

# And That Is That: How My Grandmother's Battle with Dementia Taught Me to Speak Without Words

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# **And That Is That**



## **How My Grandmother's Battle with Dementia Taught Me to Speak Without Words**

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**Advisor: Prof. Paula Mathieu**

**English Department Honors Thesis**

**Submitted: April 8, 2010**

*For the children and grandchildren yet to come*

I would like to acknowledge my advisor, Professor Paula Mathieu, for helping me do justice to the story I needed to tell.

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## Author's Preface

For as long as I have been writing non-fiction, I have been writing about my grandmother. Or, perhaps I should say, I have been *trying* to write about my grandmother. Our relationship was always something I had difficulty putting into words, primarily because even I did not know why we were so close. There were the obvious reasons – she was an extremely involved grandmother, we had similar personalities – but these always fell short of accounting for the full depth of our bond. The best I can do is to say that I always felt, even as a little girl, that my grandmother intimately knew me. It was as if some tiny piece of her had been cut off, reshaped, and reborn two generations later as me. In high school, I began the process of attempting to quantify our relationship in writing – one short piece, entitled *As the Sun Sets*, even won a national award. However, I could not help but feel that such works barely scratched the surface of what I was trying to say, and I found myself drowning (as the aforementioned title may suggest) in sappy clichés about family and the elderly. It was not until my junior year of college, in the months following my grandmother's death, that I was able to recognize the intricacies and implications of my relationship with her. I began to tackle the subject again, but this time, I approached it with a fresh perspective. I was no longer writing from the center of her illness, as I had been with *As the Sun Sets*; instead, I was looking back on it from beyond its ending, finally able to comprehend the full duration of what she had endured. More importantly, I was

no longer writing from a child's perspective, a perspective that contained a narrow understanding of what it meant to be a granddaughter. I now saw myself as more of a peer to my mother and grandmother, as the newest link in a chain of strong women, and as the owner of a shared history. In several ways, then, my view of things began to broaden, and when I let myself loosen the boundaries of what I once thought my grandmother's story was about, the words came freely and naturally.

On one level, the following is the story of my grandmother's battle with a tragic condition known as frontotemporal dementia (FTD). This disease, which manifested itself gradually throughout her 70s, broke down her ability to use and understand language. Unlike Alzheimer's Disease, which is so deeply connected with the word "dementia" in the public consciousness, frontotemporal dementia does not affect memory or the capacity to recognize familiar people and places. Whereas an Alzheimer's sufferer may go off on long-winded (though grammatically and linguistically correct) tangents about events that never happened, someone with FTD knows his or her personal history perfectly well but is incapable of expressing it to others. The journey from thought to speech is interrupted, and words come out jumbled, incorrect, or missing altogether. Because the particular kind of FTD my grandmother suffered from is relatively uncommon, my family found itself moving through uncharted social territory, constantly trying to explain to friends and acquaintances what made our experience different from that of other caretakers. Similarly, when I began

researching other creative nonfiction work on dementia for this project, I came across mounds of Alzheimer's literature, but very little on FTD. This scarcity of existing writing reaffirmed my belief that I possessed a story worth telling.

This work, however, is far more than simply a clinical tale of my grandmother's neurological decline. It is equally, and, perhaps, more importantly, an exploration of memory, both on an individual and generational level. It is a story not only of what my family remembers, but also what we have done with those memories. It was memory – particularly a shared, familial kind of memory – that enabled us to reclaim our relationship with my grandmother from the wreckage of her illness and that gave us a chance to discover a world beyond language.

In order to honor the power of memory in my writing, I chose to express my childhood relationship with my grandmother solely in terms of the memories I have of her. These can be found in italics, scattered throughout the main body of the text, and they refer solely to the years when she showed no signs of illness. They are always in present tense because that is how they offer themselves to me – outside of a greater historical framework, as if they are suddenly occurring again and again each time I recall them. I was extremely conscientious about only choosing moments I genuinely remember, not things I have been told or have seen in photographs. I also tried my best not to romanticize or fictionalize any of these memory snapshots. If, for example, I could not remember what the weather was on a given day, I simply didn't include it. It is my hope that in attempting to stay



so true to how my own memory functions, I have been able to produce something of genuine value and emotional weight.

The issue of time also played a large part in my construction of this narrative. I chose to separate it into two halves largely based on the fact that my family's awareness of time shifted so drastically after my grandmother's diagnosis. Before we knew that the amount of quality time we had with her was going to be limited, we paid little attention to the months and years that were passing by. For this reason, time in the pre-diagnosis period is marked in my memory by events, events that are often hard to pin down to a given date. Changes in my grandmother's behavior are understood temporally in terms of where they occurred in relation to other family milestones: was it before or after Jamie's birth? Before or after my parents' divorce? Post-diagnosis, however, chronicling time became almost an obsession for my family, and, so, I felt it was appropriate to call greater attention to specific dates in that part of my writing. In this way, the reader may share in the sense of urgency that we felt, a sense that turned time into an adversary instead of the benign force it had always been.

Finally, I wrote the following pages as much for my family (both the living and those yet to be born) as for myself. It is a chronicle of an amazing woman with an arguably ordinary life, as seen through the eyes of someone who knew her for a relatively short time, yet felt inexplicably familiar with the workings and motivations of her heart. Imagine if such insights existed for all the relatives lost to us, particularly those we were born too late to meet? It is, perhaps,

a thought powerful enough to encourage even the most reticent hand to pick up a pen or a laptop and give voice to the stories waiting to be told.

## **Introduction**

In the end, the right words remained elusive. Once she was gone, the necessity of preserving and introducing her solely through language proved overwhelming, and, ultimately, impossible. There was the eulogy at the funeral, beautifully written by my uncle, who holds a doctorate in English and whom I consider to be a true master of our language. He stood before the congregation and traced her personal history, outlined her most memorable characteristics, and threw in some humorous anecdotes to lighten the weary silence that seemed to descend with the incense upon our shoulders. Though we smiled and wept and nodded in recognition, and though all that he said was undeniably true, I was struck by the sense that it was not enough. No matter how long he stood at the pulpit, no matter how many friends and acquaintances followed his lead and shared their memories and stories, it would never be enough – would never capture who she was. You could not know her unless you had, in fact, known her. You could not understand her unless you had felt the way a room seemed to grow warmer when she entered, or stood in the wake of perfume that she trailed behind her, or knew the gentle tunes she hummed so well that you heard them like lullabies in your sleep.

Later, the summary of her life was condensed even further when it came time to select words for the grave marker. There was, of course, the standard name and date (Gilda R. Forte, 1927-2008), but one more line remained unfilled, one more line that would let visitors know something about the woman who now

lay beneath the stone. We struggled with different options, finally settling on the popular phrase “Beloved Wife and Mother”, fearing that anything else would leave unsaid what was most important. How do you ever convey the meaning of a life in a handful of words? When I visit her place in the cemetery, sometimes I walk among the neat rows of carefully carved stones, searching for some inkling of the way these people must have been. I stop at a granite marker bearing a male name, close my eyes, and try to imagine the sound of a watch being picked up from the bedside table, the faint scent of cigar smoke lingering on the edge of a collar, the feel of rough hands in the night. But it is impossible; the names all blend together into one faceless identity, and, to me, *this* is the great tragedy of death, this loss of that indescribable essence of a person which exists in the realm beyond language.

And yet, when a loved one is gone, all that remains is the words we have for them; if we want their memory to persist at all, we must make a concession and allow it to move among the confines of human speech. I, therefore, set out to do what I have already acknowledged is impossible: to filter my grandmother’s life through the lens of language. Ironically, it was her own loss of language that allowed us to connect in a way that makes this telling possible. Somehow, I seek to redeem the ability of language to capture and define existence, redeem it from its dishonorable place and inadequate use on the headstones of our ancestors. It will never be enough, but, at least in my family, it can do more than it has up to now. I hope that someday, my children’s children can find in some word or phrase

that I have written an understanding of this remarkable woman, an understanding that will never be uncovered in the cemetery, no matter how many weeds they tear back from the stones.

## PART I: DISSOLUTION



*Posing before Junior Prom in April 2005*

## **Whispers**

*Grammy is making her way up the walkway. I can see the burgundy red hood of her car glistening in the light of the spring afternoon. She opens the door, and I instinctively reach out to hug her. Her arms, browned from weeks of working in the yard, grasp me tightly. I can feel the metal of her rings and bracelets press into my back. On her neck, the image of the Virgin Mary that hangs from a golden chain taps me lightly on the cheek as she bends forward. Her smell, something between vanilla and lavender, tinged with Lysol, envelops me. Over her lips runs a shimmer of mauve lipstick. On her ears, two delicate gold hoops tremble with her excitement. Her blonde hair is soft as it brushes my forehead, and I can feel her smiling. We hug so tightly that it is hard to tell where her body ends and mine begins. Every arrival starts this way, and I think to myself that even if I were blindfolded and made to hug all the people in the world, I would know her touch in an instant.*

The ringing of the telephone punctuated the days of my childhood with the regularity of a clock. In my earliest memories, my mother is on the phone with Grammy, bouncing my brother, Ryan, on her hip and recounting every mundane detail that had occurred since they last spoke. Other times, she had Grammy pressed to her ear as she did laundry, took out the trash, and went on errands - the geographic range of their conversations expanded with advancing technology. Over the years, Ryan and I got bigger and the phones got smaller, but Grammy's

presence on the other end of the line remained unchanged. When I got older and began to sleep late into the morning, the first sound that would reach me through the closed door was my mother's voice, an early indicator that my day would begin with the comforts of normalcy. Occasionally, my mother would turn on the speaker function so she could move about more freely, and Grammy's voice would enter the room like a brisk gust of wind.

Such a constant stream of communication might suggest that these two women were separated by vast distances, sending recipe instructions and neighborhood gossip over hundreds of miles of telephone wire. In reality, however, we lived only fifteen minutes away from one another, nestled in the neighboring Boston suburbs of Wilmington and Woburn, and Grammy visited with a regularity that rivaled her phone calls. I can recall stretches of time when the doorbell would ring every day, and Ryan and I would rush out from our rooms to see Grammy maneuvering her way across the threshold, arms loaded down with shopping bags. She was not a wealthy woman by modern standards, but she rarely came empty-handed. In the summers, she brought sundresses with matching socks and ribbons, or resin lawn statues cast into the shapes of friendly animals. In the winter, she brought Christmas ornaments for the beloved artificial tree we wrangled out of the attic every December. These became more ornate as the years passed, containing sounds, lights, and movements all their own, so that when we turned on the tree each evening, numerous little worlds sprung into life between its branches. Grammy's presence, then, pervaded our home even when



she was not there, and, growing up, it felt more like we were a single family, one that just happened to be spread between two separate homes.

The summer before I turned thirteen, my mother and I began to notice a faint ripple in the otherwise undisturbed surface of their daily conversations. It was so slight that, for the most part, we paid it no mind, but it was there all the same. A noun simply dropped out of each one of their discussions, dropped out to the extent that Grammy would resort to using roundabout descriptions that enabled my mother to fill in the blank for her.

“I went outside this morning to put away the...oh...you know...the...the...oh, *come on*, you know the thing...the thing that’s long and green and you use it to water the flowers? What’s the word...”

“The hose.”

“Yes, that’s it. So, anyway, I picked it up...”

