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Gone

Devan Grote
Gettysburg College
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Author Bio

Devan Grote is a junior English major with a Writing concentration and business minor. Born and raised in southwestern PA, she believes in faith, family, food, and Friday nights with friends - and that a little alliteration and a good book never hurt.

Devan Grote

Gone

Alzheimer's disease slowly eats at the mental and physical abilities of its victims. One day you may realize you've lost your car keys for the third time that week, or you've forgotten the name of a new golf partner from your round that morning. Suddenly, when you sit down to balance your checkbook, the scribbles on the ledger are meaningless. You forget the way to the grocery store that you've frequented for twenty years. On Sunday, you have no recollection of a wedding you attended Saturday, and you search the deepest crevasses of your mind to recall who the child is that is sitting on your lap calling you grandpa, grandma, daddy, or even mommy. Eventually, dates become meaningless. Days become timeless. Faces become nameless. You lose your ability to hold a conversation, navigate through the house you built with your own hands, turn on the stove you've stood at every night, recognize your spouse of fifty years, smile at the group of people surrounding your bed, or even swallow the food they place before you. Finally, you lose your heart. Not the heart you gave away to your husband on your wedding day or the heart you exerted while doing something you loved; that heart faded months ago. You lose the heart that pumps blood through your veins and sustains life. That is when Alzheimer's concludes its course - when the vacant shell that remains finally withers into dust.

According to the Alzheimer's Association's 2009 Facts and Figures publication, for an estimated 5.3 million Americans, Alzheimer's disease is an unfortunate part of life. Yet, this mysterious disease, the most common form of dementia, remains shrouded in improvable theories, dangerous studies, and endless "ifs" and "maybes."

On a dreary, crisp November day, I visited Mount Macrina Manor nursing home, only minutes from my house, in Uniontown, PA. The Catholic based facility contains 120 patients in need of professional care for various health issues, including Alzheimer's. Mount Macrina houses two highly developed Alzheimer's units, and is familiar to me since I spent many of my fall afternoons last year sitting on its front porch with my grandfather, a past patient.

Accompanying me on the visit was Michelle Hauser, the former Nurse Manager of the Alzheimer's units at Mount Macrina. Hauser wore a purple corduroy jacket and dark washed jeans as we walked through

the front doors. Her husky stature stood a head taller than my own, her deep burgundy hair bounced in a perfectly styled bob, and her vivacious voice carried through the halls letting ex-co-workers and patients know of her presence immediately. Though she stepped down from her position for personal reasons, there was no denying Hauser was the ideal tour guide. It seemed that she knew each patient's name and life story, as if her mind compensated for the loss of each of theirs.

Our first stop was the Hearth 1 unit; the locked-down Alzheimer's ward, which houses patients who are still mobile, and therefore considered likely escape risks. Opposed to the Hearth 1 unit, the Hearth 2 unit upstairs houses patients who are in more advanced stages of Alzheimer's disease, and who are in no way risks for escaping since they are immobile and often unresponsive. But in Hearth 1, many tend to wander off without the knowledge of where they are heading or why, only to be stopped by the keypad secured doors. The few nuns who lived in Hearth 1 seemed to be the exceptions, having well-conditioned plots behind their getaways. As Hauser keyed in the security combination to open the doors, she recalled how they would dress in their classic black and white habits and wait for a naive visitor to pass by their room.

"They would simply ask the visitor to help them with the door or onto the elevator. Who's not going to listen to a nun? We always had to keep an eye on them," she said as the doors swung open.

As we walked slowly through the homey hallways lined with rich carpeting, soft lighting, and warm colors, Hauser explained the philosophy that embodied the unit.

"We use the Woodside Philosophy, which allows patients to be as independent as possible. If they want to sleep during the day and walk around at night, wondering in and out of rooms, they can. Even if they decide to sleep in someone else's bed, we'll try to redirect them, but the last thing we want to do is bring them back to reality. Our main concern is safety, but we also work to keep the agitation level down," Hauser explained.

