VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

Living with Alzheimer Disease and Other Types of Dementia: Stories from Caregivers

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Introduction
Living with Alzheimer Disease and Other Types of Dementia: Stories from Caregivers

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Abstract. This symposium includes twelve personal narratives from people who have provided care to a spouse, parent, another relative, or friend with Alzheimer disease or related dementias (ADRD). People with ADRDs often face years of cognitive decline with memory and thinking that eventually require help from others to assist with their daily activities. Most people caring for older adults in the US are unpaid family members, friends, or other informal caregivers. People providing care often experience emotional and physical stress, or financial burdens. This symposium also includes three commentaries by experts in the fields of bioethics and philosophy, justice in healthcare, family caregiving, and end of life choices. These narratives provide a forum for exploring caregiver needs, suffering, benefits, and joys, as well as opportunities to improve the way we support caregivers and people with dementia and Alzheimer disease.

Key Words. Medical Ethics, Narratives, Alzheimer Disease, Dementia, Terminal Care, Caregivers, Challenges, Joys, Health Care Economics, Social Justice, Empathy

Introduction

Alzheimer Disease (AD)[1] is the most common type of dementia and affects nearly 5 million people across the United States (Goren, Montgomery, Kahle-Wrobleski, Nakamura, & Ueda, 2016; Okonkwo & Asthana, 2017). Other conditions, such as Lewy Body Disease or frontotemporal disorders, also cause dementia, but these are less common than AD. All Alzheimer disease or related dementias (ADRDs) cause progressively worsening cognitive decline that eventually interferes with an individual's ability to perform activities of daily living, ultimately requiring assistance from caregivers. An estimated 85% of the people caring for older adults in the US are unpaid family members,

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[1] *In this symposium we use both Alzheimer Disease and Alzheimer's Disease based on author preference.*

friends, or other so-called "informal" caregivers (Kahn, Wishart, Randolph, & Santulli, 2016). Society relies heavily upon these informal caregivers to tend to and care for older adults, particularly those living with ADRDs, who often face years of memory and thinking difficulties.

Caregivers commonly make major sacrifices to help relatives or friends living with ADRDs to navigate their daily life. Given that they are unpaid, informal caregivers have to balance caregiving with other existing family and work obligations and commonly experience significant emotional and physical stress, which can lead to health risks and injury for caregivers themselves (Kahn et al., 2016; Werner, Mittelman, Goldstein, & Heinik, 2012). Informal caregivers experience high rates of depression and mental health problems (Family Caregiver Alliance, 2020; Monteiro, Santos, Kimura, Baptista, & Dourado, 2018). They often take on financial burdens, especially when caring for someone in the later stages of the disease (Grabher, 2018; Kahn et al., 2016). Women are more likely than men to serve as informal caregivers, and the long-term effect on their finances is significant (Family Caregiver Alliance, 2020; Kahn et al., 2016). Over two-thirds of informal caregivers report having to reduce their work hours or take unpaid leave to provide long-term care to a person with ADRDs, missing out on wages and ultimately, pension and social security benefits (Family Caregiver Alliance, 2020; Goren et al., 2016).

The loss of memory and thinking abilities associated with the ADRDs taps into deep-seated concerns and fears about loss of personhood and autonomy, and these diseases remain highly feared and stigmatized (Davis, 2014; Werner, Karnieli-Miller, & Eidelman, 2013; Werner et al., 2012). One consequence is that individuals may deny or avoid acknowledging symptoms, and physicians remain reluctant to disclose a diagnosis of dementia (Livingston et al., 2017; Low, McGrath, Swaffer, & Brodaty, 2019; Marzanski, 2000). The stigma and fear associated with ADRDs not only affects individuals with these diseases, but amplifies the burden that is placed on informal caregivers by causing them shame or embarrassment, social isolation, and delays in seeking help (Kahn et al., 2016; Werner et al., 2012).

Woven throughout stories, we see examples of late diagnoses and a failure to recognize symptoms early on, guilt and shame experienced by caregivers combined with anger and frustration both at their situation and sometimes at the person with dementia. Caregivers experience challenges as they negotiate the loss of autonomy for the person with dementia, for instance, when car keys are taken away, or they must make painful decisions to move a person to a facility rather than staying at home. Many stories describe the need for lying, or what some term "compassionate deception," as a way of meeting the person with dementia where they are at, rather than constantly insisting on the current reality (Tuckett, 2012).

Notably, many authors who share their stories in this symposium express gratitude for being able to provide care for a loved one. They describe the joy in their loved one's ability to spend more of their years aging in place at home despite having an ADRD. They convey recognition of new concepts of personhood in the individual with an ADRD, even if it is drastically different from how the person once was. They go on to describe heartbreaking moments when, finally, the burden of the disease becomes too great, forcing them to transition their loved one to a skilled nursing or memory care facility. We see how caregivers make meaning out of their suffering and the struggles they have endured. Yet, we wonder whether these positive recollections are a way in which the authors are grappling with their own conflicting feelings, which also include frustration, guilt, or anger.

While the stories contain themes of gratitude, some authors express their own end-of-life preferences, which are influenced by their caregiving experience. These authors describe, often in painful terms, wishing for the death of their loved one, or never wanting to find themselves in the same situation, making references to taking their own life before this could happen, or tattooing a do-not-resuscitate on their chest. These sentiments convey the pain and suffering that people associate with ADRDs and suggest that the experience of caring for someone with ADRD leads some individuals to see the disease as a state worse than death when contemplating their own future.

In fact, not all the authors describe loving relationships with the person for whom they provide care. Author Sunnie Songeun We shares her story in which she is responsible for caring for her abusive father with dementia for over a decade until his death. She writes about the alienation she felt when expressing her rage and guilt over having to take on the caregiving responsibilities for a man who abused her. Instead of validating her feelings, confidants would tell her she must not mean her harsh words, "Well, he *was* your father . . . you must have loved him deep inside." Another author, Sheri L. Yarbrough, also describes a complicated relationship with her mother. Yarbrough writes, "I realized that I had to put our past behind us so that we could live looking forward." The two authors remind us that family dynamics are complicated. Existing wounds are not erased by dementia and old age. People take on caregiving responsibilities despite their complex relationships.

A few authors mention sharing caregiving duties with others or having significant social support. However, for the most part, the authors describe being the primary individual responsible for caregiving. While not the majority, some stories address how to live after caregiving has ended, with some becoming advocates, volunteers, setting up memory cafés, or taking part in other forms of advocacy in their post caregiving life.

The Call for Stories

In the call, we sought true personal stories from people who are currently or have cared for a family member or close person with ADRDs. The narratives in this symposium were written mostly by women. They include daughters (N=6), a son (N=1), husbands (N=2), an ex-wife (N=1), a son and daughter duo (N=1), and a daughter and granddaughter pair (N=1). We were interested in hearing about caregivers' experiences, challenges, benefits, and joys. We also aimed to learn about the needs of informal caregivers as decision makers develop policies and laws aimed to support them.

Authors were asked to consider the following questions:

- What surprised you about the experience of providing care for someone with Alzheimer disease or another type of dementia? Were there things you did not anticipate?
- Is there anything you wish you had told your family member or the person close to you before their symptoms were severe? If the person you were caring for is no longer living, is there anything you wish you could tell them now?
- Were there any benefits or joys to caring for someone with Alzheimer disease or another type of dementia?
- What have you found challenging in your role? How has the experience affected you physically, emotionally, or economically?
- What would you like to tell someone who is considering playing the role of caregiver?
- What would you like people who develop policies and laws to know about the needs of caregivers?

The editors of *Narrative Inquiries in Bioethics* published the Call for Stories in the NIB newsletter and on the NIB website. Additionally, the call was posted on the NIB social media platforms, including LinkedIn, Facebook, and Twitter. It was distributed through the American Society for Bioethics (ASBH), and the Medical College of Wisconsin (MCW) list serves. We cast a very broad net in our call for stories. Many colleagues and institutions helped us distribute the call, including the Knight Alzheimer's Disease Research Center (ADRC) at Washington University School of Medicine in St. Louis, the ADRC at the University of Michigan, the Penn Memory Center at the University of Pennsylvania, and Geisinger Health. Colleagues working in the fields of biomedical ethics, public health, and psychiatry also helped us distribute the call through their clinical or research venues and social media accounts. The call was shared on social media and in newsletters by the Validation Training Institute (VTI), Memory Care Home Solutions, and CaringKind in NYC (formerly the NYC Chapter of the Alzheimer's Association).

Despite all our efforts, the response to the call was slow to start. We think that discomfort and embarrassment on caregivers' part in sharing their stories may have contributed to the difficulties we encountered gathering stories initially. The NIB communications coordinator reached out to the contact for education and outreach at every ADRC across the United States to ask for help distributing the call. The NIB managing editor asked the first few authors to pass the call on to anyone who might be interested in sharing a story. One of those authors, Walt Zerrenner, distributed the call to members of the Fox Valley Memory Project, the Wisconsin Dementia Resource Network, and the State Task Force for Care in the Community. Hard copies of the call were posted at libraries and churches, a strategy that might be especially important for older adults who may not be online or using social media. Our colleagues sent the call to family and friends. Despite the slow start, we were successful in the end and are able to share 12 narratives in print and an additional nine narratives in the online supplement.

The Narratives

Most of the NIB authors in the symposium are females, and woven in these stories, we often find the expectation that women will do the primary caretaking, even when there may be male relatives who could arguably do the same. As mentioned above, over half of the authors are daughters, which is consistent with the data—a disproportionately low number of males serve as informal caregivers (Kahn et al., 2016). We welcomed stories from authors outside of the United States; however, we only received stories from caregivers in the United States. This is not surprising, given that our recruitment of storytellers picked up once we relied on word of mouth and posted flyers in libraries and churches in the United States. While we do not know demographic details about our authors, the details of their stories suggest that the most disparate people are not represented in these narratives. The authors all have adequate housing, access to food, and access to health care (albeit not always ideal).

We received several inquiries from potential authors for this symposium who were interested in submitting original poems about their caregiving experience. With their proposals, several authors shared photos of loved ones who they provided care to or are still caring for, which we understand is unique to this symposium—the journal does not typically receive such responses. Perhaps the sharing of these sentimental mementos demonstrates the intense emotions that are tied up with caregiving, which may be difficult to convey in a narrative. Sending photos of the person with dementia also serves as a way of remembering and memorializing the person, perhaps before they got dementia.

The Commentaries

This symposium includes three expert commentaries. The commentary authors read and studied the narratives and were asked to draw out themes and lessons learned.

Dr. Nancy S. Jecker is a Professor of bioethics and philosophy at the University of Washington School of Medicine, Department of Bioethics and Humanities who writes and teaches on bioethics and justice in healthcare.

Ms. Carol Levine, MA, is a senior fellow at the United Hospital Fund in New York City and the former director of the UHF Families and Health Care Project. Her work focuses on family caregiving.

Dr. Judith Schwarz is the Clinical Director of End of Life Choices New York. In her role, she counsels families and patients suffering from incurable, progressive, and terminal illnesses about end of life decisions.

Conclusion

These narratives demonstrate the challenges that informal caregivers experience in providing care to people with dementia or AD, even if they describe feeling gratitude in retrospect. While more than 5 million Americans are currently living with AD, this number is projected to increase to nearly 14 million by 2050 (Alzheimer's Association, 2020). We must find strategies for identifying and assisting informal caregivers, who in their caregiving role, show dedication and compassion and are at risk of experiencing undue emotional, physical, and financial burdens. This will require resources and policies on the national level.

In addition to policies, there is a need to change attitudes and increase the public's knowledge about ADRDs. This may help alleviate the shame caregivers often feel, causing delays in diagnosis or treatment for the person with dementia or AD and apprehension for the caregiver in seeking assistance from others. However, as caregivers' stories illustrate, there are legitimate reasons to fear ADRD given its emotional, physical, and financial impact. Healthcare workers and case managers who interact with informal caregivers can offer support and information about coping strategies so that informal caregivers are equipped to manage the burdens that caregiving generates. Policies and services that support caregivers could reduce the burden and stigma associated with dementia and are needed to ease the strain on informal caregivers.

References

Alzheimer's Association. (2020). *2020 Alzheimer's Disease Facts and Figures*. Retrieved from https://www.alz.org/alzheimers-dementia/what-is-alzheimers/women-and-alzheimer-s

Davis, D. S. (2014). Alzheimer disease and pre-emptive suicide. *Journal of Medical Ethics, 40*(8), 543–549. doi:10.1136/medethics-2012-101022

Family Caregiver Alliance. (2020). *National Policy Statement.* Retrieved from https://www.caregiver.org/national-policy-statement

Goren, A., Montgomery, W., Kahle-Wrobleski, K., Nakamura, T., & Ueda, K. (2016). Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcomes: findings from a community based survey in Japan. *BMC Geriatrics, 16*, 122. doi:10.1186/s12877–016–0298-y

Grabher, B. J. (2018). Effects of Alzheimer Disease on Patients and Their Family. *The Journal of Nuclear Medicine Technology, 46*(4), 335–340. Retrieved from http://tech.snmjournals.org/content/46/4/335.full.pdf doi:10.2967/jnmt.118.218057

Kahn, P. V., Wishart, H. A., Randolph, J. S., & Santulli, R. B. (2016). Caregiver Stigma and Burden in Memory Disorders: An Evaluation of the Effects of Caregiver Type and Gender. *Current Gerontology and Geriatrics Research, 2016*, 8316045. doi:10.1155/2016/8316045

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., . . . Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet, 390*(10113), 2673–2734. doi:10.1016/s0140-6736(17)31363-6

Low, L. F., McGrath, M., Swaffer, K., & Brodaty, H. (2019). Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners. *Dementia (London), 18*(7–8), 2856–2905. doi:10.1177/1471301218761911

Marzanski. (2000). On telling the truth to patients with dementia. *Journal of Medical Ethics, 26*, 108–113.