It was a hiccup, an almost imperceptible bump in the road, and my mother often assisted her without even realizing what she was doing. These corrections were masked by what I like to call our family language - that intimate way of speaking the women in my family often use with one another. It is a language in which two speakers appear to mold into one, a language that enables us to complete each other’s sentences and finish one another’s stories before they are even done being told. It makes our dialogue move swiftly, bouncing from one subject to another and from one speaker to another with lightning speed, so that it

seems normal to let someone else's words roll off of your own tongue. It seems normal to be one step ahead of the mother, daughter, or sister you are talking to, because you know their life nearly as well as your own. It seems normal to give what they ask of you because in your conversations you are always giving and taking, giving and taking. In this way, the earliest signifiers of Grammy's disease were lost in the current of our family speech, and life moved on as it always had.

*I am twelve years old. Thanksgiving dinner is over, and we all lay motionless across various pieces of furniture in my uncle's family room. A football game on low volume is playing on the screen. My grandfather faces the T.V. as if he is watching it, but I can tell by the gentle drooping of his head that he is already fast asleep. Uncle Paul strums lightly on his guitar in the corner. My mother whispers to Aunt Martha on the end of the sofa, careful not to wake Jamie, who is not yet a year old. I lay back in a green leather recliner facing the doorway to the kitchen, where I can see Grammy bent over the sink. She wears her signature yellow gloves and flower-printed smock and is scrubbing the pans furiously. This is her contribution to every holiday, and she performs her duty so quickly and effortlessly, we often stand around wondering if we ever ate at all. More often than not, she puts on her smock and begins clearing plates while we are still passing around the potatoes and green beans. A family gathering has not reached its proper conclusion until I have watched her arms moving rhythmically*

*in and out of the sudsy water, a tower of glistening plates and cups teetering at her side.*

*“You can’t get anything done right,” she often moralizes as she tears open a fresh package of Brillo pads, “without a little elbow grease.”*

Even when the loss of nouns from Grammy’s everyday vocabulary began to become more apparent, it was truly hard to conceive that anything could be wrong with her. Though only five feet tall and under 100 pounds, Gilda Forte (or Jill, as she was known to all who loved her) was a physical powerhouse. When my mother and I would go to the mall with her, she walked at such a rapid pace that the two of us had to struggle to keep up. In her 70s, she could have easily passed for a woman fifteen to twenty years younger. At her job as a security monitor at the local elementary school, she spent her days chasing children around the hallways and playground, braving the harsh New England weather with indifference when much younger teachers and aides were reluctant to go outside. As silly as it may sound, our family had an image of Grammy as an indestructible being with endless amounts of energy. I always thought she’d be around to see my own children born, living at least into her 90s and handing out advice to the multiple generations below her – a vision of the quintessential matriarch. When we would pull up to her house for a visit, we would almost always find her in the yard, pulling weeds out of her meticulously groomed flower beds. Or, if it was the middle of winter, she would be cleaning the inside of the

house with an almost religious zeal, one of her signature flowered smocks wrapped around her waist and a mop or a sponge clasped tightly in one hand. In any case, she was completely in control of her body and her home, and we were all in the habit of looking to her for strength, wisdom, and inspiration as we struggled to make sense of our own lives.

Of course, looking back on this time with the advantage of acquired knowledge, there were other signs that indicated something was amiss, signs that we simply attributed to the natural emotional changes inherent in aging. The most striking of these signs was her attitude toward Jamie, my only cousin on my mother's side, born when I was twelve and Ryan was eight. Though she verbally expressed her love for him and her excitement over his birth, she adopted an unspoken hands-off policy which was extremely uncharacteristic of her traditional grandmotherly style; with me and Ryan, she was like a second mother and did not hesitate to care for us as if we were her own children. With Jamie, however, she was noticeably fearful, always passing him off to someone else when he was placed in her arms, and she was nervous when he would cry, uncertain how to soothe him. My mother and I discussed the incongruous nature of her behavior, but we were not particularly alarmed, for she had always been prone to strange moods. She was over 70, after all – was she not entitled to finally assume a more relaxed attitude toward grandparenting? It was an unsettling shift, but not unexplainable. We did not know that, beneath the surface, her brain chemistry was changing in unalterable ways.

## **Declarations**

Two years passed. I somehow made it through the shark-infested waters of middle school with my self-esteem at least partially intact. In the fall of 2001, our eighth-grade class trip to Washington, D.C. was cancelled on account of the World Trade Center attacks, and in its place, the faculty threw together an event called “The New England Adventure”, which essentially was a fancy name for driving us to states and museums most of us had already seen. The Basketball Hall of Fame in Springfield, MA was hardly akin to the Lincoln Memorial, but for me, a girl of fourteen who had never stayed away from home for more than one night, the four day trip was exhilarating. The first night in the hotel, my roommates and I polished off bags of candy and bottles of soda as if we had been deprived of them all our lives. We played Truth or Dare, talked about sex, and generally felt we could manage pretty well on our own. And yet, when it was time for bed, I will always remember that each of us pulled some kind of raggedy stuffed animal from the depths of our suitcases.

In June of the same year, my mother had a hysterectomy. It was the first time in my life that a close family member had to have major surgery, and we were all a bit tense in the days and weeks leading up to the procedure. It went smoothly, however, and my mother even convinced the doctors to let her leave early so that she would be home in time for our last day of school. When Ryan and I found her propped up on the sofa-bed that Monday afternoon, she looked and sounded just like her old self. Despite this reassuring reunion, I was aware of

a vague uneasiness hovering over me, an uneasiness that would continue to linger for weeks after her surgery. I knew its source: a brief phone conversation I had with her not long after she came out of the anesthesia, when her voice was still heavy with morphine. The person on the other end of the line spoke slowly and incoherently, as if her words had to travel through a vat of molasses before reaching my ear. I had to strain to hear her, but I knew why she was calling. I assured her that everything at home was fine. Her voice trailed off until it was entirely inaudible; I don't think we even said good-bye. When I hung up, I was shaken. The person I had spoken to was not my mother, was not anyone I could even equate with the strong-willed, boisterous, insistent person I felt I knew better than anyone else. In our conversation, which seemed to have ended before it began, I had a glimpse of a potential future, a future where the rules of dependence would be reversed, and I would be the one dispensing advice and administering soothing words. I was given a bitter taste of my mother's mortality, and, though she was herself again within a few weeks of the surgery, something inside of me had permanently shifted – ever so slightly – toward adulthood.

As for Grammy, she continued to call and visit with her usual regularity, and her verbal condition remained largely unchanged. It didn't improve by any means, but it didn't seem to be getting worse, either. We continued to fill in the blanks of her sentences, and chalked it up to a bad case of elderly forgetfulness. *Too much time in the yard, we decided, not enough time reading the newspaper.* After all, we reasoned, don't brains need stimulating just as much as muscles do,

particularly in the second half of life? What mattered to us was that she was still the same old Grammy, still wearing her signature smocks, still able to put together a flawless outfit, still ready to offer her practical guidance when we needed it most.

*Her house is filled with plants. They line the windowsill in the dining room, their leaves pruned to perfection. Some are spotted with bright blooms, while others look like they have been yanked from distant climates, such as the cactus that sits in a corner. The plant that most fascinates me is downstairs, however, in the darkness of the basement. It has no flowers - only tall, broad green leaves that reach toward the ceiling. Grammy tells me its shape gives it the name "mother-in-law's tongue", and it needs remarkably little to survive. When my mother was born over forty years ago, she says, it was given to her as a gift. I find it difficult to imagine that this same plant has been growing for so long, and I touch its leaves in disbelief. They are cool and leathery, and I can understand their name, for they do look like silent tongues. I imagine they have seen much, though they say nothing.*

In October of the following year, my family's foundation was violently and unexpectedly shaken to its core. Less than a week after I turned fifteen, I returned from school to find my father home from work and a red suitcase sitting at the top of the stairs. My parents were standing at opposite ends of the room, but

the atmosphere was eerily calm and tinged with finality. I knew what was going on, but I made myself ask anyway. I was still wearing my backpack, and my shoulders began to burn under its weight. My father announced that he was leaving, and in the space of a few breaths he confirmed the fears that had been lurking in my mind since childhood. With the exception of a single argument a few months earlier, there had been no warning signs that I could see, no smashing of dishes or slamming of doors. And yet, I had felt it coming on for years. My parents lived in two separate worlds, despite sharing a home and a bedroom, and my father absented himself on business as frequently as possible. For most of my childhood, my mother had acted as a single parent, though a decade of practice did not make the real thing any less devastating. There had been no divorce on either side of my family for as long as we could remember, and we were now heading into territory that was reserved for the lives of other people, troubled people. In the span of a few hours, my mother was thrown into a social category she had turned her nose up at for years – the separated, the divorced, and the broken.

Later that afternoon, in the bathroom, I scrubbed feverishly in the sink to remove scarlet-colored stains from my jeans. Red: the color of the suitcase, the color of my mother's tear-soaked cheeks in the kitchen, the color of shame. What were the odds that nature would, for the first time and on the same day, force me into both physical and emotional maturity? My mother shook her head when she heard, and told me to use the stash of feminine products under the bathroom sink



that she no longer needed. It may sound strange, but I felt as if I were taking on the part of her that was missing, that I had stepped in to fill a vacancy inside her. Perhaps together, I thought, we would form a single woman of incomparable strength.

Over the course of the next eighteen months, Grammy was indispensable to all of us, but particularly to my mother. Despite her verbal shortcomings, her maternal instincts roared into the foreground and she took control of the situation. My mother needed so much, both financially and emotionally, and, though my grandfather usually made out the checks, Grammy doled out the moral support in abundance. My grandfather was largely overwhelmed by his horror at the situation, but Grammy acted admirably in the midst of our crisis. It was a skill she had learned early in her life, when her own mother was killed in a Boston fire at age 52. The tragic details of this story enabled it to survive for over fifty years, passed down in hushed tones from generation to generation, as if retelling it too loudly could hasten the arrival of a similarly disturbing event. When my mother first told me about the fire, I felt as though I were there on Hanover Street, on March 21, 1947, watching the flames leap out of the garment factory windows. I swore I could see my great-grandmother rushing out with the other women she worked with, a cloth pressed to her mouth to keep the smoke out of her lungs. I felt that I was standing there as she made that fateful decision, the decision to go *back* inside the burning building. And for what? For her wallet, stuffed with photographs of her family and other personal items. For those tangible signifiers

of memory that she could not bear to lose and for which she would give her own life. Grammy was only nineteen when the fire claimed her mother, and she soon had to endure a series of trials: the wake held in her living room, the open casket despite the facial disfiguration, the screaming relatives, the fainting and bewildered older sister. Not long after her mother's death, Grammy also had to accept the new woman in her father's life, a woman he brought back to the United States after a trip to Italy. I cannot ever understand the depths of what she felt or experienced, but I imagine that the steel we recognized in her later was largely set in place during those traumatic years. And, so, she knew what my mother needed from her after my father left; she knew that she needed someone to remind her that we could make it, that we *would* make it, and that things could certainly be much worse. Forever an optimist, her advice was often brief but powerful.

The night before one of my mother's numerous court dates, which always threw her into a fit of anxiety for weeks, she would call Grammy and ask how she was possibly going to make it through the next day, being forced to face my father and listen as he tried to find ways out of the financial obligations he owed us. Grammy would be incredulous.

"What do you mean how are you going to do it? You're going to go in there, and you're not even going to *look* that son-of-a-bitch in the face, and the judge is going to laugh him right out of the courtroom." She would pause for a moment, letting her words sink in. "And that, is that. Now go get some sleep."

Short and simple, but enough. More than enough.

