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Narrative Medicine

Why I Brought My Mother Home

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Abstract

Background
According to the Alzheimer's Association, in the United States more than 16 million adult family members provide care for a relative with Alzheimer's disease or other dementia. The economic value contributed by unpaid caregivers is $234 billion dollars. Such caregivers are vital to the ability of the U.S. to meet caretaking needs, as the projected number of individuals suffering from dementia will nearly triple over the next 30 years. A meta-analysis found that decisions to provide family caretaking are rooted in long-standing family relationships. This essay explores one family's decision to move from long-term institutional care back to family-based care in the home setting.

https://www.alz.org

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This is a story many of you could write, as a slightly different version.

The elements of my story may already be or likely will become familiar to you—elements of the decline of an older family member still wanting to live independently.

Initially, we watch; we see them be heroic about and then oblivious to their increasing deficits. We monitor; we assist, but this is only possible to a point.

We then wait, for that moment when we can seize the opportunity to wrestle control for the sake of safety and sanity—in this case, my mom's safety, and my sanity.

My mother was admitted to Memorial Hospital Jacksonville's geriatric unit shortly after being sold a brand-new SUV. She told the dealer her 3-year-old RAV4 with 29,000 miles was "making noises" and she didn't want it to break down. This 81-year-old, with difficulty walking due to severe degenerative joint disease of the knees, was convinced to enter into a 72-month loan on a new RAV4 with "lower payments." Never mind that she was unable to operate the gear shift or see the start button, now cleverly placed by some obviously very young engineers behind the steering wheel.

Somehow she got the car to the bank and then returned home, with the assistance of several kind strangers demonstrating again how to use the gear shift. Once at her 2-bedroom patio home (specifically bought for her retirement), her inability to put the car in park or shut the engine off resulted in the car dragging her down the small driveway and into the median of her cul-de-sac. As she struggled to stabilize herself, she frantically yelled for help. Thank heaven for Florida palm trees, one of which stopped the car, and for helpful neighbors, who called me immediately. Charlie and Jack came to her rescue, assured me she was not physically harmed, and then set the tone. “Marilynn, you need to see a doctor.” Mom, somewhat uncertain, finally agreed to go see the doctor. We drove straight to admissions.

As you likely have observed in older relatives or patients, my mother was deemed to have little working frontal lobe executive function. After a week’s stay to allow the usual observation and testing, my husband and I drove her to a memory care unit that had immediate availability. She was eventually coaxed out of the car and into the “senior community” by their director of nursing, whose skillset displayed a high level of familiarity with reluctance.

With Mom safely recovering from the initial shock, we began the process of both supporting her and going through the many steps of putting things in order—reviewing bills and bank accounts, arranging home vet visits for her cats (fleas, ugh!), and recognizing our own limitations, calling in a hoarder clean-out service. After storing her furniture and having her home repainted, we had easy-to-clean, laminate flooring installed, and started up full service daily cat care.

Meanwhile, Mom started asking when she could go home. My husband and I tried to help her adjust by taking her out for meals and then to church, which she missed terribly. She remained disoriented to the day, month, and place, but like many strong, stubborn parents who have molded their children into future physicians, she knew her routine and wanted to follow it. That meant being in her home—“It’s paid for”—and with her cats—“I miss my babies.” Complaining started after we arrived for each visit. “Get me out of here.” This mantra was followed by opining that she was not getting enough food and the only activity acceptable to her was to remain in her room and watch TV.

She was not entirely wrong. When I came at mealtimes, she was noticeably less active, meals were of small portions and she had parallel conversations with only two other 2 women. “My friend only eats peanut butter for all her meals.” “This woman holds her baby doll all day.” “That man keeps telling the same story over and over.” Cognizant that her identity was one of not belonging in this new environment and that she did not have much in common with the other residents was disconcerting. Watching her become unhappy and feel caged, and hearing her ask repeatedly, “Let me live my life, why can’t I go home?” was disheartening.

My fairly physically active otherwise physically healthy mother was not adapting to her new environment, even after 4 months. The staff at the memory unit advised us to visit less often to help her adjust, but she did not give in. She clamored more frequently for her old way of life. This behavior was exacerbated by taking her out for meals, shopping, or church. I soon recognized these events as dopamine burst responses induced by pleasurable community activities. Between outings, she appeared to be having withdrawal symptoms. And she just simply did not understand why she was there, except to recover from the incident with the car.

The final “straw” in the evolution of our family’s decision to bring her home was the start of physical complaints I could not explain, interpret or rectify. The Certified Nursing Assistants were very nice but their training limited their ability to interpret her new constant cough, recent headaches and lightheadedness, and several falls and one middle-of-the-night episode of chest pain. Taking her to outpatient appointments resulted in diagnostic tests, and talking with her primary care nurse practitioner steered medication changes, but not being with her or knowing how she really was doing limited my ability, as her personal “physician-daughter”, to assess her as well as her response to new medications, including donepezil, memantine, and diphenhydramine or trazodone at night. Simply put, it was substandard care. She was unhappy, and I was unhappy that she was now more physically vulnerable without good rationale, and we had the means to change this.

So we cut a deal—she would stay at our home for dinner, overnight and breakfast, and then go to her home (thankfully located near our home) during the day to take care of her babies, the cats.

Is it a perfect situation? Not unexpectedly, it is not. We get lots of pickiness, criticism, occasional meltdowns and demands but overall, she is happier most of the time and I can work without worry. I can assess more easily her physical and emotional health, and I can also gauge the rate of progression of her dementia.

I recognize I am exceedingly fortunate and indebted to my husband Mark, who, as “house spouse”, otherwise known to female physicians as chief child and pet care provider, accountant, and business/personal manager, agreed to take this role on because of his love for me and commitment to our family. I give him a break when I can but most importantly, Mom, Mark and I eat breakfast and dinner together, go to church together, and occasionally go shopping together. It is what a family does.

It has been a long process of adjustment to become my parent’s parent, especially when she still tries to advise me (“Don’t you need a jacket?” “Mom, I’m fine, it’s Florida!”). Life has come full circle. I take care of her as she has taken care of me, spurring me to achieve my best and providing me with activities and educational opportunities. There is no other way to repay her for the love and devotion she gave to me, which enabled me to become a physician.

Will our situation change as her illness progresses? Undoubtedly, but the big-picture perspective and openness to change I have now practiced will help ensure peace with future decisions.

This story ends, or rather continues, by acknowledging the tremendous effort required of all family members, who, like us, are called to step into roles to make decisions and provide the level of support needed for their loved ones’ transitions and daily care activities. I thank them profusely for the peace of mind they provide and sacrifices they make.

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Dr. Gracious asks that readers contemplate sharing their own stories, toward building wellness through the medical humanities. Please consider emailing an essay, poem, photograph, artwork, or link to music or dance at Barbara.Gracious@hcahealthcare.com or submit your work directly to the journal.

Conflicts of Interest

The author declares she has no conflicts of interest.

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