recognized it, but I didn't want to talk about it.

I was complaining (*AGAIN*) to my therapist one mid-winter day, going on and on about how dreary it was in Oregon, how I wanted to travel but couldn't, and how my husband and I were not seeing eye to eye. I might have thrown in a little whining about how my kids didn't call me that much anymore.

My therapist, in her continued infinite wisdom, gently asked me what I was doing for myself.

"Um. Nothing," I sighed.

I wasn't actually doing anything for myself. I stopped running. I wasn't writing. I was working myself to distraction. I wasn't baking, which I loved, and I stopped calling people on the phone because I couldn't deal with repeating the same things. I was complaining that my kids weren't reaching out to me, but I had closed myself off emotionally. I was tired. I was tired of trying to control my caregiving experience. I was tired of waiting for Mom to die and tired of answering the same question.

"How's your mom?"

Because I was her caregiver, I was the person people asked. This was a frustrating question for me to be asked. My answer differed from day to day because I didn't want to talk about my real feelings.

I wanted to tell people, "She is dying slowly," because that was the daily truth, every single day.

But instead, I would say things like, "She's hanging in there."

"Yesterday was a good day."

"She's doing all right."

Truly, I felt that if people wanted answers about how she was doing, they should visit her and find out. It did seem to me that I was the only one spending any time with her. However, part of my caregiver burnout was being THE person who showed up for everything.

It is difficult to watch someone die. It is awful to witness the progression of Alzheimer's or dementia. I'm not sure why I was able to do it, but I realized that others couldn't do it. The odors in the building, the sadness in the residents’ eyes, and the fear in their family's eyes as they visited.

The entire process of visiting a memory care home is overwhelming. I had to brace myself every single visit. Who would be there? Who would be gone? What would it smell like? Would Mom be upset with me? Would that loud lady who hits people be awake? Would someone be dying right in their room?

Nursing homes, memory care homes, and all homes like them are dreadful. I went each day for my mom, and I endured it for my mom, but by the time I reached the big decline and the long first winter, I was well aware that other family members couldn't go. They couldn't handle what was happening. My middle son told me he would go to Wednesday night dinners, but he didn’t want to go into her memory care. And my sister’s youngest son also said he couldn’t visit the memory care anymore.

I did not judge them because it wasn't fair to them. It was too raw and terrible for them, and they could not let it in. I could. I was my mom's person, and she was mine. But my caregiving tank was empty, and it was my therapist who observed it and helped me put some things in perspective.

“It doesn’t matter if I’m burned out,” I explained. “My mom needs me, and I have to do whatever I need to do to take care of her.”

My therapist leaned in and asked, “Why do you have to do that?”

“Well,” I started but hesitated because the question was valid. So, I tried to explain my feelings about it. “I’m doing it because my mom gave up a lot of her adult life after my dad left to take care of me and my sister, and now it’s my turn to be there for her.”

No. Matter. What.

I listened to my therapist give me some pushback. “But Jennifer, if you keep burning yourself out, you could get sick, be so tired you have an accident, or maybe even fall asleep while you’re driving, and then what would your mom do.”

I sat back to think about that.

She continued, “The only way you can take care of her and really be there for her is if you take the time to recharge your own emotional battery.”

Or, as my son said, to squeeze out my emotional sponge.

As I sat on the couch, wringing my hands and wiping the tears from my eyes, she sat a little bit forward in her chair, leveled her eyes with mine, and took a deep breath. My therapist had one last thing to say during that session. “I strongly invite you to take more time for yourself. You don't have to do it all. And I don’t think your mom would want you to push yourself so hard. Relax. Breath.”

And so, I did.

One evening, after my therapist had strongly "invited" me to take more time for myself, I was sitting in a diner with some friends. We were chatting about life and kids and what we had going on for the upcoming holidays. A woman at the table asked me about my mom and how she was doing.

I gave her my go-to line. "She's hanging in there."

She mentioned that her mom had dementia when she died, and though she wasn't her mom's primary caregiver, she recognized the strain it put on her sister. I nodded.

"It is hard," I said, "but I'm the only family she has close by, so I'm the person who takes care of everything."

My friend asked, “How often do you go see your mom?”

“Almost every day,” I replied matter-of-factly.

Her eyebrows went up, and she said, "Wow! I thought I was doing a great job by going to see my mom once a week. I couldn't imagine going every day."

That hit me like a brick. My friend went once a week and thought that was enough. It was enough for her. What would be enough for me? I had to figure that out.

"It keeps me very busy," I told her.

"Good for you, though," she added. "Your mom is very lucky to have you."

I couldn't tell if she threw that last part in to lift my spirits or to ease her conscience. Either way, the message to me was clear from many people in my life. I was doing a lot. Some would say too much, and others would say not enough, but what mattered was what I thought about my caregiving responsibilities.

It took some time to wrap my head around the idea that to take better care of my mom, I had to take better care of myself. I had to give up control. I could control how much time I spent with my mom and how much I worked, but my mom's emergencies, her temper, or the winter weather were completely out of my control.

I pressed forward for a little while longer, ignoring my caregiver burnout and my therapist's advice. I still believed that I had to be present for my mom, and I had to make sure I was close by and ready to be with her when she died. I couldn’t let go of trying to control that.

By this point, I had a lot of thoughts running around in my head. I had to show up for my mom. My mom was lucky to have me. I had to do this, NO MATTER WHAT. I didn't question why I was doing it. I simply did it.

But it was during this time that I started wondering why I was doing this. My sister was not doing it, and it appeared more and more like she chose specifically not to do the day-to-day. I realized that when she said she would move to Oregon, she likely had no intention of doing that. That idea hung with me for a long time, to my detriment. Why was I doing so much for my mom when my mom and I hadn’t had a great relationship? Why was I giving up so much to be her caregiver when, historically, I was her least favorite daughter?

I didn't have all the answers or even any answers yet, but the questions started bubbling to the surface. Knowing myself, I knew those questions would stick around until I'd answered them.

And I persevered.

Each day I visited my mom was another day I was reasonably sure she recognized my face and wouldn't forget that I was a kind lady and that I was her person. But I continued to crumble under the pressure behind the scenes where no one in my family might find me coming apart. My husband told me that I needed to check with my doctor and ask about some medication for depression. I stared at him and asked, "Do I seem depressed?"

He quietly answered, "Yes."

I had no idea what to say to that. I thought he understood that I was sad because I was grieving my mom's upcoming death. I'd told him about anticipatory grief. My husband understood how things were going because he visited my mom with me so often.

How could he think I was depressed? Didn't he understand my mom was dying?

Though it took some time, I realized that the grief and anticipation I was experiencing appeared like depression on the outside. Others saw that, especially those close to me, like my husband. But I also believed deep in my heart that what was pressing on me was just a long, slow grief. I had to decide for myself. Would a pill make the emotions less heavy? Would some medicine make it easier to hold back the constant flow of tears? Would medication help me grieve?

Perhaps.

I was mired in emotions.

I would go visit my mom and suffer through the visit. I listened as she talked about her stolen money and how someone was mad at her. I nodded as she talked about how she was quitting her job, how no one picked her up for church, or how I wouldn't give her a cell phone or something else she thought she needed. My mom and I had some memorable times, but during the worst of my caregiver burnout, I mostly cringed through the visits, day after day.

I worked everything in my life around visiting her, and as that first long winter continued and I ushered in 2019, I was crushed under the pressure of everything I was doing. I gazed up at the deep grey clouds and the fog and the gloom that were pressing down on me, and I couldn't find my way out.

I went online and read about depression and the warning signs, and while some of the signs seemed like things that I was experiencing, I was also aware that a lot of what I was going through presented more like grief.

So, I made an appointment with my doctor, and I asked her if she thought I was depressed. My doctor gave me a questionnaire.

Perfect.

A series of questions about how I was feeling. As an over-achiever, I had to earn high marks on this exam. I handed it back to my doctor, confident I got an A. She tallied it up and glanced up at me over her reading glasses, "What you're going through is more sadness and less of a depression."

"So, I passed?" I asked, and she chuckled.

"At least you still have your sense of humor."

My doctor suggested the same thing my therapist did, which was to rest and do more of what I loved, like walking, running, writing, baking, taking some time away from visits with my mom, and doing things for me instead. I thought about that advice as I drove home. How could taking time away from caregiving make me a better caregiver?

"I'll just feel overwhelmed by all the things I'm doing instead of visiting her," I told my husband later that evening.

He nodded and said, "But it might be good for you."

And they were all right. My therapist, my doctor, and my husband. This did end up being the next helpful thing for me to do.

I cut back on the number of days I visited my mom. I called her on the phone instead, and when I couldn't reach her on the public phone in her building, I would call the nurse's phone line at my mom's place. Someone would track my mom down so I could talk to her without even being a bit upset at me.

Other things I started doing were calling my kids more to chat. I went to coffee with friends. I took on different responsibilities with my husband's business and started doing things I liked, like filming and video editing for his online ads and instructional videos. It was fulfilling to jump back into doing creative tasks, which I enjoyed. All this taking time for me also had the side benefit of keeping my mind off obsessing over my mom being alive and dying.

I volunteered for the Alzheimer's Association and their Walk to End Alzheimer's. It was surprising how much being around other people who were going through the same thing actually helped my mindset.

I started running again and doing yoga, which helped me sleep better and feel better about myself.

The hardest thing for me was traveling. My husband always wanted to go to the beach for a day, but to me, 90 minutes in the car was too long, and what if something happened and we had to come back? That 90 minutes made the difference between me being nearby for my mom when she really needed me. I had to make decisions for her, I had to help her, and heaven forbid that she die alone because I was at the beach taking time for myself.

Letting go and putting myself first was difficult. I had to make some compromises. My husband and I decided to travel more locally and scheduled weekend trips away instead of getting on a plane as we used to.

Letting go of spending so much time with my mom helped me relax a little bit, and though I still needed to be close by just in case, I started to turn my melancholy feelings around.

Overall, the biggest change in me was that I became much less resentful about how much time I spent away from my regular life and caring for my mom. Because I was taking care of myself, I was able to spend time with my mom and be less upset and stressed. Because I'd exercised that day or I was going out with friends after a visit with my mom, I found it easier to sit with her and take in a silly Hallmark movie.

I found some of the balance that I needed. I stopped resenting that I couldn't travel or that my day was interrupted because my mom was taken to the emergency room. It wasn't perfect, but it at least set me up for all the changes coming my way.

With caregiving and with Alzheimer's, the road is unsteady. Things are always changing, and honestly, things are always headed downhill. Sometimes, it's a gentle slope, and the changes are so small you don't recognize them, and then unexpectedly, a big decline hits, and there are no brakes.

It's a scary ride.

And as it turned out, I found some balance in my caregiver life just in time for the fast trip downhill.

I was lucky that filling up my caregiver tank helped me prepare for everything coming our way.

Taking care of myself – a little

2019

I HAD FINALLY FOUND A GROOVE with my plan to take care of myself so that I was able to take better care of my mom. The timing couldn't have been better because as life wound its way into the spring of 2019 and thanks to lots of tea, candles, and Netflix, I survived the winter and my seasonal affective disorder.