*I am seven years old. We are at my uncle's house – his old house, that is, before the move to Boxford and the transition to perfectly-manicured lawns and sweeping entryways. This house was built by Grammy's father, and she comes every afternoon to clean and let the three dogs outside. On this particular day, I come with her and watch as she moves through the house like a well-oiled machine, leaving the scent of Pine-Sol in her wake. We end in the kitchen, sipping cool water out of tall glasses. My elementary school has closed for the summer, and time seems suspended in perfect stillness, caught somewhere in the light that falls on the kitchen floor. Suddenly, a ripple of motion breaks through the haze. A ladybug scurries toward the edge of the counter, loses its balance on the freshly-cleaned surface, and starts to fall. Before its wings can even open, my hand is cupped and ready, and I feel the lightness of its body drop into my palm. Grammy smiles with approval as I guide it back to safety.*

*"Ladybugs are good luck," she says. "You must never hurt one."*

*I nod and watch it walk in circles on the marble surface. For years afterward, I will carry them outside and set them free.*

The first two years after my father left exist in my memory as if they were a single moment in time, a moment characterized primarily by stress and tension. Though it was a relief to no longer have someone in the family who didn't want to be there, his absence meant that those of us who were left behind had to assume

entirely new domestic roles. In a matter of months, my mother became well-versed in the financial aspect of maintaining a family, something she never had to manage before. I, in turn, became a confidante and sounding board for her as she worked through her new challenges, learning lessons on economic self-sufficiency that most of my peers knew nothing about. Ryan, being the only male left in the house, though only eleven years old, morphed into a kind of handyman, able to fix any small mechanical or structural failure that popped up unexpectedly. My mother spent many evenings on the phone and around the kitchen table with my grandfather and Uncle Paul, her voice unnaturally high as they spoke of mortgages, savings plans, and insurance.

In those turbulent months, it was easy for some of the changes taking place in Grammy to slip through the cracks. Later, when we reflected on the course of her illness, armed with the new medical vocabulary that accompanied a diagnosis, we were able to see what had been lost in the chaos. We could isolate moments from our history and examine them, as if we were scanning a photo album for snapshots that had captured something strange. One of these overlooked (or underestimated) signs was an increasingly fragile emotional state. Grammy had always been sensitive, able to cry with joy or fear at a moment's notice, but her responses to the actions or statements of others became markedly irrational. At times, she would sit at our table and spend much of her visit crying, lamenting over some comment my grandfather had made that she normally would have let pass with nothing more than a sarcastic reply. On the first Thanksgiving

we celebrated without my father, she threw what can best be described as a kind of tantrum. I came down the hall to find her standing in the middle of our living room, pacing back and forth and wiping angry tears from her face. Seeing that she had gotten into one of her states, I quickly veered left through the kitchen doorway to find out what had happened. I could see that the turkey had been moved to the counter, and my mother was bent over it with the concentration of a neurosurgeon.

“Did you know Grammy’s crying in the living room?” I whispered into her hair, which smelled faintly of warm stuffing.

She sighed. “Honestly, I can’t even deal with that right now. She’s upset because I wanted Grampy to help me lift out the turkey instead of her. Now she thinks she’s being left out.”

It was an explanation that might have sufficed for three-year-old Jamie, but before I could question it, Grammy had stormed into the kitchen and was collecting her bag and coat from where they had been dropped only fifteen minutes earlier. “I’m going for a walk,” she sniffed, working her right arm into a puffy sleeve. I glanced at the thermometer on the window. Below freezing. I briefly considered the fact that Grammy was not the type to go for an unplanned walk, no matter what the temperature. What if she didn’t come back? What if, in her distress, she became confused and lost her way?

My mother looked over at her, eyes narrowed with disapproval. “Ma, don’t be ridiculous. Sit down.”

Grammy sniffed louder and zipped herself up defiantly. She picked up her purse and started to head for the door. My mother didn't say anything else – it was clear that she had decided to ignore her, hoping to call her bluff, but I was not so sure she would back down. I intercepted her by the stairs and began to reason with her, knowing it would be difficult for her to contradict me. She always listened to whatever I had to say with a kind of reverence.

“Come on, Grammy, you don't really want to leave. Besides, Paul and Martha should be here any minute, and Jamie is going to want to see you the minute he comes through the door.” It wasn't true, but I was desperate. Her lower lip continued to quiver and she made some small protest, but after a few more moments of persuasion, she pulled off her coat and began to head back to the dinner table. The potential crisis had been avoided, but the extreme vulnerability and childlike anguish written on Grammy's face that afternoon never left me. It felt strange to stand there and speak down to a woman I had always looked up to; it was unnatural to act like I knew so much more than she. How could I, when, compared to her seventy-three years, I had barely lived at all? I remember the expression she wore as she stared out through our front window, her gaze fixed, yet distant, as if something only she could see stood on the lawn, demanding her attention.

It is not that these mood changes went unnoticed by our family, but somehow, they seemed much more acceptable – almost expected – given the heightened emotions we all experienced during those years. We were all prone to

break down unexpectedly, to make a big deal out of little, everyday struggles.

Perhaps these outbursts of Grammy's were simply proof of her human weakness,

proof that she could not always be the pillar of strength we needed her to be.

Perhaps sometimes she needed someone to be strong for *her*.

## Promises

*I am ten years old. The hallway that leads out from the stage is dark and narrow. Small, sweaty bodies push against me, and I am momentarily overwhelmed by the smell of hairspray and cheap make-up. I can see my dance teacher up ahead, herding the mass of sequins and tulle toward the crowd of waiting parents. My heart still races from the thrill of knowing that, only moments before, thousands of eyes had watched me leap and twirl my way across the stage. Suddenly, the hallway widens into a lobby, and I immediately see Grammy's face. She is clutching a stuffed rabbit, its soft white body decked out in frills nearly identical to my own. I know I have countless others at home just like it – only the color of the tutu changes year to year. But it doesn't matter. It doesn't even matter how many steps I forgot, or that my hair began to unravel by the second verse of the song. All that matters is that she is there, as always, holding the only trophy that makes a difference.*

To help my mother out, Grammy volunteered to drive me to my weekly dance lessons in a neighboring town. I had started to dance at the age of three, barely out of diapers, and it ignited a fire in me that kept burning all the way to high school. I was a pointe dancer, a rare specimen in a world of hip-hop, jazz, and contemporary ballet. I loved the discipline it required, the demands it placed on the body to become a piece of art – and more than that, a piece of



conversation. To translate music into tangible beauty, to tell a story by extending one limb and retracting another: that, to me, was the essence of dance.

Over the course of the two years that Grammy drove, I was aware that we talked less and less during the ride there. In the early days, I would fill up the twenty minutes with idle chatter, discussing my classes and friends at school, all the things I was expected to say. As time passed, I subconsciously began to simplify my stories, providing her with an ever-shortening synopsis of my day. I could tell that if my speech was too long-winded, I would lose Grammy's attention, even though the familiar question – "How was school today?" – had been full of its customary eagerness. Eventually, we spoke very little, and, instead, she would hum songs from her youth or melodies of her own creation. The interesting thing about this silence was that it was not at all awkward or uncomfortable, as you might expect it to be. It was not filled with tension over what was not being said. Instead, the space inside the car somehow seemed less empty than before, even though it now contained only her music. Perhaps I did not mind the silence because I have always disliked mindless conversations, ones that end in the same place they began. Sometimes, I think, you can learn more about a person with the radio off and your own voice still, with nothing in the air but the tune of a song that played before you were born.

One particular afternoon in mid-winter, somewhere between 2003 and 2004, I found myself sprawled out on the soft blue fabric of our living room

couch, leafing through the pages of a history textbook. My mother was on the phone with Grammy, her head tilted at a familiar angle as she cradled the receiver between her cheek and shoulder. A mid-year exam loomed ahead of me like an illuminated road sign, but I was unable to focus. Something about the flow of my mother's conversation kept seizing my attention, though I was not sure why. I closed the book and pressed my chin into its cool cover, trying to listen to the rhythm of her speech. My mother's side of the discussion went something like this:

"Oh, you went to the store?"

"...Macy's?"

"You bought some boots."

"Oh, you mean with the fur at the top? Yeah, those are great."

"The place at the end...oh, you stopped at Brigham's?"

"Who?"

"With the brown hair...oh, you saw Marie? What did she say?"

"You mean Jenny? She's applying to college next year."

"Who are you talking about? Oh, Justin. He's still in middle school."

"The things that roll...oh, yes, he skateboards."

This manner of conversation continued for another twenty minutes, with my mother posing and answering her own questions. I suddenly realized what had seemed so strange about the phone call: she was doing nearly all of the talking. She was no longer just filling in a blank every few minutes; she was telling

Grammy's entire story for her, like a translator. For the first time, the magnitude of the linguistic issue our family was facing became clear to me, and I began to wonder how things had possibly gotten to this point. When my mother finally hung up the phone, I called her into the living room and asked if she realized the extent to which she was carrying the conversation. She did not. For a few moments we sat under a heavy silence. As I thought back on phone calls from recent weeks and months, I found it was difficult to distinguish Grammy's voice from our own.

*My mother and I follow Grammy up the stairs toward her kitchen. At the top, she turns to us, hands squarely on her hips. "Now, what can I get for you?"*

*We both immediately visualize the large pepperoni pizza and two loaves of bread we polished off at a nearby restaurant on our way over.*

*My mother shakes her head. "No thanks, Ma, we already ate before we came."*

*Grammy looks stricken for a second, then collects herself. "Ok, I'll make you something. I have deli meat, pasta, hot dogs..."*

*We settle in at the table and exchange smiles, knowing it is useless to protest.*

In March of 2004, I completed the Catholic sacrament of Confirmation at my local church. Behind the rows of flowing red and white gowns, the pews were

packed with adult family members, their faces flushed from the constriction of pants and dresses that resisted the winter's weight gain. Every so often, a child's cry would pierce the air and hundreds of shoulders would tense, all minds wondering if the parent would have enough sense to step outside. My grandfather sat directly behind me, and I could hear the whistling of his hearing aid even through the din of the church. I felt annoyed. It should have been Grammy giving me away – Grammy who was so religious and the closest thing I had to a spiritual guide. But I knew that she could never have stood at the front of the church, feeling the weight of the crowd's eyes on her back and knowing the exit was so far away. She had always been prone to panic attacks and bouts of claustrophobia, but in the years immediately preceding my Confirmation, they had been occurring with greater frequency. For example, when we squeezed eight family members into a limousine for my mother's 40<sup>th</sup> birthday celebration, she cried desperately and begged to be let out. So, on Confirmation day, she stood at the back of the church, where the breeze from the open doors could reach her, and escape, if necessary, was only a few footsteps away.

Later, when the ceremony was over, and my mother and I were finally alone in our kitchen, she could not wait to tell me how proud she was of Grammy. I agreed – she had apparently lasted the entire hour and a half without so much as a nervous wringing of the hands. But there was more to it than that. My father had shown up at the church, slipping in through the back door after the sacrament was already underway. No adults in the family, aside from my mother, had seen him

since his ignominious exit nearly two years before. Grammy caught sight of him immediately; after all, there were not many others standing with her in the back. He was looking at her, his face contorted as if he were about to say something. When my mother heard about the incident, she asked anxiously what Grammy had said, hoping she had not attempted a verbal attack and been embarrassed by her diminished vocabulary.

“Not a damn thing,” Grammy replied, and, as if for emphasis, briskly smoothed out a wrinkle in her pants. She went on to say that she had stared straight ahead for the rest of the service, never once honoring him with so much as a glance.

As I listened to my mother retell this conversation, I was struck by the way Grammy had been able to maintain an aura of strength and defiance with no words at all. In this instant, her language impairment meant nothing, for she still had the power to choose who was worthy of her conversation, however limited it may have been. I could not think of a more significant silence.

