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Remembering Time

By Jonathan Carey

My parents were dressed in their Sunday best, heading to a church revival. I was 12 and still the baby of the family, so staying home alone was out of the question. My grandmother Lillian, who preferred to be called Nana, came to babysit me. She relished a little time away from the doldrums and senior citizen gossip that engulfed the high-rise building where she lived, five minutes from my house in Petersburg, Virginia. That evening, as the sounds of “The Young and the Restless” echoed through the house, I tiptoed downstairs to give Nana a playful scare.

I crept down the steps and wove through the kitchen, streaks of moonlight illuminating my path. As I rounded the corner to the living room, I could see the dim, bluish glow from the television casting shadows through the room. I peered in stealthily. To my surprise, I didn’t see Nana in her usual spot near the window that looked out onto the yard.

Nana instead lay slouched and sunken in a loveseat far from the window. “Nana,” I blurted out, instantly abandoning my childish plan to frighten her, “why are you sitting over there like that?” Her eyes peered up at me. “I just don’t like sitting near that window anymore,” she said. “There’s a man out there walking around and you never know who gonna come through that window.” I stood there in a state of confusion, then darted to the window to cut on the deck light, anxious about what I would see. “Nana, there isn’t anything out there,” I said, with a slight giggle. “Ok, you just watch,” she retorted. “I know I ain’t sitting by that window no more. Y’all think I’m crazy.”

Now, Nana had always been on the paranoid side. Growing up, my older brother often told me the story about finding a gun on top of the refrigerator in Nana’s house, the place where she lived when he was a kid, before she moved into the high-rise, Gillhaven Manor. The constant checking and rechecking of locks, and placing a hand just above the stove when anyone finished cooking were commonplace for her. But tonight I noticed something different in her eyes. It wasn’t just paranoia. Her face was riddled with fear and bewilderment. It was a look that made me worry about her for the first time.

A few days later I approached my mom as she was frying chicken for dinner, to tell her about that night and the change I had noticed in Nana. I explained to her what Nana claimed she saw—and the strange way she stared at me after making that statement. “Well, you know, paranoia and seeing things are symptoms of Alzheimer’s,” my mother replied. The words bounced around in my head for a moment. Observing my distress, my mother began to explain to me that Nana had been diagnosed with dementia years earlier. But the symptoms were subtle, at least to a child, and it was only now that the outward markers of the disease had begun to reveal themselves to me.

More than 5 million people suffer from Alzheimer’s disease in the U.S. This pernicious dementia progresses in a slow but predictable fashion: the so-called mild phase is followed by the moderate and then the severe phases. Each phase can last from one to two and a half years. In the mild phase, the disease is often missed, because the symptoms—behaviors such as forgetfulness—are often attributed to the normal impairments of old age. In 2001, the year I became aware of Nana’s illness, she was at the onset of the moderate stage, although we did not know it at the time. During this stage, the definitive markers of dementia, such as paranoia and bizarre behavior, arise. More and more brain and nerve cells become damaged, making simple tasks difficult. In the final phase of the disease those afflicted lose all ability to interact with other people or the world around them. They often display an intense fear of being alone and an inability to control their emotions, and they lose the ability to dress and feed themselves, as well as control over basic physical abilities, such as holding in their urine. Constant care is required.
I stood there, frozen, attempting to process what my mother had said. My family was filled with nurses. Medical journals and magazines cluttered the bookcases throughout our house. I knew, even as a young teen, what eventually happens to people with Alzheimer's. A neighbor a few houses down from us had Alzheimer's. I recalled the neighborhood chatter about him: how he would often ask family members, “Who are you?” and the day he wandered down the street, confused and completely nude. To me, the idea of seeing Nana slowly deteriorate to the point where she did not recognize me or remember our life together was unbearable. “But those things won’t happen for a long time, Jonathan,” my mom said, attempting to calm my emotions.

My mother and I had no clue that evening what the future had in store, or how we would cope. Researchers have done hundreds of studies on family caregivers and the news is dispiriting: Being responsible for a family member suffering from a chronic illness takes a huge toll on one’s mental and physical health. Caregiving has been linked to depression, poor diet and increased stress. But as it turned out, our drawn-out, devastating loss had some benefits. Caring for my grandmother was more rewarding than I could have ever imagined. The good times outweighed the hardships. And as I looked more deeply into the scientific literature on caregiving, I learned that the experience is not uniformly bad for all families. Some manage even to thrive. These are families that incorporate the ill person into their lives, even as they deteriorate, and don’t experience the illness as a tragedy. Families that share the burden among multiple people and incorporate a lighter emotional tone to the experience tend to fare better. Psychologists have also observed cultural differences in how families manage caretaking. Both Asian-American families and African-American families such as ours tend to approach long-term illness with attitudes, behaviors and beliefs that reduce the stress and trauma of the caretakers. The strong bond between my mother, grandmother and me proved essential to managing the hand we were dealt

