

FOREWORD

ANYONE WHO IS ABOUT TO JOURNEY as a caregiver or anyone who wants to understand what caregiving is truly like must read about the experiences of a caregiving daughter, Susan A. Marshall. She openly and candidly shares with us her excruciating journey as a caregiver for both her mom and dad.

As a caregiver sees their loved one's character and personality change into someone they've never known before, the heartache is immense. Add to that the need to give personal daily care reversing the roles of Mom and Dad, parent-child, you can see how the grieving, depression, anxiety, and irrational irritability change and upend one's life.

It is unfortunate we do not have a medicine to cure the loved one who is ill, to give the caregiver the necessary patience, understanding, acceptance, humor, and perspective that are so critically needed at this time. While no medicines like that are available currently, we do have *Mom's Gone Missing*. It will not cure or take away the pain but it will help the caregiver survive and maybe even thrive.

In *Mom's Gone Missing*, we see the ups and downs in the various contacts with nurses, doctors, lawyers, siblings, even ourselves. In one form or another, they make our own life, our daily, hourly caregiving journey either that much easier or that much harder.

SUSAN A. MARSHALL

So, after the guilt, soul-searching, anger, feelings of not being respected, feelings of being over-burdened, of not being understood, responsible for doing it all, pain of losing your parents, we end up learning about ourselves. About how by understanding and appreciating what is truly important, including the need for humor and laughter, we can have a stronger life resulting from better knowing ourselves.

In *Mom's Gone Missing*, we learn that money is not the antidote to life's discomforts. That it is us in the end who determine what is right, how much we want to be heard, how much we need to handle fear, that we must build while we can, enjoy as we may, endure as we must, and relinquish without complaint.

"Comparing what we have, what we know, or how we believe we have fared with the fortunes of others—good or bad—distracts us from discovering, developing, and deploying the uniqueness that marks our moments."

Marty Schreiber

Former Governor of Wisconsin

and author of *My Two Elaines*:

Learning, Coping, and Surviving as an Alzheimer's Caregiver

P R E F A C E

WRITING ABOUT FAMILY EXPERIENCES is always fraught with the dangers of misinterpretation, colliding viewpoints, and hurt feelings. With this danger at the forefront of my mind, I set out to bring the experience of Dad's long journey through Alzheimer's disease, Mom's experience as his lifelong partner and caretaker, and Mom's rapid decline and death surprisingly soon after Dad's passing. My sole and sincere reason in writing this is to offer information and encouragement to anyone who is now or will one day be confronting the declining health and ultimate passing of a parent or beloved family member.

It's a tough road. Families are made up of a collection of people who, despite having similar DNA and childhood circumstances, are entirely different from one another in temperament, experiences, needs, and abilities. Some cope well, some don't. Some can think objectively, some can't. Some can set aside personal experience to serve a pragmatic purpose in a given moment, some can't. And the temptation to judge one another in moments of high emotional distress is acute.

So, with no *mea culpas* for telling this story from my perspective—the only one I can accurately represent—I do acknowledge with full gratitude, sincerity and humility the idea that my siblings may see this as a work of utter fiction. Their experiences, feelings, judgments and contributions are not adequately reflected here. They can't be because I am not them and we have

not collaborated in this work. That's a risk. I accept it, ask forgiveness for any unintended sleight, and honor their differences with reverence.

Additionally, I have been struck by the incredibly personal way in which excerpts of this book have touched people with whom I have shared them. Each of us has a story, comprised of life's experiences and blended to a formulation that is in many cases bitter-sweet. Depending on where you are on the spectrum of those experiences, your formulation may be more bitter than sweet or vice versa. Perhaps you are currently living a dark or lonely chapter, perhaps you are reveling in bright sunshine and golden opportunity or perhaps, like many of us, you are somewhere between these clearly marked episodes in something a little vaguer and less emotionally charged waiting to see what comes next.

I worry that our social media tools and habits have squeezed out the opportunity to feel and learn from all our experiences. We post pretty pictures and wry stories of how we made our way through something laughing all the while. In doing so, I believe we deny ourselves the true emotion—good or bad, light or dark—and prevent others from truly engaging with us, especially if they are living a particularly challenging time.

For some, this book might feel heavy. You may feel profound sadness at certain times. If this is the case, please allow yourself that discomfort. Because here's the crazy good news: Hidden inside the difficulty is a veritable goldmine of discovery. About yourself, about others, and about purpose. You'll find characteristics like compassion, patience, humor and commitment. You'll discover a depth and strength you may not realize you have. This, in turn, may open a door or window or the

MOM'S GONE MISSING

tiniest of cracks that may let someone in who has wanted to comfort you or seek your shoulder because you understand.