*I am nine years old. The car motor hums gently as we drive through residential streets in the half-dusk of early evening, the tires continually pushing the first autumn leaves toward the edge of the road. I lay my head against the cool glass of the window, watching my breath make little circles of fog that I steal back with each intake of air. A stuffed rabbit sits securely clasped in my lap, my fingers melting into the soft fabric that feels so much like fur. I see the white pickets of a*

*fence come into view somewhere up ahead on the right. Grammy's voice suddenly rings out from the passenger seat.*

*"Oh, Debbie, pull over! Look at the horses!"*

*The car slows a bit but stays in the center of the lane.*

*"Ma, I'm not pulling over, we don't even know those people."*

*"Oh, but just for a minute! I want to see them. The people won't even know, and if they do, I'm sure they won't mind."*

*This is typical of Grammy, always stopping in the midst of a drive to caress some unsuspecting animal or admire a particularly stunning garden. My mother relents and pulls over by the fence lining the road. Two chestnut-colored horses stand in the middle of a pasture, their heads bent low and their tails flicking away the gathering swarms of late-summer mosquitoes. They look up when they hear our approach, hesitate a moment, then amble over, probably expecting to find food in our palms. Soon their long necks are bent over the white-washed wood and they are nuzzling Grammy's face and hands, their warm mouths searching for something and their heavy breath becoming more visible in the increasing dark. Muscles ripple beneath their skin as they shift their weight, and I reach out to touch the one closest to me, admiring its beauty. Grammy presses her face into the brown muzzle of the largest horse, her golden curls mixing with the fringes of dark mane, and I can hear her whisper, "Oh, I love you, I love you, I love you" over and over, while the engine of the waiting car drones dully behind us.*

In January of 2005, Grammy called to let us know that she had found it. After a minute or two of guessing, we were able to gather that “it” signified a prom dress she had spotted during a visit to Cohoe’s, a new boutique in Lexington. “Oh, it’s just beautiful! You *have* to come see it tonight,” she gushed, emphasizing that the store had a limited supply of this particular style. My mother pointed out that the prom was three months away, it was sleeting outside, and she needed to go grocery shopping that night. Grammy didn’t seem to hear her. Before I knew it, we were easing our way onto the icy highway, and I could feel my cheeks tingling with a mixture of cold and excitement. If it had been my mother who called and said she had found the perfect prom dress, I probably would have hung up the phone right then and there. Our taste in clothing lay at opposite ends of the fashion spectrum: she gravitated toward anything vibrant, excessively embellished, and, most importantly, comfortable (in my mind, a synonym for unisex), while I was drawn to the delicately feminine – solid colors enhanced with touches of lace and ribbons. Grammy completely shared my stylistic views; I would have trusted her with stocking my entire wardrobe. When I was young, Grammy, my mother, and I would go shopping for back-to-school clothes together, and I viewed Grammy’s presence as a kind of insurance policy against potential fashion emergencies. This is why, when she called to reveal her miraculous find, I immediately trusted her judgment, knowing that even if she had

been presented with a thousand dresses, she would have picked out the one that had my name woven into its seams with invisible thread.

When we met up with Grammy at the boutique, she anxiously bustled ahead of us, apparently fearful that the dress of our dreams had been snatched up in the three hours since she had last been there. I was not so worried, considering that most of the girls I knew hadn't even secured dates yet, never mind figured out what they were going to wear (having a steady boyfriend solved this problem for me). Grammy approached the end of a rack full of indistinguishable pink tulle and threw up her arms in an aspect of triumph. I scrunched the muscles in my face, suddenly uncertain – I couldn't even make out the outline of a dress amid all that material. "It's, you know, what do they call it – a fairy-tale dress," Grammy remarked, and eased the sparkling mass of fabric off the rack. I was caught off-guard, not having planned to wear a ball gown. After all, years of watching juniors and seniors march through flowered archways during the promenade had taught me that the current style was sleek and form-fitting, something that flaunted your curves and made the prom chaperones raise their eyebrows at one another. I couldn't remember anyone bursting through the arch looking like they had just escaped from the recesses of Walt Disney's imagination.

I hesitated. "I don't know...I wasn't really planning on buying a big dress."

Grammy frowned. "Oh, come on, you have to at least try it!"



My mother nodded in agreement, no doubt thrilled by the excessive nature of the gown. I finally agreed to try it on, and the three of us hauled it, Christmas-tree style, into one of the tiny fitting rooms in the back. I slipped into it as best I could, my movements severely limited by the size of the room, and when I turned around to face the mirror, I could feel my breath catch in my throat. It was beautiful. There are really no other words to describe it: simply beautiful. Somehow, what had looked like nothing but a monstrous ballet tutu on the rack actually contained a gorgeous, beaded bodice with a sweetheart neckline that perfectly accentuated my shape. Once again, Grammy had been right. How could she tell? How could she know that the dress would fit my body like a glove?

I took a deep breath and stepped out into the store, where my mother and Grammy were waiting expectantly. They both came at me at once, their voices high with excitement and wobbly with tears. I twirled around amid the displays of winter jackets and scarves, sensing the way the fluorescent lights bounced off the crystals on the dress like thousands of flecks of ice. A woman shopping nearby stopped and smiled at us, calling out that I looked lovely. Grammy thanked her, her eyes radiant and her hands continually running over the fabric of the dress, as if to assure herself that it was real. Finally it occurred to me to wonder how much it cost, and my mother reached for the red price tag dangling under my arm. I saw her eyes go wide. "Almost \$300." I could feel gravity return to the store. This was 2005 P.D (Post Divorce), an era where literally every cent mattered. \$300 for a dress was not only unreasonable, it was irresponsible.

Grammy clicked her tongue as if to cut the discussion short. “Ah-ah. Doesn’t matter. Anything for my Stephe.” This was one of her favorite phrases, and it still slipped out easily, the words managing not to get lost somewhere in her mind. She hugged me, and I felt like crying, knowing she was far from wealthy herself, but also knowing she would spare her last cent for my sake. I felt my heart rate return to normal, and Grammy straightened up and adjusted her purse on her shoulder. “Now, go take that off and we’ll go to the place up front and take the things from the wallet and that will be that.”

I twirled around one more time, watching the store and the dresses and the shoppers dissolve into a single blur of iridescent light, the multiple layers of the skirt twisting around my legs like unseen embraces.

## Warnings

*There is a glass table in her screened-in porch. Always, a cantaloupe sits in the middle. We never eat it, and its perpetual presence fascinates me. I am six or seven, and I run my hands over its strange surface, a surface that reminds me of the coarseness of asphalt. It is real; I can smell the trapped juice, sense the life that is beneath the surface. For a long time, this is what I envision when I think of Grammy's house. Cantaloupe, and the tall cans of Pringles potato chips that wait for me on the counter.*

A few months after the prom dress expedition, my grandfather called our house, audibly shaken. He had just received a call from the owner of a local frame store, where Grammy had gone to have a finished piece of her needlepoint framed. The owner was concerned, explaining that Grammy had been extremely confused when it came time to pay, unable to work out the correct assortment of bills, despite the assistance of the cashier. The man on the phone, having taken down Grammy's number to let her know when the job was finished, felt obligated to call and make sure she had gotten home safely. My grandfather assured him that she had and thanked him for calling. When he confronted Grammy about what happened, she became upset and attempted to blame the cashier at the store.

My mother sighed. "I had a feeling something like this was going to happen. She's starting to get confused."

I was silent for a moment. "Maybe she shouldn't be driving anymore."

We both sat there, letting the implications of this idea sink in. Eventually, the decision to put an end to her driving would be made for us, but at the time of the store owner's phone call, we suddenly felt the weight of her autonomy resting in our hands, and it made us all uneasy.

Grammy never went back to get her needlepoint piece, something she had worked on for the better part of a year and had been immensely proud of. My grandfather picked it up for her and hung it in the living room, but she seemed to hardly notice it. The experience with the cashier had marred her work in some irreparable way. I believe it caused her to see something else when she looked at the carefully woven picture behind the glass, something none of us could fully understand or see for ourselves, because we had not been there with her.

*The phone rings at 9 am. I am four, or eight, or thirteen – it does not matter. A warm, soft voice melts over the telephone wires as it travels from her house to mine. As soon as I say "Hello?", she starts singing:*

*Happy birthday to you,*

*Happy birthday to you,*

*Happy birthday dear Stephie,*

*Happy birthday to you!*

*I normally hate the birthday song and am embarrassed when my classmates screech it at the top of their lungs, but this private rendition is*

*different. It is intimate, spoken right into my ear, a song that seems to have no place anywhere else.*

As 2005 wore on, the phone began to grow silent. Grammy no longer called every morning, and when she did, the conversations were brief. Her attention span started to dwindle, and my mother admitted to me that she censored what stories she chose to share with her, opting only to speak of airy, inconsequential subjects, even if more meaty dramas were unfolding in our household. One day, she told Grammy that she thought she should see a doctor. It was the first time anyone in the family had confronted her with the reality of her situation. At first, she was silent, and then she said, clearly and deliberately, “I know, but I don’t want to deal with that right now. I’ll go when I’m ready.” According to my mother, the resolve in her voice was striking. And so, we backed down, assuming that when she felt her lifestyle was truly being hindered by her loss of speech, she would do something about it. It was as if, with her acknowledgement that she understood her situation, or thought she did, the burden of responsibility shifted slightly off of our own shoulders. After all, she was still very much the headstrong, assertive person she had always been – should the choice of how to deal with her health not have remained her own?

The warning signs that something was very wrong, however, continued to flash before us in ways that became increasingly difficult to ignore. The principal of the elementary school where Grammy worked as a beloved hall monitor

suggested she cut her hours by half, though there were no indications that this was a result of a tightened budget. A longtime neighbor of my grandparents called our house to speak to my mother, expressing her concern that something wasn't right and citing a recent run-in she had with Grammy where conversation was virtually impossible. Later that year, Grammy nearly backed her car into the white picket fence at the end of our driveway. When my mother ran out and told her to put the car in park, Grammy stared back blankly. Further questioning revealed that she had no ability to explain the basic functions of driving, such as which pedal was the gas and which was the brake; her brain was operating on a kind of mechanical memory, telling her where to place her hands and feet and in what order she must move them. When this unconscious pattern of movement was interrupted by my mother, Grammy was thrown into complete confusion. Looking back, it is difficult for me to fully understand why my family was so reluctant to do something about all of these signs. I am ashamed that we closed our eyes and let them pass, as if the problem would somehow fix itself. I recognize that there was a significant period of time when she was driving while cognitively impaired, and that our family was extraordinarily lucky that she never hurt herself, or, God forbid, someone else. At the same time, I remember what it was like to be in the moment of her deepening illness, a moment characterized by various contradictions. Yes, she was confused, but she was also sure about many things, like her personal history, her sense of morality, and the day-to-day routines of her life. Yes, she struggled with words, both written and spoken, but she never had

trouble recognizing us. She never wandered out of the house or exhibited other behaviors associated with Alzheimer's Disease, the only form of dementia we were familiar with. We began to realize we were dealing with a new kind of demon, and we let its unfamiliarity breed apathy, not knowing the horrors it contained.

*I am ten years old. Grammy pulls the car up in front of the dingy strip mall at the edge of her town. It is a rainy day, and I dodge puddles as I run across the parking lot to the cover of the overhanging storefronts. I know where I'm going, and I wait impatiently by the door as Grammy gathers up her purse and locks the car. Her hair is wrapped in a kind of clear plastic to shield it from the rain. When she reaches the curb where I stand, we enter the bookstore together, a little bell tinkling to indicate our arrival. I make a beeline for the back of the store, where I know the children's chapter books are shelved – series like "The Boxcar Children" and "The Baby-Sitter's Club." I search the titles hungrily, running my fingers over the spines until I find one I haven't read. I rush back to meet Grammy by the counter, gripping the book tightly in one hand, already eager to get started. She looks amused and slightly baffled by my excitement, not understanding why, at nine years old, this is the place I choose to go when she offers to buy me anything I want. She pushes the money for the book across the counter and tousles my hair gently. When we leave, I wait for her to open the umbrella before heading back into the rain.*

The turning point came in February of 2006, when, after a period of little communication with Grammy, my grandfather called to tell my mother she had not been eating. He downplayed the severity of the issue, perhaps as a way of maintaining the illusion that he had everything under control, but my mother decided to head over and check out the situation for herself. She came upon a shocking scene: Grammy was bed-ridden and incredibly weak, barely able to raise her head off the pillow. At slightly over five feet tall, she weighed only 84 pounds.