My husband and I made it through the holidays, and spring came around, the sky lightened, and my mom eventually forgot that she ever lived anywhere but that little shared room in memory care.

Mom's memory loss was stable. I was a familiar face. She recalled we went to dinner once a week on Wednesday. She'd forgotten a lot, but the things she held on to stayed the same. This was a gentle time for us.

Sometime that year, my mom fixated on "working" at her memory care. I think this was because it was a way for her to make sense of her life. My mom always enjoyed having a sense of responsibility and loved working with people. I believe that her idea that she worked at her memory care, assisting the residents, even though my mom *was* a resident, helped her cope.

The side effect, however, was that sometimes she got irritated with the long work shifts, not being able to leave work and go home, and when things didn't go well and she felt bossed around unnecessarily, she wanted to quit but then got worried about where she would live.

When I showed up to take my mom to Wednesday night dinner, she would often tell me she couldn't go because they were making her work an extra shift. When that happened, I relied on a sweet med aide who would help me out when mom was upset about leaving "work."

She would take over and say to Mom, "You're done for the night. You can go with your family."

My mom would say, "I'm not going to lose my job?"

The kind aid would reassure her that her job was safe, and they would see her tomorrow. But this work at her memory care thing did not always go well.

One evening, my husband and I showed up to visit with Mom and enjoy some television with her. As I walked up to the front door, a laundry basket with her roommate's name on it was sitting inside, and I thought, "*That's odd.*" I wondered if Mom's roommate was moving out.

I punched in the door code and entered the building. My husband and I walked around the corner and down the hall past the dining area and the television room and peeked in the door to Mom's room.

She was standing up, bracing herself with one hand on the end of her bed frame. She was using the other hand to take the sheets off her bed and had a basket of her things next to her. I glanced around her room. It was chaos. An overflowing box from her closet was sitting on her walker. My mom had emptied the drawers of her nightstand, and the contents were all over the floor. The rest of her clothes were lying over a chair and disorganized.

Mom glared at me when I walked in, and her eyes shot daggers my way. She had on her angry face, and she was giving me the Nana lips. To me, it was obvious we were in for a rough evening.

Mom was upset at her very long work hours that day. She'd had an argument with one of the aides who didn't understand Mom's "job" at the facility. Mom thought she'd been unfairly reprimanded when she worked so hard. She was angry.

Mom yelled at me as she tried to pull the sheets off the bed. When she demanded to leave that night and go back "home," my husband told her we couldn't move all her things out that evening.

He said, "We can have the movers here tomorrow."

I hoped that a therapeutic lie would be enough.

My husband and I sat with her and waited, knowing that someone would be around with a dose of her anti-anxiety medicine soon, and after a good night's sleep, my mom would forget about this.

That is the way of Alzheimer's. But that night was one I will never forget. Mom was angry, feisty, challenging, and frustrated, and as I took her sheets and started to make her bed for her, I told her that I wanted her to rest. I reassured her that I would speak with her "boss" and make sure she could quit her job and go home.

After thirty minutes of listening to my mom rant and rave and yank the sheets off the bed I'd tried to make, a nurse came in with a pill to ease mom's mood. The pill would take another thirty minutes to kick in, but I sat on her bed and waited.

I grabbed my phone and started a playlist of familiar music, and as we listened to John Denver sing about leaving on a jet plane, she finally sat on her bed and took some deep breaths.

My mom stared right into my eyes as if she was completely aware of who I was and said, "Jennifer, I just don't understand what is going on." For that moment, it seemed she did realize I was her daughter. This was such a rare occurrence, and I had to fight back the tears.

"I know, Mom," I answered. "We'll get it figured out tomorrow. I promise."

And the mood in the room eased. I cleaned up a little, helped Mom into bed, and turned off the light.

I walked out that evening, and many like it, hoping I did enough.

Every day of the last two years was a crazy experience. This time was beautiful, scary, and filled with sadness, but also lots of laughs and quiet moments of bonding. In those moments, I would not have been able to be truly open with my mom and accept her for who she was if I had not done so much caregiver work beforehand.

The work I did was more than simply accepting that I was a caregiver and not judging myself. It was also accepting my mom and not judging her for how she was being, her meanness, or her childlike behavior.

Lastly, I had to be ready for anything. During these months that mom lived in memory care, I had time to breathe. I had time to learn how to take care of myself and time to let go of resentment. I was able to be WITH her as Alzheimer's slowly, quietly took my mom from me, one little memory at a time.

Alzheimer's is a long, progressive disease, and it keeps going and going and going. Sometimes, my mom looked as if she was dying right before my eyes. On other days, she was practically speed-walking with her cane. On the best days, she would dance, sing, and smile.

One day, I walked in expecting the worst because my previous visit with her had been dreadful. Mom popped up from her chair in the dining room and said, "Hi Jenn, how are you."

She knew who I was.

I was floored.

Other days, her case manager would call me, and we would discuss medication changes, and my mom's mood would quickly level out. The meds kept Mom balanced. It was bad if she was too sad, but it was also a worrying sign if she was too giggly or happy.

Every day was different.

I had no way of knowing what each day would bring. The only thing I truly grasped during this time was that I still had a long road ahead.

I was strapping in for the rollercoaster ride to come.

Lock those moments in your memory bank

Late 2019

ABOUT A YEAR AFTER I MOVED my mom into memory care, Mom’s roommate abruptly went into the end of life. She was fine the day before, and without warning, she was dying.

Hospice and end of life were part and parcel of memory care, and I'd known it was happening in the building before, but now it was right in front of me, and there was no avoiding that the end might sneak up at any moment even if everything seemed fine.

So, though my mom had stabilized in her decline, and she lingered, alive and dying, I was aware she could go anytime.

After her roommate went so quickly, I left my mom each time wondering if it would, by some chance, be the last day she was alive.

One day, when my sister and I were visiting, my mom just stared at us, her eyes glassy and shiny. Mom giggled and laughed and said made-up words, laughing at the words coming out of her mouth.

My brother-in-law was with us that day, and he said, "I'll have whatever drugs she's on." And we all laughed.

Mom didn't say one intelligible thing during that visit, and the first thing I did when I left the building was call my mom's case worker. Suzie always told me to call her no matter how small I thought the change was.

"No one knows her better than you, Jennifer," she explained. "If you are worried about anything, call me right away."

My mom's medical group, Elder Place, loved her. Her snark, her wit, even her anger. My mom was the feistiest person they took care of. So that day I called Suzie, and I told her that mom laughed and laughed, but made no sense; that she stared at us and giggled the whole time, and her eyes didn't look right.

Suzie passed my concerns on to my mom's doctor, and I got a call the next day.

Mom had been on her antipsychotic medication for a while now. She was gaining water weight. Her skin was puffy and tight like a balloon that had been blown up with too much air and was ready to pop.

One of the side effects of the antipsychotic was weight gain and a higher chance of stroke. The doctor told me that mom likely had a series of TIA's. TIA stands for transient ischemic attack, and it's a temporary period of symptoms similar to those of a stroke that usually only lasts a few minutes and doesn't cause any permanent damage. 2

The doctor described them as a series of mini-strokes, but I was shocked by the knowledge that these strokes didn't cause any damage. Either way, knowing that my mom may be having TIAs and that she may have an actual stroke and die got to me, and so after that day, I started turning back and watching her for a second or two before I left.

If I helped her sit in a chair in the TV room, I would hug her goodbye, take our photo together to document her existence in this world, and that she was in front of me, smiling or glaring, and I would walk away.

I would walk slowly enough and wait just a few seconds for my mom to turn her attention to someone else, to the TV, or to close her eyes, and then I would turn back and stand and observe her. I would soak up that moment and effectively lock it in my memory bank to treasure.

The photo was already on my phone, but I had to turn back and imprint that moment in my mind.

Because now, I was completely aware that any day, I might walk out that door, hop in my car, and drive home, and it might be the last time I ever saw her alive.

This became another part of my grief and my goodbye. For a moment, I took it all in and learned to accept that life had handed   
my mom a raw deal, and she was going to die from this horrible disease, and I wanted to remember it.

I was determined to remember every single bit of it because she couldn't.

Your mother has a word

Early 2020

DURING THE BIG DECLINE OF Alzheimer's, I visited my mom in her memory care almost every day, so I had a lot of days that ran into the next, and nothing in particular stood out. Most days, I walked up to the door, punched in the code, and listened for the magnets to release so I could open the door and walk in.

The building had a beautiful foyer with a comfortable-looking stuffed chair and a huge, framed picture of a mansion by the sea in Greece. The room was inviting and probably meant to be like home, though it was definitely not. The administrator's office and the nurse's room were on the left side of the foyer.

To the right was a hallway with more beautiful photos of palm trees, fancy gazebos, and beachy views. Halfway down the hallway was the television room on the left and the dining room on the right. On every visit, I always glanced in those two communal areas, and if Mom wasn't in either place, I kept walking down the hall and turned right to go to her room.

I had no clue what kind of mood she would be in.

If she were staring at a plate of half-eaten food in the dining room, she would often be ready with a complaint.

"This food is terrible," she would whisper. "Did you know they are making us drink muddy water?"

I would pull up a chair at the table and sit down. "Oh, my goodness, that IS terrible." Because at this point, I'd learned that arguing with her was folly.

If she was in the television room, they were usually enjoying a Hallmark movie, and those were generally my easiest visits. The movie gave us common ground to chat about, and for the most part, we sat next to each other and smiled and laughed.

My mom loved one actor who was in a lot of Hallmark movies, so when one of his movies came on, she would grin and say, "I'm going to marry him someday."

Most days were fairly good. My mom and I would chat, catch some television, or sometimes do a puzzle, and at the end of our visit, I would kiss her cheek goodbye and leave.

I remember clearly one day in particular: my mom was in the dining room, staring out the window, watching the cars on the busy street.

I sat down next to her and scooted my chair in. "Hi, Mama."

I'd started calling her Mama instead of Mom because all the ladies who worked at the memory care called her Mama. When I called her mom, she would sometimes squint her eyes like she didn't understand why I called her mom because I was NOT her daughter.

She glanced at me when I sat down and said, "See all those cars out there?"

"I sure do."

"What would it take for me to get one of those?"

"Well, you'd need a job so you could buy a car." It was obvious to me where this was going.

"I already have a job." My mom reached out and brushed her fingers over the tablecloth, making sure it was straight. "I work here, but they haven't paid me in a long time."

My mom was the type of person who had to be doing something with her time. She had never been one to sit and stare out the window, thinking her thoughts. She was a doer.

"We can ask about your paycheck," I offered. "I can help with that."

Mom nodded. I'd had this conversation with her many times. She worked at the memory care center; the owner gave her a room, worked her too many hours, and never paid her, so she wasn't ever able to leave.

On this day, though, I'd brought a diversion with me to take her mind off her worries about work and money and how to escape this awful situation.

I'd brought nail polish and a file.

My mom was always a put-together lady, and she loved having her nails nicely painted. We didn't do it often anymore because nail polish and a file were not allowed at her memory care. The memory care used to have a spa day once a week, but they had to stop doing it for some reason. I never found out why. I always wondered if someone tried to drink the nail polish or stab someone's eye out with the file.

