

Like Freckles, or Blue Eyes

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When he was in his late 30s, my brother ran five Chicago marathons. On those sunny October mornings, our entire family - our parents, my brother's wife and kids, and us four - got up early, packed up strollers and snacks, bundled up in hats and gloves, and set up camp at the 17.5 mile mark to cheer him on.

Waiting for him, we adults held tightly to steaming cups of coffee while the four littles waved signs and high-fived runners of all ages. We clapped when the elite runners sprinted by, and cheered even harder when we saw someone struggling. We played I-Spy, shouting when one of us saw a runner dressed as Kermit the Frog, Superman, Elvis, even a lobster. To this day, the kids still talk about the guy in the pickle suit.

One year, my mom, hardly an athlete herself, suddenly jumped off the curb and dashed into a group of women dressed in pink T-shirts, all her age and her same physique. She ran right into the middle of their pack and high-fived every single one of them, shouting 'you go girl' the whole time. They laughed and hugged her back, and for that instant, my mother was one of them. She'd found her group, and in that moment, she was running a marathon.

Today my mother spends her days quietly traveling through time. Diagnosed three years ago with early-onset dementia, each day she runs her own

personal marathon, through fog and haze and sharp, clear memory along a path that only she knows.

Most of the time she's here, present; to talk to her, you would never really know that in a few hours she won't remember you at all, much less that you had a lovely chat, let alone what you'd talked about. It won't matter to her, unless she knows it matters to you. If she knows that, if she can sense that in some way she's caused you concern, or frustration, or god forbid, sadness, her easy manner goes away in an instant and she disappears into her own muddled world. So we've learned not to let it matter.

This journey isn't new to us. My mom's father was diagnosed with Alzheimer's disease in his 70s. At the time, I was in college and at 20 wasn't focused on faraway grandparents. They lived in Florida, and the first time I knew something was wrong was when my friend Georgia and I stayed with them over spring break.

On that trip, Georgia and I shared their guest room. The second morning we were there, I woke up to my grandfather screaming at my grandmother.

"I will not allow her to share a bedroom with a man!" he yelled. My grandmother tried to explain that my friend's name was Georgia, not George; I walked into the living room to try to help out.

Grandpa looked straight at me. "Who the hell are you?"

My grandmother lit a cigarette for him and led him out to sit by the pool. I went into her bedroom and called my mother, crying. Something's wrong with Grandpa, I said. Do you know what it is?

She did.

My grandparents lived this way a few months longer, but when he became threatening, my grandparents moved to Lexington, Ky., where my aunt and her family lived. My mother told us very little about what was happening to him. Out of fear or grief or a combination of the two, she didn't talk about it and we didn't ask.

Before he died, my aunt enrolled Grandpa in an Alzheimer's study at the University of Kentucky, where he was poked, prodded and otherwise studied in early attempts to trace the disease through his mind.

My guess is that for my mom, the research part of her father's disease made his death count for more

than just Alzheimer's being something that happened to him. It gave it a name and a reason for it to have happened, but it also put her on notice that this could be her fate, too.

Several years after my grandfather died, my uncle - my mom's older brother - called with the news that he had it too. This time, the decline was faster. As a doctor, my uncle understood the path the disease would likely follow, and rather than fight it he seemed to submit to it. Within a year, he didn't recognize his wife, and shortly after that he died, surrounded by his family but alone in his own world.

His death was harder for my mom, because in watching her brother, her fear sat vigil too. We all felt it. At the funeral, my father grabbed my hand and wouldn't let go. I remember thinking at the time

that it was an odd reaction. I hadn't realized he and my uncle were that close. I understand it better now. My father was looking ahead, and in reaching for my hand, he was reaching for a lifeline.

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My mother's grief over her brother quickly turned to resolve. She vowed to fight what seemed inevitable, and so she did.

My mother owned her own financial planning business, and spent years helping women - elderly, widowed and newly divorced - take charge of their money. The more confused she started to get, the harder she worked for it all make sense - actuarial tables, tax rates, equity distribution, she was all about taking the long view to maximize return. Making the numbers make sense helped her keep order in her mind, and she and her clients did well. For a time.

Janet, her secretary, started noticing things - missed appointments, misplaced papers, phone calls Mom thought she'd returned but actually never made. They agreed to put the day's paperwork in a folder, which Janet and my mother went through together every morning over coffee. Janet took notes and then went back to her office to make the phone calls my mom was sure she'd handled before.

Together, the two of them kept the business going, but it soon became obvious to my parents that it was time to think about doing something else.

They had already decided to sell their house

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and move closer to us; it just happened sooner than anyone thought. My dad, recently retired, made it his job to sort and paint and pack up the last 35 years. At work, Mom referred her clients to another firm. As her workload slowed down, my mother started to talk about what she should do with the business.

For their 50th wedding anniversary, Dad suggested it would be nice to take the same drive through Canada that they'd taken on their honeymoon, and not have to worry about the business. It would, Mom said.

So Janet and the family helped her close up shop. We accepted boxes of client files, some of which are still in our basement. My kids played school with the dry-erase board from her conference room; just the other day I found two bags of post-it notes and several boxes of pens that she'd given me from her supply closet. She and my dad sold her business for nothing but the peace of mind it gave them. On her last day, the people on her floor surprised her with champagne.

And that was it. Without the imposed order of forms and filings, my mother started to drift. She and my dad did go to Canada for two weeks, but after they got back my mother never really returned. Instead, her mind visited what and where and when it wanted. We'd go shopping, and she wouldn't remember what she was shopping for. We brought her to baseball games and gymnastics meets to watch a grandchild, but if my father left her

side she'd start to wring her hands.

Mom became fascinated with Sudoku puzzles. She and my daughter spent hours on the couch, Sara curled into her grandmother, pointing to squares and numbers that helped the puzzles make sense. She survived sepsis from gall bladder surgery, but the medication and what we suspect was a small stroke only took her further away from us.

These days, she only leaves her apartment if she's comfortable with where she's going. My house. My brother's house. Her cottage in Wisconsin. She loves to do jigsaw puzzles at the table my dad set up in front of the picture window in their living room. She watches the news, and Judge Judy. She can still read her mystery novels, but knitting, her favorite hobby, isn't possible anymore. Mostly, she's happy and content, and for that we're thankful. We live in the present with her, knowing that soon we'll lose her to the past.

People often ask if I'm afraid for myself, or for my brother, as we stare down this family curse. The truth is, I am. I lose my keys a lot and forget words. I joke with my husband about dressing me up in goofy outfits when I won't know any better. I also do my share of crossword puzzles, try to

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exercise regularly, and look up advice from experts on how to prevent dementia. I trust, maybe naively, that in my lifetime Alzheimer's will become something chronic but manageable as research and medications evolve.

What I don't believe is that I can spend the time away from my present life - from my husband, my children and, while I still have them, my parents - to worry about what might be my inevitable future. That may be part of my inheritance from my mother, too.

As a young girl in upstate New York, Mom spent her summers canoeing and fishing with her grandparents at their camp in the Adirondak Mountains. There's a picture on her desk of her and her brother when they were about 8 and 9, one sitting at each end of a canoe and both of them smiling so wide you can almost feel the sunshine on their faces and the ice-cold water my mom's touching with her hand.

My mother spends much of her time these days running the film of her life back to that time, when she was young and full of life. My hope is that on this new journey, she'll run straight ahead, braids flying behind her, one foot firmly in front of the other. I hope she'll see us there too, cheering her on.

You go, girl. 🍷