Perhaps the most devastating phase of Alzheimer's is the early stages, when you can see your mind slowly leaving your body. You have no control over your own deterioration, but you get a front seat pass to watch the process every minute of the day. Maybe a sense of relief, or else a lack of despair, arrives when the disease progresses to a point that alters reality. You no longer have to watch as your memories walk out on you, taking your independence, intellect, and identity along with them. You can't grieve for what you've lost, if you don't know who you are. Worse than living in a world without purpose, without time, without memories or love, would be the act of re-enter the plentiful life you once lived and realizing, for just a moment, that you are no longer a coherent part of it.

Avoiding reality and minimizing agitation levels is especially important for those afflicted by Sundowner's Syndrome. From dinnertime until around nine o'clock, "the Sundowners" face an increased amount of confusion and agitation. Though scientists have yet to understand the causes of Sundowner's Syndrome, popular theories suggest it could result from sensory stimulation overload and fatigue that comes with the end of the day or a possible hormonal imbalance that occurs at night.

In between Hauser's conversations with staff members on duty, she told me stories of just how far the nurses go to play along with the patients' distorted worlds. For the woman who worked in a clothing store her whole life, they supplied catalogues, hangers, and sales receipts. For the aging hairdresser, they gathered varieties of wigs and beauty supplies. Then there was Joe.

A life-long coal miner in the local mines, the only memory that remained engrained in Joe's deteriorating mind was his countless years spent working the night shift. Each evening, while most other patients lay in bed, Joe woke up and began his day just as he always had. Before leaving his room, he strapped on his black leather miner's belt and adjusted his heavy, nicked-up miner's helmet, both of which the nurses provided. Before officially beginning his nightshift, Joe stopped by the nurse's station to pick up his lunch bucket, packed every evening by the staff.

During the proceeding night and early morning hours, Joe roamed the dimmed hallways as he would the tunnels of an abandoned mineshaft. With his cognitive abilities so depleted, yet small hints of his past life so vivid, he spent the time eating lunch from his bucket and relieving himself behind an artificial tree tucked in the corner.

The nurses did nothing more than kept watch of his feeble step and made sure there was a small garbage can behind that particular artificial tree. As the first signs of sun lightened the sky, Joe was content; he was peaceful in doing what he knew. As other patients began another timeless day, Joe returned to his room, removed his helmet and belt, and ended yet another nightshift.

I strayed from the congregation that Hauser attracted at the nurses' station and walked down the hall of the Hearth 1 Ward alone. The wooden framed shadow boxes mounted just below each patient's name on the outside of the rooms attracted my attention. Katharine's held a picture of herself in a wheelchair playing bingo and another of her grandkids surrounding her as she lay in bed. Edith's had small ceramic angels throughout the box, along with a picture of her and her husband in the nursing home's living room. One after another, the shadow boxes contained the lives of the names they accompanied, as if they somehow trapped each patient's fleeting memories in a polished, glass-incased box just as Hauser trapped them in her mind.

Pearl's box was scattered with black and white photographs. In one, she stood in an open field with tall stocks of wheat blowing to the left in perfect unison. She had a sundress on and a young man with suspenders wrapped around her.

Catching up with me from behind, Hauser noticed me staring inside each box. "Aren't they wonderful? They help the patients find their rooms on their own," she remarked. "When they forget their name or how to read it, all they have to do is look for their picture. We found that Pearl only recognizes herself in the past, so we used photos from her younger days."

Curiously enough, as we walked past each room, I noticed not a soul was inside. As we rounded the corner at the end of the hall, the living area came into view. Eighteen women and two men sat among the scattered couches and chairs as a small grey haired man with a red bow tie set up his keyboard.

"Oh, this is great," Hauser said quietly now that the residents surrounded us. "Some days they don't even know their names, but when this man comes in and plays polkas, you can see them mouthing the words and singing along. They remember lyrics and even prayers if they learned them when they were young."