Mom grabbed the file from me and stared at it like she should remember what it was. She'd done the same thing with a fork. She handed it back to me. "You do it," she said.

I filed straight across her nails first, went back over them, and rounded the ends a little bit like she used to do. When I was done, I asked, "What do you think?"

My mom held them up and frowned. "I want them rounded more."

"Sure, I can do that."

And I rounded them a little more.

"What do you think now?" I asked.

She glared at them and frowned even more. "Give me that." Mom reached out and grabbed the file from me.

She began furiously sawing at her nails. She put her head down and went after them like a redwood tree in the forest that needed to be cut down.

All of a sudden, she stopped filing. Mom smiled at me and said, "Your mother has a word."

And I waited for this word.

And waited.

And waited.

A minute passed, and I practically held my breath while waiting for this word. Also, I didn't want to interrupt her because she'd said, "Your mother." Most of the time, she didn't remember she was my mother, so I didn't want to say anything that would cause her to lose her train of thought and forget I was her daughter.

She kept looking at me and opening her mouth like she was about to speak. But after a few seconds, she glanced down at her hands and sighed.

When she brought her eyes back up to meet mine, I was ready for her word, but she didn't speak. Mom stared at me, and the sunlight glinted off her eyes. She'd had cataract surgery years ago, and after the surgery, her eyes flickered in the sun.

My mom returned to filing her nails, peeked up again, and said, "Your mother has a word."

And again, I waited.

But this time, instead of silently thinking about this illusive word, she put her hand up to cover her mouth and started giggling. And I laughed along with her.

A few seconds later, she repeated, "Your mother has a word.

But again, she had no word. We kept giggling as she said it a few more times.

It was like playing peek-a-boo with a toddler. It's fun at first, and they keep doing it over and over, and you keep laughing because they're laughing, but in the back of your mind, you're wondering when they will be tired of playing peek-a-boo because you're tired of it already.

That's how I felt about my mom's word. It was fun until it wasn't as much fun anymore, and I just wanted her to tell me what that word was.

My mom locked eyes with me one last time and said slowly, "Your. Mother. Has. A. Word."

I studied her, watching me, and her face scrunched up like she was trying to remember this word. She sucked in her breath, and her eyes lit up. She was going to say it!

I waited.

And waited.

And waited.

And then it was gone. Mom's face fell, and her eyes glossed over again.

The nail file was still in her hands, so she went back to work. My mom filed and filed her nails, turning them into sharp points, like spears, and little arrowheads on the tips of her fingers.

"Wow, mom," I said. "You really did want your nails rounded."

She giggled and shrugged, and we laughed some more. Mom always said laughter was the best medicine, so we had a healing dose during this visit.

"I've got a word for you, Mom."

And she waited.

"Rawr." I put my hands up like claws and pretended to be a cat.

That did it. She cracked up. Her loud, cackly laugh.

This was one of the better visits with my mom. She was talking but not complaining; she was happy and not angry. I shifted her upset at the beginning to a fun activity, and as a bonus, she remembered, at least briefly, that I was her daughter. Generally, I'd take a lot of laughing any time over her tears and confusion.

I remember this visit most because she didn't ever say her word. That word was in her mind somewhere, but she couldn't remember.

Mom never said, "Your mother has a word" again.

I will always wonder what it was.

It could be ten long years

Early 2020

THE THING ABOUT THIS ALZHEIMER’S journey is that I had no idea how long it would last. I had this person who was dying, but she was still alive, and though I was losing her day by day, those days went on and on into what resembled a grief-stricken infinity.

There is no way around the sadness.

This took a toll, but I did my best to balance the toll with the happy memories I saved.

I took pictures of my mom every time I was with her unless she was in a terrible mood, and she would hate pretending to smile for the photos. Sometimes, she was yelling or crying, and she wouldn't want me to keep a photo of that, but I was making memories every time I snapped a picture. And I'm not going to lie. I did unknowingly snap photos of my mom glaring in my direction or crying her eyes out. These photos are only for me. They are memories of her and what we went through.

I have thousands of photos on my phone, and though they are hard to look at sometimes, I have captured a reminder of almost every day of this journey. Because that is what this long goodbye is all about: taking the good with the bad. I realized I would have this good-bad sandwich pressing on my life for a long time. But I also had no idea how long it would last. I might be looking at a decade or more, though I hoped that wouldn't happen for my mom's sake.

Sometimes, thinking about that was overwhelming.

Dementia and Alzheimer's are slow-moving diseases, and I knew enough to know that my mom might live for ten or more years. I was acquainted with people whose mothers had lived with Alzheimer's for 20 years. My mom had brain surgery in 2009 and was diagnosed with dementia in 2013.

When I was staring down 2018 and 2019, I thought, *My God, how can I take another few years of this? What if my mom does live for ten more years? Oh my goodness, how will I make it through those ten years? What if it's longer than that?* With new medications, more studies, research, and rapidly improving care for people with Alzheimer's and dementia, people who are relatively healthy in their older years, like my mom, can be maintained, as it were, in their disease. A body with a beating heart and a failing brain kept just alive enough with medication.

This is a terrible way for someone to go.

It is truly the longest goodbye.

I went through an incredibly difficult time with all this in early 2020. When I thought ahead to the year, I hadn't scheduled a spring break trip. Gone were the ideas of New Zealand or Ireland or Mexico. My frustration was that we wouldn't be able to travel anywhere, but I was also struggling with my own winter blues in Oregon.

When my mom was still in assisted living, I was able to call her and check and make sure she was doing well. These trips into the winter sunshine were medicinal for me.

When I stopped my winter traveling in 2018, I thought my mom wouldn't make it through the summer of 2019 – her big decline was so severe – I told myself I could make it through one more winter. Instead, my mom stabilized in her memory care, and the summer of 2019 came and went, and I was facing down another winter in Oregon.

As the rains moved in, the temperature dropped, and my mom lingered in her Alzheimer's, I drifted through the holidays in a fog. The grief was with me, and in the grey dampness, this pressure to make it through the winter weighed me down. At times, I thought, *I'm going to have to leave and go find some sunshine*, but I would toughen up and keep pushing forward.

I volunteered with the Alzheimer's Association as a Walk to End Alzheimer's outreach person for the upcoming 2020 summer Walk season. Our kickoff meeting was in downtown Portland in January. All the volunteers sat close together; we ate food, laughed, and hugged our friends we hadn't seen since the last walk.

This was one of my last normal experiences.

I started chatting with a gentleman, Bob, whom I'd talked to many times. He was retired and ran a few caregiver support groups in the local area. Bob also helped people navigate caregiving decisions. After the gathering, he sent me a direct message on Instagram, telling me it was lovely to visit with me again, and he asked a question. It was a well-meaning inquiry, but I didn't realize the tailspin it would put me in.

Bob asked, "What stage is your mom in?" referring to what stage of Alzheimer's she was in.

I'd read about the general stages of Alzheimer's, but I'd only learned the basics. After Bob's message, I went online to do my research. I am an over-achiever, after all. I thought, most likely, my mom was nearing the end and only had a year or so left. Perhaps. But as I read these stages and the details of Alzheimer's progression, I freaked out. 3

The first few stages were descriptive and relatively short. My mom had already progressed through those, but Stages 6 and 7 had very descriptive sub-stages like Stage 6B through 6E. As I read Stage 6E, I learned it lasted, on average, 2.3 years. My mom was into Stage 6 for sure, but then I made the mistake of reading Stage

7 and all those sub-stages.

Once I started reading more about Stage 7, I realized that my mom was certainly at the end of Stage 6, but she was also at the beginning of Stage 7, which had six parts, too. And then I read the words that spun me out of control.

Each of these parts of Stage 7 might last a year to 18 months!

Oh my!

Math was never my strong suit, but I added up all those years. If my mom progressed somewhat normally through each part of Alzheimer's Stage 7, she could live seven to ten more years.

And I froze!

I was aware that people did live with Alzheimer's for ten to 20 years, but I had never seen it charted out like this. I'd never allowed myself to believe that Mom might possibly live that long. This was an idea I had pushed away, but looking at all this detailed information brought it home. What I'd held as an abstract timeline that was rare was actually not that unusual, and my mom COULD live for ten more years.

I started crying and worrying about how old and grey I would be. I did more math. I would be 61 years old. I didn't want to be that old at the end of my caregiving journey. And then I thought, *How in the world will I make it ten MORE years?*

This caregiver road had already been long and taxing, and I didn't think I would be able to make it through ten more years.

I literally freaked out.

I had canceled New Zealand, and I'd had a lousy time in the happiest place on earth. I had stopped my winter traveling to find the sunshine I needed. I had put so much of my life willingly on hold and had let go of the resentment, but I realized at this moment, staring down ten more years, that I made those choices willingly but also made them believing it would not be that long.

Ten more years seemed awful.

Ten more years seemed like an eternity.

An awful amount of time for my mom and for me.

I told my husband what I had learned about Mom’s Alzheimer’s stage and that she might live ten more years.

“I just don’t know how I’m going to do it,” I cried.

My husband reached over and pulled me close. “We’ll get through it, no matter what happens.”

It helped to have his support because I understood it was extremely difficult for him to give up so much of his time, too.

Again, I went to my therapy appointment, and I spewed out all my worry. I was shaking and crying and in a terrible way.

“I don’t want her to live ten more years,” I sighed. “But I also feel selfish because that means it’s like I’m wanting her to die!” And as I usually did in therapy, I started crying and reached for a tissue.

My therapist patiently waited for me to wipe my tears. “I mean, my mom wouldn’t want to live that long with Alzheimer’s either. It’s her worst nightmare. I just don’t think I can handle TEN MORE YEARS!”

I was still fighting back resentment at being left to take care of my mom.

My therapist did what she always did, which was to help me put things in perspective. She focused her eyes on mine and said, "Jennifer, you need to plan for your mom to live ten more years."

I stared at her.

My therapist didn't blink. Instead, she added, "What will **you** do with those ten years?"

I stopped, took a deep breath, and reflected on what I would do at that moment if I were 100% certain that my mom was going to be alive for ten more years.

Silence lingered for a moment, but I finally said, “I wouldn't have put off New Zealand. I wouldn't put off traveling in the winter, and I wouldn't avoid talking to my family because my *emotional sponge* was full.”

My therapist leaned back and nodded.

“I’d have to keep on living my life,” I said, and the realization of what I was saying dawned on me like a thin ray of sunlight bursting through a crack in heavy curtains. My mom was alive and dying, but I couldn't put my life on hold while she was living. I had to live, too.

That moment, sitting on my therapist's couch, was the key to letting go of all my resentment. That was the final piece that fell away. The *could* and the *would* of this entire journey that my mom and I were on. I *could* put off a restorative vacation. I could do it, for my mom and in a way for me, but *would* I do it? *Would* it be for the best? I realized I had plenty of things I was able to do. I could endure, but would it be the right thing for me?

This huge awareness also led me to one last question that day, “Why am I doing this?” Though I knew this wasn’t her question to answer.

“Doing what?” my therapist replied.

“Well, I am my mom's caregiver. I’ve rearranged my life, and I’ve learned a lot and learned to let go, and though I felt put upon at first and I fought against it like a house on fire, I did it. And now … here I am, maybe staring down ten more years. And no matter what, I know I’ll do it. But why?”

