

His Daughter, the Caregiver

Short Essay

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My dad had a stroke in 2015, leaving him paralyzed on the left, unable to walk, talk, or eat. The nursing home he was transferred to downgraded my dad's room when we applied for Medicaid. He was moved into a shared room that the nurses tended to much less often. Nearly every day, I was chased out of the building as I left, being asked when the next payments were coming. Staff stopped turning him every 3-4 hours and cancelled his therapies even though he was entitled to them while Medicaid was pending. My mom and I were caught in a war against them, with pressure on us to take him home.

So, my mom and I eventually brought him home. Everything he needed, from bathing, medications, insulin injections, PICC line infusions, albuterol treatments, and feeding tube maintenance, now became our responsibility. My mom was nearing retirement, but instead she quit her job and began working from home as a tax preparer. She had no other choice, given Medicare, Medicaid, and the nursing home could not provide adequate care. Her days with him started at six in the morning and ended around eleven at night, of course without compensation. I was 21, had just graduated college, and wanted to pursue medical school at that time. Instead, I gave up on my dream and found a job that allowed me to work from home. We managed since the cost-of-living in Fayetteville, NC was low. Together, however, we barely had enough to cover the cost of everything he needed: medications, medical equipment, diapers, gloves, oral care, etc. We now found ourselves fighting against the insurance company.

Luckily, the doctor who cared for my dad throughout his recovery supported us in this war with insurance. He used his knowledge of the system to manipulate insurance into covering more expenses. For example, our policy stated that oxygen tanks are only provided to those whose oxygen levels are consistently below 90%. My dad's oxygen, however, would fluctuate between 89% and 91% on a daily basis. His doctor reported all of the 91% as 89% just to ensure we could keep an oxygen tank in the home at no additional cost. If not for this, my dad would not have had the oxygen he desperately needed whenever he aspirated or experienced an asthma attack. On multiple occasions, his oxygen saturation would drop from 91% to 70% before an ambulance could arrive. Access to home oxygen saved his life.

Doctors like my dad's inspire me. The ones who do everything in the best interest of the patient, even if it means fighting insurance companies. But how many of those are there? If another patient were in my dad's situation and couldn't get the same support, then it would fall on the family. When you become a caregiver, expenses add up fast. Deciding between affording insulin

pens or vials, being able to provide eight new diapers a day versus four, reusing the same oral cleaning sponge or not... it adds up. Cutting costs comes with health risks, and it may be the only option if the only income is disability.

Another factor that eases the burden of caregiving is help from loved ones. However, my dad's oldest son played no role in my dad's care after the stroke. He claimed to have no obligation to help. In contrast, I was the youngest child and only daughter. Yet, I was willing to give up my future because I felt indebted to the wonderful stay-at-home dad who raised me. I never understood how my brother, much older, successful, and stable in life could refuse to help. It was clear that living in America changed him. The American dream, where we prioritize work, money, social obligations, and success.

In Viet Nam, however, family always comes first. For example, when my grandpa had a stroke in Viet Nam, his two sons and my mom carried him in a hammock through the watermelon farm and down the dirt road to the nearest hospital. All four kids and twenty grandchildren took turns visiting my grandpa in the hospital, even if that meant riding a bicycle or walking for two hours. Here in America, on the other hand, my brother was an hour away from UNC Hospital by car, but never visited once in the six months my dad was at the hospital. I was angry for a while, resentful almost.

Caring for my dad was not an easy task. The first few years were characterized by fear, being on alert 24/7, and just genuine busyness. Year four is when I got comfortable and started adding in normal components of life. I started seeing friends for lunch and went back to school. My mom and I took our first vacation together since my dad got sick. Still, I started to feel the regret of not having a truly normal life, and I began to understand why people choose not to enter the caregiver role. I had only been doing this for a few years and could not imagine the burden felt by parents of disabled children or spouses of disabled veterans who fulfill this role their whole life. I felt those negative emotions: whether it was the third trip to the emergency room for the same feeding tube problem in one week, or the 3:00 am coughing fit that snapped me out of a sound sleep to perform suctioning because I feared my dad would aspirate on his own saliva again. I couldn't always be that "inspiring" person who gave up their life to be a caregiver. It gets tiring. It wears you down. I never let my dad see that side of me though. I never wanted him to know how hard some days were. I never wanted him to feel any guilt.

Looking back on the six years as my dad's caregiver, I don't regret a thing. I loved every moment of it, whether it was shaving his beard and watching him run his one functional hand across his cheek feeling for stubble, cleaning him while reassuring him to not be embarrassed, or performing hand massages to keep the swelling down while reminiscing about holding his hand to walk to school as a kid. I always felt better at the end of the day knowing I gave my best for him. I love taking care of people, and being there for him gave me so much motivation in life. However, it's not for everyone. With the lack of resources, especially in cities with underdeveloped healthcare, it can be almost impossible to navigate. My minimal knowledge as a medical assistant gave me enough background to manage the tedious aspects of his care, but what about those who don't speak English or are aging themselves? What about the illiterate who cannot navigate a Medicaid application? What measures are in place to support families

that struggle paycheck to paycheck or can't find flexible work when they enter into the role of a 24/7 caregiver? What about the cities without wheelchair transportation? Or families in apartments, trailers, or homes without enough room to accommodate a hospital bed, Hoyer lift, or wheelchair? It is not an easy task. I only hope that there are more resources in the future to not only support the patient, but the family as well. As much as I love my dad and felt I could handle it, it was not enough. I still needed help, and so will many others.

A stylized graphic of an eye, rendered in shades of gray. The eye is composed of concentric circles for the iris and pupil, with curved lines above and below representing the eyelids. The text is centered within the eye graphic.

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Her research focuses on the health of military children and she plans to become a physician specializing in Pediatrics.