A Journey of Faith

A Mother’s Alzheimer’s, a Son’s Love, and His Search for Answers

Edward Grinnan
I peered out the kitchen window into the moonless winter night, the fresh snow blanketing our yard barely a shadow, and wondered, *Did I remember?*

“Can you see her?” I called upstairs to my wife, Julee.

“No.”

Julee’s vantage point was superior to mine. She was better able to track our golden retriever Gracie’s movements, thanks to the bright green collar light I always turn on before letting her out at night up here in the Berkshire Mountains of Western Massachusetts. But had I? Had I remembered? I always remembered, until recently, it seemed.

“Maybe the battery is dead,” Julee said. No, I’d just replaced that collar light. At least I remembered to do that.

A sickening panic stirred within me. Not out of fear for Gracie. She could handle herself at a lean, fearless seventy-five pounds. Besides, the bears were all asleep for the winter. No, this was fear for myself.

There is a strong history of Alzheimer’s dementia in my family. My mother died of it, as did both her sisters, one of her brothers, who may have fallen victim before a stroke killed him, and my Pop-Pop, the only grandparent alive in my lifetime. My memories of him are fuzzy, and I was too young to understand why he had such trouble remembering my name or whom I belonged to. That memory deficit came in handy, though, when he couldn’t recall if he had given me the customary quarter he always bestowed when I visited and slipped me another one, and sometimes a third. “Did I give you your quarter yet?” he’d ask, and I’d shake my head in mock shyness, thinking it was all a game.

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Among the current generation, some of my older cousins on my mother's side are already showing possible signs. Maybe that’s why I have developed this near phobic reaction to even the most minor misfire of memory. The slightest lapse can set off an inner frenzy of doubt about my own brain health and start me brooding about my family’s history and my own susceptibility. It feels at times as if I am trying to outrun my own shadow.

“There she is!” Julee shouted. “Down by the apple tree.”

A minute later, a cheerful bark at the side door proclaimed that Gracie was ready to be let back in and receive her bedtime treat. Removing her collar, I noticed that the light was indeed off. Julee guessed that Gracie might have extinguished it herself, rolling in the snow, which she enjoys, crazy golden that she is. I wasn’t so sure.

My mother was diagnosed with Alzheimer’s about thirty years ago and died eight years later, several years after her older sisters, Marion and Cass, both died in memory care units. This book, in part, tries to sketch out that journey and the impact the disease has had on her children, we who ultimately became her caregivers: my brother Joe, a lawyer; my sister, Mary Lou, a school psychologist; and my sister-in-law, Toni, also a lawyer and the most practical person I’ve ever known. Then there was me, the youngest, who everyone said was Mom’s favorite, living in New York, which sometimes felt like light-years away from Michigan, where Mom and my siblings lived and took on so much responsibility for her care.

The Alzheimer’s journey is a difficult one millions of families have traveled, filled with pain and anger, empathy and hope, faith and prayer, and even on occasion joy. Ours was no different, as you will learn.
Yet looking at my family only makes me look at myself, at my own complicated relationship with the specter of Alzheimer’s. Watching my mother slip inescapably into dementia, like a schooner slowly disappearing into a fogbank, its sails billowing with an implacable wind, compels me to dwell on my own vulnerability. I understand one’s genetics are a fifty-fifty proposition. Although my father died in his early seventies of heart disease a few years before my mother showed symptoms of dementia, I take so much after my mom, from her grass-green eyes to her eruptive giggle. “You’re just like her,” I’ve always heard. The resemblance is unmistakable.

Wanting to know is the key. Knowing is one thing—you can know something without wanting to know it. Wanting to know is quite another. Wanting to know is what makes us human. Wanting to know the future, wanting to know love, wanting to know ourselves, wanting to know and love God. If there is a way to predict that I, too, will slip into that miasma, do I want to know it? Accept it? Prepare for it? Deny it? Dread it?

