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## When the Last Light Fades

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## **When the Last Light Fades**

*Kaitlyn Graham*

*Step One: Patient will experience an increased desire to sleep.*

Driving down back country roads in a '99 Ford Contour, my imagination runs wild. I roll down my window with the gray crank lever, stick my hand out of the window, and wave my arm up and down through the wind like a scarlet cardinal bird, swooping and diving against the whistling wind. I glance at my brother, Matthew, as he sits next to me, head buried in his baby blue Nintendo Gameboy as his thumbs glide rapidly across the keys, too busy in his games to focus on the outside world around him. My eyes flicker back to the outside. There is something about the air in the country that just smells different. Everything is just better in the country. Maybe it is the mixture of fertilizer and dirt that keeps my imagination entertained. Maybe it is the lack of pollution and factory emissions that are always present in the city air. Whatever it is doesn't matter, though. My imagination runs wild in the car. I am in a highspeed car pursuit, running away from the evil, scary monster that is chasing me. It is my job to slay the dangerous pterodactyl-like creature that jumped from house to house following us before we arrive at my great grandparents. Other times, I am the lead singer in a rock band, throwing a concert on a float in a parade, my braided pigtails slapping me across the face as I throw my head back and forth.

Saturdays were my favorite days growing up as a child. Every week was like clockwork, my family- from my great grandma down- gathered at my great grandparents' house for dinner. There wasn't a holiday that could outweigh the excitement I felt each Saturday. They lived in the middle of nowhere, Ohio, where the only things surrounding their house were cornfields- or soybeans, depending on what the farmers planted that year- and farm animals.

During the summers, my great grandpa Clarence and I would take walks along the property. Some days we would trek out to the three apple trees far away from the house. During the fall, we would pick apples for my

great grandma, and she would make us fried apples to eat after we were finished playing outside. I would help him in the garden, my bare feet squishing in the mud as I watered the plants. My grandmother would laugh as she locked the screen door, pointing to the water hose and tell me the door would be unlocked after I rinsed all of the mud off. After we finished in the garden, we would go to the property line where the neighbor's wire gate began. They had donkeys and cows, and they even allowed me to pet and name them like they were mine. And in my head, they were. The cows weren't as friendly as the donkeys, but they let me pet them, nonetheless. The donkeys would come running every time we walked up to the fence. Most of the time, we would bring them carrots, or apples that we had picked from the trees. But on the days we didn't bring them food, we would pick handfuls of grass and feed them. It was one of my favorite things to do.

On August 30, 2005, the day after Hurricane Katrina made landfall in New Orleans, Clarence went under the knife to have cataract surgery. The surgery, though it was a relatively easy procedure, held devastating news for the family. Everything was fine at first. The anesthesia wore off, bandages were changed and eventually removed, and he was back to normal... except he wasn't. He began forgetting simple things: where he set his keys, who a distant relative was in the family when they were mentioned in stories, the names of his grandkids. His mouth began twitching uncontrollably- his lips pursing together as if he was going to kiss someone, jutting out from his face before they were pulled into a straight line, a mix between a smile and grimace. He had impeccable balance, yet now he was stumbling as he walked from his recliner in the living room to the dining room table. Enough was enough. Two weeks after his surgery, my grandma and great grandma took him back to the doctor. They had thought maybe Clarence had a small stroke while under anesthesia, since it was common in older people. Tests were run and, by the first month of the new year, our family had results. The doctor's diagnosis: Lewy Body Dementia.

Soon after, his health rapidly began to decline. They put him on medication. Some to help the disease, others to counteract the side effects of the medications to treat the disease. Clozapine, an antipsychotic usually prescribed to treat severe schizophrenia, was one of the harshest drugs prescribed for him, due to the severe side effects like tremors and mouth twitches. In total, he took two antidepressants and three different medications to help lower his blood pressure, tremors, and swallowing, all of which came with side effects of their own. He began sleeping more, taking naps during the day and then waking up when we got there. I would come running into the house and he would wake up. We would go about our usual routine. As weeks turned into months, he would wake up less and less, and before long, he'd sleep the entire time we were there.

Interlaced in all of the bad days, there were good days of course. I

cherished those days the most. We wouldn't go on our walks anymore, and he wouldn't speak as much, but he was awake. His eyes would dart from person to person as conversations were carried on around him, and my eyes would focus on him. Occasionally, he'd look at me, and the hint of a smile would fall into his eyes and I would feel the warmest ray of sunshine falling onto my perpetually cold skin for the first time in what felt like years. In those few seconds, I would feel joy like no other.