My therapist was resting her chin in her hand, and she sat up in her chair and leaned forward a little bit. “Do you know why?”

I shook my head. “No, I really don’t. Not right now.”

“Well then, you have something to think about, don’t you?” she answered.

That question lingered with me for a while, and honestly, I didn’t figure out the answer until after my mom passed away.

I thought about it, and if my mom did live ten more years, some of them, she would be unconscious and wouldn't even realize I was with her. Alzheimer's Stage 7 told me that. My mom would eventually end up bedridden. She would eventually not be able to talk. What would I do with myself during those visits? My mom would forget how to breathe, how to swallow, how to eat, and every other little thing we do as humans that we don't pay attention to, and, in the end, I would be sitting beside her, holding her hand while she gasped for air.

That was the end she was facing, and I had to be with her for that.

It could be a long ten years, but my mom wouldn't want me to give up living my life to be with her while her body was still alive.

This was another cycle of bringing myself back to a grounded reality of living with my grief and merely trying to be open to whatever was coming my way. I had to leave behind any last lingering resentments and press forward with no regrets. That was one thing I always held close to my heart.

When my mom was gone, I didn't want any regrets. I didn't want to say I wish I had gone to see her more. I wish I had called her more. I wish I had taken her shopping more or spent more time with her. I had no regrets up to this point, and I wasn't going to start with that. Thank goodness my therapist helped pull me together that day in early 2020 before COVID tore everything apart.

Those words my therapist said to me rolled around in my head for a few more days, and I finally decided to plan some vacations and be positive about them.

I booked a trip to New Orleans for spring break in 2020, and I also made reservations at a hotel in Orlando so my husband and I could go on our fall vacation to Disneyworld. We hadn't been in a couple of years, and he'd told me he wanted to go.

You can probably tell where this is going.

When I finally let go of a little more of my fear and resentment and accepted my caregiver path, the world started to shut down.

Just as I was ready to open up, the world closed its doors.

The beginning of the end

Spring 2020

THE IRONY WAS THAT RIGHT as I'd taken steps to recharge my caregiver batteries and return to some light traveling and vacations, the coronavirus came along and changed all my plans.

At first, I pushed ahead and said, "We're going to New Orleans no matter what."

"We're healthy, and the likelihood that we will be exposed is minimal."

New Orleans was only a five-hour flight, it was in the United States, and it was close enough that if I needed to, I could be back home quickly. We were ready to go, but things got worse.

In the middle of March, I realized that if we went to New Orleans, my mom's facility would want me to quarantine for 14 days when I got back. I was still an essential person in her care, and due to restrictions, my sister and I were now the only family members allowed to go in and physically be with her. My husband wasn't even able to visit with me.

While watching the CDC news briefing on March 14, 2020, I heard a lady say nursing homes would be closed to visitors.

I turned to my husband and said, “That’s Mom.”

I called, and sure enough, my mom's place was closing its doors the next day, so I went to visit my mom twice on the last day her memory care was open.

The first time, I went in, studied Mom’s room, and compiled a list of everything she might need for the next couple of weeks.

I kissed her on the cheek and said, “I’ll be back in a bit with some stuff for you, Mom.”

“Can I go with you?” she asked.

I shook my head. “Not today, Mom. There’s a flu going around, and I don’t want you to get sick.”

Mom nodded, and I dashed out the door to go shopping.

On my last visit that *last* day, I sat on Mom’s bed because we were confined to visiting in the bedrooms and were no longer allowed in the community area. I had no idea how different things would be and how long our separation would last. I held Mom's hand and played her songs on my phone, and we sang along, though I was desperately sad.

I pulled up my Allan Sherman playlist and started us off with “Hello Muddah, Hello Faddah” which always made us laugh. But it was hard to smile, and I didn’t want to say anything to my mom because it would confuse her. We kept on singing and laughing, and when the song ended, I switched over to some Anne Murray, and we sang, “Could I have this dance for the rest of my life” and Mom still recalled all the words.

Though I was swallowing back my emotions, I knew we didn’t have much time left on that visit, and I didn’t want to leave. I thought it would be a month or two and I would be back inside to visit her.

We just needed to flatten the curve, right?

This wasn't going to take that long. And I thought there was no way that any government was going to leave so many older citizens locked away in nursing homes, away from their families for more than a few weeks. Anything more than that was cruel.

This goodbye to my mom was difficult. I focused on smiling and being upbeat, knowing that I would cry my eyes out later.

Finally, the med aide came to the door and said, “Your time is up. You have to go now.”

My mom glanced at me and asked, “What’s going on?” They had never asked me to leave in all the times I had visited her.

I slowly put on my coat. “There's nothing going on, Mom. They are just being extra careful today.”

I hugged her a few extra times, and as I walked to her bedroom door, I turned back, trying to capture that moment in my mind because it would have to carry me through a while.

When I turned my head, my mom was looking right at me. She said, "What is it, Jenn?" like she recognized me and sensed something was different.

"Oh, nothing, Mom," I choked out. "I just wanted to say goodbye one more time."

And that was it.

Looking back, I would have spent hours with her if they’d let me. I would have stayed until someone dragged me out. I had no idea it would be the last time I held my mom's hand, hugged her, or smelled her, even if it was inhospitable.

I thought I was living the long goodbye every day, but this last day with Mom broke my heart wide open. All I understood then was what I was hearing on the news. The government issued a stay-at-home order. We had no idea for how long, but I thought it couldn't be more than a month or two. There was no way they would keep family members away from Alzheimer's patients for longer than that.

When I walked out of the facility that day, I turned to my favorite med aide at the door, who was saying goodbye to us. I said, "She is going to forget me."

I was holding back my tears. She nodded and did her best to hold back her tears. We would have hugged days ago, but instead, we stood apart and wrung our hands.

The days turned into weeks.

The weeks turned into months.

Mom didn't forget me. She saw my face through her window too much for that.

My sister traveled to visit us almost every month despite the pandemic, and we put camping chairs in the back of my car and opened them up in front of Mom's window, and we sat and talked to her.

Day after day.

If the window was open, we wore our masks. If the window was closed, we would have a cell phone on speakerphone. We didn’t ever talk about anything specific. The road noise usually made it difficult to have a real conversation. But at least once every visit, Mom would lean forward and try to peek out the window. “Why are you sitting out there? You should come in.”

“We have to stay out here for now, Mom,” I would answer.

“Why? I’m not a good host if you don’t come in and sit down.”

“Because there’s a flu out here, and they won’t let us come in just yet.”

“Oh,” she would nod. “That’s right!”

“We’ll be in there with you as soon as they let us.”

That was how it went, day after day, week after week. For weeks on end.

But I'm going to be honest. Those window visits broke me.

I'd scrolled through pictures of window visits on Instagram. Friends would share Facebook articles with me about how wonderful it was that we could visit our family through a window. At first, it was beautiful, but after a few weeks, I was devastated. I was angry, and I hated that godforsaken window. I hated the sun, the rain, the wind, and the neighbor's yappy dog. Those window visits were not beautiful or inspiring. They were torture for me, and I wanted to shout from the rooftops and change the world.

As my mom's primary caregiver, I wanted to be inside that building, helping to take care of her. I wanted to hold her hand, cut her hair, and paint her nails. I wanted things to go back to the way they were. I wanted my presence in her life to be important.

I kept my social distance from others.

I followed the rules.

I thought that any day the *powers that be* would change and allow caregivers in again.

I hoped and even prayed for the first time in 30 years.

I hadn’t spoken to God in quite a long time, but my mom always believed, so I hoped He would help.

“Dear God, I know you haven’t heard from me in a long time, but I’m having a very hard time, and if you can do anything at all so that I can go in and see my mom again, I would so appreciate it. I know I should be thankful that she’s alive and I’m alive and all that, but right now, I just want to be INSIDE with her. Please help us if you can. Amen.”

But nothing changed. The rules didn't change. The curve wasn't flattened. The doors to my mom's memory care remained closed.

Governments around the world, including Oregon, locked up their seniors and kept their families from them to save their lives.

It made them trapped targets for COVID.

Do you see a way out?

Late Spring 2020

AS AN ALZHEIMER’S CAREGIVER TO someone who is alive and dying, most of the days are about pushing through.

I visited Mom at the window, I took my photos, we chatted and laughed and talked, and though it was different, and some visits were difficult, my mom got used to it. She eventually forgot that I ever came inside. This was a blessing for her. Not so much for me, but at least she adjusted.

When she asked why I was outside, I repeated, "There's a bad flu going around, and when the flu goes away, I can come back in."

Mom would nod as she remembered, and all would be well.

Those window visits with my mom were breaking me, but I didn't allow that into my head and certainly not into my heart. I had to do everything in my power to keep seeing Mom and keep visiting so she didn't forget me. Despite the horrors I was seeing on the news about other nursing homes in other places, it didn't occur to me that my mom would catch COVID.

That's what they were calling it now.

Gone were the tongue-in-cheek coronavirus jokes. COVID-19 was life and death, and it took over the world. But I was only focused on my mom. I BELIEVED the day would come when I would be able to go back in and hug her.

Most days, I would have given anything for a poop hug.

I had a lot of memorable window visits with my mom. In the beginning, so many people around the world were sharing photos and videos of visiting their family members through windows. I was part of a group, being supported and held up by a community of folks who were in the same boat.

But as time passed, the weight of the thousands upon thousands of people doing the same thing I was doing took me down in a spiral. The government and its various authorities had locked away those folks in nursing homes. Those decision-makers walked away from the matter to take care of more important things, like the people in hospitals who were dying and the essential workers who needed PPE.

But for me, nothing was more important than taking care of my mom at the end of her life, giving her the grace that Alzheimer's had taken away, and being present for her.

I was broken and alone. And as much as I wanted to be with my mom, I was fully aware that would put others at risk. So, I stayed at the window, and when her memory care got an iPad, I talked to Mom through that video screen.

As the weeks and months wore on, I became more active in writing letters to politicians. I posted publicly on social media and begged anyone in a position of authority to think about change. I advocated safe visits, rapid results tests for employees and visitors, and outdoor visits in pleasant weather. I begged, and no one listened.

I wrote to my local politicians, and I wrote a letter to the Oregon governor. Then I waited for a phone call or a letter back because I thought what I wrote was so important, but my words fell on deaf ears. I posted that letter to the governor online on social media and still, nothing changed. Those that did care couldn't do anything about it, like me.

A few reporters reached out about interviewing me and perhaps even my mom. This gave me hope, but the news would turn to other virus happenings, and I was left alone again to drive to my mom's memory care, pop up my camping chair, and visit through the window.

There was too much news and too many things to focus on, and as soon as a reporter contacted me, they moved on to something more important. But nothing was more important to me than my mom.

Sometimes, Mom took the fact that I wasn’t going inside the home personally. One day, she put her little orchid plant in front of the windowsill and tucked her head behind it so that I couldn't see her. Mom wouldn't acknowledge me. She sorted through her old magazines and word-search puzzle books and ignored me as I talked.