It was true. As the one-man-band began his show, the previously silent and empty figures gently tapped their feet, bobbed their heads, or sang along with every other word of "Roll Out the Barrel." One of the most astounding effects in many cases of Alzheimer's disease is the ability to retain sporadic memories from the past, while being unable to form new ones. Deterioration of brain cells begins in the hippocampus, where new memories form, but cells in other parts of the brain that store old memories could remain untouched for years.

Due to autopsies conducted on the brains of Alzheimer's patients, scientists have been able to analyze the overall damage. Each of the 100 billion nerve cells in the brain, commonly known as neurons, contain long branching arms, which connect with each other like a canopy of limbs on the ceiling of a forest. Each connection, called a synapse, makes it possible for information to travel throughout the brain. The 100 trillion synapses in the human mind allow people to do everything from blinking their eyes to learning a foreign language. With Alzheimer's patients, the number of synapses slowly declines, causing a failure in transferring information, and eventually the death of neurons.

While all humans experience a loss of neurons as they grow older - often the cause of a grandmother's relentless disappearing glasses - Alzheimer's patients lose an excessive amount. Though the deterioration begins in the hippocampus, the death of brain cells spreads to other parts of the brain, leading to impairments such as loss of speech, depth perception, or temperature judgment. The course and speed in which the

disease travels after leaving the hippocampus, however, is different for each victim. Some may lose their ability to navigate through a room, while others need to constantly pace. Some may live with Alzheimer's for twenty years, while others pass away within three (Alzheimer's Association).

Though scientists understand most of the fundamentals of Alzheimer's disease, now the sixth leading cause of death in America, they are missing the key to advancement: the cause of the deterioration of neurons (2009 Alzheimer's Disease Facts and Figures).

I noticed immediately as I entered the living room full of patients that the overwhelming majority were women. Studies, however, proved that gender is not a factor. The fact that women live longer than men is the sole contributor to the disproportion.

In most cases, two men surrounded by a room full of women would have considered themselves lucky or else ran in terror, but neither moved from their seats. It was clear by the lack of conversation and simply the hollow look in their eyes that they didn't know anyone else in the room. Though most patients remain in the ward for years and see each other every day, their short-term memory, in charge of remembering new faces, failed long ago.

Almost as perplexing as the disease itself, I wondered what drove the nurses in the ward to continue coming to work every day. The patients would never remember their good deeds from one day to the next. For years, they cared for the same people; growing to know their families, their unique habits, their mood swings, and their remaining hints of joy. Yet, the relationship, no matter how strong, would always be one-sided. The nurses very rarely became anything more than strangers. There was no hope of reversing someone's diagnosis, or even helping them return home after time. So, what was it that kept them going? When I posed the question to Hauser, there was no hesitation. "I loved them. They were such productive people at one point, and they constantly made me laugh. All you could do was smile and laugh."

Silver walkers scattered the living room like vehicles in a used car lot. The woman they called "Mama," whose only memory was breast-feeding her children, sat rocking a baby doll against her chest. It wasn't until I spotted a silent woman seated across the room that I softened my gaze. Legs neatly crossed, she wore matching pastel pants and a sweater set with embroidered flowers, something only the kindest of grandmothers could wear. Her perfectly primped perm was rounded and grayed like the silver frames of her thin glasses. Her body appeared able and her face displayed the wrinkles of a woman just entering her seventies; one that should be cooking at the church fish fry, playing bridge with the ladies, or preparing a Sunday meal for her family. But she was empty. Through the lens of her glasses, her eyes gave way to a deep void.

Where do these people go? They no longer live inside of themselves. They leave their bodies, the way a snail leaves a conch shell. Do they live their days lost in the haze of a never-ending cloud, with one foot in this world and one foot in another, in a state of coma, unaware of their own body's movement? Maybe God prematurely carries their minds to heaven, where all worries and illness vanish, and allows them to watch from above until their bodies break down and eventually join them in paradise. That's what I choose to believe for my own sake.