*Step Two: Patient will experience a decrease in muscle mass, resulting in the weakening of muscles. Health providers should expect sudden drops in blood pressure, irregularities in the patient's heartbeat, and at times it may be hard to detect.*

With Clarence sleeping constantly, our walks shortened to the garden and back. I no longer ran barefoot through the mud and got yelled at by my great grandma for trying to come into the house without washing my feet off. Instead, I walked steadily next to my great grandfather as he focused on walking. Before long, we limited our walks to the indoors. I would help him walk-- his right hand in my left, his left hand on my shoulder— through the house to the back door. He would stumble a little; I would balance him. He would smile. It was one of those smiles that if you blinked or looked away, you would miss it. But it was always there. We would walk to the screen door and stare outside. I wonder what he thought about, but I never asked.

The more that he would sleep, the more I stayed inside. My cousins and I would play hide and seek in the house, or dance on the piano foam mat in the sunroom as he slept in the living room. I would visit him often in his recliner just to see if he had woken up, before I would go back to playing. My uncle took over, and instead of Clarence and I wandering around the great outdoors, my uncle and I would take walks down the country road or through the woods to a small creek on the edge of the property. The worn-down royal blue recliner became the only thing Clarence visited during the day. He would leave the recliner long enough to use the restroom, before he was back in it, one leg draped over one of the armrests.

Staying in his recliner only made things worse for him. It wasn't long before he lost the ability to walk by himself and began using a walker. Even when he walked, he would be accompanied by my grandma or great aunt. Being able to walk was slowly washed away like the tides washing away the sand at the beach.

*Stage Three: Patient will experience a decrease in appetite.*

Clarence rarely finished his dinner anymore, though food was something that he had cherished for as long as I have known him. We thought maybe he was just coming down with the flu, because even with the

disease slowly eating away at his mind, he always got excited about dinner. As his body began to cave in on itself, he would stop coming to the dinner table. I would fix a plate for him, making sure only to get his favorite things- mashed potatoes, green beans, buttered noodles- before pulling up a stool next to his recliner. Stabbing a green bean, my only focus was to make sure the food stayed on the fork as I moved it through the air and eventually into his mouth. He wouldn't talk much, but you could tell in his eyes he liked the food. They'd crinkle on the outsides just enough for me to know that if he could, he would smile. Over time, we transitioned into soft foods and then moving to just liquids. No matter what it was though, I made sure to feed it to him. I would give him small bites of food and as he chewed, I would take a bite from my own plate. He would never finish all the food, and I would never mine, but no matter how much was left on the plate at the end of dinner, it was my duty to make sure he was fed. It was a job well done. It was the first duty stripped away from me when he was moved into the hospital.

*Stage Four: Patient will experience hallucinations and visual distortions.*

Throughout the course of his disease, there was always one consistent phrase he would mutter, no matter where he was. "I want to go home."

When we would leave, while he could still walk, he would get up, slip his shoes on and mutter his goodbyes. It didn't matter how long he had lived in that house; it wasn't his home. We would explain it to him, that no, he wasn't going home with us because he was already home, and he would slip his shoes off and sit back down without another word. When I was younger, I always thought that maybe he was tired of the disease and wanted to go to Heaven. He had always been a strongly religious man, and at the time, it made sense. However, as I grew up, I began to change my viewpoint on the phrase. "I want to go home."

This single phrase, muttered from the lips of most Lewy Body Dementia patients, is common. The destruction of memory starts from the newest memory to the oldest memory. After the disease devours so much of a person's brain, they start thinking in the mindset of a child. His home that he wanted so desperately to return to was his childhood home, or so I think. His home was no longer a part of us; our family. The idea of family no longer pertained to us, because to him, we were strangers.

It's hard watching a family member slowly fall into the grasps of death, knowing the Grim Reaper was waiting, inches out of eyesight with a hand around the very essence that brought us life, but the disease brought harsh realities to light. He was fighting another war, and this time, the country wasn't an ally. This war wasn't fought between countries, and he didn't have

people to shoot at. There were no ships to board, and no seas to sail. This war raged solely in his mind, and he had no one in there to help but himself.