I have become convinced we are a country collectively and individually trying to come to grips with a disease that steals our memories, our very ability to think. If the great French philosopher and mathematician René Descartes was correct—we think, therefore we are—Alzheimer’s deprives us of the very faculty that makes us a person, that defines our existence. What other disease does that to the ones we love? To ourselves? What other disease erases who we are?

I thought back to the signposts of my mother’s illness. When did it start? What did we miss? Is there a moment when you know or is it an accretion of incidents? It’s hard to say.
I remembered visiting her once back in Michigan with Julee. Mom was making coffee for our breakfast. She was a whiz at cooking bacon and eggs and toast, and timing it all perfectly. But suddenly Julee shouted. Mom had forgotten to put the carafe under the drip basket and coffee was overflowing all over the place. Mom couldn’t remember what she’d done with the carafe, but I finally found it in a cabinet and got it in place while Julee sopped up the mess. Mom seemed strangely indifferent to the whole episode and Julee reminded me that Mom usually had tea in the morning. We didn’t mention it again, and I hadn’t even thought about until now.

Not very long ago I’d done the exact same thing with our single-cup coffeemaker. I’d put the pod in place and dutifully started the brewing process only to hear Julee yell seconds later, “You forgot the cup!” Admittedly it was Monday morning, but it was to be my second cup of coffee so I had no excuse. And as I tossed and turned, I tried not to recognize the similarities between my slip of memory and my mother’s and having to sop up the mess with paper towels. It had been the start of a busy week. I’d stayed up too late the night before. I had a lot on my mind. Yet still…
Q Why did you write this book?
A A writer is supposed to write about what he knows. And I know about Alzheimer’s because I’ve gone through it with my mother, her sisters, and my grandfather. But it’s not just me. It’s a huge subject. It’s estimated that over 6 million Americans over 65 are living with Alzheimer’s in 2023, two-thirds of whom are women. That overall number could double in the coming decades if no cure is found. But when you consider how a person’s dementia impacts the family, then it’s fair to say millions of people suffer the effects of Alzheimer’s in one way or another. What family’s heart hasn’t been broken? This book promises hope and understanding.

Q What was important for you to share with your readers?
A I would like people to know I care. I know what they’re going through. All journeys end. Life ends. And the Alzheimer’s journey ends. And as in all journeys, there are moments of beauty. There are moments of hope, moments of grace, as well as tears and even laughter. So, in writing this book, I tried to find those relatable moments. My mother’s Alzheimer’s had such an impact on my family. And I wanted to share what we learned with others. Perhaps the most important lesson is… to cherish the time you have with your loved one and be grateful.

Q How did your faith help you in your journey with your mother’s illness?
A For me, the only times of real personal growth have been in the dark times. I don’t grow much when I’m happy. But when I’m
struggling or in pain, that’s when my spiritual growth occurs the most. I wanted to show that not only was this a journey of faith for me, but it was also a journey of growth, of deepening my faith, of deepening my love for my mother, and understanding her love for me, even in the ravages of Alzheimer’s. And I want people to know they’re not alone. It’s why I wove into the book the stories of our Guideposts readers, which I found to be moving and so encouraging to my own faith. My sincerest wish is that this book will encourage you and uplift you in faith.

**Q** What can someone do if they’re concerned they may develop Alzheimer’s?

**A** With my family’s history, I am obsessed with my brain health. I freak out at every little misfire of my memory. Many Guideposts readers have shared the same fear with me. It’s a common one. The number-one fear of folks over 50 is getting dementia or Alzheimer’s. A good part of the book is exploring that fear and how I dealt with it through medical options, such as finding a neurologist and getting brain scans. So many people doubt their faltering memory. I totally identify. I’m praying for you. Live in the day. Let God guide you.

**Q** What can I do to support caregivers?

**A** Caregivers are God’s angels on Earth. Caregiving is both a burden and an act of love. Indeed, it is a burden of love. I think caring for a loved one with Alzheimer’s is the loneliest form of caregiving, as the person we love and who loved us slips slowly away. If you know someone who is a caregiver, make them a meal, do an errand, visit, and, most importantly, pray for them. And remember, God is the ultimate caregiver of us all.
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