I was introduced to Marty Schreiber by a mutual friend who asked if I would consider sending him my manuscript. Marty wrote with clarity, compassion, and deep honesty in his book *My Two Elaines: Learning, Coping, and Surviving as an Alzheimer's Caregiver*, about his journey with his wife, who suffers from Alzheimer's disease. Marty's book came out at the same time we were relocating Mom. It was an important resource for me and a small group of community members who strove to make Oconomowoc, Wisconsin Dementia Friendly.

Marty's first impression upon reading my manuscript, which he shared with me with characteristic candor, was that this book "has so much pain!" He told me he was looking for tips or suggestions to lift his spirits. He worried that someone who might be hurting might be left feeling even more bereft with this book. I immediately felt horrible! What kind of human must I be to share such pain without a thought to how a reader might feel?

As we talked, he understood that my writing is not a bitter cry seeking pity. Rather, it is a hand extended to those who are in deep distress feeling as though no one understands them. We imagine no one has been quite where we are and that is true.

Our experiences are uniquely ours. However, others have trod similar terrain in all its twists, turns, sudden drops, craggy faces, and tiny pebbles that trip us up. And they have likely also been surprised by the unexpected bursts of sunshine that encourage us onward. Sharing our experiences creates community, connection and a chance for profound healing.

Marty also shared a beautiful personal story about a fall he took, his rehabilitation, his temporary use of a cane and his conclusion that in any difficult personal journey, "You're gonna

SUSAN A. MARSHALL

meet canes.” If you ever have a chance to ask him what that means, please do! (I’m happy to share the meaning, too. Shoot me a note at susan@susanamarshall.com)

I am genuinely excited to have you read this book because I want to encourage you in your darkest moments to stop, rest, regain your footing and set out again. The person you are helping—in great or small ways—needs your positive energy however quiet or tentative it might be. Determining to be happy in your moments with them will bring goodness you cannot fathom.

You, even in your private moments of uncertainty, crankiness, and fatigue, can make a world of difference each time you interact with someone who loves you. Please never forget that. What doesn’t make sense now may turn out to be the most incredible blessing of understanding and peace in the aftermath. Trust that.



MONDAY, JANUARY 4, 2016, A NEW day in a New Year that I was excited to welcome! I had big plans for the year – another book, new client work, and a refreshed sense of determination and optimism that this was going to be one of the really good years. I was going to eat better, sleep on a more regular schedule, and keep a focused, serene mindset to take a step forward each day.

At 7:30 am, the phone rang and I heard my brother’s voice, “Mom’s gone missing.”

What? My ears heard the words, but my mind couldn’t comprehend them. Mom lived in Arizona. My brother was calling from Colorado. I answered my phone in Wisconsin. Stunned, I didn’t say anything for a few seconds, and then heard, “Find her.”

With a click, my world changed in ways I could never have imagined. And certainly would never have asked for.

I sat staring out my second-story window, not having a clue what to do. Moments later, the phone rang again. It was a deputy from the Maricopa County sheriff’s department wanting to know if I knew Mom’s license plate number. A Silver Alert had been issued in the state of Arizona and part of the protocol was locating the vehicle. No, I didn’t know the license plate number. How could I?

“Is there someone you can call to find it?”

I couldn’t think. Dad lived in an Alzheimer’s facility – had for the past two years. How had a Silver Alert come to be issued? Who reported Mom missing? *What was going on?* I was

struggling to process the information and feeling a strong need to clear my mind of fear and confusion in order to decide what to do—from 1900 miles away! The officer encouraged me to get busy and promised to keep me posted on anything they learned.

Despite wanting to stay focused and purposeful, I was flooded with emotion. Why was it up to me to find Mom? Why should my New Year be hijacked by this random event? I hadn't seen Mom since February, nearly a year earlier; brothers were there for Christmas just weeks earlier. Why couldn't they take care of this?

Oh, it was tempting to launch a pity party. And I'd have been justified in doing so!

Where, after all, had my family been when I needed them so many times over the years? Like when I wanted help to attend college but was told there was no money. Or when I was in a violent abusive relationship far from home without a means of escape, begging for someone to come help me. Or when I was a single mom suffering a horrible reaction to a flu shot, lying on my back in a tiny apartment with a toddler to care for. Where was Mom then? Where had my family been when I needed help?