Although, outside in the real world his hallucinations were ever-present. He would ask about the babies crawling across the floor of the living room when there were no children present in the house. He would complain about the dogs using the restroom in the house and insist on cleaning it up when they didn't own animals. One time, before things got terrible and he lost the ability to walk, he was staring out the window, watching over the front yard. He had insisted that there were construction workers digging up the lawn, and there was no way he was letting that thought go. Before we could register what was happening, he had disappeared into the bedroom, loaded a 12-gauge shotgun, and went outside. He screamed at the 'workers,' threatening to shoot them if they didn't get their equipment and leave, when there was no one in the yard. We finally coaxed him back inside, took the gun away from him, and removed all the guns from the house.

*Stage Five: Patient will experience confusion and incoherence.*

Our visits would no longer start and end on Saturdays. My grandma, brother, and I started spending the night on the weekends to help my great grandma take care of Clarence. Occasionally, my cousin would spend the night with us as well, and we would spend the majority of the time in the depths of the furthest bedroom. That house had become both heaven and hell. From the outside, it was pristine. The hedges were kept trimmed and neat by my uncle, the grass was mowed and fertilized by my brother, and the gardens were tended to by my grandma, aunt and myself. From the outside looking in, it was a family helping care for their elderly great grandparents.

Inside, however, was hell. My great grandfather, his memory trapped in a steel cage locked with so many different mechanisms it could challenge Fort Knox, no longer knew anyone he once cared greatly for. The man I had spent so much time looking up to, who had swept me under his wing and threw me over his shoulder like I was his own child, no longer recognized who I was. My brother stayed in the bedroom the entire time we were there, watching T.V. and playing his video games. He couldn't stand to watch our only father figure evaporate into thin air. His mind was disappearing, and he didn't speak anymore. When he did, it was nothing but jumbled mutterings and confused questions.

My grandfather no longer looked at me with a smile in his eyes as I played on the living room floor. Now, he stared at me like I was a stranger who broke into his house. Staring back at me like a deer caught in the headlights of semi-truck on a backroad's country road, I no longer felt the sunlight hitting my skin. Instead, the thunderstorms rolled in, hail pelting down all around me until everything was shattered and broken, and I was left

soaking wet, crying in the rain. I was trapped on the outside, or he was trapped on the inside. Perhaps it was both. No matter what I did or said, no matter how many hugs I gave him or pleas I sent up to heaven to help me find the keys to unlock his mind, it was pointless. Nothing helped. I was no longer something that brought him joy, and if I was, I no longer recognized the happiness in his eyes.

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The American flag is draped across the open coffin, providing a warm blanket for the numb, lifeless body. I pretend as if he is cold, and that covering him up would somehow make up for the fact that we are preparing to lower him into the ground for his body to become nothing more than a rotting piece of flesh as we slowly begin to forget his favorite food, color, and movie. We erase him from the new Christmas cards, Thanksgiving dinners, and Saturday afternoons. We forget that he's even gone until one day... boom. He pops into your memory as if he was an item at the grocery store you forgot to pick up the night before. People I have never even met are gathered in the dark warm glow of the halogen lights, preparing to bury a pillar of the family. It feels like we should be gathering at a family reunion rather than a funeral with the way everyone interacts with each other. These strangers stand around talking to each other, laughing, as if my grandfather wasn't a lifeless corpse, lying dead in a casket fifty feet from their conversation about burnt garlic bread and unseasoned spaghetti sauce. I want these people to leave. They have no right to be here, laughing in the presence of him.

I was nine when we buried my great grandfather. Standing three steps to the left of the coffin, I didn't cry or move. I just stared. Stared at the strangers telling me stories of my grandfather, even though they hadn't visited him since he first began to get sick. Stared at the rigid, pale body beside me. Stared at the one flickering bulb in the ceiling because it was driving me insane. All I could think in that moment was how disrespectful it was of the funeral home director to not fix a flickering light before hosting the funeral. I was a terra cotta soldier, standing in place, waiting to safely welcome my grandfather into the afterlife. I was there to look out for him, it was my job. I couldn't just abandon my post because he was dead. No. It was my job to steady him when he tripped, to feed him when his tremors took over his ability to even hold a pen. It was my job to make sure he was protected even now.

I was cold. Everything about my being, from my skin to my eyes to my soul. Every aspect of my being was a bitter cold that refused to go away, no matter how many forced hugs and fleece blankets were given to me. I thought maybe that I had flown to Antarctica in my sleep, and that we were

really paying an ice tribute to my grandfather. Perhaps we were trying some type of new ritual to bring him back, and in order to do so, the recipe required the heat of a living body. Maybe I was just dying. After all, dropping body temperature was one of the last symptoms in the long list of signs someone is about to pass.