I told her about the kids and the grandkids and how my husband's work and my work were going, and she continued to be fake busy. I tried jokes, and she didn't laugh. Finally, I had to pack up my chair, say goodbye, and leave. My mom wouldn't remember that I visited her, but it still hurt my soul.

One day, my husband and I were sitting in front of the building, tucked in a shady corner. By now, it was June, and it was a hot, clear day. The sun was baking the side of the building where my mom's bedroom window was. Even the front of the building was blinding, and the sunshine reflected off the windows so harshly that simply walking by was like walking into an oven.

My husband and I found a corner of shade along the wheelchair ramp, and a med aide moved my mom's wheelchair over to a lower window in that corner. My mom had to lean forward, doubling her little body over her legs and gazed down to see us, but they opened the window, and the air conditioning rushed out and kept us cool.

Because the window was open, we had our masks on and had to talk louder because my mom couldn't read our lips. She leaned as far out the window as she could until her hair was pressed against the metal screen, and she said to me, "Do you see a way out?"

"No, not yet," I answered.

I have no idea if my mom believed me. She might have thought I didn't want to take her out. Regardless, she asked me, "Do you know when I can get out?"

Shaking my head, I said, "No, I don't. We just have to have a whole lot of hope that it's soon."

I tried to have a whole lot of hope, and I did my best, rain or shine, to visit my mom at the window at least a few times a week. I ordered to-go food from our Wednesday night dinner pizza place. My husband and I brought her favorite chicken wings, and we ate outside while she sat at a window and ate inside. But it wore on me, and it was something my mom didn't understand. In a few months, she forgot that I ever came inside to visit her. But I remembered.

I felt cheated and slighted, forgotten and stuck.

I couldn't have known it would last so long, but the signs were all around.

On one of my last window visits, I sat with my mask on and waited as my mom scooted close and pressed her face against the window screen. Her hair pressed into the square pattern of the screen, pushing it out until it almost popped off. Mom turned her head right and left and strained to look out as far as she could, then she said, "What's the danger of me being out there?"

For what seemed like the millionth time, I said, "There's a bad flu out here, Mom, and we don't want you to get it."

"Ah," she said. She sat back and nodded her head. "That's right, I remember."

My mom wouldn't remember that after I left, but I couldn't forget.

Be still and know

July 2020

WHEN THE PANDEMIC STARTED, AND I was watching the news briefings from a Kirkland, Washington nursing home, they talked about all those people in that nursing home who were dying of COVID. I thought to myself that it was terrible. But I also thought it would never happen to my mom – it was something that happened to other people.

I thought that doctors, hospitals, and the *powers that be* would learn what they needed from early outbreaks in nursing homes and figure out how to keep it from happening.

But it dawned on me that I was in for a much longer physical separation from my mom in June when the college I work for canceled all in-person classes through the end of 2020. Other groups I belonged to decided not to meet in person until after March 31, 2021. My last clue that I would remain outside my mom's memory care came when I found Oregon's plan for reopening on the internet. Nursing homes would not open until a reliable vaccine was found.

At that point, all the news media told us that a vaccine was at least a year away.

My intuition told me that this pandemic wouldn't be over quickly. I checked in with my mom's care team and told them my concerns, and I was surprised when they offered to meet me in person.

I walked into the medical building with my mask on and stood on the marker on the floor by the front check-in window. The receptionist’s eyes lifted and crinkled like she was smiling. She led me back to a room, and Suzie walked in and sat in a chair spaced at least six feet away from me. An on-call nurse was also with her.

After the pleasantries, I asked, “If a vaccine is a year away, do you think it will be that long before I can visit Mom in person?”

Suzie answered, "Yes. It's likely to be quite a long time."

“Do you think they’ll do some sort of testing before then, so if I test negative, I can go in?”

She shook her head, “Not anytime soon. I’m so sorry.”

I stared right at her with tears in my eyes. “Do you get to go in?”

Again, Suzie shook her head. “No, I only get reports from the nursing staff.”

Pressing forward with more questions, I asked, “Are they testing the workers? Do they quarantine before they start working there? Are they keeping track of where they’ve been so they don’t bring the virus in?” I didn’t want to let it go. It was all so unfair.

“I don’t know the answers to all those questions, but I do know that they are not testing the med aids that work there. And they don't have any quarantine protocols.” Suzie paused and added, “At least for right now.”

“But if I’m quarantining all the time so I can go back in and see Mom and the workers aren’t, how come I can’t go in?”

Suzie laced her fingers together in her lap. “I understand you’re upset, and I’m so sorry. I know the rules don’t make sense, but this is just how it is right now. I can’t do anything about it.”

Hugging my mom was at least a year away. I walked out of the room crying, sobbed as I got into the elevator, and kept reaching under my mask to wipe my nose. When I got outside and pulled the mask off, it was soaked with tears.

I was alone on the outside, and Mom was stuck in her memory care home while I was forced to put my trust and my mom's care in the hands of strangers who would never love her as I did. I had to rely on people who were not her family.

Soon, I was trusting different strangers each day as turnover in her care home became chronic.

I had no one to turn to. No one was going to help me, my mom, or anyone in my situation. So, I settled in for the long haul. I set an alarm on my phone and called Mom almost every day so we could have "lunch" together. She recognized my face most of the time. She smiled. Sometimes, she would grab an old People magazine nearby, read it, and ask about Liam and Miley or Blake and Ryan.

Mom and I would laugh.

Sometimes, when it was quiet because neither of us had anything to talk about, my mom would watch me, smile, and say, "You're so beautiful."

This always filled my heart, and I would reply, "Oh, thank you. You're so beautiful, too, Mom."

She would smile like she remembered I was her daughter and say, "I love you," and I would tell her I loved her back.

So much.

I had no idea.

In my mind, I held onto this dream that one day, there would be a vaccine. And it would be like the Contagion movie; I would have my medical bracelet on, and they would scan it at the entrance of Mom's memory care, open the heavy door, and let me in. The courtyard would be in the middle, and the people inside would be walking the halls or sitting in their wheelchairs, watching me as I walked in. A stranger in their midst.

Turning to the right, I would run down the hall, tears streaming down my face. I would come around the corner to the open dining room and behold my mom sitting at a table. Rushing over to her, I would throw my arms around her neck and cry and cry even if she didn't recognize me or couldn't talk or smile. I would hold her and squeeze her and never let her go. I would run my hands through her hair, hold her face gently, and gaze into her eyes.

In my dream, I would always say, "You're so beautiful, Mom."

And everything would be ok.

Mom and I could make it through everything after that.

That was my hope.

I went to bed every night thinking about it.

In mid-July 2020, my mom turned 82, and we planned an outside pandemic birthday party for her. My husband set up a shade tent near the dining room window and invited we family and friends. There were 14 of us, pushing the new outside limit on gatherings announced by the Oregon state Governor. We ate pizza and chicken wings, and I made a cake. The day was hot, the cake melted, the sun was blinding, and we all wore masks because my mom's memory care windows were open. My mom was bent over at the waist, looking out at all of us, and we were yelling over the road noise so she could hear us with the masks. The only other shaded place on the property besides our shade tent was the garbage area. Many people gathered by the garbage cans to cool off, take off their masks and gear up to return to the boiling window.

The local accordion man, who used to play at my mom's memory care every Saturday before COVID, came and played outside at the window. Everyone took photos. My mom met her newest great-grandson for the first time through the window, and we sang her happy birthday. My mom seemed to enjoy having us all near and so many people to talk to.

I went home after that party, dreaming of Mom’s next birthday and how we would be able to celebrate in person. When the pandemic slowed, I would be inside again, caregiver extraordinaire, taking care of my mom to her end.

I would hold her hand every day, cut her hair, which was long by July, and paint her nails. Mom and I would laugh and sing "Take Me Home Country Roads" together.

It had to be that way.

When COVID came

August 2020

AS IT TURNED OUT, THAT nightmare in the Kirkland, Washington, nursing home played out in my mom's memory care. COVID got in, and though we weren't told much in the first few days, it was much worse than we realized.

All the family members, with loved ones inside the memory care, were reassured via email that it wasn't that bad and that only one employee tested positive. Still, while I held onto that hope, the virus was making its way around the building from person to person and infecting almost everyone who lived and worked inside.

I thought my mom, sister, and I would be together in the end, but that is not what happened.

Mom tested positive for COVID on August 12, 2020, and her doctor called me with the results. I asked my questions. “How is she doing?”

“Your mom doesn’t have any symptoms right now. So that’s good,” the doctor explained.

“How often are you going to be checking on her?” I asked, wondering if they would be allowed inside the memory care.

“The nurses will keep me updated. But your mom is a tough lady. I’m sure she’ll be fine. Even if she does start to show symptoms, she’s strong. I’m sure she’ll make it.”

I had to agree.

I had hope.

COVID would not be the end of her. Not after everything she'd been through.

A few days later, on a quiet Saturday afternoon, we were relaxing watching television, and my oldest son was visiting from out of town. My phone started to vibrate, and I glanced down. I was getting a call from a blocked number. By now, I'd figured out that this was mom's doctor's office calling with their daily update. I answered, not expecting much, but the news was bad.

My mom was struggling to breathe, she was in pain, she had a fever, she wasn't eating, and the nurse on the phone told me they were going to put her on liquid valium and liquid morphine.

My mind crashed, and my knees buckled.

I started crying, and I remember the nurse saying, "I'm so sorry."

These were familiar drugs. Liquid morphine and valium were end-of-life-level medicines.

I lost it.

I called my sister. “Mom took a turn, and she’s bad. If you want to come out here, you should do it now. I don’t know what’s going to happen.”

Her husband was talking in the background. I was on speakerphone, “We’ll get our dogs dropped off at the kennel and leave as soon as we can.”

My sister and her family were on the road in a couple of hours. They arrived in the middle of the night, but not before my mom's place called and asked if it was okay to send her to the hospital and make her more comfortable. The paramedics were standing by to take her.

The most difficult hours of my life were upon me. As her caregiver, I understood my mom's wishes. This was my time to honor her and what she wanted. My mom had a do-not-resuscitate order. She did not want any life-saving measures. Mom would never have wanted to live this long with Alzheimer's anyway, and as much as I didn't want her to suffer, if this was her end, she would be livid with me if I sent her to the hospital to be kept alive on a ventilator.

My mom wanted to go if it was her time, and I had to let her go.

I talked to my mom's best friend and called my sister again to make sure I was truly honoring my mom's wishes.

I asked them both because I had to be sure. “Am I doing the right thing? If they take her to the hospital, they’ll just put her on a vent.”

My mom’s best friend sighed, “Jenn, she’d come back and haunt you for the rest of your life if you did that.”

My sister agreed. She said, “If they ventilated her and she lingered in the hospital, she would hate it.”

Meanwhile, the nurses at Mom's memory care kept calling. These were nurses I'd never talked to before because I didn't learn until later that the state of Oregon had moved in and taken over. State nurses were working in the building. Each time I was on the phone with my mom's memory care, the paramedics were asking in the background if they were taking my mom to the hospital. I said *no* more times than I can count. I had no doubt I was doing the right thing for my mom.

Finally, out of frustration, the executive director of my mom's memory care called me at 9 o'clock at night crying. “Please, Jennifer, will you let them take your mom to the hospital? Please!”

It had to be so bad.