Why should I jump when a brother issued orders? Why should I fly to the rescue after having been left on my own so many times? Why should I care?

This is not about you! my adult mind scolded. *You don't have time to make it about you! This is a serious situation that needs attention right now.*

So, while a flood of unhappy memories churned within me, I simply had to set them aside, clear my head, and decide on a course of action that was very different from the plan I had in mind when I woke up.

MOM'S GONE MISSING

Besides that, I could not ignore a responsibility I had been assigned in 1997. That's when Mom and Dad set up a family estate trust that named me as Mom's Medical Representative. The brother who called had been named successor Medical Representative, which meant that if I was unable to fulfill the role, he was next up. None of this had been executed yet but having it in writing made this my baby.

Thus the year began.



SOME OF MY EARLIEST MEMORIES ARE of living in West Allis, Wisconsin and attending church and school at Mary Queen of Heaven. I had more siblings than I wanted—five in all—and was pressed into baby-sitting duties from an early age. I hated the responsibility, especially with three younger brothers who were little brats. I'd line them up on the couch (we never called it a sofa), stare at them and say, "I hate you," in the ugliest voice a young girl can muster. They laughed.

In second grade, my best friend, Vicki Burch, and I vowed to become nuns when we were old enough. I remember hurling ourselves down the biggest hill in the neighborhood during Holy Week to show Jesus how much we appreciated His suffering and death for us and how eager we were to show our devotion to Him.

I was impressionable. Oversensitive, Mom said.

I resented that judgment, especially since Mom was always harried and often crabby. With six children from toddler through early grade school, I can appreciate now why. I didn't then. She seemed unhappy a lot and I remember thinking, "She never wanted all these kids. Why have them?" Over the years, I came to believe that she and her best friend were engaged in a silent baby derby. Whoever had the most kids won. Trouble was, her best friend was married to an attorney who made a lot of money. They had thirteen children!

Not only did Mom lose the baby derby badly, she ended up with more children than she probably ever wanted. This was naive speculation on my part, of course, but I was convinced it was the truth. Especially since our limited resources forced Mom

MOM'S GONE MISSING

to buy generic foods (no Velveeta cheese or Skippy peanut butter for us!) and gave us the job of stirring yellow food coloring tabs into white globs of oleo margarine.

From early on, I was pseudo-mom for my siblings. It seemed like anytime someone fell off a bike or skinned a knee, I was the one they ran to. Especially the boys. Where was Mom?

As a family we were always busy. We six kids started swim lessons early—Dad never did learn how to swim, and Mom learned as an adult. She harbored a secret fear that one of us would drown one day and the world would judge her a horrible mother. Again, pure speculation on my part, but why else would she put us through weeks of torture in either freezing cold winds or scorching sun? Wisconsin weather can be very fickle, especially in June, when most of our swim lessons started.

No indoor pools for us, either. We were at City Park, which was a man-made lagoon, in full exposure to whatever Mother Nature threw at us. I remember bright purple fingers, chattering teeth, and wicked sunburns. Those were the innocent days before we knew the dangers of unprotected sun exposure. My anxiety was sky-high on testing days. I dreaded having to re-take a level of lessons and would have drowned trying to advance, should it ever come to that.

Fortunately, it never did.

From swim lessons, every one of us graduated to Swim Club, a competitive program run by the city. Mom signed us up when we were eight or nine and there was no dropping out. We swam competitively through our grade school years and for many of us through high school. I was convinced more than once that Mom fed us right before practice with the hope that one of us would convulse during practice and croak.

SUSAN A. MARSHALL

I used to see her fall to her knees next to her bed as we were heading out the door to jump on our bikes for the day's adventure. I fancied that she was praying for God to take one of us home in a way that she could mourn without fear of judgment. More dark speculation on my part. Can you see a pattern developing?

Did these dark thoughts make me a bed wetter? Whether it was these thoughts or something else, I was one for a long time. I remember I would dream I was in the locker room after swim lessons and thought I was on a toilet. When I woke up, the bed was soaked. My older sister who shared the bed grew to hate me. I can appreciate why.

Mom took me to see a child therapist. I wore summer dresses with bright pink and orange polka dots and played with toys I thought were stupid. I silently vowed to tell the woman nothing and to keep my animosity toward Mom to myself. It was nobody's business but my own and had nothing whatsoever to do with wetting the bed. Eventually, I got over that, but Mom spent many hours washing and drying soiled bed sheets. I almost felt sorry for her at times. Well, no, I didn't then. Looking back...