Monteiro, A. M. F., Santos, R. L., Kimura, N., Baptista, M. A. T., & Dourado, M. C. N. (2018). Coping strategies among caregivers of people with Alzheimer disease: a systematic review. *Trends in Psychiatry and Psychotherapy, 40*(3), 258–268. doi:10.1590/2237-6089-2017-0065

Okonkwo, O. C., & Asthana, S. (2017). Dementia Trends in the United States: Read Up and Weigh In. *JAMA Internal Medicine, 177*(1), 58–60. doi:10.1001/jamainternmed.2016.7073

Tuckett, A. G. (2012). The experience of lying in dementia care: a qualitative study. *Nursing Ethics, 19*(1), 7–20. doi:10.1177/0969733011412104

Werner, P., Karnieli-Miller, O., & Eidelman, S. (2013). Current knowledge and future directions about the disclosure of dementia: a systematic review of the first decade of the 21st century. *Alzheimer's & Dementia, 9*(2), e74–88. doi:10.1016/j.jalz.2012.02.006

Werner, P., Mittelman, M. S., Goldstein, D., & Heinik, J. (2012). Family stigma and caregiver burden in Alzheimer's disease. *Gerontologist, 52*(1), 89–97. doi:10.1093/geront/gnr117

Personal Narratives

Role Reversal in the Art of Caregiving

Sara Baxter

I get off the elevator on the third-floor memory care unit of my mother's facility armed with strong resolve and a plastic baggie filled with Golden Oreos. I will no doubt need both.

I start the routine of looking for my mother. Sometimes she is sitting in one of the upright chairs—the kind you might find in a formal living room—facing the elevator. But today the only one occupying the chair is a slim, well-dressed man with a gray mustache.

I nod to him and turn right to go in the common area of the floor. The residents are all sitting in a silent circle. The TV is on, but no one seems to be paying attention. I spot my mother three chairs in and wave to her. She looks at me blankly.

"Hi, Ginny," I say.

I no longer call her "Mom" as she doesn't seem to recognize that name (or me), so I've started calling her by her first name. She responds better to that than "Mom," which I suppose is appropriate—her role as my mother is gone.

"Guess what?" I say, way overenthusiastically. "I'm going to take you outside today."

She stares at me for a few seconds, as if trying to process this. "No," she says. "I want to stay here."

It's ironic that she doesn't want to leave the place where she lives, as there was a time she disliked it so much she tried to escape. The kind of escape where alarms go off and the staff panics and you're automatically moved to the locked third floor.

"Come on," I coax, "it will be fun." She just shakes her head.

We're three weeks into a potassium crisis. My mother's levels are much lower than they should safely be. This situation has required increased doses of potassium pills and weekly blood checks.

My mother likes neither.

So I am here for our weekly trek to the lab.

The first week she went with me happily, obediently holding my hand as I led her off the elevator and out the front door into the sunshine. "This is going to be fun," she remarked, having no clue where we were going or what was going to happen to her. "We can only hope," I said to myself silently.

The next week I was not as successful. When I went up to get her, she refused to go with me. I pulled the Oreos out of my purse and waved the bag in front of her. "Look what I have," I say. "Come on. We'll eat one in the elevator." She definitely wanted the cookie, but she didn't want to leave. She sat defiantly on the overstuffed sofa in her room and told me to "just go on." I had to abort the mission and try again the next day.

Her mental state and the way I have to deal with her is much like that of a two-year-old. I redirect, distract, and yes, bribe. But unlike a stubborn toddler, I can't pluck her up and make her do anything she doesn't want to do.

My mother was diagnosed with semantic dementia in 2014. My parents were divorced, and my mother moved down to Atlanta to be nearer to me 20 years ago. So even though I have two brothers, the responsibility of caring for her fell to me.

The signs started appearing at least two years before her diagnosis. She would forget words and constantly repeat herself. At first, we chalked it up to the fact that she lived alone, was fairly isolated, and didn't have a lot of interaction with people. But then the signs got worse: she lost more of her communication skills, was unsure of where she was going when she was driving, had trouble writing checks and keeping her finances straight, and started cutting back on feeding herself (and her dog) because she thought she had no money.

I was also getting calls from her friends, who were noticing big changes. Her brother voiced his concerns as well. At first, I felt helpless. I knew there was a problem, yet when I broached the subject with her, she denied it, saying it was just "old age" and all her friends were like this. I called her doctor, but he was limited in what he could tell me and how much he could help. I made an appointment for my mother at a memory disorders clinic and ran up against an eight-month wait. In the meantime, her doctor referred me to another neurologist. He turned out to be useless—he agreed with my mother, saying it was normal aging. I knew better.

I persisted, kept the first appointment, and we finally got a real diagnosis. Even though we now knew what we were dealing with, the whole situation was still overwhelming. Like many people, I don't do well with unknowns. And everything pertaining to my mother was an unknown. How long would she go on like this? What would we do when things got worse? At that point, though confused a lot of the time, she was still with it enough to be argumentative and difficult. She fought me on everything. She was not going to help me help her. It was so frustrating, and I didn't always handle it well.

My mother was a bright light. She was funny, smart, and brave. She raised four kids as a single mother. She had a contagious smile and the ability to strike up a conversation with anyone (which could be embarrassing to a teenager). After she retired, she started traveling, seeing the world via cruises. She liked the instant camaraderie of a cruise ship and made friends every time she went. So I thought she would do well in an independent or assisted living facility surrounded by people and ready-made activities.

Of course, she fought me on that as well. I began touring places anyway, wanting to be prepared if or when things went south.

And that's the way things were headed. Every time the phone rang, dread filled my stomach. It could be my mother saying she had fallen or the police telling me she'd called them for no reason. Or the guy from a "We Buy Ugly Houses" type firm saying she'd sold him her house (yes, that really happened). Later, when we were able to get her driver's license revoked, I hired caregivers to come in a couple of hours a day. Some of them would call me from her driveway—she had locked them out.

Because my mother was well off financially and was becoming a danger to herself, we were advised to file for guardianship and conservatorship for her own protection. It is a long, expensive process, and I wouldn't recommend doing it unless absolutely necessary. On December 21, 2015, I was named the guardian of my mother, and my brother was named conservator. We left the courthouse that day having complete control over my mother, and both of us felt profoundly sad.

Having guardianship gave me the legal power to move her into an assisted living facility a mile from my house, which I did two weeks later. Though I knew it was for her own good, I had to trick her to get her there. It was one of the worst days of my life.

Though I had been doing much of it before, I was now entirely responsible for her care. My mother became like another child to take care of (and I already had two teenagers), arranging doctor's appointments, wrangling with the staff at her facility, and dealing with her deteriorating memory, which posed challenges at every level. I became her advocate because she could not do it herself. It was stressful and emotionally draining. It also was heartbreaking to watch my mother slip away slowly.

Along with her memory went her personality. She lost her spark. She didn't laugh much. And she became mean and often physically combative—with me, the staff and, sometimes, other residents. It was a side to her I had never seen.

There is no doubt that being a caregiver to a person with Alzheimer's Disease or dementia is extremely difficult. However, I consider myself very fortunate—I had a lot of support. My husband was so good with her (we used to joke that she liked him better than me). My daughter helped when she could. I am self-employed and work from home, so I had a lot of flexibility with my schedule. I also got a lot of help from the staff at the memory care clinic—they gave great care to my mother, support to me, and offered classes in caregiving and dementia that were very helpful.

The most valuable lesson I learned was to stop arguing. I remember one of the nurses telling me, "you will never win an argument with someone with dementia." So instead of arguing with her, I started agreeing with her. Some examples:

"They don't feed me here."

Instead of, "You just ate lunch," I would say: "I am so sorry about that. I will talk to the staff."

"You never come to see me."

Instead of, "I've been here three days this week," I would say: "I know, work has been so busy. I will try to come more often."

"They are stealing from me." (Sometimes this was true).

Instead of, "No one is stealing from you," I would say: "Well, that's not good. Let's see if we can find what you are missing."

It changed the whole dynamic. I no longer felt like I was banging my head against the wall when dealing with her. She seemed calmer. While there still were frustrating times, that approach made our interactions much better.

I also joined a support group offered by her facility. In January 2018, after she'd been there two years, the facilitator asked what we each hoped the new year would bring. I thought to myself, "I hope I am not here needing this group next year." But I didn't say it out loud. There were a few new people who were just starting their caregiving journey, and I didn't want to alarm them by basically saying I wished my mother would just pass on. But I did.

She didn’t know who anyone was anymore. She couldn’t follow basic commands such as “drink this” or “put your foot here.” She would sit and stare into space and sleep a lot. Though she was well cared for, her quality of life was nothing.

The cruel truth about dementia is that you lose your loved one twice. We lost the mother we knew long ago. And then we lost her physically on April 11, 2019, at the age of 83.

As I look back on that time, of course I wish I had done some things differently. I wish that I had had a conversation with my mother early on about her dementia so I could gauge how much she understood and what she was feeling. For some reason, I never did that. I also wish I had been more patient. None of this was my mother’s fault. Yet sometimes I would snap at her when I was frustrated, or avoid the situation by not visiting her for a few days.

But at the end of the day, I am glad that I was able to provide my mother with the care and (most times) compassion she deserved. When she died, I was holding her hand as she took her last breath. I considered it an honor to be with her. And although I no longer buy Golden Oreos, whenever I see them in the store, I think of my mother and smile.

I Don’t Talk to My Wife Anymore: One Couple’s Account on Dealing with Alzheimer’s

Bernard ‘Bernie’ Binning

It is said one-half of marriages end in divorce. Marcie and I are of the other 50%. We are not by any means exceptional. Besides having that dreamy gaze into each other’s eyes, we are a team. We tag-teamed on raising our kids. The two of us joined together as leaders in Boy Scouts, and as a team, we took part in Big Brothers Big Sisters.

But the most important team effort was Marcie’s undying support to me being on our city’s full-time fire department for 27 years. I was already on a volunteer fire department when we got married. Fire and police hold records in divorces, with the ‘24 hours on, 24 hours off’ schedule being a little obstructive to family.

Did Marcie ever waver? Never. She was as dedicated to the fire service as I was. We are a team.

Years ago, on the “The Tonight Show,” Johnny Carson asked Truman Capote to describe the word “marriage” in as few words as possible. Capote answered, “Unfinished sentences.” This has stuck with me. A long-partnered couple can communicate in a very special, almost Neanderthal way, each of them knowing what their mate is thinking. Now, apply Alzheimer’s Disease to one of the partners.

Dementia. Alzheimer’s. Words that were not familiar to our generation a half-century ago. We knew of senility, senile. Maybe a light-hearted, “touched in the head” or even “doddering” was used.

“All-Timer’s”: noun Alz ·he i ·me r ‘ s disease, ‘alts-,hi-merz-, I couldn’t even spell it until recently.

The Alzheimer’s Association lists seven stages of Alzheimer’s:

Stage 1: No impairment
Stage 2: Very mild decline
Stage 3: Mild decline
Stage 4: Moderate decline
Stage 5: Moderately severe decline
Stage 6: Severe decline
Stage 7: Very severe decline

In September of 2012, our son Mike, daughter Sandy, and I noticed Mom’s memory slipping. Our next-door neighbors easily picked up on Marcie’s trouble too. She created a knack for taking a couple of past family stories and weaving them into one, sometimes coinciding with a present situation. All of us thought it was her way of trying to deal with our daughter, Dawn’s recent passing.

It wasn’t. Marcie was diagnosed with Alzheimer’s. It was at this time we recalled that Marcie’s mother suffered from dementia. It was little things at first, déjà vu being prevalent. She ‘remembered’ seeing things that were impossible for us to have seen, or being somewhere that was impossible for us to have been.

When overtaking a semitrailer truck, she would wave, knowing that the truck driver remembered her “from the other time we saw him.” She would say, "We parked next to this same car the other time we were here." Or she would walk up to strangers and, much to their surprise, greet them like long-time friends.

During this time, I took over doling out her medication as I caught her taking them out of the prescribed sequence. Our doctor said she couldn't be left alone anymore.

I started keeping notes. When we would have an appointment with the doctor, I would mail a detailed report ahead explaining Marcie's new or changed symptoms—I didn't want to allow myself to forget anything that I wanted them to know and understand. This stage of our Alzheimer's experience makes me stop, think, and wonder when my mind goes blank; am I sharing Marcie's condition? Am I flying under the radar? How would Marcie react if our roles were reversed?

It is very uncomfortable talking about Marcie's symptoms, whether in front of her or behind her back. This feels disgraceful. She is, by nature, a suspicious person. Her lifelong ability to mistrust has worsened with the onset of Alzheimer's. I need to state the difficult time I have doing this—writing behind Marcie's back, just as I did when I reported to the doctor. While encouraged to write this piece, I had and still have great reservations about doing so.