At the hospital, they ran numerous tests, finally settling on a diagnosis of *temporal arteritis*, an inflammation of the blood vessels leading from the neck to the head, often characterized by symptoms such as appetite loss and jaw pain. In the weeks preceding her hospitalization, Grammy had tried to describe this jaw pain to my mother, but her jumbled speech made it difficult to determine exactly what was wrong with her mouth – the way she described her discomfort, it could have been something as simple as having burned her tongue, and it did not seem to warrant a doctor's visit. The physicians acted quickly, performing a brief operation to relieve the pressure in her skull and prescribing medication to keep the swelling from reappearing. But the ordeal was far from over. As Grammy was rehydrated and began to gain her strength back, she grew vocal, and her verbal failings were immediately noted by hospital staff. In a matter of hours, her illness moved from the realm of family matters to the discourse of doctors. It was broken



down, torn apart, and consumed by medical labels, everyone seeking to find answers, to find the one word that characterized all of her symptoms better than any other. She would have to be admitted to the psychiatric unit, we were told; there would have to be extensive diagnostic testing. And, of course, we consented, knowing it was long overdue, grateful that the decision to do something had finally been made for us.

That first night in the hospital will remain burned into all of our memories for years to come, despite the fact that we did not see the worst of what went on with our own eyes. After my mother and grandfather finally went home to get some rest, Grammy panicked, believing she had been abandoned in an unfamiliar place. When we spoke to the nurses over the phone, they told us that she had repeatedly left her bed and run toward the elevators, begging anyone who would listen to take her home. Finally, she was sedated, and when she was moved to another wing for psychiatric testing, the E.R. staff handed my mother a note they had found. It was small, a fragment of white paper covered with mostly illegible red scribbles. Words began to take shape, then stopped abruptly. But there was more than enough there. In the middle was her name, scrawled in her characteristically clear penmanship: *Jill Forte*. Scattered around this was the word *Please*, repeated several times and, at one point, followed by the only phrase on the paper: *I am sooo...* In the upper right corner was my uncle's name, *Paul*. And then, near the top, my mother's name, *Debbie*, appeared, nearly touching the word

*Love*, which had been circled violently with fiery strokes of the pen. This note – this cry for help – was, far as we know, the last time she ever tried to write.

In the weeks that followed, Grammy would undergo countless brain scans, a veritable alphabet soup of acronyms that I cannot even begin to define. All of her thoughts and memories were translated into colors and shades, regions of activity and non-activity. Eventually, a diagnosis emerged: a language-based variant of *frontotemporal dementia*, a form of dementia that differed significantly from Alzheimer's Disease and that was relatively rare for someone of Grammy's age. The demon had been named.

## PART II: RECLAMATION



*Grammy's sister (Dolly), my mother, me, and Grammy in 1989.*

## **Predictions**

*I am seven years old. As soon as our front door closes after Grammy, Ryan and I scramble up the steps and onto the living room couch. We lean over the back and yank aside the blinds, hoping we haven't missed any of the farewell ritual. She looks up and waves from the driveway, then disappears into her tiny car. We watch as it backs slowly onto the street and then proceeds with incomprehensible slowness away from the house. She knows we are watching. Right before the train tracks that run alongside our yard, her car slows almost to a stop. We catch our breath. Suddenly, a thin white hand emerges from the driver's window, waving gently and with the composure of the most polished Miss America.*

*"I see it!" Ryan shrieks, his three-year-old eyes growing impossibly wide. I nod and smile, waving my arms wildly in the window. We love this moment, this distant good-bye, this test to see how far she can drive before her hand blends imperceptibly into the sky.*

Frontotemporal dementia: a disease marked by cell loss and scarring in the frontal and temporal lobes of the brain, eventually progressing to deeper neurologic structures.

Finally, after nearly six years of unanswered, as well as unasked, questions, we had a name. We had resources. We had something we could plug into a Google search, something that could connect us to others going through the

same challenges. The more we learned about the disorder, the more we began to recognize that Grammy's behavioral changes over the years had been caused by more than just advancing age. The initial signs of FTD (as I will refer to her illness from now on) are easily confused with psychiatric conditions like depression or bi-polar disorder. Patients become apathetic and sullen, as well as subject to heightened emotional states. In Grammy's case, her FTD progressed in the left temporal lobe of her brain, something that occurs in only 20% of FTD patients. This meant that her language center was the first to break down, though her memory remained intact for the majority of the disease (UCSF, "What is Frontotemporal Dementia?"). The doctors were quick to distinguish her condition from Alzheimer's, and they pointed out that her language difficulties should not be confused with an inability to understand her circumstances or surroundings. In other words, the old Grammy was still very much present, and it was going to be up to us to discover new ways to connect with her.

Like most progressive neurological disorders, there is no cure for FTD. Grammy was put on several behavioral medications as a way of regulating her moods. She was also put on Aricept, a drug traditionally used for beginning-stage Alzheimer's patients as a way of slowing disease progression, though it seemed we had passed the point where this could have been most effective for her. The average time from initial symptoms to end-stage FTD is eight years. By the time of her diagnosis, we could trace Grammy's symptoms back six years. Suddenly, a clock was ticking over our heads, calling us to attention and forcing on us a kind

of reckoning. We recognized that our old lives with Grammy were already relegated to the past. We now had new roles as caretakers, and the roles of husband, son, daughter, and grand-daughter became secondary in some way. Grammy's memory was not degenerating, but it was also not really expanding. We were images frozen in time for her; she would remember us as we had been before we heard the clock ticking. We could only hope that we had already given her the best of ourselves.

March 4, 2006: Grammy was admitted to the Geriatric Psych ward at Lawrence Memorial Hospital for evaluation and balancing of medications.

The psychiatric facility at Lawrence Memorial Hospital was the first time we saw Grammy placed in a group of her medical peers. Granted, most of the other patients there were not FTD sufferers, but they usually shared similar qualities: a glaze of confusion over the eyes, sudden waves of speech that lacked coherence, an inability to understand why they were really there. In some ways, Grammy seemed so much better than these other patients – in other ways, she seemed much worse. Her body was still recovering from the shock of the artery condition, and the first time I saw her after her admission, she seemed to be only a dim gray shadow of the woman I knew. It was like she was teetering on the edge of existence, and when I hugged her, I pressed so lightly that it was hardly a hug at all. I feared that the slightest touch would shatter her. By the end of her stay,

however, she had regained much of her former vivacity, and the nurses were bringing her sheets and towels to fold, having quickly discovered that she could handle linens with a swiftness and precision that would put most modern housewives to shame.

Despite the kindness of the staff, the atmosphere of the hospital wing was laden with a sense of desolation that made me anxious to leave. Most patients only stayed at the facility temporarily, and so it lacked even the artificial domesticity of a traditional nursing home. Instead, the floors were icy beneath our sneakers, and the rooms gleamed with bleach and sterility. Doctors passed quickly between rooms, ordering tests on tissue-thin sheets of paper. Occasionally a patient hung about at the end of a corridor, regarding us warily as we passed. Once, an elderly lady shuffled up to my mother and peered into her face with a desperate stare.

“I don’t know what I should do now!” she cried in panic. “What should I do?”

My mother, caught off-guard, searched for an answer in the nearly-empty hallway. Her eyes rested on a chair propped against the wall.

“Why don’t you sit down for a little while?” she offered.

The woman’s hardened features collapsed into the looseness of relief. “Ok.” She settled into the chair and closed her eyes. We continued on in search of Grammy.

*Grammy cries out with excitement as she leans over the cardboard box that sits in the middle of our kitchen. Inside, a ball of orange and white fur is curled up on one of Ryan's old baby blankets. We stare at it as if it has fallen from the sky, though, in fact, we adopted him that afternoon from the Humane Society. He is the first cat to grace our household, and we are all a little unsure of what the next step should be. Grammy reaches in to pat him, and he responds to her touch by stretching his little body into a golden arc. She coos at him for a while, then looks up at us with a decided expression. "He will be good," she predicts, "because he has known a hard life." I consider this and recall the early tragedies of her own life, the way she turned the disappointment of losing her mother into her own well of virtue and strength. I also watch the ease with which she handles the kitten, and I remember the story she often tells of how she freed a bumblebee that had become entangled in her Welcome mat. She had used her bare hands to release its feet, and it never once tried to sting her. I am amazed that such extremes of gentleness and strength exist so harmoniously within a single person. I am only thirteen years old, but I can see the woman I want to become.*

March 17, 2006: Grammy came home from Lawrence Memorial Hospital, still weighing 84 pounds.



The month Grammy spent in the hospital marked an important moment in the trajectory of her illness, not only because it provided us with a diagnosis, but also because it seemed to have flipped some neurological switch, a switch that propelled her disease forward with alarming speed. The time spent away from home had jarred her out of the routines that were necessary for her cognitive stability. Even after she came home, she remained very much a patient. My grandfather, a man who, like many others of his generation, had spent his entire life worried only about the financial end of home ownership, found himself learning to wash clothes and clean curtains at the age of 76. The fight over driving privileges that we had anticipated for so long never occurred. By the time Grammy returned from the hospital, she seemed to have lost all interest in driving. Occasionally, walking past the unused car in the driveway, she would pat the hood affectionately with her hand, but nothing else was said. In addition, the Prednisone she had to take for her artery condition caused her to gain a great deal of weight, and we saw a new physical version of Grammy emerge. Her stylish clothes no longer fit, and she began to lose interest in caring for her hair or doing her make-up – changes that, to anyone familiar with Grammy, were more indicative of her decline than anything else.

Not all the changes triggered by her hospital stay were negative, however. The medications she was taking for her emotions made her much more grateful for my grandfather's sacrifices than she had been before. She would often sit at the table while he prepared her meals, remarking that he was so good to her. She

would never have conceded such comments before her illness. Though my grandfather had been a devoted husband, fifty years of marriage had taken a toll on them both. As the decades passed, they had come to recognize only each other's flaws and had turned a blind eye to the benefits of their union. Grammy's newfound gratitude, then, became an unexpected consequence of her disease, a sudden gift that enabled her and my grandfather to ultimately part ways on better terms than they had been in years. Near the end of her life, when nearly all words had forsaken her, she was still able to communicate that she loved him. It was a powerful moment, a moment where the rest of the family members standing in the nursing home room felt quite small, dwarfed by the presence of a history none of us could ever really know.