I didn't have any idea how bad – I only had my imagination, but if these people so desperately wanted my mom to go to the hospital, it had to be a horrifying scene. And my mom was only one of many. How many other family members were getting phone calls like me? I was well acquainted with most of the people who lived in my mom's memory care and their families. The ache in my heart pinched so tight it was hard for me to breathe.

I experienced everything that night like I was at the bottom of a well, screaming up. I had no idea what was happening above, but the heaviness of my choices and sounds around me pushed me down, and I realized no one was going to come to help me.

I was alone, and in that darkness, the only thing I held onto was that I had to honor my mom. It was difficult, but I kept saying through my tears, "She wouldn't want that."

"She wouldn't want that!"

My mom wouldn't want any life-saving measures. She wouldn't want to be kept alive on a ventilator. I didn't doubt that.

It seemed like people were begging me to save my mom's life, and they thought I was letting her die. But over the years, I'd spent so much time with her during good and bad times, and it was my job to help her leave this earth with dignity and grace. And if it was her time to go and it was COVID that was doing the taking and not her Alzheimer's, no matter what, it was my job to make sure her wishes were granted.

My mom deserved that.

The next day, we got word that everyone at Mom's memory care with COVID was being moved to other facilities, either the hospital or other nursing homes. The on-call nurse asked again if I wanted Mom to go to the hospital, and I said no.

Mom was moved to a COVID nursing home about 20 minutes away. It was only then that we learned that many of the residents and staff at Mom’s memory care had tested positive, but we still didn't realize the full story of what happened.

That would come in a few more days.

My sister and I had a video call with Mom that Sunday morning before she was moved. Mom had an oxygen tube around her nose. She was confused, and at one point, she said something like, "You guys look great." This made me smile. Mom looked terrible, but at least she sat up and talked a little.

On Monday morning, we received a call from the COVID nursing home. They told us that Mom was doing OK, that they had run some tests on her, and that they would call us with the results.

In the meantime, as long as my mom was with them, we were only to call once a day between two and three o'clock in the afternoon to receive a status update. My sister and I were told not to call outside those hours. The nursing home would call us if anything else happened and we needed to be updated.

And that was that. We were "allowed" about three minutes a day to check in and find out how Mom was doing. That was all they had time for us.

The days passed. My sister and I got our daily update on mom, we ordered take-out food to the house, we barbequed, we played cards, and we all sat on the couch watching dashcam and rando-naughting4 videos on YouTube. All of us went out on walks. We ate and slept. My sister and I were a comfort to each other.

And every day, it was annoyingly the same. Mom was stable. Her fever was the same. She was eating a little. Her oxygenation levels were lower than they should be but steady.

Finally, on Wednesday, I asked if we could visit her at the COVID nursing home window or on a video call. I thought it was a long shot, but they said yes.

“Can we come over right now?” I asked. “We can be there in 20 minutes.”

“Yes, of course,” the nurse replied. “Just come to the window by the front door when you get here, and we’ll set up the iPad.”

My sister and I arrived within an hour. I walked to a window at the front of the building and told the nurse who we were there to visit.

About 15 minutes later, they finally brought Mom to a window. It was an old building; the windowpanes were cloudy and scratched with age, with wood frames holding the glass squares in place. Not only did we have to contend with the blurry glass and the wood frames, but the entire window was covered in an old thick screen with a tight weave.

It was better than not being there, but we struggled to see Mom.

The screen made it hard for our cameras to focus, but she was in a pink sweatshirt I'd never seen before and gray sweatpants. Mom was sitting upright in a wheelchair and the nurses helping her were covered from head to toe in personal protective equipment. They had on goggles, masks, splash guards, gowns, and gloves. I wondered how Mom was handling it inside the strange building.

Mom had been deaf in one ear and relied on reading lips most of her life. Not only did she have Alzheimer's and was in a strange place she wasn't familiar with, but she also couldn't read anyone’s lips because of the face masks. By this point, Mom's only frame of reference for life was in that memory care home she'd been in for the last two years. Did they bring anything with her that was familiar? I had no idea. Things were so out of my control.

All my grief and all the years I'd spent preparing for her death and being with her at the end were gone. All my plans were wasted, and I had nothing to cling to but the voice of a nurse on the other end of a phone line for a few minutes each day.

Nothing was as it was supposed to be.

All I could do was accept what was in that moment.

My sister and I were visiting Mom, and she was in a wheelchair, sitting upright in front of us at the window of a COVID nursing home. She was on the other side of glass and dust and weaved wire, two feet away, and I couldn't touch her. The nurse handed my mom a phone and put it on speaker. I had my cellphone on speakerphone on the other side of the window, and we said hello.

“You look great, Mama,” I said. “I love the snazzy sweatshirt.”

“How do you like your new place?” my sister asked. We tried to talk like nothing was wrong and everything was going to be fine, but she was medicated and confused.

Mom stared at us like we were strangers, but she would listen to us and smile a little. Did she recognize us? Did she recognize our voices and remember who we were?

She said a few words, "Where is everyone?"

That one was understandable. “We’re right here,” I answered. However, she seemed more confused after I said that.

Mom asked, "What happened?"

“You got a bad flu, Mom, but you’re going to be just fine,” I explained.

We continued the small talk until she drifted into a medicated sleep. As her eyes closed, she slowly lowered the phone she was holding, and her voice was far away. My sister and I tried to keep talking, but the phone in her hand went down to her lap. Mom's eyes kept popping open, and she would gaze at us, and then her eyelids would flutter down again.

With everything in me, I willed my mom to open her eyes, pick up the phone, and talk to us, but she drifted off. She opened her eyes a few times and smiled at my nephew pacing around in the background, and we took comfort in that.

Mom eventually stuck the phone between her legs so she no longer had to hold it. She rested her hands on the wheelchair arms and drifted off to sleep. She would rouse every minute or so, focus on us, try to smile, and slowly nod off again.

My sister and I watched her sleep for about 15 minutes, and I went to the facility door and told them we were leaving and that Mom was asleep at the window. My gaze stayed on my mom as we walked to the car and drove away.

I wondered if it would be the last time I visited her at the window, and I had to turn back and capture that memory, just in case.

The best-laid plans

August 2020

MY SISTER AND I DROVE AWAY, and even though we were worried and sad, we were comforted that we were able to visit Mom that day. She was upright. She was in actual clothes and didn't have an oxygen mask on her nose. My sister and I decided Mom would probably pull through this COVID thing and be fine.

“She was sitting up in a chair, she talked a little and smiled. She seemed okay, so I think she’ll be fine,” my sister said, and I wondered if she was trying to convince herself it was okay.

“I don’t know how she’s going to be when she recovers, though,” I added.

We didn't have any idea how she would be afterward, but we thought she would live and we would have an incredible story to tell. I thought that she would be different when she did pull through, and COVID would steal away some of the years Mom had left. She would likely be weaker, and perhaps she wouldn't laugh as much or talk as much, but we would return her to her memory care, and eventually, we would be able to give her hugs and kisses.

My sister decided to stay one more day, and if the news was the same on Thursday, she and her family would drive home on Friday. The news was the same, and they went home.

The next day, only 36 hours after they left, my husband and I were walking our dogs, and my phone started buzzing in my pocket. Recognizing the number, I glanced at him. The nursing home was calling me.

"This can't be good," I said as I answered.

Indeed, it was the worst news.

It was 11 o'clock AM on Saturday, August 22.

Mom's fever had spiked, her oxygen levels were dangerously low, she wasn't eating, and she was having trouble breathing. The nurses were giving her more morphine and more valium. I asked the nurse if she was going to be OK, and he said it was hard to tell. And then I asked the question I feared the answer to the most.

“Is this the end? Is she at end-of-life?”

“It’s hard to know exactly, but I’ve seen this a lot, especially lately, and so in my opinion, yes. She’s near the end,” he answered.

He couldn't say when, but she didn't have much time left.

I had always imagined I would be with my mom when she died. Her Alzheimer's would progress, we would recognize the signs that she was at the end of her life, and I would take my go bag and sit with her for as long as she took to die so that she was never alone.

I had planned her death. I would be on one side of her and my sister on the other. As my mom stopped swallowing and struggled to breathe, I would wipe her brow and prop up her head. I would be beside her with a soft kiss on her forehead to tell her that she was okay and it was okay if she left us.

I would be right by her side until the very awful end that Alzheimer's brings.

That was my plan.

So, when the nurse validated my fears that my mom was actively dying, I pushed to be with her even though it was a COVID nursing home. The nurse asked me to think about it for an hour or two, but when I told him I didn't want to do that and I wanted to be there, he reluctantly agreed. I hung up the phone and called my sister. At the moment, I only saw the end and that I should be with her. I didn't comprehend the virus or the danger.

I called my sister right after I hung up with the nurse. “They just called from mom’s place. She’s a lot worse, and the nurse said she’s at the end.”

My sister was silent on the phone, so I kept going. “We’re out with the dogs, but I’m packing a bag as soon as I get home. They said we could be with her, so I’m headed in.”

I thought the second I told my sister what was happening that she would be on the road back to Oregon to sit with Mom and me while she died. Though it was COVID and not Alzheimer's, I still believed it would happen the way I prepared for it. My grief allowed for nothing less. I was blinded and thought her dying had to be a certain way. I had to control how it happened.

My sister was quiet on the other end of the line but finally said, “Jenn, I’m not coming back. I’m not going in there.”

I was shocked. I don’t even remember how the conversation ended. I only remember my heart beating and a head rush of emotion.

As I got home, showered, and packed my clothes, I received three phone calls: one from my aunt, one from my mom's best friend, and the last one from my sister.

They all said the same thing.

"Your mom wouldn't want you to risk your life to be with her."

"She would want you to stay safe."

I was stunned and frustrated. Didn't they all realize that mom deserved to have someone hold her hand when she died? Didn't they understand what I had gone through? Didn't everyone understand that this was not the way I had planned it?

I called the lead nurse at the COVID nursing home, and he told me all the protocols they go through. He told me how infectious Mom was, and he explained that the longer I was in the building, the higher the chance I would have the virus. Then he told me that when Mom died, I would need to quarantine alone for two weeks.

Once I got off the phone with him, I sat on my bed, staring out the window into my backyard. With everything inside me, I wanted to be with my mom when she died. That was how it was supposed to be. But the fear in everyone's voices was evident. I had to consider the risk.

My mom's best friend called back and said, "Jennifer, if you go in when your mom is gone, you cannot hug your husband. You cannot be with anyone. You have to think about that."

So I did. I sat with it for a few hours. I thought about Mom alone in that nursing home, not recognizing anyone and suffering, and everything pulled me to go to her. Also, I also knew from seeing her on Wednesday that she was heavily medicated. I'd learned enough about end-of-life hospice to understand that Mom was not aware she was suffering. The nurses were making her comfortable.

My caregiver soul wanted to be right beside her, but my mind tossed COVID and illness and my own health into the mix, and I came to believe that my family was right. My mom would not want me to risk my life.

My husband sat down next to me, and I asked him, "If it was your dad, would you go in?"

He stared straight into my eyes, shook his head, and said, "No. I wouldn't."