**Sass Personified**
Lillian Ann Pegram had been a nurse her entire life, spending most of her career as an aide at Central State Hospital, a home for the criminally insane. She always wanted to be a teacher but was unable to afford the necessary classes for certification, so nursing became her pathway to helping others. As a little girl, she watched her mother clean houses to earn an honest pay, not an easy task in Petersburg, Virginia, or anywhere in the south for blacks, period, during that time. She stood in breadlines as a child during the Great Depression, and would later tell us that her family was so poor that she couldn’t tell the difference between the Depression and her everyday life.

That summed up her personality in a nutshell: unfiltered and honest, but also naturally humorous. Nana always made wisecracks, and she had no problem tossing a sarcastic jab anyone’s way. Humor was the centerpiece of the relationship that my mom and I had with her. We always approached life with a grin.

Studies suggest that when people use humor while taking care of a sick family member, the health of both people benefits. In a 1998 study, psychologist Dr. Martha Buffum, then of the California School of Nursing, found that people who brought a sense of levity to the task of taking care of a spouse or parent with dementia tended to have more positive emotions and enhanced well-being. Many caregivers expressed “Alzheimer’s disease near disasters” that they could eventually look back at and laugh over, which brought a sense of relief. Humor became an essential part of their caregiving duties. Participants wrote that Alzheimer’s itself wasn’t funny, but that laughing was better than crying.

Buffum’s study brought to mind one memorable Christmas evening, about five years after I learned about my grandmother’s dementia. Scraps of red, blue, and golden wrapping paper glistened in the glow of Christmas lights wrapped around a plastic tree. As I walked past the bathroom toward my mother’s room, there was Nana, gazing into the mirror, brushing her gold-blondie hair in a strange way. “Nana, what are you doing?” I blurted out. “Getting ready for bed. What it look like?” she responded. I yelled for my mom to come into the hallway. She stared at my
grandmother with a look that led to a head-shake. “Nana! That’s a toothbrush!” she exclaimed. A moment of stillness passed before bellows of laughter flooded the hallway.

Nana was sass personified. I would never imagine, though, that her joking side would become pivotal in her care and that it would help my mother and me cope. No matter the circumstances, Nana always maintained her humor, and we all laughed together. She had the amazing ability to make others feel comfortable about her disease, and often poked fun at herself and her memory loss—even in bankruptcy court.

Before I get to that story, I need to explain that Nana hid her forgetfulness expertly, even fooling the doctors who gave her a monthly cognitive test to check on her deterioration. Nana studied for those tests assiduously, reminding herself of how to tell time and read numbers. She sailed through them for a while, blinding even my mom, who did not realize how far behind Nana was in taking care of her bills. Eventually, though, she ended up in court.

At the onset of the proceedings, as Nana sat in front of the judge, bank statements in hand, the judge asked, "So, Mrs. Pegram, what brings you before my court today?" Nana, without hesitation, blurted out, “Well, I’m here because I can’t pay my damn bills. I got hoffhammers.” My mom, Nana, and others in the courtroom couldn’t hold back their laughter—she could never say Alzheimer’s. The judge cracked a smile and helped Nana through the bankruptcy process.

**Holding on to What We Had**

Nana was a regular in the kitchen and could create a five-star meal from scratch. She was an expert with eggs—fried, scrambled, or an omelet, she could do it. She was always there in the morning to make me breakfast and help me get ready for school, as my parents had to leave for work early. Gradually her eggs went from fluffy and delicate, to runny, to underdone and riddled with eggshells. It got to the point where I had to fix breakfast myself. In fact, eggs were the first food I ever cooked. Still, my child mind couldn’t see deeper into what was taking place.

Mom, I later learned, had begun to notice the changes in Nana’s memory three years before I did. It happened one evening when they were poring over receipts and bills to prepare for tax season. Nana was something of a math whiz, able to perform mental calculations in a matter of seconds. My mother asked her to write down a $566 tax deduction. Nana sat stoically, pen in hand, gazing at the paper. “Nana, did you hear me?” My mom repeated the number again, and again Nana sat in a state of bewilderment. It wasn’t until my mother spoke each individual digit that she was able to write down the number. “Well, why didn’t you just say that?” Nana blurted out.