On June 4, 2006, I graduated as salutatorian of my class. I gave a speech that I had spent days preparing, days in which I had agonized over word choice and sentence structure. In the end, I was proud of what I had created, and my family and friends praised me for my success. Grammy, of course, was not well enough to attend the graduation, though she understood that a significant change was occurring in my life, and she often referred to my leaving for college as "going to that big place." Despite the fact that she was becoming more and more removed from the events of my day-to-day life, I never felt that the essence of my relationship with Grammy – nor its strength – had diminished during her disease. When I would see her, much of our interaction was the same as it had always been. Looking back now, I realize that this was because the bonds we formed in

my childhood were often not dependent on language. Many of Grammy's expressions of love had been tactile: fingers running through my hair and down my back, hugs so tight they nearly took my breath away, kisses that tinged my skin with the burgundy gloss of her lipstick. But there was more to the durability of our relationship than merely a reliance on physical senses. There had always been something between us that defied explanation and that transcended the bonds we shared with other family members. My mother often said we were kindred spirits, incredibly similar despite the fact that the gulf of an entire generation separated our lives. Long before Grammy's illness, I discovered the inadequacies of language, for I could never put into words the unspoken understanding that I felt existed between us. I can't remember ever baring my deepest thoughts or feelings to her in conversation, yet I always knew she understood me better than anyone else, even my mother. For me and Grammy, then, FTD turned out to be a much more forgiving disease than Alzheimer's would have been. I knew that as long as she recognized me – as long as our eyes could lock and our memories recall the feelings that existed between us – nothing that really mattered had been lost. Many afternoons in the final years of her illness were spent sitting side-by-side on a couch, Grammy's still-manicured nails speaking softly into my skin.

Thinking back on 2006, a year when so much was changed and lost for Grammy, I find it interesting to consider all the things she didn't lose. She didn't lose her desire to take care of others, even when she herself required so much

assistance. When we would visit, she would call out, from her place on the couch, a broken version of her familiar command to eat: “Go ahead, look in there...there might be some things...see if you want them.” She didn’t lose her awareness of the small rituals in our family that mattered, such as checking for our cat before opening the front door. Even on her last visits to our house, when she hardly spoke at all, she would pause before the stairs, look around, and ask, “Where...?” My grandfather, on the other hand, who had no cognitive impairment to speak of, would often swing the door open without a thought. It may seem like a small detail, but to us it spoke volumes about Grammy’s level of awareness and the endurance of her reliability, something that all the brain scans and neurological tests in the world wouldn’t pick up on. In addition, Grammy didn’t lose her ability to recognize when she was needed, or her desire to help our family as best she could. She began every visit to our house with the same gesture: handing my mother an envelope of money. Though it had been several years since the divorce, we were still struggling financially, and we likely would have lost our home had it not been for my grandparents’ help. Even after Grammy could no longer write checks herself, she would be restless until my grandfather handed over the envelope, often interrupting his conversations with an exclamation of “Hey!” and a gesture toward his coat pocket. In these ways, Grammy remained a strong presence in our family, and we continued to see her personality break through the shadows of her illness, like the sudden piercing of a lighthouse beam over a darkened sea.

December 8, 2006: Grammy was admitted to Winchester Hospital with a fractured hip after falling in the hallway of her home. She underwent surgery that night.

## Translations

*I am nine years old. The sky is purple, an unnatural color, like the sky in a picture book. The air is punctuated by the sound of a basketball hitting the asphalt. Suddenly, a pause, and then the swoosh of the ball gliding through the net. Ryan jumps up and down in ecstasy, his blond bangs flapping against his forehead.*

*“Do it again, Grammy, do it again!”*

*She laughs and runs after the ball, which has rolled into the yard. When she comes back, she repeats the ritual we have been watching all evening: the ball bouncing under her palm, her legs bending like a ballet dancer’s, her hands suddenly arresting the ball mid-bounce and swinging it between her legs, then tossing it towards the net and sinking it every time. We have never seen anyone throw basketballs like this, especially not grandmothers, and the sight both confounds and exhilarates us. I try out Grammy’s technique and hear my own swoosh of success. I am so excited, I run in circles, my arms extended and my cheeks stinging from the deepening cool.*

*“We should go in,” Grammy says. “It’s getting cold.”*

*We protest. Please, just one more shot for each of us. She agrees. I throw my hair back in triumph, and notice that I can already see the moon sitting like a sideways smile above the houses. I am happy.*

December 13, 2006: Grammy was moved to the rehabilitation section of the Wilmington Health Care Center to learn how to walk again.

The moment Grammy was wheeled into the rehab facility, she began searching for a way out. She would tell nurses, doctors, janitors – anyone who would listen – that she wanted to go home, not understanding that she had a broken hip and had been brought there to facilitate her recovery. When we walked into her room, her eyes would brighten, like the eyes of a prisoner whose chains had just been unfastened, and she would sit up straighter, stating resolutely, “All right, let’s go.” It was the same tone we had heard for years when she would visit our house, the tone that signaled to my grandfather that it was time to pull himself out of the armchair and warm up the car for a few minutes before they left for the night. Always my mother would respond the same way: “Not yet, Ma, in a little while.” She had read somewhere that this was the best way to answer time-centered questions from dementia patients, the assumption being that they cannot follow a more detailed explanation and their lack of comprehension will only stress them further. But I wondered how Grammy’s mind received these vague responses; I thought how awful it must be to constantly await a departure that seems never to come. It was so hard to tell how much she could actually understand, how many coherent thoughts lay in some kind of mental Limbo, trapped somewhere between formation and expression.

The rehab was a disheartening place, despite the kindness of its workers and the festive décor that reminded its residents it was the holidays. Brightly lit Christmas trees stood at either end of the long hallway, and red and green crepe paper was wrapped around the reception desk. A bulletin board on the wall was reminiscent of ones from my kindergarten classroom. Large construction paper letters spelled out the news of the day, along with interchangeable magnets for varying weather conditions and events.

TODAY IS SUNDAY, DECEMBER 31.

IT IS COLD AND SUNNY (smiley face sun)

HAPPY NEW YEAR'S EVE! (party hat magnet)

Beneath the façade of warmth and seasonal goodwill, however, lay a reality that was impossible for a visitor to miss. Most of the residents at the facility were not there for rehabilitation, but were staying indefinitely, and nearly all were elderly. Next to the crepe-paper-covered desk were parked wheelchairs of old men and women who preferred to stay out of their rooms so that they could observe the comings and goings of staff and guests, perhaps waiting to spot a familiar face among the crowd. They often were frighteningly thin and leaned weakly over one arm of their chairs, so that I caught my breath as we approached, part of me wondering whether they had not already passed away. My grandfather would walk quickly past them, anxious to avoid anything that would force him to associate Grammy - with her strong arms and piercing eyes - with these seeming harbingers of death. My mother, however, always stopped on the way to say hello



and ask how their day was, and they would usually break out into grateful smiles and sit up a bit straighter in their chairs, answering her with surprising clarity. The sad reality was, despite their evidently poor physical health, they were better able to converse with us than Grammy was, and it soon became apparent that in many ways, she was in the worst position of anyone in the nursing home.

Her isolation was painfully obvious when we would visit her in the common room where the residents ate their meals and watched T.V. We would often find her sitting at a table by herself, facing a wall or empty space, not looking at anyone or anything in particular. Most of the time, she was sleeping. Other men and women would be talking to one another, even if their conversations made no logical sense, even if they were carrying on completely different conversations at the same time. They, at least, had the illusion of social relations. In their mind, they had friends, even boyfriends and girlfriends. They flirted with nurses, introduced themselves to guests, and told the same tired stories of the past over and over again. But Grammy's dementia robbed her of this, too. The rehab workers didn't deliberately neglect her, but they naturally spent more time with those patients who would willingly interact with them. Grammy spoke most coherently with us, and she viewed the workers as enemies - strangers who were keeping her away from home against her will. When they did get a word out of her, it was, much to our embarrassment, usually in the form of a curse or a spiteful remark, hardly indicative of the demure woman she had always been. Once, my grandfather stopped by our house after a visit, visibly shaken, and

related how she had snarled at a dark-skinned aide, her mind searching for the racial epithet she could not find, until she finally uttered, “You...you....you’re so...*ugly*.” The aide seemed to be aware of the discriminatory undertone of the word, but brushed it aside with tact. Incidents like these repeated themselves every day during the course of her stay, and my mother and Uncle Paul often went shame-faced to meetings with nursing home staff members, who delicately let them know that Grammy was among their most difficult patients. Rehabilitation therapies for her hip were a struggle every morning, they reported, because she did not understand what they were for and resisted the painful process of learning to walk again.

Still, I was grateful for the fact that Grammy had not lost her spirit, even as she lay in an unfamiliar room being poked and prodded by unfamiliar hands. She did not have the quiet resignation I noticed in the other residents, even though she spoke so much less than they did. Instead, my mother often remarked after we had left her, “My God, she looks so *angry*.” Whatever it was – anger, willpower, or sheer physical health – she somehow managed to get through her therapy and learned to walk again, all the while not understanding her injury or actively working toward the goal of recovery.

February 13, 2007: Grammy was released from the rehab and continued to regain her physical strength once she returned home.

*I am six years old. I sit at the immaculate dining room table with my hands folded expectantly in my lap. Grammy is moving briskly around the kitchen, pulling bowls and dishes from the cabinets and containers of ice cream from the fridge. Her sundaes are a work of art consisting of three flavors and covered with warm hot fudge that drips down the insides of the tall glass to form a chocolate glaze. I watch as she sprays whipped cream with one hand and selects a bright red cherry from a gleaming bowl with the other. She sets the finished product in front of me and kisses me firmly on the top of the head. I admire the artistry of the dessert for several seconds before greedily digging in with the spoon, careful not to let a drop of cream or fudge fall on the spotless carpet below.*

*Later, she takes me out to the shed at the back of the yard where my mother played house as a little girl and shows me the stickers she had taped to the walls and ceilings – bright, '70s-colored bubbles with words in them. I stand in the small room that smells of stale air and gasoline and trace the psychedelic constellation, trying to decipher my mother's childhood secrets somewhere in the scattered words. Later still, I go home and try to recreate Grammy's sundae, but though I use the same ingredients, it is different, and I leave the half-eaten dessert in the sink to melt.*

The months she lived at home were characterized by a kind of restless repetition, where each day became nearly indistinguishable from the next. Despite this strangling sameness, this period of time was also marked by an excessive

chronicling of Grammy's every movement. The home health aides who came in several times a day to assist with feeding and personal hygiene were required to make journal entries about their visits. As a result, my family came to possess a binder filled with hundreds of pages mainly describing Grammy's meals and bathroom habits. Although I certainly understand the practical reasons behind this kind of journaling, it had a somewhat eerie, science-experiment feel to it, as if Grammy were merely a laboratory specimen. Nearly every entry, for example, resembles this one, dated September 14, 2007:

*Jill was pretty calm today. She ate a grilled cheese. I had to cut it up and feed her with a fork. She didn't sleep. No bowel movement.*

It was not only the home health aides who left an impersonal record of Grammy's days, however. Once we had received a diagnosis, my family, too, became obsessed with documenting the stages of her illness. My grandfather saved calendars marked up with doctor's appointments and hospital visits, and my mother translated these into lists, organized by date, that provided a detailed description of Grammy's medical history. The overt reason for this was to keep ourselves well-informed; if we ever had to rush to an unfamiliar hospital, we would have all the vital statistics at our fingertips. I suspect, however, that this chronicling also provided a sense of control over the situation, a hope that, perhaps, some breakthrough might be reached through all this writing, something

discovered that no one else had seen. As I sit here now, however, surrounded by the paper record of Grammy's illness, it all seems a bit pointless. There are so many empty words; there is so much language that says nothing at all, that tells us nothing of the person Grammy was. Of course, that was not the scope of these records, nor was it their purpose. But what a tragedy it would be if this were all that remained of her legacy – simply a white binder, stained with food, yet with no trace of life.

One thing you can deduce from the journals, however, is the feeling of entrapment that weighed upon Grammy, a sensation she could not verbalize but which made her constantly aware that there was something she ought to be doing. The nurses often wrote about her “pacing”: she traveled from the living room sofa to the den, from the den to the kitchen, and from the kitchen back to the sofa in a never-ending loop that my grandfather - with his arthritic knees and shaky balance – found exhausting just to watch. I imagine her muscles were responding to the memory of countless mornings of walking the track at Lexington High School, or doing laps around the mall in the hours when most of the merchandise still lay sleepily behind steel caged doors. For nearly eighty years, she had never been a woman who was content with sitting idly in corners, letting the day work out its shadows on the walls of the house. Having to resign herself to a future of passivity and calm without fully comprehending why was, perhaps, the most difficult transition she had to make.