I wrote a lot while I was growing up. It was my way of acknowledging and dealing with emotion. I loved creative writing classes and remember a period of time during which I would ask myself, "What color and texture are you today?" The two I remember most distinctly were brown corduroy and blue gauze. I have no recollection of the reasons why.

One cloudless autumn day, sitting on the swings at Regner Park in West Bend—where we endured swim lessons—I mused in writing about the thick layers of leaves beneath my feet. I wondered how many layers had been laid down over the years

MOM'S GONE MISSING

and how many feet had crushed them. I wondered how many stories had been lived in that park and what my time that day meant. No answers presented themselves.

By this time, Mom had started college. She knew she wanted something more than motherhood and wifery in later years, so she began a long and tedious journey to get a college degree. I was incensed that she could be so selfish, especially since my youngest brother—the true troublemaker of the family—had just started kindergarten. We all had needs for her to meet, I reasoned, and we were not getting the attention or affection we needed.

Case in point: I asked Mom to take an essay I had written for my high school literature class to show her college professor. I was beginning to think seriously about writing as a possible vocation and wanted to know whether I had any ability. Mom was making gravy when I approached her. I set the essay on the counter next to the stove and presented my request. She swept the paper to the floor, saying she had far more to worry about than my writing.

That was the moment I decided she had declared war. All the pent-up questions, all the carefully disguised abandonment, all the rage I felt at being so summarily dismissed took full bloom. Having been raised to be a good girl and wait my turn, I didn't say a word. But I'm certain the writing I did that day and for many days going forward was agitated.

It wasn't until decades later when I read Mom's journals that I had any sense of what she was going through and trying to manage within herself. Never did I pause long enough to realize that I was but one of six needy children always poking at her for attention or answers or help. I consider her damn near saintly now.



DAD WAS ALWAYS A BIG DEAL. Football phenom, stellar student, handsome boy. Mama's boy. His sister adored him and suffered bitter jealousy at the same time. He was revered throughout his hometown as a model athlete first for his high school then for Marquette University. Local newspapers were full of glowing stories about his prowess in sports—football, baseball and basketball. His name is on the Wall of Fame at his high school, which we visited with Mom before Dad died. His celebrity status reached a pinnacle when in 1948, as captain of the Marquette University football team, he presented a football autographed by the entire team to General MacArthur's son. Art was such a fine asset to the community.

We kids never knew this. We only discovered it when after his death we found a scrapbook his mother had kept during those years. Mom never talked about these days, either. I suppose she was too busy raising a family and trying to find some validation for her own hard work.

Dad was playful. He loved Neil Diamond music, dancing—he and Mom won a polka contest somewhere along the way—and laughing with his friends. He was handsome and charming and of course I loved him with a little girl's passion. As a youngster, I couldn't understand why he had gotten mixed up with someone as cold as Mom and I often wondered when he would ditch her for someone nicer. Of course, I never considered what impact that might have on the family.

While my siblings spent hours in the family room watching TV, I loved to sit sideways in a chair in the living room reading. My favorite moment of the day was when Dad would get home

MOM'S GONE MISSING

from work, hang his coat in the closet and flash a smile my way with these words, "There's my little bookworm." I was smitten.

One of Dad's favorite play times involved tickling us kids until we screamed for relief. We'd laugh until we couldn't breathe, then begin to panic and scream for Mom's help. She would stand at the edge of the living room shaking her head. "There's no way I'm getting involved in that!" She'd turn away and we were doomed.

He also loved to scare us at night by playing clock man, a character from Shirley Temple's Storybook, a TV series in the early 1960s. After we were tucked into beds on the second floor of the house, he would turn off all the lights and pound up the stairs one ringing footfall after the other, ticking loudly. We screamed until we were drenched in sweat, even though we knew it was Dad. Such delicious terror.

As we grew up, we learned about Dad's participation in community associations and at church. I was honored to make signs for the Knights of Columbus golf outing Dad helped organize. As Vice President of Personnel, he would get calls at home from striking union members when negotiations failed. We heard the word "scab" used a lot, but we didn't know what it meant and never felt any particular danger. Good thing.

We used to count his mistakes when he read scriptures during Mass. His nickname among his friends was Altar Boy because he never used profanity. Other friends called him St. Francis of Assisi because of his love for wildlife. He refused to hunt because he couldn't bear the thought of shooting Bambi. Dad was a gentle man with strong principles and firm boundaries. We were proud of him but not particularly keen about his rules. I don't think any one of us really knew Dad, but we all felt pretty sure we couldn't be as good as he was. We did try, though.