

My mother has always been a central figure in my life. She can be my biggest cheerleader and my harshest critic—sometimes within the same breath. Never much of an athlete, her intelligence and wit are her hallmarks. She regularly dispenses practical and oftentimes unsolicited advice on any subject under the sun with humor and sarcasm. Even though I can often love her and hate her in the same moment, I always know that she will be there for me. But my mother has a secret, an insidious secret she never planned on revealing. It began a few years ago, when my mom was driving my little sisters and I to swim practice. “Remind me what pool you are at,” she would casually and repeatedly say as we headed towards town. I thought nothing of it, as at times we had three separate practice schedules at as many pools. One of us would shout “Wylie,” “The High School,” or “Whitmore Lake,” without glancing up from the Nintendo DS clutched tightly in our hands. I rolled my eyes thinking, why is she interrupting my fifteen minutes of peace before practice with such a mundane question? Why can’t she keep our schedules straight?

My mother’s mother came to live with us when I was seven. They did not always get along, but I remember hearing “that’s what families do,” and soon she was living with us. She seemed like a normal grandma to my seven year old self, although she occasionally said things that didn’t make sense and talked to dead people. I remember my grandmother reading to me. She would read the same newspaper article over and over again, each time with the inflection of surprise in her voice as if it had just happened. She would take us outside to play and then abruptly forget us; going into the house and leaving me to gather up my two toddler sisters. I just assumed that was normal for adults.

My mother’s sister was a teacher with advanced degrees who was known for her innovative teaching methods with learning disabled children. She was well known and well

loved in the district where she worked, and could not go to the local store without being stopped by a former student eager to update their favorite teacher on their latest accomplishments. She worked tirelessly and endlessly with my youngest sister, who at eighteen months was diagnosed with autism. She performed the miracle of bringing my baby sister out of her world and into ours. She received many a heartfelt letter from parents of her students thanking her for her dedication to their son or daughter. One day, she unexpectedly retired. It surprised me, as she loved her job and seemed far too young to stop working. I asked why. Mom did not elaborate, only tearfully whispering, “Cognitive issues.”

My mother and I spend a lot of time in the car together. It’s a product of living out in the country and the myriad of activities my sisters and I participate in. Recently, the recurring question of “Where am I taking you?” surfaced. Perhaps I had enough—buckling under the weight of a heavy school schedule, practice, work, and life in general. I barked back, in the most surly teenage voice I could summon: “C’mon Mom, we’re going to the high school. What’s wrong with you?” In the quietest voice, she turned to me and choked, “I really don’t remember where I am supposed to be taking you.”

At that moment, I couldn’t breathe. My world collapsed. My head was suddenly flooded with all those signs that I had never pieced together—when she studies the art my little sisters bring home, drinking in the details for a painfully long time in an attempt to burn them into her brain, when she cannot control that slightly elevated panicked pitch when she cannot find her keys. I witnessed the look of sheer terror in her eyes, as she knew I now understood. All at once I realized that her fear had nothing to do with losing her keys, and everything to do with losing herself. Those twelve words told me everything I needed to know about her secret--the horrific secret of inheriting early onset dementia.

That moment in the car marked the beginning of my world becoming unraveled. As this truth began to sink in, I mourned the slow, agonizing, and impending loss of my mother; and then immediately felt guilty for doing so, knowing that my little sisters will not have the precious gift of the extra “good” years that I had with her. I grieved for the carefree teenage world I had known--as with the receipt of this information I was instantly and reluctantly thrust into adulthood. I felt angry and resentful that as the oldest child, I carried the burden of understanding what a heartbreaking and tortuous death sentence my mother had--at least my sisters were too young to comprehend. Once my anger subsided, I again was guilt-ridden and shameful for even having such selfish feelings. I feared what my mother will have to endure. I worried about what would become of our family. I agonized about my dream of college--should I now go locally, and give up those opportunities to far away schools? Should I even go at all? I may now need to help take care of her and my sisters---and I know I need to soak up as much of my mom as I can before she becomes an empty shell.

I now drive myself to school and my activities. Obtaining a driver's license became necessary and was the first adult task I undertook after discovering my mom's dementia. My 2001 minivan has become my therapy room. As I slip into the driver's seat, for a split second, I feel the rush of adrenaline and freedom a teenage driver feels. But that quickly fades, as I remember why I am driving, and the weight of adulthood and responsibility quickly bears down on my shoulders again. There have been many solo drives I have made screaming at the top of my lungs with tears streaming down my cheeks attempting to make sense of my new normal. My teammates no longer ask why I come to practice with a red face. My friends no longer ask me to join them for a casual unplanned outing. My little sisters, left once too many times waiting for their ride, now ask me to cart them to their activities. Keeping track of the

food in the house and driving to the grocery store a couple of times of week has become part of my new adult routine. With the difficulties my mother must now face, these are the realities she does not need to know.

Although I don't have all the answers yet, and I still don't know if I understand the full gravity and impact of my mom's dementia, it was on one of these solo drives that it became crystal clear what I was going to do with my life. I will always be there for my mom, as she has been for me. I will still chase after my dream of college and my love of science--but with a renewed purpose and my mother's blessing. If I can understand the chemistry of dementia, then perhaps I could make a difference and develop methods to halt the chemicals from damaging the brain. I would pursue my love of chemistry and science to help understand and prevent the insidious disease from erasing the very essence of her. I understand it will be a long road to pursue such a passion and likely it will be too late for my family. If I can save someone else from losing themselves to the sinister disease of dementia, it will all be worth it.