Nana had always been extremely independent. Well into her seventies, before we knew she had Alzheimer’s, she had no issues walking around the city, or catching the bus to Wal-Mart by herself. She also gave herself daily insulin injections to manage her diabetes, a process that requires precise measurements. Even after the dementia was diagnosed, my mother decided to interfere as little as possible with Nana’s routines. Mom knew how much Nana valued her independence. So she allowed Nana to continue giving herself her twice-daily insulin injections, but she tried to keep tabs on the process with frequent reminders: “Nana, did you take your shot today?” We did our best to stay focused on the moment.

Dwelling on the changes that a progressive disease like Alzheimer’s will bring—the loss of cognitive skills and memory—is known as pre-death grief. This is a fairly new concept that investigators have come up with to better understand the caregiver experience. “People grieve for the changes that they see, and their family members, long before that person has died,” says psychologist Allison Lindaur of the Layton Aging and Alzheimer’s Disease Center at Oregon Health & Science University in Portland. Experts are discovering that when people focus on the losses to come, they tend to have more issues with depression and worse physical health. They also tend to experience caregiving as a greater burden and struggle more with the responsibilities.
For a 2015 study on pre-death grief published in the journal *The Gerontologist*, Lindaur conducted in-depth interviews with 22 African-American caregivers over a six-week period. She discovered that African-American caregivers experience relatively low levels of pre-death grief, and she identified three main reasons: reverence for elders, a family approach to caregiving, and a focus on the qualities that the ailing person retains, as opposed to what they have lost as a result of the disease.

That last factor turned out to be the most important. In describing her study to me, Lindaur recalled one family that did a particularly good job of focusing on the memories that their loved one maintained.

“One gentleman kept telling the same stories over, over, and over about his experiences living and growing up in the Jim Crow South,” she said. “And, you know, the family has heard this story thousands of times, but they’re not going to say ‘Oh, Grandpa, we’ve heard that before.’ They’re just going to sit and listen because when he tells those stories, his personality comes through and he engages with them.”

I never stifled a moment where Nana could be herself—sass, kookiness and all. One afternoon, not long before that Christmas night with the toothbrush-comb, I was outside playing basketball. Nana came out the back door, shuffling her feet across the concrete.

“I came out here to play some ball with you!” she shouted. Laughing, I yelled, “Okay, check up then!” and bounced the ball towards her. We played until dusk. Nana was never much of an athlete, but as my shots careened off the rim she couldn’t help but be herself, chiding me about how badly I was playing. We both laughed. It was a moment where Nana was again her comedic and honest self.

**The Culture of Coping**

The use of humor within African-American caregiving scenarios has roots that hark back to the days of segregation. “Humor as a coping mechanism is historical in the black community,” explained Dr. Peggye Dilworth-Anderson, a professor in the department of health policy and management at the University of North Carolina who has studied the care of dementia patients in the African-American community. During slavery and the Jim Crow era, humor was a way for black people to gain favor in the white community, and also a tool to subvert discrimination. “We have used humor historically to deflect pain,” she added.

But the use of humor by caregivers is hardly exclusive to the African-American community. Dr. Julie Robison, a professor at the Center on Aging at the University of Connecticut, studies the role culture plays in how families approach dementia care. Robison, who is white, explained how her family used humor when their grandmother began suffering from dementia.

“She was a very funny person and loved to laugh, so we would make a joke about it if she made a mistake,” Robison said. “We would tease a little bit, only so much that she was in on the joke and didn’t feel like she was being made fun of.”

Family connectedness can be as powerful as humor when people are struggling to care for someone with dementia. African-American, Latino, Korean, and Chinese caregivers tend to their responsibilities with a sense of family duty and community. Brothers, sisters, aunts and uncles, even cousins provide secondary support to the primary caregivers. Robison describes this phenomenon as “intergenerational helping,” where young, middle-aged and old band together through major life events and crises.

“The older generations help the younger generations with raising their kids. It’s just expected that you would help an older person in your family if they need it,” Robison explained.
This approach to caregiving is so ingrained for many Latinos, Asians, and African-Americans that to not provide care would be considered taboo, according to a 2014 study by public health expert Jennifer Pharr of the University of Nevada, Las Vegas. Pharr found through interviews and focus groups that within these minority communities caregiving was an expected part of life, passed along from generation to generation. Pharr described this phenomenon as “cultural embeddedness.” On the other hand, she found the opposite scenario amongst white caregivers, who tended not to have witnessed family caregiving growing up, and considered it an unexpected and even unreasonable obligation.

“We’re not recognizing that our elders are holding for us the links to our ancestors,” Lindaur said of white families. “We don’t recognize that the elder informs our day-to-day life as we live it now. It’s just a very different feeling.”