Marcie's routine of repeating questions became the norm. She would ask a question, and in 15 minutes, ask it again as if it was the first time. At first, this tries on one's patience. A series of the same repeated question could last an hour or more. As the disease progressed, the fifteen-minute intervals shortened over time, cutting down to five-minute repetitions. One needs to learn and remember that one has complete control over one's own emotions, but the partner with Alzheimer's has a complete lack of control.

We were to visit Sandy's family for four days in August 2015. Marcie took three days to pack her suitcase. Right before we were to leave, Sandy was put in the hospital with a gallbladder attack.

Marcie went into a tantrum. "Sandy always spoils our plans whenever we plan on doing something special." Marcie couldn't tie Sandy's emergency and our four-day visit into the one it had become. The tantrum turned into an anxiety attack. In the 60 years we've been 'dating,' I have never seen Marcie this angry. Never. I took her to the doctor. Since then, she has been on lorazepam for her anxiety. She will blindside me every now and then, but if I can downplay it fast enough, she might cool off. She is an angrier person with this Alzheimer's, not like the Marcie I lived with all those years.

We did go on the four-day planned trip, not just as a visit, but to help Sandy recuperate. Within two days, Marcie was inflicted with a serious case of 'homesickness.'

The next month, we planned another four-day trip to visit Mike and his family. The four days were shortened to two days. The third morning as we were heading home, Marcie said, "It will feel so good to be back home." After that, we were able to take overnighters, but our days of taking mini-trips were over. Familiarity plays a huge part in Alzheimer's.

I spoke of Marcie as being angrier. I need to reveal my own battle with anger. After sharing our lives for over 50 years, we consider it a happy and blessed marriage. However, Alzheimer's drives a sharp jagged wedge into those thoughts. Frustration quickly becomes anger, and there are times when one lashes out at the Alzheimer's patient. The caregiver is desperately trying to learn to cope by use of "on the job training." I am embarrassed here because I have lashed out at Marcie. That happens when one's Soulmate makes those emotional rendering comments and makes one's heart leap up into one's throat.

There were going to be many of these trying moments when I needed to look away and do the mandatory "ten count." Or even the "Exit, Stage Left" maneuver and slip into another room to collect my wits. Marcie's bouts with anger sometimes stem from frustration, maybe knowing or realizing she is losing her memory.

A spring morning when we were into the greater decline, I asked my life's partner and supreme cook if she wanted to make pancakes for her husband.

Pancakes it was to be. Before, she always could cook or bake by memory. This time Marcie couldn't even comprehend the directions printed on the back of the box. We tag-teamed the effort and made it through. I got my pancakes.

Something can be learned here. We tend to accept our responsibilities as married couples, playing out the husband/wife role, depending on each other as we do. Over the years of being together, we had taken a lot of this for granted.

When Alzheimer's comes between this match, the marital relationship changes. In a way, the bond becomes stronger. Normally both partners are independent. But, the Alzheimer's patient loses that independence and relies more on his or her partner. The partner, in turn, watches over his or her spouse with Alzheimer's and is now a caregiver by on-the-job training, spreading his or her marital obligation net wider.

"For better, for worse, for richer, for poorer, in sickness and in health, to love and to cherish."

Marcie now needed to be constantly watched, an undertaking very similar to parents babysitting their little ones before they traveled off to kindergarten. I was now:

- Doling out Marcie's meds.
- Watching over and giving her a pain-reliever.
- Helping her choose her outfit—a squabble ensued when changing from winter to spring clothes.
- Helping her in and out of the car with her walker, walking side by side, hand in hand again.

Marcie and I have developed a lifetime teasing and biting romance. We act out what could be construed as a tired quarreling married couple, always snapping at each other. Some people probably thought we really don't like each other, but if they could catch the glint in our eyes, people would accept our ability to tease and laugh at life. We laugh at ourselves and laugh at each other, sometimes using our favorite loving adoring words: "You Old Bag," "Old Grannie," and "You Old Man."

When I would be home and Marcie would come home from her work earlier than expected, I started, in turn, to ask her co-workers to call me so I could get my "girlfriend out of the house." It made for good laughs as her friends would call and giggle to warn me.

Marcie and I took this a step further, and I invented my imaginary 'girlfriend,' which Marcie would quickly bring my manly fantasy to ground by exclaiming, "In your dreams, Binning!"

I have, in the last couple of years, curtailed such humor because of our struggle with Alzheimer's. I'm not taking a chance of Marcie turning inward and letting our old comical routines lead her astray. Both of us deal with her Alzheimer's imagination. Those fun times of ours are gone now.

During a clinic appointment, I hooked a 100-page booklet from their display stand. The book is titled: "Caring for a Person with Alzheimer's Disease," by the National Institute on Aging. About mid-way, it explains, "One needs to keep in mind, one is not talking to the Alzheimer's patient, but talking to the disease." Please, read that over, because these are very powerful words. "One needs to keep in mind, one is not talking to the Alzheimer's patient, but talking to the disease."

Marcie cut my hair and our son's hair for 43 years. In April 2017, she raised the comb and scissors over my head and said, "Now, where do I start?" I answered my helpmate, "We start by returning the tools to the box." That spelled the end of home haircuts for this lad. Marcie took this termination very well and never questioned our giving up on our homespun haircuts.

In May of that year, Marcie looked at me and said, "Where's my husband?"

Me: "I'm your husband."

"No, you're my Daddy."

All the time Marcie and I have been together, she has never called her father "Daddy" or even called me that. After another give and take, I tried to switch her back on the main track by: "Why, 'You Old Bag,' You know me!" I'm the only one who uses that nickname for her. 'Old Bag' should have brought her back. It was I who had to switch over to the sidetrack that evening. It was another Alzheimer's on-the-job training: getting along by going along.

The following month, the inevitable happened. My Soulmate of 56 years and I were separated. She slipped outside without her walker and fell. I was told by the medical people 50-ways-to-Sunday why I could not take care of her anymore. She needed a 24/7 level of care, which they claimed I couldn't provide.

Bless the caseworker's heart when she was trying to convince me to agree to give Marcie up. I asked her pointedly just to imagine how she would feel letting her husband go. I noticed her eyes teared up. It is easy to tell someone else to do it. Believe me—it's a real bitch to do it though.

I tried to counter by telling them I could still be by her 24/7. I had always planned when this stage came on, to install motion detectors covering each outside door. So I did, and tested them, even without my hearing aids. When I returned to the hospital, they asked if I would be able to hear them while sleeping. Score: Hospital = 1, Binning = 0.

With my keen, sensitive Scandinavian mind, I said I'd get a pair of leg shackles for us to wear and purchase a two-place loveseat. My dear daughter, ever supportive of her father, even abandoned me. Our dear physician comes to my aid, saying, "Superglue would work, too." I was outvoted again. Hospital = 2, Binning = 0.

Marcie is a patient in the dementia unit of a swell local health care facility now. Our once happy home is now silent as a tomb.

We are having a time of Marcie adjusting to her new home. I started dropping by daily to visit until the staff asked that I come only two times a week to allow Marcie to adjust to her "new home." Hard on Marcie, hard on me. In her mind, she connects me with "home."

When friends ask to visit her, they wonder if Marcie will remember them. She may or may not at first. But I can say 15 minutes after they leave, she will more than likely forget the visit. This should not, by any means, be a deterrent. The most important thing is to put a smile on her face!

I mentioned our taking day trips. It would be a nice treat for Marcie and me to enjoy a leisurely ride in the country as before our separation. As I write, the fall colors are starting—our favorite time of the year. However, to return her to the nursing home after such an outing would be disastrous. Another point won by Alzheimer's.

Once in a while, the nursing home would let Marcie call me at home in the evening. Her only subject was she wanted me to come to take her home. The calls ranged from 'her paying the motel,' and she finished her job or work and is ready to come home. These calls always digressed badly to where I finally needed to tell them she shouldn't be able to call me anymore. Talking by phone only connected us together and made our separation worse.

My visits take an up-or-down quality. Sometimes I need to leave in 10–15 minutes because our get-together is heading 'into the dumpster' and I can't bring her out of it. These times my Soulmate is telling me how much she hates the place and wants to come home with me. It is heartbreaking, to say the least.

I try to be there when Marcie is at the top of her anxiety medicine's effect. If I have hit it right, we will depart an hour later under congenial terms. The staff suggested I come around during an activity, which does work. Marcie is divided between me and the both of us taking part in the activity.

Another item that happens between us is absolutely deplorable. That is lying to her. I cannot tell Marcie the truth when she asks the same pointed questions about going home. Most of our conversations are very one-sided, and she tends to zero in on this subject.

Another instance of lying is when making my departure at a favorable time. When I feel things are going sour, the plan is to leave before things explode. Usually, the lie is such that a friend is stopping by the house for me to help him with a project. Once Marcie asked me if I was coming home (back to her) after finishing the work.

Ninety days into her stay in the nursing home, I've taken to grade our visits on a scale of 1 to 10. A number 1 being the 10–15 minute "in the dumpster visit" to number 5 being a congenial visit, lasting about an hour. There will never be a number 10; there will never be a perfect visit.

A number 1 visit is with her crying as I leave. "When are we going home together?" "When are you going to come and live with me?" "I hate this place. I want to go with you." Sometimes these questions are asked in the first 15 minutes. But, the real "quarterback sack" is to hear her ask, "Are we ever going to be together again?"

Marcie and I do not have any meaningful conversations. When I mention one of our friends, she says she remembers them, and the subject fades away. There isn't a chance of holding a husband and wife discussion.

Naturally, both of us want to live together again. However, our new situation with Marcie in the nursing home provides her with regular organized daily activities that I cannot provide for her at home. For instance, some of their added mini-homemaking chores make Marcie feel at home. In Marcie's mind, she is helping them, or she thinks she has been working at her place of employment.

You can understand why I titled this writing: "I Don't Talk to My Wife Anymore." It is very trying to look into those blue eyes and ask if anyone came around 'this morning.' For instance, when I know someone stopped by to see Marcie on a certain morning, and I ask if anyone stopped by, her sad answer to me is: "No, nobody has come to see me today."

This isn't a random weekly happening. I could have easily gone on and on with our Alzheimer's events from the past five years. Dealing with an Alzheimer's patient is a 7-day-per-week task. This writing only scratches the surface of everyday occurrences.

I am attempting to prepare for our future. (Fire Service labels this as "Pre-Fire Planning.") I have taken the opportunity to observe the others in Marcie's dementia unit, who are advanced beyond her and me in this illness.

Marcie and I are presently in Alzheimer's 6th stage, and when we slip into the next stage, our 56 years of closeness will separate and drift away. I know Marcie won't see me as I see her. We don't get to choose the way we depart this world. Things could be worse, depending a lot on how you want to look at it or want to deal with it.

I gave the good fight, and kept on, knowing I was waging a losing battle. We are established at the nursing home now, and I am more than comfortable with the care my Soulmate is getting. With that acknowledgment given, there is still the stigma, "What if I could do better?" Let it be known and understood, we who are left will ask: 'Have we abandoned our life's partner?' The truthful answer is: It's imagined abandonment.

I may seem rather cold some times in this writing when sharing Marcie and my Alzheimer's burden. Marcie and I have been wrestling with Alzheimer's since 2012. The books, numerous articles being read and studied, and other folks sharing their experiences helped to take some of the edge off, aiding me to deal with this in a somewhat calm manner. I recall the statement: "One needs to keep in mind, one is not talking to the Alzheimer's patient, but talking to the disease." And, I assure you I have my private, "Daily Tributes to Marcie and My Successful Lifetime Partnership."

Acknowledgment

On behalf of my Soulmate, Marcie, I give my deep appreciation to Dr. Vijay Aswani and Dr. Michael J. Schulein for convincing me to openly share Marcie and my experiences fighting the losing battle with Alzheimer's Disease. I need to give my heartfelt thanks to our kids, Mike and Sandy, for not allowing me to back out of this task. I extend my gratitude to our next-door neighbors, Jerry and Eileen, who shared their experiences of their parents with dementia, worked along with Marcie during her confused times and helped me by proofreading this project.

* * *

The Trip to the Dentist

Elizabeth 'Libby' Bogdan-Lovis

"Lib, if I ever lose my mind, just get a gun and shoot me."

"Mom, that's not an option."

My mother and I had that exchange decades in advance of any mental difficulties, but as is so often the case, when dementia surfaced, it was only in retrospect that it was apparent that she had been experiencing cognitive decline. Her decline had surreptitiously flown under my family's collective radar. With the wisdom of hindsight, it is now evident her memory loss coincided with the news of my sister's unexpected death. The youngest of seven, my sister died at age 33 in her sleep, of underrecognized cardiac issues. As we drove north to central Wisconsin for the funeral, my mother was mostly quiet, allowing me and my sibs the mental space to plan the sequence of funeral arrangements. When she suddenly spoke up, it was with uncharacteristic, off-the-mark observations, unrelated to our shared loss and the shock of my sister's sudden death. Gazing out the car window, she pondered why the geese had begun migration so early in the fall. As we pulled into the town center, she wanted to know why we planned to stop at the florist, "Just what did we need to buy?" We wrote off, "Mom is acting weird" as irrational but understandable manifestations of grief.

