

When Love Becomes Caregiving

“For better or for worse” is a common phrase we have all heard. It is commonplace in our culture to make this vow and follow it up with a happy, celebratory party. Wedding vows are often accompanied by images of future children, a home, and maybe even a dog. I have to admit, on my wedding day last year, these were some of the things I thought about. We, as people, don’t like to think about the "worse" part until it is staring us in the face. And it will. Sometimes, "worse" looks back at you in the mirror with a sad and tired expression. Sometimes, "worse" is an external challenge that you and your family or spouse must fight together. Sometimes, "worse" is looking into the eyes of someone you love and recognizing that everything about them—and your relationship with them—has changed forever.

Do we ever think about what it would be like to go from a spouse, a partner in crime, or a helper to a caregiver? Do we ever consider the possibility of the person who raised us, who loved us, and who read to us every night becoming dependent on us? Do we think about ourselves transitioning from being a child to becoming a caregiver?

No. We don’t.

We recognize that hard things happen, but we like to bubble-wrap our own families in optimism. Then, layer by layer, that protective wrapping comes off, and we are left to discover what marriage means to us, what family means to us, what faith means to us, and what "worse" truly looks like.

Don't get me wrong—there can be beauty in "worse." We can grow closer during hardship. Sometimes "worse" is when we really get to meet ourselves or learn more about each other. Sometimes we can experience love on deeper levels. We can come to understand the mercy and grace that, as a person of faith, I believe only God can give.

A common question we ask in patient interviews as medical students is, "Do you have a support system?" But what happens when I am that support system? What happens when you are?

It is estimated that 41.3% of caregivers of frail older adults are adult children, and 38.4% are spouses (Wolff JL and Kasper JD, 2006). I have watched my parents and grandparents become part of this statistic firsthand. I continue to witness them navigating these role transitions through different seasons of life.

Dr. Paul Kalanithi, in his book *When Breath Becomes Air*, writes, "As a resident, my highest ideal was not saving lives—everyone dies eventually—but guiding a patient or family to an understanding of death or illness." I wonder how well we prepare families for this transition. Is this something we teach in medical school, or is it learned only through experience and patient testimonies? As a 23-year-old medical student, I am currently striving to understand anatomy, pathology, and illness scripts. My future role as a provider feels structured: we are taught how to ask the right questions, how to best show empathy, and how to perform physical examinations so that we can help our patients. It all makes sense.

But guiding family members through the shift from loved one to caregiver does not fit neatly into our lesson plans. The truth is, no one can teach someone the best way to love another person because love is deeply personal. In medicine, whether as a doctor, nurse, family member, or caregiver, the best way to learn care is often by example—by witnessing those who have walked this path before us. I have had several such examples in my life.

When I was younger, my grandpa began to decline. I watched without fully understanding as he stopped driving, started napping more, and became increasingly confused. Now, I recognize what I could not grasp then: my grandmother and father stepped into caregiving roles. My grandparents' house, just up the street from my childhood home, has always been filled with love. It is a living museum of family history, with wedding photos, high school graduation pictures, and Christmas cards from family friends. I have only ever seen the house this way, but, during the years of my grandpa's last, I imagine that this house became a patient room to my grandma and father.

I never had to change my perception of my grandpa. To me, he had always just been my grandpa—the man who hated leftovers, who walked behind everyone at Disney World, who preferred the old hymnal at church, and who was unwaveringly generous. But now, as an adult, I wonder how my grandmother and father's perceptions of him had to change as his mind and body declined.

I watched my father transition from occasional visits to daily trips, then to trips several times per day. He never complained about his new role that I can remember,

though it must have been difficult. He had no formal medical training, yet he helped however he could.

I wonder what my grandmother's prayers looked like during that time. Did she pray for God's will? For healing? For strength? In thanksgiving? Likely all of these and more if I know my grandmother. She had to balance being both a wife and a caregiver, reconciling that the man she had loved for decades was changing before her eyes. She had to learn how to physically support him, help him dress, and, in the end, sit by his bedside in the hospital, knowing that while caregiving had been exhausting, she would miss him every day. I watched her keep her vow until the very end.

Now, I watch my other grandfather and my mother transition into caregivers for my maternal grandmother. When I think this grandma, I think of the copious amounts of butter she likes on bagels, her love for animals, and the fresh cookie dough she always had around when she was younger. Again, I have never had to blur the lines between family member and patient.

I do not know the questions my grandfather has asked himself along the way. Perhaps he first wondered, "How will I cook and do laundry like she always did?" Now, his questions might be, "Will she recognize me today?" and "How well will my knee hold up while helping her?" Also with no medical training, he now has to navigate many hard-to-pronounce medications that he doesn't know the mechanism of.

That would be scary to anyone, and yet he keeps his vow too. He still calls her "dear" every day.

I wonder what it is like for my mom to switch between being a daughter, a voice of reason, and a caretaker every day. I wonder what it is like to call her siblings not just to catch up, but to provide updates on their mother's condition. Caregiving reshapes every relationship, not just the one with the person receiving care. I have watched my mother debate care decisions with her siblings and father. I have watched her sacrifice time and energy to be with her mother every day. And I have watched her, after leaving her parents' house, finally allow herself to acknowledge her sadness and struggle.

And me? I watch, I listen, and I strive to learn from them – my family, my community, the people I care for and work alongside. I take in their stories, their strength, and the daily challenges that they face. Reflecting on each of these things adds to my faith in God's design and my understanding of the human experience. I store up this information and add it to my curriculum – the lessons not found in medical school lectures but passed down through lived experience.

We often talk about the “hidden curriculum” of medical school, the idea that there are many unspoken lessons that shape our patient interactions, professionally act, and how we practice medicine. But there is also a hidden curriculum that doesn't come from classrooms or white coats, but from family. This hidden curriculum helps teach us how to navigate struggles with a united front, celebrate when the time comes, and how to grieve together. These lessons are just as important as the scientific knowledge that is also essential for healthcare.

As healthcare providers, we must recognize that caregiving is an essential part of a patient's journey—one that we will never fully understand and cannot prescribe a perfect plan for. But I hope to be the kind of doctor who makes caregivers feel seen. I hope I never forget to ask the family member bringing a patient to an appointment, "How are you doing?" and to genuinely listen. I hope I never forget to say, "Thank you for what you are doing."

Medical students are often asked, "Why do you want to be a doctor?" Many respond that they want to help people, that they have family members in healthcare, or that they are fascinated by the human body. These are all valid answers, but there is usually a deeper truth beneath them.

For me, that deeper truth lies with my family and the examples they have set for me. I have no immediate relatives in professional healthcare, but I come from caregivers. I want to be in healthcare because I have witnessed my grandparents honor their vows in sickness and in health. I want to be in healthcare because of my father's quiet faithfulness and my mother's loving persistence. I want to be in healthcare because my family has shown me what it truly means to holistically care for another human being.

So, to all of my teachers, both in the classroom and in life, thank you.

Sources:

1. Wolff JL, Kasper JD. Caregivers of frail elders: updating a national profile. *Gerontologist*. 2006;46(3):344-356. doi:10.1093/geront/46.3.344
2. Kalanithi, P., & Verghese, A. (2016). *When breath becomes air*. First edition. New York, Random House