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### *Stage One: Denial*

Tuesday, February 9, 2010.

I had been impatiently awaiting this day since February 9, 2009. My ninth birthday—one step closer to being a teenager. My mom and I talked while we stood on the corner, huddled in our coats as we waited for my bus to arrive. She asked me where I want to eat when I get home to celebrate my birthday, but I'm not sure yet. I think I want to go to LongHorns or AppleBee's. I board the yellow bus- we affectionately called the Twinkiemobile- and wave my mom goodbye from the window, balancing the store-bought cookie cake with blue and white icing on my lap. I loved taking in desserts for my class on my birthday, and this year was no different. My day is pretty normal for a 3<sup>rd</sup> grader. We eat the cookie cake, they sing me happy birthday, and my teacher begins to talk to us about multiplication. My mom picks my brother and me up early around two, and I'm so excited. I bound down the hall, my Hannah Montana Messenger bag strapped across my body as I head towards the office. It's my birthday, I got a cookie cake, and I'm getting picked up early? I was so excited! This was the best birthday ever!

The car ride home is silent. I sit in the back of our white minivan, tapping my feet together in time to the music on the radio as I stare out the window. The drive isn't long- ten minutes maybe- and before I know it, we're pulling into the driveway, and we're walking inside the house. Why is she so quiet? I throw my bookbag on the floor, toe off my shoes at the door, and practically jump onto the couch. She swallows. The television isn't turned on like it is every other day, and my brother doesn't grab for his video games instantly. Instead, my mom sits on the couch beside us. She's sad. I can see it in her eyes, but I don't know why.

“Papaw fell today...”

She goes on, tells us he fell between the toilet and the bathtub, that Mamaw hurt her back while trying to pull him out from the small area. He was in the hospital, taken by ambulance to the number one hospital in the area. My brother runs into his bedroom, slams his door and cries; my mom follows him. I sit on the couch, unmoving. I cry, but I don't cry for myself. I cry for my mom and my brother, because they're both crying, and I don't

understand why. Papaw fell. He's in the hospital. He'll be fine. I have fallen off my bike plenty of times, and at the end of the day, I always get better. So will he.

### *Stage Two: Anger*

We wait for my grandma to get home at half past five before we pile into the car and head to the hospital. The car ride is relatively quiet, the music at a low murmur in the background. I sit still, hands folded together in my lap and lean my head against the window as we drive. I glance over at my brother as he sits next to me, and the happiness in his eyes as he plays his Gameboy has disappeared. His eyes are puffy, and he doesn't sing to the music. My eyes flicker back to the outside: fluffy snow covers the ground, the red and green glow of the stoplights turning it different colors as the light changes and we pull off. It's dark as we drive under streetlights, and I long to be outside of this car right now. Though when I get my wish, I immediately want to leave again.

My grandfather was admitted into the ICU immediately after he arrived. In order to prevent infection, only three people could enter the room at a time, and anyone under the age of twelve was not permitted into the room. I was not allowed into the room to see him. My grandma and mom would take turns visiting him to watch me in the waiting room. My brother stayed in the hospital room constantly. I didn't understand how they could keep me out, keep me from visiting him. I hated the hospital for it. Day after day, I would go to school, and then go to the hospital to sit in the waiting room while everyone else got to continue visiting and seeing Clarence. Every day that passed that I sat and did nothing, the rage inside me grew into an enormous fire. It wasn't fair.

Over the course of the five days he was in the ICU, I became very aware of the hospital around me. The eggshell white walls surrounding me, and the constant 68-degree temperature felt like I was shoved in a refrigerator with no hope to escape. Hand sanitizer was everywhere: hanging on the wall outside of each room, every table in the waiting room, and at the reception desk. People would see me in the waiting room, offer me smiles like they knew why I was sitting in there. Maybe it was kindness that tugged at their lips when they saw me. Maybe it was just pity; the little girl locked out of the room because the relationship she had built with her great grandfather wasn't strong enough to overshadow her age.