In the following months, the little signs escalated. She called to ask that I remind her how to make her favorite chili recipe. She was flummoxed by the commands on her computer. She reported that she heard annoying music constantly playing in the background. It was a repetitive "Happy Birthday" song. "Didn't I hear it?" She was convinced that a rogue child's toy, stuck on a constant play loop, was hidden somewhere in the recesses of her old Victorian home. Despite such concerning signs, she generally carried on, managing daily life functions and enjoying especially those familiar routines of running the used book business with Grandpa Ed, her life and business partner of 25 years. As Ed described it, they were a "team," and they shared a special joy in getting a particular book to "just the right person" who might uniquely treasure it. They had an enviably joyful and loving relationship that was visibly on display at their kitchen table. In one plexiglass paper holder, a "Dort loves Eddie" note, and in another, "Eddie loves Dort."

The drive from my mid-Michigan small town to her southern Wisconsin small town averaged seven hours, but within my nuclear family of five surviving siblings, geographically, I lived the closest and was generally on call to provide care and advice. Stymied by the report of repetitive music, her local family physician threw up his hands and discounted its clinical significance. And that non-interventionist low-key approach satisfied my mother just fine. Insistent about her certainty that the music was *real*—that rogue toy, or maybe one of those battery-operated greeting cards that launch into annoying tunes when opened—my partner and I went for a visit to try and help. Now, truth be told, her speculation as to the music's origin was not beyond the pale. The house was a hoarder's dream. During his 1960's tenure as an administrator at Chicago's Malcolm X Junior College, Grandpa Ed heard social organizer Stokely Carmichael describe his inventive survivalist strategies for those times when money was scarce. Mr. Carmichael stayed well-fed by harvesting foods discarded behind grocery stores, items that, for one reason or another, had been deemed non-saleable. Morally challenged by consumer waste, Ed began a career of dumpster diving. In addition to foodstuffs, over the years, he had rescued large quantities of material items, i.e., "stuff." That stuff was stashed in the nooks and crannies of their mid-century Victorian house. Admittedly, it included an array of toys and greeting cards, and so the notion of a hidden musical irritant was believable. Soon after our arrival, we began a scavenger hunt for the offending culprit and source—with no success after two days of searching through boxes and mounds of dumpster detritus. Importantly, it also became clear that no one else in the house heard music. We next researched the reported phenomenon of radio wave transmission through silver fillings in teeth. Nothing there either. Finally, a geriatric consultation in Milwaukee led to a diagnosis of auditory hallucinations. Obviously, Dorothy was hearing things.

In the following months, my mother began to experience "stomach trouble." A scan detected a tumor in her large colon that caused a painful blockage, and the physician recommended surgery. At the hospital intake, she was asked to state the purpose of the visit. Looking bewildered, she replied, "Well, I really don't know!" The staff person was visibly alarmed, so I prompted my mom, "Yes you do, Mom. Remember? You have a tumor in your colon." "Oh, that's right! I'm here to have that growth removed!"

When she came out of post-surgery anesthesia, Ed and I were shocked by her dramatic cognitive decline. Frantically, desperately, she searched for the IVs and catheters and methodically pulled them out. When I tried to explain the logic of their post-op necessity, my consummately civil mother defiantly swore at me. She had to be sedated and physically restrained, tethered to the bed like Ahab to the white whale. Episodically she would regain consciousness, and each time she would renew her battle with the restraints, verbally lashing out at anyone in the room, demanding that she be allowed to go home *now*!

Along with the tumor excision and a colon resection came the diagnosis of terminal colon cancer. She was incapable of understanding her diagnosis, and so in her presence, the resident delivered the prognosis to me. Eddie loved Dort, but she had named me as her durable power of attorney for health care. From that day forward, my mother no longer knew my name.

Her post-surgical recovery was uneventful, so she was sent home. After a week, I traveled home as well. From then on, like a scientist, Ed observed and daily recorded subtle changes, always hopeful that "she'd come back" to him—back to us. He conscientiously called me every evening with his "report" detailing her medication regime, diet, exercise, mood, etcetera. He carefully wrote down such information on the back of errant pieces of paper and assembled them for his nightly call. Those calls were his respite—his opportunity to have another sentient adult validate that day's caregiving. My sibs and I periodically visited and helped, but mostly, it was Ed's burden. The 24/7 caregiving took its toll on him. My mother had always done the cooking and cleaning. He was now responsible for food preparation, dressing, ensuring bathing, toileting, and cleaning up when she'd soiled her clothing, which was often.

Mercilessly, when someone has dementia, life goes on, along with the need to attend to daily routine health maintenance. But that's not easy. Unable to adequately brush her teeth, a rotted tooth became septic. Ed and I began calling around to find a dentist in her rural Wisconsin town—one that would be up to the challenge after hearing our full disclosure on what they might expect. We eventually located a practice willing to see her. My mother had always been phobic about the dentist. That visit haunts me to this day.

Unaware of her surroundings, she docilely shuffled into the office, but her guard then went up when she recognized the familiar dentist's chair. She struggled against us as we muscled her into position. Sedation was never discussed, and we soon realized that even injections of Novocain were out of the question—this just needed to get done and get done fast. I straddled her legs, steadying them with my own legs and arms, but facing her feet. I couldn't look at her face. Ed leaned his weight into her torso to keep her still. Then, with the aid of his assistant, the dentist used a wedge to hold her mouth open, and they proceeded to extract the offending tooth. Throughout the 5-minute procedure, she continuously shrieked and moaned from the back of her throat. Undeniably, for me, and for Ed, we had jointly engaged in torturing a woman we deeply loved.

When it was over, Ed was crying, and the facial expressions on both the dentist and his assistant registered looks of trauma as well. Logically, Ed and I knew she needed the tooth extracted; that *was* in her best interest, wasn't it? At a gut level, it certainly didn't feel like we'd served her best interests. That episode subsequently and profoundly influenced my decision-making at the time of her death.

The cancer and dementia progressed in tandem, and she quietly sobbed through the waking hours of many days. Which one caused her the most pain, the most anguish? She couldn't tell us, and so that secret was our shared burden. At night, Ed would lightly wrap yarn around her ankle, and then his own—linking them together so that he would awaken when she tried to leave the bed. I shared my concerns and fears with her general internist, that she couldn't continue to stay at home, that Ed's 24/7 caretaking could not possibly go on. He replied, "You'd be surprised." I was. Ed wanted her with him at all costs, and whether it was avoidance on my part or simply the path of least resistance, I acquiesced to his wishes.

Yet when I got the phone call that she had fallen and was in the ER where not only was a blood clot discovered in her leg, but she additionally had renal shutdown, I was forced into a weighty, solitary decision-making position. I thought back to her expressed wishes, and to the tethering experience in the hospital, and the torture in the dentist's chair. I thought about her tearful daily existence. When the nephrologist successfully convinced Ed as to the merit of inserting stents to restart renal function, I said no. I again said no when my sibs questioned my decision, declining IV fluids as she lingered for four days, two days beyond the prognosis. Paradoxically, even with the passage of time, I regularly revisit and challenge that certainty.

I didn't shoot her, but I did let her die.

* * *

It's What Indian Girls Do: Narratives in Caregiving for a Parent With Dementia

Mary (Rina) M. Chittooran

Introduction

Every caregiver's story is unique because every caregiving relationship is unique; however, the story of my relationship with my mother, age 88, who lives with me, is influenced by our cultural roots in India, and by the cultural traditions and expectations that guide our behavior.

After months of memory lapses and increasingly bizarre behaviors, my mother was diagnosed in May 2019 with moderate dementia of the Alzheimer's type. One month later, subsequent to intense bouts of sadness and comments about not caring if she died, she was also diagnosed with depression. During the next six months, my mother's symptoms devolved at an alarming rate into confusion, hallucinations, and delusions. She reverted to her days as a high-ranking government official's wife in India, with an army of servants at her disposal—she began to order people around, constantly asked who was coming to visit, and reminded me to "tidy the house" and "cook enough food for all our guests."

Early on a December morning, my mother came upstairs to the kitchen and had a bad fall that she still doesn't remember. When I found her sitting on the kitchen floor, unable to get up, she told me that she'd "just had a nice breakfast and was going downstairs to get something." It turned out to be a severe pelvic break that left her incapable of standing or walking, and that the doctors said would take at least 12 weeks to heal. She spent the next month in the hospital and a rehab facility, where she received excellent care; however, mentally and emotionally, her condition declined dramatically.

In the ER, she was sure she'd checked into a hotel and complained about not being able to use the bathroom. "What kind of hotel doesn't have a bathroom? Even the *worst* hotels have bathrooms!" Hospital staff insisted that she use her walker at all times and that a nurse accompany her to the bathroom, something that further enraged her. She grumbled, "Do you know how many times I've gone to the bathroom by myself in the past 88 years?" When she was discharged from the hospital, she tried to tip "the maids" because "that's what you do, when you've spent a nice night in a hotel. These people don't earn much."

In rehab, she quickly developed the reputation of being a sweet but determined old lady who wanted her own way. She threw her clean clothes into the laundry hamper several times a day, rearranged all her possessions so we couldn't find them, and secreted food in her bureau for future consumption. She'd tell me how the nurses were always talking about her, how they were plotting to take her house, and how they kept hiding her things and stealing her money.

The kids and I spent Christmas and New Year's in rehab with my mother, brought in treats and special home-made meals, opened gifts, attended chapel with her, took her for "walks" around the facility, and did our best to feign good cheer. My mom was released to our home right after the new year and subsequently had a month of visits from home health care and immediate family. In the meantime, we took turns sleeping on the couch near my mother and pretended that our aching backs and muscular pains didn't bother us. We cleared out her living area and donated some of her things to make room. We also purchased medical supplies and equipment for her, including a video baby monitor that turned out to be my lifeline once I moved back to my own bedroom. "See your baby's every move!" it promised confidently.

As of this writing, everyone has left, with promises to return over the next few months to see my mother and to support my caregiving efforts. So it's just my mom, me, and Ollie, our little Maltese mix, who has become extraordinarily protective of his grandmother. My caregiving is supplemented by regular visits from a home health agency and a South Indian, Christian, private duty nurse, whom my Mom had serendipitously met nine months earlier in the ice cream aisle at our local grocery. Mom is healing physically, but her mental and emotional condition varies, making it hard to predict what any given day will be like for all of us.

Things I Had Not Anticipated about Caregiving

There is no way that I could have anticipated how caregiving would change not only me but the relationship between my mother and me. I couldn't have predicted how caregiving would result in a complete role reversal between us, in an Asian family where respect for and obedience toward one's elders are expected. I didn't know how strange it would feel to suddenly become a mother to *my* mother, who now bears a greater resemblance to a balky two-year-old than the woman who raised me. I was unprepared for the all-consuming nature of the work of caregiving, the overwhelming sense of responsibility, the crushing loneliness, and the constant urge to run away from it all. I was also not ready for (but agreed to) requests for my caregiving services from friends and family when the time came for them to need a caregiver. Nor could I have anticipated how the entire family would come together to provide support for my mother and me. Perhaps most unexpectedly, I found that I had grossly under-estimated my own strength, resilience, and competence as a caregiver.

The Joys of Caregiving

I've experienced undeniable joy in the time I've spent caring for my mother. Oddly enough, some of my greatest joys come from small successes in areas of caregiving that are similar to providing care for one's own young children, for example, toileting, baths, meals, and bedtime routines. In her lucid moments, my mom recites poetry and sings childhood songs. She tells me stories about how she and her family hid from the Japanese army in the rubber plantations of Malaysia, and how she only attended college for eight months before she was forced, at 18, to have an arranged marriage to my father ("All I could think about was how big his moustache was!") When she's being particularly imperious, I call her Maharishi Maharani Purnima Ghaghde, which means nothing at all, except that it makes us laugh. We watch public television and Hallmark movies at deafening volume, share meals at favorite restaurants, go to church on Sundays, and smile fondly at Ollie's sweetness. And I wish, with an aching heart, that those times would last forever.

The Challenges of Caregiving

It's challenging being a caregiver. I seem to spend most of my time nowadays telling my mother to "*Use your walker!*" although she's deaf, does not consistently wear her hearing aids, and therefore doesn't fully hear me. She responds, "You want water? Why are you asking me for water when I'm looking for my *walker*?" And, "Daughter? *You're* my daughter. What a stupid thing to say."

As my mother's dementia progresses, I see her revert to childish behavior. She loses her filter, delivers throwaway insults with cheerful abandon, and comments on my dark skin (a curse in the Indian community) and the unibrow ("like Frida Kahlo's") that I don't have. She is suspicious of the medicine I dole out to her and hides her money in the unlikely event that she runs out. She fights me constantly because I'm the one person who stands between her and freedom. "Go away! Do you have any idea how many times I had to clean *your* bottom when you were a baby?"

The most challenging aspect of being a caregiver is how it has consumed every minute of my time. I had served as a caregiver for my husband, who spent almost nine months in hospice at home, but while he got sweeter and more compliant as his health declined, it's the complete opposite with my mother. Everything revolves around her needs and her expectation that people will immediately comply when she wants something. When in frustration, I ask her, "Do you have *any* idea how much everyone's turned their life upside down and inside out for you? How it's all on me, not my *dear* brothers?" she responds with, "It's what Indian girls do. It's expected. And I'm your mother. I looked after *you*." When she's being particularly mean to me, I invite her to go live with one of my brothers, and she says, "No. You're the only one I want to look after me." Interesting, considering that in our Indian culture, aging parents generally move in with their youngest son and family.