Though researchers continue to study possible causes ranging from head trauma to a lack of education, in truth, the only known risk factors are heredity and old age. Most cases develop in people over the age of 65; however, five percent of victims develop a rare hereditary form called "younger-onset" Alzheimer's, which can afflict a person as young as thirty years old. Though researchers know the gene APOE-e4 increases the risk of "younger-onset" Alzheimer's, they are clueless as to ways to alleviate the danger. The current state of Alzheimer's research seems to be nothing more than medical experts watching a burning building collapse, without the means or knowledge to stop it (Alzheimer's Association).

Due to the second blatant risk factor, old age, advancing medicine in the past few decades has proven to be bittersweet. While leading causes of death, such as heart disease, breast cancer, prostate cancer, and stroke decreased between the years of 2000 and 2005, Alzheimer's disease increased by forty percent (2009 Alzheimer's Disease Facts and Figures). With each passing year beyond the age of 65, the risk of developing the disease skyrockets. If I were given the ultimatum, though no one ever is, to live to an old age or preserve my knowledge, my memories, and my sense of self, then let me die early. Let me die fully intact, with both feet in this world and ready to enter the next. I tense with fear at the thought that I could wake one day to realize that my forgetfulness is larger than the everyday mistake; that before long I'll be nothing but a hollow structure of skin and bones, no longer myself, yet for some dismal reason, still alive.

As people continue to live longer lives and advancements in Alzheimer's research remain nonexistent, alarming predictions appear. With the aging of the 78 million baby boomers in America, Alzheimer's disease promises to reach an all time high. Over 10 million baby boomers can expect to develop Alzheimer's, tripling the current number of victims (2009 Alzheimer's Disease Facts and Figures).

The frightening facts show why in the last decade clinical studies and research funding have increased rapidly. Not only has the growing support come from threatening statistics, but also from the growing number of people affected indirectly, yet very deeply, by the disease. For each of the millions of sufferers of Alzheimer's disease, a family watches the slow death of their loved one's body and spirit.

Two summers ago, my grandpa and I sat quietly on the brown flowered couch in my grandparents' living room. We were silent but provided needed company for each other. There was nothing to talk about, or perhaps nothing he could talk about. He was always a quiet man, who taught me to refrain from meaningless speech, but when he talked, and especially when he yelled, people listened. Lately though, Alzheimer's had stolen his words. Harder to handle than the knowledge that I would never hold a conversation with him again was the look on his face when he began a sentence only to realize he no longer knew the words to complete it.

"Where...where's my...my...my...where's my..." He'd drop his eyes and shake his head in fear and defeat. Whatever he was looking for wasn't worth the struggle. He was too proud of a man to accept the helplessness that had slowly overtaken his mind in the last three years.

Every so often, he would turn his head towards mine and smile, but his eyes were different – they were vacant. They searched my face, gently, calmly.

"Who are you?" he'd ask, not coarsely, simply curiously.

"I'm your granddaughter, Pap." And I'd remind myself to smile.

Where did you go? I'm the one you took for rides on the tractors every day after lunch. I'm the one you used to sing to if no one else was around. I'm the one you always yelled at for running barefoot around the yard.

"You're...my granddaughter?" A smile would come over his face as he'd stand and kiss me on the cheek. I could feel his rough, boney hands, deformed from seventy years of farming and countless year of arthritis, touch the ridge of my back. His thin, straight hair, which always assured me of blood relations to my curly haired family, would touch my equally straight bangs. We'd sit back down, and he'd continue to stare at me with the same gaze I imagined he gave me when he held me in the hospital after I was born. Twenty years later, he saw his granddaughter, once again, for the first time.

Little did I know that within a month, my Pap would walk through the doors of Mount Macrina Manor with his suitcase in hand. Within three weeks, he'd be bedridden and forget how to swallow his food. Then, three days later, only 72 hours, Alzheimer's would finish its course. It would take his heart, not the one that belonged to my grandma for the last 62 years (she still has that one), but the one that keeps him from waking up at four o'clock every morning to work in his fields; the one that keeps me from kissing him on the cheek every time I say goodbye. Like everything else, it was gone.