### *Stage Three: Bargaining*

Clarence was in the hospital for five days before my mother told me they were transferring to hospice. The nurse on duty snuck me through the

halls and into the room to see him. I felt like I was a spy, sneaking behind enemy lines to rescue my family from the evil disease that had captured and stolen my great grandfather. He was asleep when I went in, and it was something I was used to. The steady rhythm of the machines and monitors beeping was the only thing keeping the room from complete silence. I didn't know it at the time, but it was a warning of his forthcoming death. I thought hospice was just somewhere that could help him more than the hospital. I thought it was a sign that he was getting better. They transferred him to hospice where I would spend every evening the next week in his room. My mom had surgery the first day my great grandpa was in hospice, and even then, we didn't stop visiting him. We couldn't.

I liked it when he slept while I was there. We would hold casual conversation, most of which was meaningless and only spoken about to keep the pesky silence out of the room. I would pray over his bed, begging for God to show up and fix him, to let him come back home. We still had way too many memories to make. He still had to tell me happy birthday and help me eat the cake. We still had holidays to celebrate and decorate for, games to play. He couldn't leave me yet. Each day I would pray, and each day nothing would happen. Day after day after day, I found myself praying more and more, begging for him to get better. Nothing ever worked. Not even two weeks after his fall, he caught pneumonia, and in the early morning light of Sunday, February 22, Clarence passed away in the presence of my great grandma and grandma.

#### *Stage Four: Depression*

The coldness settled into my bones as if I had just participated in the Polar Ice Plunge. Fleece blankets and scalding hot showers didn't help. Warm hugs and kind affirmations left me bitter and resentful. It didn't matter how many hot mugs of cocoa I wrapped my tiny hands around to slip slowly. The coldness was still there and would always exist. My heart was no longer complete. I had just put my only father figure in the ground. I had watched this disease eat and devour his brain until he didn't even recognize me.

My days came and went in a blur and in what felt like a blink of an eye, we were flipping the calendar to the new year, and we were preparing to celebrate my tenth birthday. We didn't throw a party. We didn't invite people over or spend time with the family. No one wanted to celebrate. It wasn't right. We went out to dinner, though, and my mom bought me a cake. My birthday was no longer my favorite day of the year. Now, it is just a reminder that with each day I age, which each day I wake up on February ninth and turn another year older, it's another year my grandfather won't be a part of. A cruel, sadistic reminder that he won't be there, that he is gone, and that no matter how many candles I blow out wishing for him to come back, he won't.

*Stage Five: Acceptance*

I don't like acceptance. Honestly, I think it's a load of crap to accept someone's death. You don't accept it. Death isn't something you can check like you do the small little box on the terms and conditions you didn't bother to read. No. You learn to live with the pain of them not being here until you can function again. One day, you wake up, you shower and brush your teeth, you get ready for your day and you force yourself to get used to it.

There is no accepting it. There is letting your grief completely devour you until you are nothing more than a robot living in the day to day motions, or there's learning to shoulder the grief as easily as you shoulder the backpack you shrug onto your shoulders. You go to school, do your homework, and you begin to learn how to become a functioning member of society as the years progress. The only thing you learn to accept is that the gnawing pit in your stomach won't go away over time, and that you will actively pretend to ignore it when your family gets together for holidays. You bottle your pain up, you write poems and short stories about it. You turn that pain into writing because you so desperately want to get it out of your system and writing helps. You rip out pages from your notebook that only have two sentences on them because they don't sound right and the longer they sit on the page in front of you, the more aggravated you get that they aren't right. The words don't flow onto the paper as easily as life flows from a body when someone passes. You obsess and fixate on how to describe death in terms that haven't been used before because even though everyone experiences death, no one experiences it like you.

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Death isn't pretty. It isn't peacefully passing away in your sleep, hair and makeup done, and then going directly into the ground. It isn't finding a beautiful way to describe it on paper. No. Death is choking on the last breath of air you managed to pull into your lungs. It's your family members finding you laying in your own waste. Death is having your remains burned into nothing or being buried six feet underground for maggots and worms to feast on your rotting flesh until the only thing left are yellowed bones in a dirt-covered coffin. You can go about your day, but the fact of the matter is that even eleven years after a loved one dies, the first whiff of Old Spice cologne will send you hurdling back through time, to a memory of being pulled in a little red wagon, or picking apples from the three trees on the property. A memory filled with petting donkeys, hiking through the woods on the edge of the property, and seeing your entire family every weekend. It's being hoisted onto the shoulders of your great grandfather as you giggle uncontrollably in a

time when your heart was still made of gold and you didn't know death existed.