I find it difficult to contain my growing resentment over the fact that, as hard as I try, my caregiving goes unappreciated by my mother. She tries to sabotage my "stupid rules" by bullying the nurse into doing things for her ("I want burgers for lunch; there's *nothing* to eat in this house"). The nurse tries reasoning with my mother but eventually gives in, despite my repeated exhortations to the contrary. When people tell my mother she's lucky to have me as a daughter, she rolls her eyes and smirks behind their backs. Recently, she commented, "What exactly *are* you doing for me? I don't need you to follow me around, watching me like an eagle." And, "You walk around like an army sergeant. You think you know everything because *you* have a Ph.D."

Being my mother's full-time caregiver has already taken its toll on me. I can handle the work of cooking, cleaning, helping her with toileting, and managing her medications, treatment plan, and finances, all while meeting my responsibilities as a full-time university faculty member. I can even handle my skyrocketing blood sugars caused by the stress and the late-night, carb-heavy meals. What I can't handle is the worry. I worry incessantly about what will happen to her if something should happen to me. Neither my brothers nor my children would be able to handle her care for too long. She'd have to move to an assisted living facility, something we wouldn't do unless it was the last resort because it would be a somewhat shameful thing to do in our Indian community. I worry about my own future if I too should develop dementia. I tell my children that if I do, they're to walk me to the lake in our neighborhood and simply push me in. They think I'm joking.

Lessons Learned

Arguably the most useful advice I can offer to potential caregivers is to warn them that their whole world will be turned upside down once they assume the responsibility of caregiving. I'd tell them how important it is to be kind to, and take care of, themselves, to accept support when it's offered and to ask for it when it's not, and that if the person they're caring for is a parent or partner (someone who once looked after them), the role reversal will be even tougher. I'd want them to remember who they were before they became caregivers, and how important it is to maintain ties to the people they once were and to the lives they once had, to their friends and family, their work, and their faith. Most of all, I'd remind them not to lose themselves in the act of caregiving, even though it is difficult to remember a life BC (Before Caregiving).

Looking to the Future

The days with my mother wear on relentlessly. I don't know whether to hope that the end is swift and merciful or that she will live many more years, even as her light gradually dims. Right now, listening to the calming strains of Mendelssohn's Violin Concerto in the background, I look across the kitchen table at my mother, who is eating her favorite *Tuscan Pane* and reading the *New York Times* upside down. I realize that she is turning into a person I don't recognize, a person I don't know if I even like anymore, and yet, she remains a person I know I love, want to protect, and keep safe. I pray for patience and understanding, for strength and courage, so that we can handle whatever the days ahead may bring so that I can provide my mother with the best quality of life I can for the time she has left with us.

* * *

“Was He Wearing His Good Suit?”

Noël Ferguson

My mother and dad were married for 49 years. He died at the age of 77 after 13 years of living with chronic lymphocytic leukemia. It was a good marriage, a true partnership. Now, at the age of 89, my mother had been a widow for 22 years, and she was into her 7th year living with Lewy Body Disease.

One evening she asked me where Edward (my dad) was. She would often see him, she said, but he wasn’t around that night. Where was he? Was he outside? Was he in the other room reading?

Running low on patience, I said, “Mom, he died 21 years ago. He is not here.” She looked straight through me, with expressionless eyes that used to sparkle and dance with life and intelligence. Eyes now deep, dark, and flat. She was silent for a moment.

“Was he wearing his good suit?’

For seven years, I had been helping her live with dignity and comfort in her own home. When I was 66 years old, I retired, sold my house, and moved in with her. I was thankful that I could because I wanted to take care of her. But there were frustrations and challenges every single day. I was fortunate to have good help from a compassionate professional who had retired from 44 years of working in our community’s nursing home. Otherwise, I wouldn’t have been able to see it through, even though I told myself at the beginning of this journey that I could do it all myself.

Watching someone you love, someone who was so beautiful, intelligent, witty, and loving lose piece after piece of herself changed me; changed all of us who loved her. You don’t come out of something like that the same as when you went into it. For me, almost four years later now, I have had to figure out *how* to remember and *what* to remember. Like the Barbra Streisand song, “The Way We Were” says, “What is too painful to remember, we simply choose to forget.” I’ve had to do that to cope with the memories, with watching my mother spiral into the shell that she almost was the evening when she posed that question.

I was stunned by her question. At this stage in the progression of the disease, she did not seem to be connecting with her surroundings. Even though she frequently mentioned Dad and was always concerned about their twin infant daughters who died shortly after their birth, this specific question really threw me off balance. My impatience melted.

Somewhere in the very deep recesses of her mind, a spark remained. I thought back on the day we had almost gotten through, how difficult it was for me, but how much more difficult it was for her. She was unable to walk. She was shuffled from chair to transport chair, to the bathroom, to chair again, cared for physically in the most gentle of ways, made comfortable under her favorite purple throw, the next step of the day being the relief of bedtime, and another day done. Yet even in that diminished capacity for controlling her own life, she wanted reassurance that Edward was wearing his good suit when he was buried.

She waited for me to answer. Gathering up my own sadness, remembering that time 21 years ago, and all the years in between, the good years, and now some very bad ones, I found my voice and reassured her, “Yes, Mom, he was wearing his good suit.”

I remembered an old Ann Landers column from years earlier. It’s probably 30 years old—I still have it. I got it out to look at it last night while writing this.

> Dear Ann Landers,
>
> I’m going to tell you about a love story that I witness every time I go to the nursing home to see my husband who has Alzheimer’s disease.
>
> Unfortunately, I know firsthand how this terrible illness affects family members, but I would like the world to know what love really is.
>
> I see a man who, as I understand, has spent the last eight years caring for his wife who has Alzheimer’s. They have been married over 50 years.
>
> He cooks and feeds her every bite of food she eats. He has bathed her and dressed her every day all these years. They have no other family. She lost a baby at birth and they never had any more children.
>
> I cannot describe the tenderness and love that man shows for his wife. She is unable to recognize anyone, including him. The only things she

> shows any interest in are two baby dolls. They are never out of her hands.
>
> I observed him when I parked my car beside his the other day. He sat in his old pick-up truck for a few minutes, then he patted down what little hair he had, straightened the threadbare collar of his shirt and looked in the mirror for a final check before going in to see his wife.
>
> It was as if he were courting her. They have been partners all these years and have seen each other under all kinds of circumstances, yet he carefully groomed himself before he called on his wife, who wouldn't even know him.
>
> This is an example of true love and commitment the world needs today.
>
> -Fort Worth reader

What that lovely man knew, and what we all hope we know, although sometimes it's difficult, is that there is still a person inside—a person who deserves the best of ourselves.

Along the way, though, I encountered many people who could make comments that hurt, that were cruel, even though we all know that innocence—or ignorance—can propel us into insensitivity.

At the top of my list were the ones who would remark "I'd never expect my kids to take care of me. I will go to a nursing home and I have told everyone in my family that's what I want." The subliminal message being, "your mother expected *you* to take care of her?"

My mother never expected any of her children to "take care" of her. She saved her money, she knew that longevity ran in her family and she was prepared for a long life. She did not make the decision that determined her end-of-life care. I did.

I also found it curious that people would ask, "and how old is your mom?" which would start that thought process I could almost see as it zipped around inside their heads, almost always ending in reassurance for themselves. (Well, she was *old*.)

Or the other common conversation would start with that same question, and then segue into an update on *their* mother, who is 98 years old and still drives and still has her garden and still lives alone in her own home, probably has her own smartphone and knows how to use it.

Subtlety is sometimes in short supply, but you learn to protect yourself mentally and surround yourself with people who care and understand.

I did not attend support groups. I did not read about Lewy Body Dementia. I made a conscious effort to stay away from any articles that glorified caregivers or any written by caregivers. I did not want to know any more than I already knew. Maybe that would not work for others, but it worked for me.

Looking back, maybe I should have, but then I already knew the ending of the story.

My mother died Feb. 4, 2016, almost 7 years to the day she was diagnosed with Lewy Body. My therapy has been to compile a cookbook of her wonderful recipes and their stories attached, which she wrote in 2004, with some still written as late as 2012 and 2013, taking me back to when Mom was well, happy, and productive, which is how I choose to remember her.

* * *

My Shattered Useless Fix-It Heart

Anonymous One

As soon as I can gather the wherewithal, I'm going to get a tattoo across my chest. In capital letters, this tattoo—my first—will read "No Code." I've read articles about first responders and physicians who ignore "No Code" tattoos because, they explain, they don't know whether the message reflects the patient's current wishes. I own a large selection of Sharpie markers. Every few days, I'll add the date.

It isn't quite accurate to say that the "No Code" tattoo will be my first. I have three blue-dot tattoos that the radiation oncologist used to guide breast radiation for the third phase of treatment for triple-negative (stage IIB) cancer. Over the dot on my sternum hangs a MedicAlert necklace that identifies me as the hearing-impaired caregiver for someone with Lewy Body Dementia.

I'm 60 years old. I work full-time as a college professor. I care for my ex-husband, who is now 67. He was diagnosed at 65, just as he was retiring from a career as an academic librarian. We are fortunate: we have health insurance; we live near medical facilities; we have some extraordinarily generous friends.

Yet so much is difficult. Peter has trouble with time, so I keep track of events, appointments, and daily schedules. Peter is easily confused, so I handle medication, bills, "estate planning," and financial planning. Peter needs help with tasks around the house, so I provide plumbing services, change light bulbs and smoke-detector batteries, assemble furniture, set up electronic devices, and much more. Peter is isolated and lonely, so he comes to my house for coffee and medications every morning, for tv and medications every evening, and to report his worries, hallucinations, house troubles, and problems whenever those arise. Peter can't drive, so I organize transportation. Peter is exceedingly anxious about the bus service for people with disabilities, so he uses the bus only to go to the gym. An extraordinarily kind friend takes him grocery shopping once a week. For everything else—appointments, errands, outings—I drive. As I mentioned, I work full-time.

I can manage all of this for now, but I will need help as Peter's condition worsens. So far, I've contacted the local Alzheimer's Association representative, met with a social worker at our healthcare facility, spoken with the ElderCare organization, and asked the primary care physician and neurologist for the name of someone who can provide information about the services Peter will need. The Alzheimer's Association representative told me to start by calling the county for an in-home assessment. I called the county. Two weeks later, a social worker returned my call and told me that the county no longer conducts those assessments. The social worker at our healthcare facility told me that Medicare would cover a week-long "respite care" stay at a nearby nursing home so that I could travel to see my 92-year-old parents. I called Medicare and learned that the week of respite care is covered only for patients in hospice. The ElderCare staff member could answer none of the questions I asked. Both doctors promised in July to find out whom to contact and get back to me. It's now October, and I've heard nothing. The score: misinformation, 2; no information, 3.

It appears that no one has an up-to-date, accurate list of services for people with dementia, though everyone apologizes for the lack of information. All of these people seem kind, and all are no doubt pressed to their limits. Still: call to mind the number of people living with dementia and the number of people trying to care for them and notice that each caregiver must figure out how to manage all of the necessary care tasks without any centralized, reliable source of information and referrals. I'm quite certain that I'm just one of the thousands making phone calls to people who can't answer essential questions, waiting for calls that never come, spending hours on hold.

On balance, the misery of medical appointments has outweighed any benefits. Productivity quotas at our healthcare facility mean that Peter's neurologist sees a patient every twenty minutes. Even so, the patient load in neurology is evidently unmanageable: the scheduler called Peter on the day of an appointment to say that he'd be meeting not with the neurologist, as scheduled six months before, but with a nurse practitioner. The scheduler called again later to say that he'd be seeing a different nurse practitioner at a different time on that same day.

Pause and consider. The neurology department is calling a man with LBD, a man who cannot drive, a man with an uncertain grasp of time, to inform him about changes in provider and appointment time—even though I am listed in every electronic and paper file as the person to contact about appointments and changes.

LBD is a terrible disease with a dismaying prognosis. In my most disconsolate moments, I wonder whether the neurology clinic staff believe that it doesn't matter much whom he sees or whether he makes it to the appointment at all.

Appointments generally begin with the Montreal Cognitive Assessment. (Its jaunty acronym is MoCA.) The neurology staff members who administer the test give the instructions in notably inconsistent ways. One rushes through the instructions for the first task, a task that involves alternating numeric and alphabetic sequences, and points vaguely at the sheet of paper. Another speaks slowly and clearly, tracing the pattern shown on the paper.

If I thought the results mattered, I might point out that demeanor and clarity affect Peter's ability to complete these tasks.

But I don't. I can't afford to annoy the clinic staff or the neurologist, so I'll say nothing, but I think the MoCA is useless as an indicator of Peter's cognitive function. I have some broader doubts about it; I've had college students who can't read analog clocks, so I wonder whether the clock-face test is a reliable indicator of anything in 2019. But be that as it may: again and again I've sat beside Peter as he's struggled, feeling increasingly overwhelmed and distraught, to draw a clock face showing the time as 11:10, to identify drawings of a lion, a hippopotamus, and a camel, to count backward from 100 by sevens, all while remembering random words. Even if the tasks have clear diagnostic value for a larger population of neurology patients, I'm certain that the MoCA tells Peter's neurologist nothing about his cognitive function because the situation makes him so anxious that he can't complete tasks he could complete easily at home—sometimes. Flux in cognitive function is characteristic of LBD, so the results would depend not only on his level of anxiety but also on the day, or time of day, or circumstances. Why have someone complete an assessment that offers no useful information and causes such distress? Peter so dreads the MoCA that I pulled up a copy from the internet on the morning of his most recent appointment and practiced with him.