Whenever I was home from school, I would make an effort to accompany my mother over to Grammy's house (I consider it a testament to her matriarchal hold on the family that we always called it "Grammy's house", even when she could no longer care for it - even when she was no longer there). The visits were largely the same, so much so that I have difficulty distinguishing between them in my memory. When we arrived, we would almost always find her at her accustomed place at the dining room table, her hands busily engaged in one thing or another. In the early days it was needlepoint, a longtime favorite pastime of hers, and when the instructions became too difficult to follow, she abandoned them all together and stitched the picture just by looking at the sample on the cover of the package. Somehow, even when she couldn't have verbalized the names of the objects she had brought to life with her spools of thread, she created finished designs as beautiful as those done in her youth. In later months, we would arrive to find her engaged with the children's toys my mother and Uncle Paul had purchased for her in the hopes of encouraging mental stimulation. These were toys geared toward infants, with large, multi-colored rings and shapes that were easy to grasp and organize. On occasions when Jamie would visit - a child whose birth served as a marker for the start of Grammy's decline - it was startling to see how far he had advanced beyond her. It was as if they were two trains passing on the tracks, each heading to a place where the other had already been. When the toys, too, eventually lost their appeal, Grammy would sit at the table folding napkins and cloth placements over and over into perfect squares.

The fact that Grammy was glad to see us was unquestionable. Her joy swam in the unshed tears that kept her eyes gleaming with moisture. It spelled itself out in the pattern of soft red flushes that dotted our arms where her strong fingertips had pressed them. It resonated in the coos and throaty noises she made into our ears when we leaned down to kiss her cheeks. Our arrival freed my grandfather from his duty as watchman, and he often went out to do grocery shopping or visit friends. The sound of the door closing after him seemed to signify that the meeting of some secret society had commenced, and Grammy would get up and shuffle down the hall to her bedroom to retrieve her jewelry box, carrying it as carefully as if she were a young girl bringing an unearthed time capsule up to her tree house. My mother and I would sit down at the table, one on each side of her, and she would begin to go through the jewelry piece by piece. Out came ruby-encrusted rings, strings of pearls, and glittering pins in the shape of elephants and dragonflies. They paraded like sentinels from the past out of the mahogany box that smelled strongly of her perfume, and she laid them on the table, where my mother interpreted their stories easily, having heard them so many times over the years.

Grammy held up a thin gold chain that glinted in the light from the chandelier overhead.

My mother smiled. “Ah, that was the necklace Eddie gave you right before you met Dad. He was hoping to marry you, too.”

Grammy nodded and replied “Oh, yes,” in a voice swollen with certainty. She remembered. She laid the necklace down in its place on the table and took out a ring on which was mounted a diamond heart.

My mother took her cue. “Ma, remember when you bought that one? You passed it for days in the jeweler’s window until you saw some other woman looking at it, and then you snatched it right up.”

Grammy chuckled. “Sure.”

In this way, we traced the events of the past eight decades in a single afternoon. There were stories of anniversary presents and weddings, gifts from friends and impulse purchases, charm bracelets from which gold and silver symbols of lost pets dangled delicately. To an outsider, the lines of sparkling objects on the table were merely an unintelligible collection of things, but to us, they were the hallmarks of a life lived with emotion and vested in beauty. Eventually, the jewelry would return to its box and would be stowed away safely in the closet for the next gathering, and the three of us would move to the living room sofa, with Grammy in the middle. Sometimes my mother would make small-talk about the neighbors or things my brother and I were doing, and Grammy would nod and respond affirmatively with single words or exclamations. Other times, we would just sit in silence for a while, each of us absorbed in our own thoughts. After one such silence, Grammy waved her arm from left to right in a motion that indicated she meant to speak of the three of us. “See this?” she asked with unusual clarity. “This is how it should be. You could come here, and



that would be that.” My mother and I agreed, knowing what she meant – that we Forte women made a family of our own, without a need for men – and also knowing that her desire to rely only on us had been made impossible by the realities of her condition. After another silence of several moments, she turned toward me and ran her thin fingers through my hair. “So pretty,” she remarked softly.

My mother grinned from the other end of the sofa. “Ma, what about me?” She indicated her oversized T-shirt and worn-in jeans which she knew had been a thorn in her mother’s style-conscious side for forty years. Grammy lowered her eyebrows as she looked her over, reached across to pluck a piece of lint from her shoulder, and contemplated for a moment. Finally, she shrugged her shoulders with an air of defeat and replied, “Ehh.” Later that evening, my mother and I laughed all the way home, grateful to be reminded that Grammy’s personality still lay preserved somewhere beneath her nearly silent surface.

When my grandfather returned with armfuls of groceries an hour later, he found the three of us still on the sofa with our arms entangled about one another’s shoulders and the late afternoon sun sending bars of dusty light weaving through our hair. He asked what we had been doing all this time. My mother patted Grammy affectionately on the top of her left leg. “Oh, you know. Just talking.” And it was true.

*I am eight years old. My mother and I climb the hill after Grammy. It runs up along the left side of her house and is steep – so steep that when you sit by the dining room window you can look straight out into a wall of lush grass and soft flowers. Grammy takes easy strides up ahead, her thin back curving gently beneath a cream blouse and her coffee-colored hair looking particularly warm in the mid-afternoon light. My mother and I have more trouble, and at times, I lean so far forward that I can feel the green blades tickling my palms. We mount the crest of the hill and, for a moment, we all stand there, catching our breath. The neighborhood street curves below, and the distant hum of a lawnmower seems to seek us out on the breeze. Grammy turns to face us.*

*“They should be coming any minute now.”*

*My mother looks doubtful. She scans the sky in all directions with a quick turn of her head. “How do you know they are going to pass by the house? They never come this way.”*

*“Because I know. Just wait.” Grammy is defiant and sure of herself, as usual. She places her hands on her hips and confidently surveys the landscape. It is hot, so hot that after only a few minutes of being outside, I can already sense my pale scalp turning pink, and I begin to get antsy. I stray over to another part of the hill to follow a dragonfly whose wings cut the heavy air with ease. Time passes. I sit down, stretching my legs out in front of me and studying the mosaic of bruises and scrapes accumulated over the past summer. I try to recall where each one came from, whether the purple patch on my left knee is from a fall off my bike*

*or a rough afternoon in the pool. It is a game I play with myself when bored. My mother, who has little tolerance for heat, rekindles the debate about whether they are going to come this way or not.*

*Grammy holds firm, but my mother finally announces the idea is ridiculous and starts to head back inside. Before she can take more than two steps forward, however, the sky behind erupts with noise and I instinctively throw my hands over my ears. Three fighter jets – part of the Air Force’s Thunderbirds – race overhead, heralding the start of an air show at a nearby military base. They come so close to the top of the hill that I am momentarily certain my mother is going to be knocked right off her feet. She ducks down in fright and utters some kind of curse that is immediately swallowed up by the engines. By the time the planes have passed, their sound is replaced by Grammy’s laughter, which I soon echo with my own. She is howling, clutching her sides and panting for breath in a way that is intoxicatingly wonderful. My mother, having gotten over her initial horror, joins in on the fun, and our three voices weave in and out of one another as our laughter rises and falls, like the brightly-colored ribbons of a maypole on a warm spring afternoon.*

Perhaps one of the most difficult parts of Grammy’s illness was the eventual loss of her ability to grasp humor. My family has always loved to laugh, and we have undoubtedly used this as a survival mechanism over the years when circumstances have proven to be particularly oppressive. Grammy was no

exception, and her bright, comical laugh often resounds in my memories of her. It was, therefore, incredibly tragic to watch such a witty woman become so stoic and impassive before our eyes, as if she were gradually being turned to stone. Sarcasm was suddenly lost on her, and she could find nothing in words or phrases beyond their surface meaning.

Despite the fact that Grammy could no longer take part in our jokes, my family forged ahead and continued to look for the humor in our situation. Sometimes it was hard to miss, such as the day my mother took Grammy for an eye exam. A young nurse presented Grammy with the L-shaped plastic device patients use at the beginning of every check-up. It has a hole on one end and is meant to be held in front of the face in a way that blocks the vision in the eye not being tested. Grammy had been using this device for decades, but on this particular appointment, she took the tool and promptly stuck her nose through the hole. The sight of Grammy's rather generous Italian nose protruding through the designated eye-hole proved too much for the nurse to handle, and she burst out into hysterics. "I'm sorry," she gasped, "I've just never had someone do that before."

My mother, who by now was wiping the tears of laughter from her own eyes, was hardly offended. "Oh, it's alright," she replied. "Sometimes all you can do is laugh."

As Grammy's vocabulary grew smaller and smaller, our ability to maintain a connection with her became increasingly dependent upon memory. Just as she used her jewelry as a means of sharing her history, my mother and I relied on photographic signifiers as a way of stimulating her mind. On our visits, we would often spread pictures on the dining room table, letting the images do what our words could not. Grammy particularly loved the photographs of me at my junior prom, posing in the pink ball gown she had picked out only two years before. As she stared at the pictures before her, her gaze would become more focused, and her responses would take on a greater coherence. Grammy was, ironically, most present with us when we all stepped into the past together.

Sometimes, when she felt well enough to walk around, she would take us on a tour of the house we knew so well, stopping at bureaus and glass cabinets so we could marvel at the objects that mattered most to her. Once again, my mother would tell the stories these belongings brought to mind, and Grammy would listen and nod with approval. With perfect clarity, her home spoke for her, saying all the things she wanted to say about her life. She had lived in the same house for over fifty years and had poured her heart and soul into its upkeep and beautification. She was as proud of it as if it were another child, and she worried over it with the force of maternal passion. During her time at the nursing home, when she spoke relatively little, she would often look at us anxiously and ask, "How is my house?". When we visited her at home – even if she happened to be sleeping – it was impossible not to be overcome by her presence and personality. Every knick-

knack and glistening countertop told the story of who she had been and who she still was, despite everything. More than any other house I have been in, Grammy's home was a living extension of herself, a book open to a page we could all understand.

The ability to step back in time and live with Grammy within her own past is not something I take for granted, however. It is not something that is easily attained, nor is it something that I believe every family could accomplish. Of course, just about anyone can take out old photographs and stroll down memory lane, but what we did with Grammy goes much deeper than that. My mother, in particular, was drawing from a lifetime of listening. She had spent 45 years being a repository for Grammy's stories, both the small, day-to-day trials and the momentous events of her past. Most importantly, she had not simply let all these words bounce off of her, the way many harried daughters would have; instead, she had stored them away, had made them a part of herself and her own history. When Grammy became ill, my mother was able to give these stories back to her and build a world where we could transcend the boundaries imposed by dementia. In this world, the old Grammy was visible again, if only for moments at a time. We were able to reclaim her from the fog that had enveloped her mind, proving to ourselves that our relationship with her could still be maintained, despite her lack of language. Some of the stories my mother recalled were from Grammy's childhood, stories my uncle and grandfather had never heard but which had been passed down to her during a late-night phone call or a mother-daughter outing.

Knowing these stories was akin to possessing the keys to rusty locks on old doors – when Grammy heard them, her face would light up with a recognition that had become increasingly rare. To this day, my mother often says, “I’m so glad I *listened*”, and, in fact, she is still listening, for she spends many nights on the phone with Grammy’s sister, rooting out the pieces of family history that remain untold.