**Teenage Angst**

As a teen, I didn’t fully understand what my role would be in taking care of Nana. I just knew that I wanted to help my mother in any way possible. I felt I owed it to both of them. My mom asked me to keep an eye on Nana’s diabetes whenever she came over. “If Nana ever says she is feeling woozy or lightheaded,” Mom told me, “get her a glass of orange juice and put one scoop of sugar in it to spike her blood sugar back up.”

A few weeks after I received these instructions, Nana was spending an afternoon at the house as my parents went about their weekly Saturday routines of shopping and yard work. I passed the time outside shooting basketball. After working up a sweat, I went back inside, into the living room where Nana always watched TV. “How you feeling, Nana?” I asked. I could see she didn’t look well. Beads of sweat were forming above her brow, and her skin had become paler in color. “I’m not feeling too good, feel like I’m getting the shakes,” Nana blurted out.

I scurried to the kitchen as quickly as I could, flinging open the fridge to grab the bottle of Tropicana orange juice. I scooped precisely one tablespoon of sugar before stirring it around in the juice.

“Here you go, Nana. This should help,” I said. “It’s orange juice with some sugar. Mom told me about it.” I watched as she gulped down the glass. Not long after, she regained her strength and was back to her usual self, albeit extremely grateful. She talked about that moment every chance she got. It felt good being able to help Nana. Helping my mother with Nana’s care never bothered me as much as seeing both of their struggles: Nana battling Alzheimer's and Mom trying her best to maintain her life, ours, and her mother’s. That was the hard part.

Robison explained that many adult-child caregivers expect to care for their parents as they become older. However, when a teenager is thrust into the equation, it's a different story. Gerontologist Diane Beach conducted one of the first studies to explore whether being a teenage caregiver had any positive sides. She interviewed 20 people aged 14 to 18 who had a parent, grandparent, aunt or uncle with Alzheimer's. Her questions ranged from: “Please describe how you faced the diagnosis of Alzheimer's disease,” to “Have you noticed a change in your friendships now that your relative lives with you?” and “Were any of those changes positive?”

Beach found that many young caregivers developed greater empathy for adults, closer family ties, and maturity as a result of their caregiving experiences. One young man noted, when talking about his mother's emotions:

“She's always been a person who doesn't complain a lot and just kind of bucks up and does whatever needs to be done. But I've caught her crying before and stuff like that. I just said to her, 'Listen, this is tough, it's tough on everybody, but you're bearing most of the burden, so it's especially tough on you.' I tried to offer more help because I thought that's what she needed.”
Many child caregivers have difficult experiences, however. A 2013 report by the Canadian Caregiver Coalition found that young caregivers run the risk of having underdeveloped social skills and may fall behind in their education and experience social isolation due to their caregiving duties. Robison notes that, due to new responsibilities, teenage caretakers may isolate themselves from their peers, who may not be able to relate to their circumstances.

I experienced both ends of the spectrum—unyielding anxiety along with the deep satisfaction of helping my mother and Nana through a difficult time. I figured one of the best ways to help them was to keep my feelings as close to myself as possible. The last thing I wanted was for them to be concerned about me. But allowing those feelings to wallow and fester did nothing but add to a collection of negative thoughts. Eventually it all spilled out in a place I always considered a sanctuary from my mind—the basketball court. One November evening during practice I found myself yelling at my teammates and picking fights every time I made a bad play. Eventually my coach took me outside and I unleashed all the pain I’d been storing up, telling him, and then my teammates, what was going on at home.

After practice, I changed and walked out into the fall night. The brisk air chilled the sweat beads left on my forehead and a sense of calmness rushed through me. I felt better. All of the frustration that had clouded my mind began to slowly dissipate. I understood that no matter what, Nana was always going to be Nana, and our family would always be whole.

Nana passed just two days after our hallway laughter that Christmas night. She miscalculated her insulin dosages and died from an overdose. For years, she had managed to maintain her medication routine, despite the Alzheimer’s. My mom felt some guilt from Nana’s passing, although she had been preparing herself for this moment for sometime, but never from an insulin overdose. However working her entire life in and around hospitals taught her to never look at the “what ifs,” but what you did and accomplished. The fact that Nana was allowed to live her life unapologetically her way and my mom letting her do so on her terms was one of her greatest triumphs.

My mom is now well into her fifties, and occasionally forgets to turn off the oven or feed her cat Ramses. When she used to take Nana to the doctor for her monthly cognitive tests, the doctor always had Nana draw a clock showing the current time. Nana could never get the time or numbers in order. Nowadays when my mom finds herself in a fog of forgetfulness, she quickly grabs a pencil and paper and begins to sketch out a clock—remembering time.