If the neurologist wants to assess Peter's cognitive function, why not ask us which tasks and situations have become harder? I spend hours with him every day, and I am sitting right there beside him.

Because LBD has "Parkinsonian characteristics," the second part of the neurology appointment is a brief physical exam to assess muscle rigidity and problems with walking and balance. We say at one appointment after another: yes, walking is more difficult, but the most severe problem is pain. At last, the neurologist refers us to her colleague, a pain specialist who looks past Peter and speaks directly to me throughout the appointment. I am not the one in pain. I am sitting beside him.

Of course, I am in pain, the anguished kind of pain. I'm watching someone who I love struggle to put his shoes on, struggle to get up from a chair, struggle to remember what he's trying to say. I'm watching him confuse evening with morning; I'm hearing his panicked report at 8:30 p.m. that the bus—scheduled for 8:30 a.m.—hasn't come. I'm hearing him say after time with friends that he feels stupid, that he can't keep up with the conversation, that he doesn't have anything to offer in social gatherings. I'm sitting beside him, driving home, hearing the beat of my shattered useless fix-it heart. I'm trying so hard, yet I can ease so little of his pain.

I know what's coming, and that's more anguished pain. What's coming next is cognitive decline, choking, aspirating, maybe pneumonia, incontinence. Already social gatherings cause distress, and what's coming is harder, so I've started letting friends know that we can't participate in the same ways. Some respond graciously, some with hurt, or anger, or judgment—it's hard to tell. Some say nothing at all. My therapist tells me to expect that Peter's friends will drift away.

Perhaps this quick sketch offers some sense of the strains and difficulties involved in providing care for someone with dementia. Those strains have consequences. As Peter's cognitive and physical difficulties emerged more visibly, I started having hours-long attacks of vertigo and vomiting. I started losing the hearing in one ear in increments large and small. The data lined up neatly for a diagnosis of Meniere's, and the moments of great stress lined up neatly with vertigo attacks: I had four attacks during the week I set aside to visit nursing homes to make the plan for "end-stage" LBD. After that week, I chose to have a gentamicin injection to treat the vertigo even though the injection might destroy any remaining hearing in that ear. Somebody around here has to be able to drive.

And if I get into an accident, somebody will need to know that a man with LBD requires care. That's why I wear the MedicAlert necklace over the tattoo I haven't had the wherewithal to get. "No Code": I've had a life-threatening illness and life-threatening complications from treatment for that illness. I've lost some faculties and planned for Peter's grim, prolonged death after far greater losses. My circumstances have offered a good long look at the end of life. So I'll do all I can to ease the ending of Peter's life, but I won't prolong my own. My advance directive is on file, but that is not enough. I need to finish my own end-of-life plan: get the "No Code" tattoo, set aside money for a ticket to Amsterdam, and, just in case, order a copy of *Final Exit*.

NIB policy allows authors to publish anonymously when stories considerably contribute to a symposium but contain highly sensitive information that cannot be de-identified. However, stories are never submitted or accepted anonymously, and all authors sign our publication agreement, which upholds standards for responsible authorship.

* * *

Moments

Scott Pearson

We set out to see the giraffe. My father had told me he'd spotted it across the field from the house on our farm in Tennessee. By then, he was several years into a long course of Parkinson's Disease and was on several medications. But he was still physically healthy, able to continue the work of our farm. I knew that he was starting to hallucinate, but in our stubbornness, we thought we could convince him the visions were not real. My brother and I, along with our wives, our children, and my mother, climbed into his pickup truck with him and drove over to the field to see this exotic animal that was not there.

As we traveled the field road past last year's soybean stalks, I had the thought that perhaps we had gone crazy as well. But then my father pointed and said, simply, "There it is." We all whiplashed around, and sure enough, a string of colorful birthday balloons had descended and become stuck in a fence row and were bobbing up like the head of a giraffe. Driving home in silence, I learned the first of many caregiving lessons from my father—to listen and not discredit the patient, no matter what.

Not long after, we gathered again to take away his guns. A life-long hunter, my father had accumulated a small collection: a couple of shotguns, a deer rifle, a handgun or two. We knew he would never try to hurt our mother, but if he saw something and went for a gun, we just couldn't take the chance. In our wood-paneled den, the center of our family life for decades, as my father sat behind his big, heavy wooden desk, where he always sat when there was business to attend to, I thought of the changes occurring in our lives. In that big desk, my father kept, among other treasures, a pair of nail clippers in the trough of the sliding drawer. When I was too young to cut my own fingernails, he would call me over and I would sit on his lap. After the cutting, he would laugh as I pressed my fingertips into his pants leg to feel the newly exposed quick. He looked smaller now, behind that desk, as my brother and I told him that we would keep his guns safe for him. He complied, but the loss of his independence was palpable.

When my father first broke his hip (he would break both ultimately), I stayed with him in the hospital. A few mornings in, he was looking grizzly. "I'll just shave him," I thought. "Can't be that hard." I told him I was going to give him a shave. He looked wary of the proposition as I left the room to buy a disposable razor in the hospital gift shop. I remember thinking that the cheap shaving cream was too thin and runny, but I proceeded anyway. I'm a surgeon, after all. For years I'd made a living by cutting people open and putting them back together. This safety razor would be a cinch.

Scrape, scrape, scrape. My father winced. Soon, a spot of blood appeared, then another. "Sorry," I said. I changed the direction of the razor. Down, then up, east to west. I could see the hint of fear in his eyes as he watched me struggle. In the medical profession, we don't like to fail—especially a surgeon in a procedure.

"Certainly, I can do this," I thought. So I persisted. Scrape. Wipe the blood. Scrape.

Finally, my father had had enough, and he told me to stop. Years later, we could finally laugh about my botched job of a shave.

As his mind and body deteriorated, I was slow to realize that my mother, alone with him in their house, was overwhelmed with the daily care of my father. Then it all changed late one spring afternoon with a trip to the emergency department. The subsequent week of hospitalization became the opportunity for relief. He transitioned from the hospital to the nursing home in our small town. "This will be temporary," I told myself. My father liked nothing more than to be in his own home. But weeks turned into months. Gradually, I noticed changes in my parents' house. His chair was moved out of the den. A quilt that appeared more ornamental than inviting to sleep under adorned his bed. Most concerning, however, was the putting away of his bathroom items—his metal razor, the C40 Ever Ready horsehair shaving brush that he kept in his white porcelain Old Spice Ship Friendship mug. I did not want to admit to myself that he probably was never coming back home. He would live in the nursing home for the final five years of his life.

Many patients, once admitted to the nursing home, are functional enough and medically stable enough to be able to take small trips. To go out to eat, to visit their home place, to see the eagles at Reelfoot Lake. But their loved ones often make unspoken excuses, just as his family and I did. We think, "Dad doesn't feel well enough to do that. He'll miss a dose of medicine or catch a cold." Or (the worst excuse), "he doesn't want to do that anymore." And the weeks and months go by.

But families need to realize that further decline is inevitable. If the patient couldn't do it then, she's even less likely to venture out now. Ask the nurses. With a little planning, they can mobilize the person and expand her activities. Don't let inconvenience keep you from taking Dad or Mom to visit the family, to return home for a little while. These windows of opportunity will start to close with increasing frequency. Then you must bring the party to them. Plan a Thanksgiving feast. Open holiday presents in the nursing home. Bring them their music, their art, treasures from days past. Perhaps this should have been obvious, but we never really gathered as a family in the nursing home until he was dying.

On one of his last mornings, after a long night, he and I had coffee. Some angel of a woman pushing a cart brought a fresh pot into the room. I attribute my enjoyment of coffee mostly to my father. When I was a boy, sitting at his left hand at the kitchen table, he would pour a single teaspoon of his coffee into my glass of milk. It was just enough to taste. Now, nearly fifty years later, he was barely awake, eyes half-open. He had always taken coffee in the morning, so I could not drink mine without him. I poured a bit of mine, after adding cream and sugar, into a separate Styrofoam cup. I let his coffee cool in the bottom of the cup and then slowly tilted a few drops from a plastic spoon over his bottom lip. Half ran down his chin, but I could tell he tasted what did stay in—a taste he had known every day for most of his life. At this point, he could no longer swallow, so too much would make him choke. But as I sipped mine, he would have a few drops, our last coffee together.

Staying with him during those last nights and days, as I took time off from my work at the medical center, I began to appreciate the small but profound moments when the nurses, and those whom we in the medical profession like to term ancillary staff, enter the room. At this point, and many of us will be there someday, care from these ancillary personnel becomes critical: the assistants who gently turn him, change his wet diaper pad, the woman who tidies up the room. One morning, I watched the person who empties the trash can as she tied up the bags. When finished, she motioned toward my father, "May I?" "Sure," I said, uncertain of her intentions. She walked over, spoke to him, kissed him on the forehead, and walked out to the next room. She did this every day. Scenes like this repeated time and again. I know of at least five different caregivers who, in the course of those days, embraced my father. Some cried; others just smiled when they kissed him. We should all be so lucky.

With particular interest, I watched the woman who came in to shave him, my mind filled with images of my own botched job years earlier. If suturing the pancreatic duct during a pancreatic resection is a skill, shaving a dying man is no less of one. Seemingly without effort, she shaved my father. Across his mandible, chin, neck, lifting his oxygen tube to get those tough whiskers at the base of his nostrils. He knew exactly what was going on, and he looked like he was getting a massage. Not a single nick. She put on some after-shave that smelled great. I thanked her as she left the room, but I doubt she realized how this seemingly small, routine act of care was, in fact, huge. I found myself aspiring to be like her—confident yet unassuming—caring while getting the job done and then leaving as though it were nothing.

We don't teach this level of care in medical school. Not that students don't learn care—they do, but too often at a superficial level. This is care, however, that most people can achieve. But patience is required, and few of us maintain presence long enough to accomplish it. Biochemistry is easier to master than patience.

I see now that the simple things mean so much. In the future, I will teach my medical students this: when a patient asks for a cup of ice, get it for them. Do it yourself. Don't say, "I'll let your nurse know." The nurses are busy taking care of their patients. No one wants to wait half an hour for an ice chip. Try it. This immediate providing of simple care is so gratifying, to you as well as the patient. Attend to simple, mundane needs because they are not mundane to the patient.

It seems to me now that all of this comes down to kindness. When we're in a situation where we don't know what to do, when someone is sick, hurting, grieving, lost—we can just be kind, in whatever form that takes: a smile, a hand placed in another's. Words can help but aren't mandatory. Presence is what is required—being there. It's easy to make excuses and take ourselves out of the situation. We may think, "I don't know how to help. It will be awkward." Yes, maybe so. But only for us, not for the person who needs the dose of kindness. Any discomfort usually fades when the caring begins. The time we can do the most good, for those who need it most, is often, and unfortunately, when we tend to retreat. "Someone else will do it. I'm too busy today. They won't even know I'm there." Yes, yes, they will. And if the eyes are closed and you don't think they are in this world, just talk to them. See the forehead wrinkle, a twitching of the eyes. They hear you.

When my father could no longer communicate, he and I developed a ritual beyond words. When I visited, I would cut his fingernails. I kept the nail cutters in the bottom drawer of the chest in his room. I would lean across his lap while he was in his wheelchair. Sometimes I would get carried away and cut too deeply into the quick. He would withdraw his hand but then extend it in tentative trust. Afterward, I could see the hint of a smile as I pressed his freshly trimmed fingertips into my palm. A father and his grieving son, merely finding a way to hold hands.

* * *

Caring Enough: The Dementia Patient Who Abused Us

Sunnie Songeun We

If you really think about it, no one's allowed to be an asshole for very long in stories about terminally ill family members, including the afflicted themselves. Listless hands plopped on hospital beds must be held, hair compulsively smoothed back from barely conscious foreheads. Everyone patiently leans in to listen to the gasps of a dying person. *Pop-pops is trying to say something! Quick, call Amanda, who's studying abroad.*

Never mind that Pop-pops has been dying for a dozen years now, wheezing out nonsensical advertising jingles from his childhood every day before his morning Jello. And yes, maybe it *is* true that the old man never had a kind word to say about anyone and would never do any of this for us, but it's also easier to mentally relegate assholes—especially the unwell ones—into a sort of harmless ol' curmudgeon trope. He's gasping for what may be the last time, and it is mandated to be meaningful so kumbaya, gather around.