I realized that no matter how much it broke my heart and no matter how different it was from what I imagined, I had to send my love out to my mom and trust that it would find its way to her. I would be with her in my heart, but not in person.

My sister and I had a video chat with Mom on that Saturday and again the next day. On both days, Mom had an oxygen mask on. She was staring at the ceiling, and the iPad was on a stand beside her bed. We only saw her profile. Mom made some noises deep in her throat, almost like she was laughing or stuttering, and she blinked, sometimes a lot. My mom was lying at death's door, and when that iPad screen first turned on and focused on her, it shocked me. Her skin was grey, her eyes were dull, and her wisp of a body appeared to have lost 20 pounds in a few days.

Death was coming, but I was holding on to hope that she might make it through.

On the first day, my sister and I talked to her, sang her songs, and told her we would take her out for chicken wings when she got better. We also promised to visit her and hug her soon.

The next day, I think my sister and I realized Mom wouldn't leave that place alive. We sang her favorite songs from when we were kids.

"I love you a bushel and a peck," "Take me home country roads," and "You are my sunshine."

My sister and I also told her some of the things we did as kids that we lied to her about.

I told her about the time I raced her little Chevy Sprint across a bridge to hit a dip in the road just right so the car would catch some air. Though I did catch air, I also accidentally broke the muffler right off her car. The instant her muffler broke, the car started to roar. I drove it home like that for an hour and parked it in front of the house.

When she woke up the next morning to do the paper route, she turned the key, and her little tin can of a car sounded like a jet engine. Mom stormed inside and yelled, "What the hell happened to my car?"

Looking right at her, I lied, "I don't know, Mom."

As mom lay in her bed at the nursing home and listened to that story, she made a noise, almost like she was laughing. She had to be laughing. What did it matter now? My sister and I giggled at those memories, told more stories, and watched Mom and each other on our little phone screens.

I took screen captures because I'd photographed this entire journey.

Mom eventually fell asleep, and we told her goodbye and that we loved her.

*Dear God, I hope Mom heard us.*

I spent the rest of that day trying not to think about Mom suffering alone and somehow going over in my mind that I was doing the right thing for me and doing what she wanted me to do. The day was a blur, and I went to sleep thinking that whatever tomorrow brought, my sister and I would have our video chat with Mom. To me, there was still a chance that she would be ok.

At 12:32 AM, I stirred to the sound of my phone ringing.

As I realized what had woken me up, I sat up, threw my legs over the side of the bed, and cried, "Oh no!"

There was only one reason my phone would be ringing in the middle of the night.

Answering, I said hello, and the nurse asked if I was Jennifer.

"Yes."

She said, "I wanted to let you know that your mom, Bobbie Lee, passed away just a few minutes ago."

The nurse told me that she went to check on Mom at midnight. Mom was struggling to breathe, so she gave her another dose of morphine and made her way around the building. When she went back to check on my mom at 12:30, she had passed away.

My mom most truly died alone.

The tears started, and a whole different type of grief engulfed me. Not knowing what happened next, I asked the nurse. She told me they would call Mom's funeral home, and if they needed anything from me, they would call me back.

I woke my husband, and we went to the living room and turned on the television. He fell asleep again, and I sat on the couch for hours, watching a television show that I don't remember and crying.

My mom had lost both her parents, and her younger brother, Richard, had passed away about 20 years before. As my mom lay in that nursing home and after I'd decided not to go, I sent a prayer out into the universe that her parents and her brother Richard would come to be with her at the end and walk with her to whatever comes next.

I did not have a deeply religious faith, but I believed in God, the connectedness of our souls, and the universe's collective energy. My mom's parents and her brother were with her. I have to believe that.

I have to trust in that.

Still, it hurt that I'd slept through my mom's passing. This was a pain unlike anything I thought I would ever experience.

Around 4 o'clock in the morning, I went back to sleep and before I got into bed, I moved a photo of my mom and her parents to my nightstand. I said goodnight to them and told my mom, “If you're still here, come and say goodbye."

I slept until eight in the morning, and my mom did not come to me in my dreams. I was comforted knowing that her spirit wasn't lingering. My husband suggested we go to the beach for the day. My mom always loved the beach. So that's what we did.

In all the years that my mom had Alzheimer's, I had been carrying around heavy, deep grief. That grief had become part of me, but that morning, I carried my grief differently. I didn't have to worry about whether my mom was suffering. And I no longer had to worry that Alzheimer's was taking more of her away from me.

My caregiver duties were done.

I had done my best, given my all, and been there as much as possible with Mom.

My mom and I reached the end of the journey together, but not together.

COVID came and she was gone.

The wave

End of summer 2020

WHAT I WASN’T EXPECTING IN this whole journey was to be hit with such a massive wave of grief after Mom died. I guess I thought that, in some way, all the grieving I'd already done would make the grief of losing her easier to bear. Like I'd put in the work and practiced grieving so I would be better at it? But that's not what happened. My grief was different when she was gone. Because it was permanent, and this second wave of grief didn't pull any punches.

It hit me all over again.

About two months after Mom died, I joined a COVID support group on Facebook because, up until this point, I was aware of people who'd had COVID. But still, I wasn't acquainted with anyone who'd lost a loved one to COVID, and in a crazy world where people thought it was a hoax, I felt alone.

In the COVID group, people started posting videos of their loved ones when they were alive and happy, and I scrolled through video after video of people smiling and laughing. A video of my mom popped into my mind, and I went to my phone to find it.

After searching through all my photos and videos, I found the video from three Christmases ago, when my mom walked into my front door wearing a battery-operated musical Santa hat. The hat moved and chimed, and she was thrilled with it. Mom had no cane holding her up. Instead, she stepped into my house on her own, with no walker or help. She smiled and laughed, and I filmed her and her cute little animated hat. And then her hat song was over, and she put her hand up to her face and reached for my kitchen counter for balance.

As that video continued playing, Mom smiled and laughed. All I wanted to do was hug her, hold her tight, and never let go. This was a moment in the past that was caught forever on my phone, and yet I wanted it back. I wanted to rush to her and tell her I loved her and her quirky ways. But she wasn't there with me. Instead, she stood on the screen, smiling for the cameras.

In the video, we all laughed, and I said, "What's up?"

My daughter said, "Hi, Nana." Mom giggled. And the video clip ended.

My journey with my mom had ended, and all I had now were pictures, videos, and memories.

It hit me like a wave that I would never see her again. Mom would never wear a silly hat through my front door and smile and laugh again. And I felt like I didn't do enough at that moment to show her she was loved beyond measure.

Why? Why did I feel that way?

My mom knew I loved her. Her soul can't have lingered with Alzheimer's for so long, seeing me almost every day sitting with her while she ate or watched the Hallmark channel and not knowing that I was with her because I loved her.

Why did that Christmas video leave me wishing I had done more? Why did I think she needed more? Perhaps it was me who needed more. Because I wasn't ready to let her go, and I certainly wasn't ready for her to leave without me right beside her.

I played that video on my phone at least a dozen times that morning, and I walked right over to my front door, right on the carpet, where she stood with her dancing hat, laughing and shaking her hips. I laid down right where her body stood three years ago, and I wished for her to be there again.

I was right where she was, and I wanted her back. I cried so hard, and I screamed and sobbed until my dog came over and licked my face. My snot and my tears were all over me and the carpet, and still, I cried and sobbed and screamed some more.

This was the most heartbroken I've ever been in my life.

My mom was dying anyway. She had Alzheimer's, a terminal illness. And yet, it seemed like she was taken from me too soon. She had more time, and I wanted her to still be here when COVID was over, and I could go in and hug her, hold her tightly, and tell her I loved her.

My mom was going to die someday, and that someday would eventually be the last hug and the last time I would whisper *I love you*, but I didn't want it to happen so soon. I didn't realize that video was going to be her last Christmas when she was walking and able to leave her place and have a meal with all of us at my house.

Through almost seven years of my mom's battle against Alzheimer's, I was right beside her, and I was right in the tight grip of grief. I witnessed her fear, and I sat right in it with her. And here's the thing I realized that day when the wave hit me, and I ended up like a puddle on my floor – there is nothing about death and grief that you can prepare for.

When my mom was here, I wanted her suffering to end. When she was gone, I wanted her back. Though I understood she would be suffering, I wanted her back anyway because my suffering was so painful that I couldn't find a way out.

Grief takes hold, and it does not ease, not a little bit, no matter how many years of ambiguous grief I'd suffered through already. That suffering was not like a practice run at grieving that made it any less painful when the end arrived.

I took all those photos and videos of my mom so that someday after she was gone, I would have them all. I wanted them to provide comfort and peace. But still, months after her passing, they are such a source of sadness and pain that I cannot fathom a day when they will make me smile.

Someday, I will be comforted when I scroll through them.

Someday, that grip will ease.

And though the grief after she passed was deep, it was different. I'm not sure how to explain it, but the journey was over with my mom. She and I had reached the end. I was her caregiver, and now, rather than being pressed down by grief that was always growing, I could reach the edges of it. I could pick it up now and carry it because it wouldn't become any heavier.

There's that saying that *when God closes a door, he opens a window*.

Roll your eyes.

I always did.

I thought it was trite and made light of pain and sadness and agony. A door closed, but instead of being sad, we're supposed to search for the open window. I didn't want to do that, but in my heart, I realized that the window was open.

This understanding started the day after my mom passed when my husband studied me and said, "You look lighter."

And I had to admit, as the days went on, I did feel lighter. I was relieved that my caregiving journey was over, and in that recognition, I didn't feel guilty for being relieved.

It's ok to feel relief.

I had been busy taking care of my mom, worrying about my mom, and spending time with my mom worrying about all the other things I had to do when I was done spending time with my mom. I was on a sit-and-spin, and it was stressful, but after she died, I didn't have any of that. I didn't have to drive in my car on Wednesday to pick up pizza and wings. I could sit at home and pull up Veronica Mars on the television.

In those years, I'd worked hard to accept my caregiver role. Allowing myself to work through all that anticipatory grief before my mom died helped me experience relief and not guilt. I had done enough to make my mom's journey better and more dignified. I had walked the path to the end with her and had no regrets. Not even deciding *not* to go into that COVID nursing home.

My grief was heavy, but every day, I carried it a little better. Wherever my mom's soul went, she had her memories back, and she knew – she understood what I did, she appreciated the choices I made, and she isn't haunting me. Wherever she is, she supports me.

Later, I learned that of the 40 total residents and employees at Mom's memory care, 35 got COVID, and seven people died. My heart was heavy for the other families who lost their loved ones in that outbreak.

In the weeks after my mom passed, my husband and I went to the beach three times. We went hiking. My dog and I attended obedience classes, which I'd always wanted to do but didn't have time for. I had more time for television, I learned to knit, I chatted with friends, and I started writing this book. I wrote the entire manuscript in three weeks. This book was in me to write. I always believed that, but I felt that I couldn't put pen to paper until my mom died. Because until that happened, I didn't have an end to the story.

This journey didn't end how I thought it would, but regardless, the end gave me a new beginning. And in that new beginning, I got the answer to the question I’d asked myself for years.

The why of it all

Fall 2020

“WHY AM I DOING THIS?” This is the question I asked my therapist about a year earlier. She told me I had to figure out the answer on my own.