## Revelations

*I am six years old. It is Easter Sunday, and rain falls from the sky in gray sheets. Grammy steps through the front door, an umbrella in one hand and a familiar white box in the other. Her hair is wrapped in a plastic bag, much like the couch in her living room, and she undoes the covering with an air of triumph, knowing her style has been undisturbed by the weather. Inside the white box are Italian pastries: rum cakes and tiramisu for my parents, two frosted gingerbread men for me and my brother. The gingerbread men are, perhaps, the most longed-for part of every holiday. Their sweetness never diminishes; all that changes from season to season is the face they wear, made of hardened sugar. Today, they are rabbits, covered in swirls of eggshell blue and canary yellow frosting. We save them for later, when we can enjoy them undisturbed. For some reason, however, I can never bring myself to eat the candy face, and so I leave it on the counter, wrapped in paper towel, until my mother throws it away.*

November 22, 2007 (Thanksgiving Day): Grammy experienced a seizure and was immediately taken to Lahey Clinic. Doctors discovered that she needed a pacemaker. She underwent surgery five days later.

By the time Grammy's heart condition was diagnosed, the burden of her care had finally become too much for my grandfather to shoulder on his own. For two years, he had channeled everything he had – physically, emotionally, and



financially – toward the goal of keeping her at home. When it became apparent that she needed twenty-four hour professional monitoring, however, he was left with little choice but to relocate her to a nearby nursing home. This move, we knew, would be her last, and the pressure of time weighed heavily upon us. I frequently found myself thinking back on the days before her illness had become so debilitating. I recalled the night we purchased my prom dress and I was amazed that, in only three short years, the hierarchal structure of my family had shifted so significantly. Yes, we had learned how to connect with Grammy in spite of her dementia, but we could not dispute the fact that our relationship with her had become inverted. She was now the one who was fearful, who needed comfort and reassurance at every turn. We – my mother and I – were now the ones who must provide this stability, who must grab the helm of the family vessel and keep to the course that had been successfully followed for so many decades. As new matriarchs, we did not falter, for we knew what would be required of us in the years to come. After all, we had learned from the best.

December 2, 2007: Grammy was admitted to the Lexington Health Care Center.

In most ways, Lexington Health Care Center was just like the other facilities Grammy had spent time in over the course of her illness. There was the same artificial domesticity, the same scent of bleach and fresh plastic lingering in

the halls, the same friendly, yet tired, expressions on the faces of the workers. The main difference for us was that Grammy was always in bed when we arrived, and, on most occasions, she was asleep. Over the course of the eight months she was there, we spent most of our visits simply sitting beside her bed while she slept, talking about our day and passing around the latest neighborhood gossip. We would bid her hello and good-bye knowing that when she eventually woke she would have no idea we had been there. The first few times, we tried to wake her when we arrived, but her sleep was frighteningly deep, and we soon recognized that it was better to let her be. We could sense her body transitioning.

Other times, however, she knew we were there. Her language skills were completely gone by now, but her ability to recognize us remained, though it was dulled by the haze of medication. It was evident when she would grasp our hands tightly over the rumpled sheets, or when she would stare at one of us and suddenly start crying. These moments, when they came, were extremely difficult. And yet, they were also incredibly profound, for she was telling us so many things without using a single word. She was saying *I love you, good-bye, thank you*; she was saying all of those and none of them at the same time. It was something that can't be reduced to language because it existed outside of it. In those final weeks, I believe we were all transitioning, though only temporarily. We were not aware of it at the time, and I am certain most of my family still does not recognize the gift we received, a gift buried under the tragedy of Grammy's disease. She helped us access a place beyond language, a place where the bonds that bind

relationships are felt, not articulated. Her dementia proved – to me, at least – that a meaningful connection with another human being is ultimately rooted in something quite separate from language, though language may have helped it to grow. It is only in retrospect, looking back on her dementia from the world I now inhabit, that I have come to understand the broader implications of this gift.

Not long after the funeral, my grandfather started bringing Grammy's belongings over to our house. It was a slow process, and it unfolded with a casual air, like the returning of a lost glove to its rightful owner. Each time he came, he would have one or two items with him: photo albums, a hat and scarf, a hand mirror. Occasionally, he would ask us to come over and get something, such as Grammy's vanity table. Over time, the artifacts of Grammy's life began to blend into our own, so that sometimes it was hard to remember whom they originally belonged to. My mother's room, in particular, took on this dualistic nature, for it was interspersed with objects I was accustomed to seeing only in Grammy's bedroom. It was as if they had merged into a single person – a new matriarch to carry my family into the future. My mother not only transformed her living space, but she also began to act like Grammy through subtle shifts in speech patterns and mannerisms. I noticed her repeating some of Grammy's well-worn phrases and bits of advice; in times of decision-making, she would step outside of herself and give counsel from Grammy's point-of-view. I couldn't help but wonder if this was how family lineages truly progress, with death being not so much a loss as a

reassignment of sorts, a unification of the old and the new. I imagined how my future children would see my mother, and how they would not know which parts of her were her own and which were Grammy's. To them, it would not matter, for she would be the new Grammy, a living embodiment of centuries of condensed wisdom and ways of being. As for me, I, too, felt my position shifting in the months after the funeral. I was becoming the new receiver of tales, the new vessel in which the hopes of the preceding generations began to rest.

*I am ten years old. We sit on the couch in my living room, our faces intermittently lit by an old episode of "The Lawrence Welk Show" Grammy found on one of the forgotten television channels. My parents are out for the night, and Ryan is already in bed, so it is just the two of us. We are huddled close together, despite the fact that the night air filtering through the windows is heavy with warmth. I lean my head on her perfumed shoulder, breathing in the distinctive smell that fills her closets and wafts out of her jewelry box even when she isn't there. I feel her perfectly-manicured nails begin to trace circles on my back, and my eyelids droop. She has a gift for touch, for applying just the right amount of pressure to coat the skin with goose-bumps. I curl up closer, watching the light from the T.V. bounce off her rings and the golden image of the Virgin Mary that hangs from her neck. The episode is nearly over; Lawrence is saying his good-byes. The notes of the closing song begin to play, and Grammy's thin chest starts to vibrate softly as she sings along.*

*“And so, ‘til we meet again...*

*Adios*

*Au Revoir*

*Auf Weidersehen”*

*Through half-closed eyes I see her lightly tapping out the tune on the faded carpet.*

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I am 22 years old. It is the beginning of 2010, a new decade, a fresh start. It is a time of technological innovation and rapid communication. Every week, it seems, a new device emerges, some new way of placing as much entertainment as possible into the palms of our hands. Our worlds are simultaneously growing larger and smaller. There is more information at our fingertips than ever before, yet we barely take time to glance up from our screens and take in what is actually happening around us. I am hardly immune from this. If my laptop is out of commission, it genuinely feels like a piece of myself has been torn away. I spend hours having mindless conversations with friends via instant messaging, or reading the mundane updates of acquaintances' lives that stream onto my Facebook Newsfeed every few seconds. My cell phone is constantly lighting up with text messages littered with poor grammar and shortened words. On my floor, sandwiched somewhere between my schoolbooks, are gossip magazines like *People* and *US Weekly*, magazines filled with poorly-written articles about the latest celebrity feuds and break-ups. It is a fast-paced life, undoubtedly, and I am rushing along with its current, trying desperately to establish myself.

For me, 2010 means the end of college. The real world looms close, waving the necessities of career choice and student loan debt in my face. My path will be law school, where I will spend three years learning the intricacies of legal language and interpreting the words of a Constitution written over two hundred years ago. In my mind, the law is one of the few remaining realms of the modern

world where language is still honored. A sense of power accompanies the written word once it is cast into legislation, a power that is reminiscent of a time, centuries ago, when literature could not be mass produced and, consequently, had to be crafted with great thought. And, so, I seek within the law a kind of refuge from the battering and abuse that our language takes in contemporary communication and writing.

Elie Wiesel, the famed author and Holocaust survivor, once characterized the current generation as “buried under an avalanche of words” and “afraid of silence” (Franciosi, 291). I see great truth in this; we fill the air, our internet pages, and our cell phone memories with words, words, words, so many that modern language has become vacuous and misused. Everyone and anyone can be a writer today. For those who doubt this, they need only to walk into a Barnes and Noble and flip through any book outside of the “Classics” section. Or they can simply spend a few moments browsing the web, wading through countless blogs and online journals where people give vent to their frustrations. I do not mean to disparage freedom of speech, or the fact that connecting with others around the world has become so easy. Conversation is healthy, but I fear we have become slaves to it, unreceptive to knowledge that may arrive by other means. Essentially, we have overworked our tongues and diminished our hearing.

Thoughts like these invariably lead me back to the experience of Grammy’s dementia. As tragic as it was, the gift of her illness was that it forced me, as well as others in my family, to shake off the chains that the modern use of

language has imposed upon us. There is more to human relationships than merely talking; there is a way of being with someone else that comes from just feeling alive together and experiencing the same things at the same time – the same slant of the sun through the window, the same taste of spring air on the tongue. A single hug can carry the weight of a thousand e-mails. Of course, the paradox inherent in Grammy's disorder was that our ability to stay close with her after her loss of language was largely predicated on an extensive prior dialogue. If she and my mother had not talked so frequently when she was healthy, perhaps it would not have been so easy to connect with her when she was ill. Because of this, I do not doubt that we need language to build meaningful relationships. What Grammy's dementia proved, however, was that there is a point in such relationships where language becomes superfluous. I have seen this concept embodied in other relationships in my life. When I was eighteen, for example, my boyfriend's father passed away after a lengthy battle with prostate cancer. We had been dating for three years and were incredibly close, yet I did not know what I could possibly say to ease his pain. After the funeral, we returned to his house and retreated to his attic bedroom. For hours, the two of us laid on his bed in the sweltering heat, just holding on to one another. I had never felt closer to him, though we hardly spoke.

In the greatest moments of love I have known in my 22 years, then, there have been no words. I am no philosopher, but it seems to me that we might feel a lot more present in these fast-paced lives of ours if we talked a little bit less and



let ourselves feel a little bit more. It is how Grammy lived her life – she welcomed conversation with open arms, but she also knew how to just *be* with someone else. It is a challenge I pose to my entire generation, and, of course, to myself: may we learn to love language again, yet still have the courage to move beyond it. If we succeed, I believe we will be amazed at the possibilities that lie just beneath our tongues.

And that is that.

## Afterword

After nearly a year of writing, I now find myself at the end of the most rewarding literary journey I have ever taken. I feel fortunate to have had the opportunity to give voice to a story that is rarely told – the story of language-based dementia, so different from Alzheimer’s Disease. My family’s experience was one that was filled with its own unique challenges and solutions, and I hope my telling has done justice to both. Although the actual text of this work did not seem to be the proper place for an in-depth scientific analysis of the frontal lobes of the brain and their degradation, I completed a great deal of research and reading on the subject before actually writing about it. Texts such as *The Executive Brain: Frontal Lobes and the Civilized Mind*, *Dealing with Dementia: A Guide to Alzheimer’s Disease and Other Dementias*, and *Language, Memory, and Aging* provided me with the background information I needed in order to fully comprehend the medical side of my grandmother’s condition. In addition, although I was unsuccessful in locating other memoirs on language-based frontotemporal dementia, reading non-fiction works on Alzheimer’s Disease, such as *The House on Beartown Road: A Memoir of Learning and Forgetting* and *Welcome to the Departure Lounge: Adventures in Mothering Mother*, provided useful stylistic examples of how to tell the story of dementia in a way that is not purely tragic. I consider my work to be the newest link in this chain of women writing about a former generation, though I see the construction of my memoir as wholly unique. It is, undoubtedly, something I am proud to call my own.

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