The kicker is that people never really know what to do with terminal illness stories when they're odiously and incongruously enmeshed with actual, undeniable domestic violence. We clamor for immediate no contact or external intervention when someone is suffering from mental or physical abuse inflicted by a family member or partner. Domestic violence stories, by themselves, are no-brainers. It's gloriously simple and cathartic to shake your finger and loudly proclaim, "Get out and don't look back. They're toxic." We shiver with satisfaction at frequently and instantly branding abusers as narcissistic assholes who shouldn't be given the time of day. The problem is that the abusers don't just disappear from our lives, crawl underneath a bridge, and quietly sit there as they reabsorb into the earth. That's not how they die. Like the rest of us, they succumb to disease and list emergency contacts and forget to update wills, forcing entire sets of families to come together at their bedsides when death comes knocking. One would assume that the inevitability of all this is obvious. Yet, after a decade of providing care for a volatile, abusive father with early-onset Alzheimer's and Parkinson's disease, I would come to understand that these two narratives—one of domestic abuse and the other of caring for a patient with dementia—would not be tolerated in the same room. People were simply allergic to this mixture. Depressingly, empathy would typically be withheld unless the unsavory domestic abuse was expunged completely. In its place should be a sorrowful, *Still Alice*-type screenplay, a tasteful sort of tragedy you could tell on a third dinner date. This was consistently my experience with even my closest family and friends, doctors who pushed for invasive yet ineffective surgeries, and hospice care professionals who smilingly directed me to hold hands and hug my empty shell of a father.

Naively unaware of this dogged expectation in the early stages of caretaking, I would hungrily latch onto conversations about aging parents who have dementia, fully expecting relief at finding folks that just *knew* what it was like. "I mean, on the spectrum of domestic violence he wasn't the worst out there, but having my mother drain retirement funds for *him*? And my sister's already-taken weeks off work. It's killing us," I'd indignantly say to someone who'd just finished rattling off about her own abusive elderly mother. Surely someone would understand the rage and guilt that came from taking care of a father whose idea of a fun time was forcing his family into a car and driving blackout drunk on the 101.

The alienation started to creep in when my eager contributions were met with uncomfortable chortles and phrases like, "Well, he *was* your father . . . you must have loved him deep inside," or, "You don't mean that. He *is* your father, after all." After his passing, this would morph into lackadaisical interpretations of my experience, a popular one being, "He died when you returned from grad school? He was clearly waiting for you to visit him one last time."

It unwittingly became an odd series of social experiments after a while, to start recounting the abuse portion of the story, tack on the burnout and resentment from providing care, and gauging reactions. Told separately, each story would elicit effusive, sympathetic responses. Someone at a dinner party could totally relate to the domestic abuse; a colleague could talk for hours about burnout in providing care for elderly parents with dementia. *Great*, I thought. *Now let me really entertain them*. Merged into one story, however, each narrative of suffering repelled the other like two magnets of the same pole. The character of my father was apparently conceivable in only one story at a time—no crossovers allowed.

Toward the latter stages of his Alzheimer's and Parkinson's disease, my mother, sister, and I were fried with burnout and these constant spinoff failures. When hospice staff would call nightly to regale us with tales of my father's wanderings, our hollow "Please stop calling unless it's an emergency" requests were met with shock and judgment. We found it therapeutic to reenact moments of persistent pressure to be *caring enough* from well-meaning people, and to share canned responses to lines like, "It must be so difficult for you that he can't remember your name. He must have loved you so much." Privately, we recalled his public rage blackouts and agreed it was quite a miracle that he hadn't been shot by someone in a convenience store.

When I talk about providing care for my father's dementia and his passing now, I like to present a sort of interactive, Choose Your Own Adventure-type story. Depending on how many feel-good moments of closure the listener requires, they can skip straight to the romanticized film script of caregiving that comforts and soothes us when we ruminate about the possibility of our own minds evaporating. *Yes, I cherished every minute I had with him. It absolutely saddens me to think that he waited for me to come home from grad school to pass away. He's family, and of course, I'd happily offer up my entire savings to make sure he's taken care of. That's just what family does. Oh, I'd do it again in a heartbeat.* I don't want to. In my stories, I'd like to let assholes be assholes, no matter if they're losing their identities and balance to plaques accumulating in their brains or not.

The Cleveland Clinic defines caregiver burnout as "a state of physical, emotional, and mental exhaustion. It may be accompanied by a change in attitude, from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able, physically or financially."

What my family and I experienced was a type of burnout that lasted years beyond the period of caregiving—guilt and shame that stemmed from the societal pressure to perform artificially loving "roles" to be perceived as *caring enough* for a patient who once inflicted trauma upon us. There is a real need to recognize that different types of traumas and illnesses can simultaneously exist from all participants in a story. That closure is not a requirement of caregiving. When we can accept that not all stories from caregivers are caring, nor should they have to be, caregivers can finally begin to heal and speak their truth.

* * *

A Siblings' Guide to Recovering Caregivers

Nina Tumosa & John Tumosa

It is much easier to fall into caregiving than it is to fall out of it. Raised in the middle of the 20th Century by parents whose lives were defined by World War II, we were taught to care for family, pets, and farm animals, although not necessarily in that order. Our father taught us, as siblings, of the importance of looking out for one another. Neither of us suspected that the person most responsible for teaching us how to be good caregivers would one day need us to care for him.

And care for him we did, through the deaths of 2 wives and his oldest son, a serious tractor accident, hypertension, several transient ischemic attacks (TIAs), and cancer, and all of those coincident with ten years of living with dementia. Our father's dementia became the defining force of our lives and it brought us closer as siblings. We reminded each other to act like adults around our father, rather than like his children. We problem-solved together on how to take away driving privileges while preserving dignity. (We replaced the ignition key of his red Mustang with just the door key and encouraged Dad to read the newspaper every day from the driver's seat.) We worried together, wondering if we would have to pick the lock on his bathroom door to rescue him again should he have another TIA while taking a bath. We were part of the medical team that worked on multiple lifestyle choices. These included reducing his risk for falling while on his 5-mile-a-day walk around the neighborhood; on finding a way to support his preferred diet of chicken nuggets with honey-flavored dipping sauce, followed by ice cream and cookies; and on supporting his right to discontinue a dementia medication that was giving him diarrhea.

Together we learned to laugh together over Dad's insistence that because Nina was just the cook, she should be told to go home at night, but she should be told nicely because she was a good cook. We groaned and laughed over his love for rides in John's pick-up truck, where he delighted in reading, every time, the price of gasoline at every gas station passed. Moreover, we even learned to smile and shake our heads over trips to the emergency room, following a fall on one of his walks, where Dad was greeted by name when he entered, and we were greeted with emergency room phone calls to the police to come interview us about possible abuse.

When Dad died, we had to learn to address our grief and our loss of focus. No one had taught us how to stop caring. We had to learn how to redirect our lives. We were no longer a team, and each of us had to find our own way. On our separate journeys, we developed very different solutions to learn from, adjust to, and move on from, our caregiving of our father.

John has become a certified nursing assistant, which allows him to volunteer at a hospice unit where he serves as a witness to the presence of death for people who are alone. This allows him to continue to care for others, but he chooses who they are and at what level he participates. With the distance of time, John has learned to process his feelings through poetry. He did not have the emotional distance to write his poems during the caregiving process but, following the death of our father, he began to heal through his poetry. Only during the aftermath, over the distance of time, could he face his feelings of accomplishment, pride at a job well done, and grief at the loss of the force that had defined his life for ten years.

One of his poems directly addresses dementia. In writing this poem, he reaches out to other caregivers following that same journey. In order to both teach others how he coped and to reach a greater audience, his poem speaks of a woman living with dementia, because more women than men have a dementia diagnosis. John used poetry to jumpstart his grieving process and hopes that others might find solace in doing the same. His poem, *The hammer and anvil*, exposes the soul of dementia, which is rarely seen by active caregivers.

The hammer and anvil

There is no time now
to recover loss
The wind is in its normal movement
but the progress of her mind
is moving backwards
Her laughter sings with a strain of tension
A wild shot of red hot emotion
crosses the deck railing
which comes close to sinking me

Her few words come out
sounding like Cherokee Code Talk
She forgot the house where we live
How long before I am a stranger?
Anger spouts from fear
as anxiety rolls in waves of Dementia
A broadside across the bow
sends me scrambling
veering into direct fire at the waterline
For better or worse
to what direction do I steer?

Good character is made
with the earth metals
Combine high carbon in timed addition
Heated in the heart's forge
Initiate the healing process
striking tears over the sins of imperfection
Sleep does not yield comfort
but is met with constant watch
necessitated by changes in her behavior

She used to read my stories
catching the rise and fall in imagination cleverly
with anticipation on the forefront
of the next ingeneous thing
I would produce

How with all the wonders
can I feel so alone in her company?
Moderate temperatures lessen danger
if she wanders while I nod from exhaustion
numb to changes under the flame of hope
I am left all the resilience
found in tiny seeds of faith
while caught between the hammer and anvil

Nina's approach to healing was different. She redirected her energy into the education of other caregivers. She worked with the museum of the Cardinals Major League baseball team to develop resource materials to use in baseball reminiscence groups for veterans and their caregivers. At work, she serves as both curator and content expert on a caregiving curriculum that is on her agency's website for both unpaid caregivers and primary care providers. Now, she is a resource for her peers who are learning to care for their parents, and spouses who are each adjusting to a new dementia diagnosis. Finally, like John, she has also learned the power of writing her experiences down to share with others but uses narrative rather than poetry.

Both paths are valid. Both are effective in providing healing. Finally, and most importantly, because we have both found ways to heal from the trauma of unexpected caregiving, we are able to work together again to plan how to best care for other family members who have recently received diagnoses of dementia.

Caregivers never stop caring. It is not in their nature. However, sometimes the solution for how to continue caregiving without sacrificing oneself is to use your experiences to help you choose how much to care. With experience comes choice. With choice, comes the satisfaction of doing a difficult job well. With satisfaction, comes peace.

The views expressed by Nina Tumosa in the article do not necessarily reflect the official policies, nor an endorsement, by the Health Resources and Service Administration (HRSA), the U.S. Department of Health and Human Services (HHS), or the U.S. Government.

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Journeying Through Dementia

Sheri L. Yarbrough

This journey through dementia with my mother has had an unexpected outcome: it made me happy. I didn't see that coming because of where our relationship was at the start. I had known since I was 24 years old that I would probably be the person to care for our parents as they aged. At that young age, I thought that their care needs would arrive with regal fanfare, then I would step nobly into my new role. What I got, 25 years later, was windchimes jangling frantically in gale-force winds.

Our journey began when a routine doctor's appointment veered unexpectedly onto the caregiver path. During the visit, I learned that Mom's cognitive changes were more than normal aging; they were the early stages of dementia. Because of the disease, she wouldn't be able to take her medicine properly, therefore, could no longer live alone. As we concluded the visit, Dr. M told me that I needed to move in with her. At 24, I had no idea that caring for an aging parent would entail moving back into my childhood home. Nor did I realize I would struggle to maintain a life of my own while caring for my mother.

Looking back at the moment Mom's care needs arrived unexpectedly, I realize the thought of living with the unspoken, unresolved issues that undergirded our relationship was why my head was spinning. Throughout her life, my grandmother's verbal footprints demeaned Mom's character and created doubt about who she was. Though Mom hated my grandmother's behavior, she kept silent to show respect.

Having a fundamentally different temperament from my Mom's, I saw nothing respectful in my grandmother's behavior, nor did I see anything respectable about tolerating it. When Mom's silenced anger would spill onto me, I would push back with everything I had. From Mom's point of view, my reaction was a lack of respect for her. I, however, just wanted her to be clear that I vehemently disagreed with her perception of respect and refused to share it.

That polarized point of view created years of difficult moments. I learned from those times that we got along best when we lived apart. However, her inability to live alone meant that strategy was no longer an option. The move back to my Mother's house was something I did willingly but not without reservation. I accepted that I had made the most rational choice under the circumstances and was committed to fulfilling my role as a caregiver. However, my guard was up.

Moving back into her house rekindled my willingness to fight as hard as I could to keep her anger from impacting my life. At the slightest hint of an impending anger encounter, I would immediately go into warrior mode. Always armed with snappy retorts, I would counter her quibbling and annoying bickering with an equally irritating response. As a result, we spent many days at odds with each other over nothing. Staying on guard against Mom's anger was something I neither liked nor wanted. But I had accepted it as the nature of our relationship.

That was how we lived for about 18 months until two small but utterly terrifying words, *breast cancer*, entered our lives. The presence of dementia meant she could not fully process the diagnosis and treatment options, so the decision-making was up to me. The first doctor we met recommended a standard treatment protocol of mastectomy, chemotherapy, and radiation therapy. Removing the cancerous breast made sense. But the idea of following up with chemotherapy then doing radiation therapy seemed like too much to do to someone who was 84 years old. So, I decided not to use that doctor. The second doctor we met came with a team that presented a treatment protocol that eliminated traditional chemotherapy. Their goal was for her to live life after cancer. Realizing that there was more life to be lived forced me to make a choice: continue living as we had been or use the time we had left to live differently.

At that moment, I realized that I had to put our past behind us so that we could live looking forward. When I chose to care for her, I committed myself to keeping her safe. But I didn't make a similar commitment to what I wanted for myself. Having to think about what I wanted for myself helped me embrace what I had in order to get what I wanted from the care relationship. My commitment to myself became living life without regret. To do that, I had to commit myself to making decisions and taking actions that are satisfying to both of us. That decision was the genesis of my central care question: "what would she want; what do you want?"

When I began this journey, I knew nothing about dementia, so I read lots of books, articles, blog posts, etc. I attended as many forums and workshops as I could to prepare me for what would come. Though I learned a lot, all that information focused on the losses I should expect during each stage of the disease. As a result, I was completely focused on watching for what she would no longer be able to do. On good days, I was overwhelmed by the question, "what symptoms will she get and how severely will they present?" Other days, I was drowning in it. It wasn't until I talked with a friend who had journeyed through dementia with her mother that I stopped to really think about what I was doing and for whom. Our conversation reminded me to focus on the question, "what would she want; what do you want?". Once I did, my attention shifted away from finding solutions for possible losses to embracing what she could do.