Why did I rearrange and restructure my entire life for over six years to take care of my mom? My sister was the obvious choice to be her caregiver. My mom preferred her company to mine, and I knew that, but I got involved in it anyway.

My sister and I decided to move my mom to Oregon, and I did that knowing I would be thrust into a role I was unprepared for, but I did it anyway. I believed it would only be temporary at the time, but regardless, I did it.

In the beginning, I felt put upon by the responsibility. I pressured myself and told myself that I was doing it because my mom deserved grace in the end. My mom had taken care of me and my sister after my dad left, and in some sentimental way, I believed that she'd given up her life raising us. My mom never dated. She never remarried.

Taking time to be her caregiver was what I owed her. At least, that's what I told myself in the beginning.

Still, I wondered why. I could have said no to moving my mom to Oregon, or I could have given up once she was here. In my early caregiving years, it might have been possible to work with my sister to move my mom back to Arizona or Idaho once my sister and her family were settled. Indeed, the Idaho pandemic rules and nursing home lockdowns were much more open than in Oregon. When I realized my mom would be locked away inside her memory care for at least a year, I could have pushed for her to be moved to Idaho.

But I persevered, just like my mom.

During those years, I did it because I believed I had to, and I didn't question why. I didn't analyze why I was doing it or why I believed I had to stay with my mom to the end. Not when she was angry with me or yelled at me or through all the poop and emergency room visits. I kept going, and I did not give up. If I was angry, I kept going. When I was resentful, I kept caregiving. I simply put one foot in front of the other and did this very hard thing without deeply questioning why.

You could say I'm my mother's daughter, and I'm stubborn, independent, and fierce, just like her because I am.

But that is not why I did it.

Only after my mom died did my dear friend, Becki, remind me of the question.

“Jennifer, I think about everything you went through, and I just wonder why. Why did you do it?”

That started me thinking about it again, in earnest. I learned so much from the journey, and I came to love my mom in a way that would not have been possible before. I accepted that was why I did it, but when Becki asked me again, I realized there was more to the answer.

And it came to me one day. The answer popped into my head as I was thinking about my mom.

I did this because it's what Mom would have done. If it were her mom, she would have given up her freedom and her independence and struggled through the caregiving process. My mom would have done this for anyone in her life: for me, my sister, her sisters, any of her brothers, her friends, and her parents. If they needed help, my mom would have helped.

My mom may have grumbled and complained her way through it (like I did), but she would have done it. In fact, my mom might have made the nana lips through the entire experience, gritting her teeth and cursing under her breath, but she would have done it. Without thinking about it, if my mom needed to be a caregiver, she would have.

And I am my mother's daughter.

While I was thinking about my why, an even more profound realization hit me. Unexpectedly, over the six years I cared for my mom, I became her favorite daughter. I went from being her least favorite person to the only person she knew.

At the end of her life, I was her whole world. My mom was my whole world growing up, and I became her whole world in the end.

That is ALSO why I did it.

The irony of life is that often, in the moments that are so overwhelming, we do not realize how much of a blessing they are. Two months after my mom passed away, every second I spent with her, good or bad, was a blessing.

I would do it all over again, every time, because of her and because that was the example she set for me. This was my sign that I'd finally accepted my role as a caregiver. I realized that when the caring was over, it was a gift.

And I will only miss her more as time goes on. Even when I am 79, I will want her to say, "You're so beautiful," so I can say it back.

"You're so beautiful, too, Mom."

No matter how much time passes, I will always dream of being at her window with my mask on, talking to her, and watching her lean down to see me better and smile.

I will NEVER not want to be outside that window again.

And I will hold in my heart the unrealized dream of being able to run into her memory care home and hug her again after months or years of separation. That will always be an unfulfilled wish in my heart.

I also talk to my mom a lot now that her soul is somewhere in the cosmos. With all her memories back, her brain is healthy, and she can hear and understand me. So I tell her all kinds of things.

This caregiving experience is my refiner's fire.

Growing up in a religious environment, I heard this term often. Fire burns, melts, and changes you, and this grief has changed me, but beyond that, this entire experience of walking beside my mom to the end of her life changed me.

This is with me every day, and I recognize that I am refined. My body may be the same on the outside, but I am forever different on the inside.

What is the purpose of all this writing and all these feelings?

If I had to sum it up, it would be that life is wondrous and fragile, and mostly it hurts. Life hurts because there is so much love in it, and when we love someone so much that it fills our insides up so completely, we can’t help but be lost and devastated and grief-stricken when they leave us.

And I didn’t realize it was happening to me. I had no idea I was changing.

I was too close to it.

For so many years, all I experienced was the stress and the weight and sadness of caring for my mom. For being the ONE person who met with the doctors, drove to her home, took the calls, picked her up, dropped her off, and searched for her in the grocery store because she wandered off. I didn’t understand that each moment, each smile, and the laughter were filling me with love and memories that would be with me after she was gone.

I lived through it all and more than that, I endured it, and the undeniable beauty of it happened all while I wasn’t paying attention.

Now that my mom is gone, I realize that I had so much love inside me from her and all these moments. And the agony comes from knowing now that I won't have any more moments with her.

I was too close to see this caregiving journey changing me.

And now that she’s gone, I can see that I am changed.

This kind of grief, well, any kind of grief, but specifically this kind of long, endless, painful, sad grief that sits on your shoulders and doesn’t let up, is so life-altering. The only reason I could carry it for so long was because of the love filling me up inside.

Like a judge's scales, a balancing was happening, and I didn’t realize it at the time. This journey was hard, sad, and stressful, and despite all those things, it was also beautiful, peaceful, and enduring.

My mom's example of how to carry on through life shaped me into a person who had the strength to carry her when she needed it. And now I have all that, and I have the strength to carry this grief.

I don’t remember the person I was before my mom was diagnosed with Alzheimer’s, and more succinctly, I don’t remember the person I was before I accepted my mom for who she was in each moment that she was fading away.

I loved her completely as she was, and as she disappeared, I loved her more than I ever thought it possible to love someone.

Epilogue

October 2022

AS I SIT HERE ALMOST TWO YEARS after writing the rough draft of this book, I realize that my mom's Alzheimer's was the end for her, but it was my beginning.

This was, beyond all doubt, the worst, most trying time of my life. However, it was also a blessing.

If I lived this life many times over again, I would do this every time. Every time I would move my mom to Oregon and become her caregiver and go through the grief. Even knowing that my sister would never move to Oregon to help, I would still choose to take care of my mom.

This is what she would have done for anyone she loved. My mom modeled that for me in ways that I couldn't discern when I was a teenager because I was simultaneously frightened and in awe of her. That helped me understand why I took care of her. I didn't realize that until she was gone, but I did it for her and also BECAUSE of her.

I would choose to do it even knowing the end would be COVID.

Every single time.

So much has changed that I have to be grateful for. As adults, my sister and I had a tense relationship, and I wasn't particularly close with my mom.

By being a caregiver to my mom and experiencing this grief, I was able to learn the beauty of acceptance. I learned how to let go of resentment and to accept people for who they are, not who I want them to be.

I was able to accept my sister for what she was able to do and give to my mom and me. Though our relationship has returned to being strained, and we are not actively involved in each other's lives, I can be grateful for the time I spent with my mom and her. And I can be grateful for my newfound understanding of my sister as a person.

I also carry with me the knowledge that my mom was so happy my sister and I were together and friends for a time. My mom didn't like that we didn't speak to each other and wanted us to reconcile. She got to witness that. Even if it wasn't for always, we did it for her.

I learned to love so profoundly that all the love I had for people before my mom died seemed tiny and insignificant.

Now, my ability to love is huge and fulfilling.

Though my sister and I have lost our connection to each other, we went through a deeply emotional experience with my mom. That is a memory we will always share.

In my life before Alzheimer's, my mom and my sister were tightly connected in orbit around each other, and I loosely drifted outside them. I never thought I would be a part of that, but as I cared for my mom, my mom and I started circling around each other. We formed that bond, and I'm grateful I had that experience.

Now, I gently orbit around the place where mom used to be, and I hope my sister does, too, in her own way.

I feel my mom pulling me through each day.

I speak to her.

I miss her.

And where I used to fear death, I've learned that when my time comes, I will be with my mom again and finally receive that hug that I was denied because she died in the time of COVID.

I long for that.

Mom will be whole, and her memories will be restored, and we can talk about it all. Perhaps we can even laugh about poop hugs.

Today, I have peace in my heart that I never had in my life before, and that is all because of my mom. This is all because I embraced my choice to walk with her to the end of her life. If she hadn't been diagnosed with Alzheimer's, I have no idea where we would be – my mom, my sister, and me. We most likely would be in our separate lives. And we might still be relative strangers to each other.

Instead, the worst possible thing I could never have imagined filled me with love and peace that I will always be grateful for.

Love your person.

Accept them.

Let go of resentment and fear. Embrace your journey, and when it's time to say goodbye, realize the end is only the beginning.

Notes

1 Anticipatory Grief - https://www.verywellhealth.com/understanding-anticipatory-grief-and-symptoms-2248855

2 Transient Ischemic Attack - https://www.mayoclinic.org/diseases-conditions/transient-ischemic-attack/symptoms-causes/syc-20355679

3 The clinical states of Alzheimer’s - https://www.alzinfo.org/understand-alzheimers/clinical-stages-of-alzheimers/

4 Randonaughting is using the Randonautica (https://www.randonautica.app/) app to get random coordinates on a phone pointing to a location to go search

About the Author

JENNIFER SULLIVAN HAS SPENT THE last ten years living her caregiver journey and writing about it on her blog and on social media. She always felt called to write books and stories but never dreamed that making her way through such an intense caregiving experience would lead her to write a memoir like this. Another part of her grief and healing was her podcast, For Those We Lost. On each of the 51 episodes, she interviewed someone who lost a loved one to COVID. The podcast and all its episodes are now part of the "Rituals in the Making" study at George Washington University, which examines death, mourning, and memorialization during the pandemic. She hopes this memoir and her podcast will help others who find themselves in the midst of personal struggles.

These days, Jennifer lives in Aloha, Oregon, with her husband and two dogs, where she writes and shares her story with anyone who might need a little encouragement. She enjoys traveling, riding rollercoasters, meditation, hiking, and camping and will drop everything to spend time with her grandkids.

You can find her at www.jennsull.com.

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That brings me to God. I left Him behind for many years because I thought He didn't care about me. My mom always believed He did, and only after she was gone did I fully come around to letting God back into my life. In the last years of mourning, writing, and crying through the editing, I know God is with me.

Last, but certainly not least, I have so much love and gratitude for my dearest husband, Brian. The years I spent caring for my mom were not easy for us, but he suited up with a smile, a hug, and a sense of humor to help me with Mom. He is a treasure, a blessing, and the love of my life. He and I made it through this most challenging time in our lives, and when I'm sad and grieving, he is who I turn to because he was there with me through it all.

I write this now, as I've lost both my parents, knowing I am the matriarch of my family: my kids and all the grandkids. It is my life’s goal to be the best mom and Gam I can be so that one day, perhaps one of my kids will write a memoir about me.

Jennifer Sullivan

December 4, 2024

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