Staying focused on what she can do allows us to do one of her favorite things: travel. Using where she is in the disease as a starting point helps me make travel plans that are feasible for her. Early flights that are less than 2.5 hours work best for her. It's also important that I carry enough food to keep her from getting hungry. That strategy allowed us to attend her 70th anniversary of graduating from Spelman College. We have a long, rich family history with Spelman College, so being there was a decision she would have made. Though we didn't attend most of the activities, we participated in the one that would have been most meaningful to her: walking through Alumnae Arch.

In the nine years since her diagnosis, she has lost her ability to identify me as her daughter. However, when she looks at me and giggles for no reason or says, "ooooh, how are you?' out of the blue, I know that she still enjoys my company. We have our fussy times when she's tired and doesn't want to put on her pajamas, or I tell her not to pour water on the floor. However, not being mired in her loss of judgment, I can regard those decisions as her way of making her own choices.

Journeying through dementia has taught me to live fully in each day. At this point in the disease, that's all Mom can do. But that's not a bad thing. She was always a worrier, and when she lost my dad, her grief was crushing. Living completely in the moment means she can only process what is happening in the present, and she no longer regrets her past or worries about her future. She doesn't have to process painful moments that come to mind or question what will happen to her. Though it's impossible to know what she's thinking, doing something soothing if she looks sad or confused gives way to happier emotions.

As her primary caregiver, I had to go through her personal documents to find records for managing her affairs. In doing so, I found a poem she wrote some time after my dad died to cope with her grief. The poem's last 2 lines, "You can cry and close your mind, be empty and turn your back, Or you can do what he'd want: smile, open your eyes, love, and go on," gave me insight into her as a person, not just as my mother. Her words helped shape the most important life lessons I've learned along this journey.

For people who are just beginning their care journeys, I encourage them to:

1. Expect the unexpected;
2. Make time to laugh and most importantly;
3. Create good memories.

Expecting the unexpected keeps you flexible in your actions for giving care. I hadn't thought about how dementia impacts the body until Mom developed diabetes. She never had any trouble with her blood sugar, so the arrival of diabetes was totally unexpected. Being flexible allowed me to adjust our eating habits to manage her diabetes. Cooking and making sure she is well fed became my primary responsibilities. Dementia has altered her perception of feelings, so she has trouble discerning what she's experiencing. Therefore, it's up to me to manage her hunger. I have to ensure that she's full before going to bed. If she gets hungry during the night, she won't sleep well. Sleepless nights make for restless days, and that's not good for anyone.

Just when I thought I had feeding under control, I got another surprise. She abruptly stopped eating meat at night. Her doctor said that one of her medications could cause dry mouth at night, so I substituted tofu for fish or poultry. She always liked food, so watching her face light up when she sees her plate makes me smile. It is those little moments when we can laugh together that bring lightness to our journey. That brings me to my second point: make a commitment to laughter.

Making a commitment to laughter is just as important as committing yourself to performing care tasks. As adults, we often get so bound by propriety that we disconnect from moments that should make us laugh. Giving care will bring some heavy moments, so it's important to give yourself time to step away from being serious. It's impossible to be stressed out or overwhelmed when you're laughing so, laugh, laugh, laugh! The things that make us laugh along the journey give us something other than responsibilities to remember. Having laughter in your life sets the foundation for creating good memories.

Creating good memories is the tip directed solely to you, the caregiver. Dementia robs our loved ones of their ability to recall memories at will. As the caregiver, you become the keeper of what is to be remembered. In our daily lives of remembering all of the necessary tasks, we often overlook opportunities to shape the memories we want to have. Taking actions that create good memories regardless of their size, give you something light to carry when the journey gets rough. The memories you create acknowledge that you've done your best under very challenging circumstances.

When creating good memories, it's important to do so with a KISS (i.e., Keep It Short and Simple). Dementia patients can easily get overwhelmed by an activity, even one they like doing. As the caregiver, watching your loved one struggle can be hard. KISSing activities allow you to use their boundaries to create events that are satisfying to both of you. That gives you something worth carrying when the journey ends.

Knowing that I've done all that I could to help my Mom have the best possible life despite dementia has made me happy. We have a new normal because of dementia, one that balances the rough, irritable moments with smooth, uneventful ones. Because of that, I'll have no regrets about what I did when the journey ends. There may be things that I will reflect upon and see where I could have done better. But during those times, I will remember to be patient with myself and know that I did my best in that moment.

* * *

Living in the Moment

Walt Zerrenner

Aline Mary Hirner was born July 29, 1941, in Edison, NJ, to Mary and Robert Hirner. She was their only child. After graduating from Perth Amboy High School, Aline attended Montclair College. She graduated from Montclair with a Bachelor of Arts in Education. In the fall of 1963, she accepted a position as a Math teacher. We met in the summer of 1964.

I was born on July 8, 1941, in New York City and the oldest of five children. After graduating from high school, I enlisted in the Marines. I was honorably discharged from the Marine Corps in July 1963 after serving four years and reaching the rank of Corporal. Taking advantage of the G.I. Bill, I enrolled in college and attended night school while I worked full time

During the summer of 1964, Aline and I met on the beach in Bayhead, NJ. We hit it off, married a year later, and built a life together. We have two children and five grandchildren. I retired in 2005, and we moved to Wisconsin to be with our daughter and four of our grandchildren.

The Early Progression

Fast forward to our annual vacation in New York City in December 2006, when I noticed the first signs that something was wrong. This was a woman who loved New York, particularly during the holiday season. That was the Aline I knew, not the person who didn't want to do anything but sleep.

We cut the trip short and returned home to Wisconsin. Our family physician listened to my recount of the trip and her behavior. He recommended an MRI and to have it interpreted by a psychiatrist. That was scheduled before we left his office.

The MRI was performed and the interpretation made by a neuropsychologist. The diagnosis was Mild Cognitive Impairment (MCI). Looking at the MRI, there was white matter on the brain, evidence of a mini-stroke. Thinking back before the New York trip, I had noticed some changes in Aline's forgetfulness. I had just attributed that to our aging process.

In 2007, we were still members at a country club and enjoyed playing golf. One day after ladies golf, Aline arrived home 45 minutes later than expected. It was only a 10-minute drive to the country club. She had no explanation as to why it took so long, nor could she recall the route she took home. It frightened her to have that memory lapse, and at that moment, we agreed that she shouldn't drive.

Her memory continued to get worse, and I noticed it was getting more difficult to leave her home alone for longer periods of time. I had to shut down my consulting business, as I could not travel and could not take her to an unfamiliar city. I had just landed a very lucrative consulting engagement with a large healthcare system and had to turn it down.

The psychiatrist administered the neuropsychological tests in 2007 and then again in 2008. There was no significant decline indicated with the two tests. However, a second MRI showed the presence of more mini-strokes but none as severe as the first stroke. The diagnosis was changed to Vascular Dementia.

Lifestyle Adjustments

We had to make some significant lifestyle changes, including vacation plans. We had a three-week trip to Italy planned that I canceled. The big concern about traveling, especially out of the country, was what would she do if something happened to me.

There were still many fun things to do. We took trips to Ski Brule and the Wisconsin Dells with the family. We were season ticket holders at the Fox Cities Performing Arts Center and Annual Partners. Aline loved to dine out, and we often did with family. Grandchildren were involved in a number of activities that we always attended. We accepted the things that we could not do any longer but enjoyed the things we still could. That is still true today. We call it "Living in the Moment."

Cooking, cleaning, medication management, and driving to medical appointments became my new normal. Dementia wasn't the fairytale retirement we had planned, but I was determined to focus on what we still could do together, and how I could make a difference.

We started participating in memory cafés through the Fox Valley Memory Project. In fact, we were part of the very first memory café. Aline continued playing bridge with her friends at first, and we took daily tours of our yard to look at the flowers and trees. We also dined out and took in shows at the Fox Cities Performing Arts Center.

Early Onset of Alzheimer's

In March of 2009, additional neuropsychology testing revealed that Aline had moved into the early stage of Alzheimer's. The psychiatrist told us that we did not need to see her anymore and suggested that we start looking at resources. She handed me a stack of information about Alzheimer's, along with a suggested reading list. I was advised to contact a neurologist for Aline's continuum of care.

Knowing that the day would come when I could no longer care for Aline at home, we evaluated the memory care facilities in the Fox Valley. We visited and toured many of them and rank-ordered them based on Aline's comfort level. There were some we eliminated and never put them on the list.

I began my education about Alzheimer's in 2009 using the information provided by the psychiatrist. I read a number of books and white papers, and I looked at online resources. Much of the information helped me understand the current situation and prepare for the days ahead.

I was still active, playing in a golf league, skiing, and working out at the Y. Aline was now at the stage where it was difficult to leave her home alone. At first, I could work out at the Y and be home by 8:00 AM before she was awake. Even if she was up, she would see the schedule on the whiteboard. That all changed when she forgot to read the board and panicked if I wasn't home.

An in-home care organization was referred to me, and I looked into their services. It worked out perfectly as all the caregivers were excellent, and Aline liked all of them. A couple of them even became friends. We had purchased long-term care insurance in 2001, never expecting to use it so soon or for Alzheimer's. The in-home care organization was an approved agency and there was no problem being reimbursed for their services. Being home alone with Aline was still challenging, dealing with the redundant questions and occasional hallucinations. Having a caregiver in the house to give me time away was very important for my own health.

Using in-home care services allowed me to keep Aline at home for as long as possible. On December 1, 2014, Aline moved to a memory care neighborhood (i.e., a specialized community for seniors that have dementia, memory loss, or Alzheimer's that can be free-standing or part of an assisted living facility). We had reached the point where I was stressed out, not sleeping well, and my own health was at risk. Aline had become very clingy and did not want me even to leave the room. She was hallucinating at night and causing me to have sleepless nights. It was time.

Aline adjusted very well at the memory care neighborhood. Her neurologist said it was because we did not wait too long to make the transition. I continued to take her out to shows, to her favorite restaurants, and to family activities. We kept a balance in her life, recognizing that I could not do the things that the care facility could do but also, I did the things that the facility could not.

During this time, I became very active with volunteer work. To this day, I serve on a number of not-for-profit boards and committees. I am a Board member for the Fox Valley Memory Project, Fox Valley Veterans Council, and BEAMING, Inc., an Equine Therapy organization. I perform committee work for the Non-Profit Leadership Institute, the Fox Cities Performing Arts Center, Wisconsin Dementia Resource Network, and the Alzheimer's Association.

In 2017, I was named Alzheimer's Association Wisconsin Family Caregiver of the year. I was also received Senatorial recognition for my work as a family caregiver. Today I facilitate three men's support groups (men caring for their wives living with dementia). Staying active helps me deal with my own loneliness.

In 2019, Aline had another mini-stroke, fell in May, and broke her left hip. She had hip replacement surgery and had a month of rehabilitation and physical therapy. She needed a month of physical therapy even though the insurance company refused to pay for more than 14 days. I had to pay the memory care facility in order to hold the room for her return, which she did after rehabilitation.

Then on Labor Day, Aline fell and broke her right hip. Once again, it was hip replacement surgery, rehabilitation, and physical therapy. This time I did not let her go back to the memory care facility where she fell. The place where she was had a room for her, and I had her stay there as they are better staffed and equipped to provide the care that she needs.

The place she now resides is licensed for skilled nursing beds, which is much safer for Aline. The cost is $1,500 a month more than my cap on the LTC insurance reimbursement. From May through December, my out of pocket expenses for Aline's care and medications exceeded $40,000.

We are working on her mobility these days in hopes that I can start taking her out in the warmer weather. She is pretty much confined to the wheelchair, but we are using the walker on a limited basis. I visit her at least every other day.

It is becoming more difficult to visit as she always thinks that I am there to take her home. Her short-term memory is very poor, and she asks the same questions repeatedly. She does not remember that she broke both hips and had surgery. Lately, she has been asking about her mother, who passed away in 2001. I tell her that her mother passed away at 86 years of age. Some days we will go over that topic several times in an hour.

It has been a journey since that first mini-stroke in December 2006. When Aline was diagnosed with Alzheimer's in March 2009, I shared the news with the family. I had explained to them that one of the symptoms was memory loss, and the day would come when she would not recognize or remember us.

The next time our grandchildren were at the house, the youngest grandson said, "Nana, you still remember me, don't you?"

Aline laughed, hugged him and replied, "I will always remember you." However, I knew the day would indeed come when Aline would not remember us, but we would never forget her. She was a great wife, a great mother, and a great grandmother. She was the kindest, most loving, caring person I have ever known. She was loved by family and cherished by all her friends and colleagues. Today Aline is in the advanced stages but still recognizes family and some friends. She lives full time at a memory care facility, where our family continues their loving care for her.

Now, in her name, I have a way to make a difference for others walking this path: The *Aline Zerrenner Dementia-Friendly Fund* within the Community Foundation for the Fox Valley Region is propelling our dream of creating a dementia-friendly community in the Fox Valley. My goal was to make it easy for people to obtain funding and not have to go through hoops for grants, and to have anyone be able to contribute to the fund.

On November 2, 2019, the first-ever Memory Café was held at the Equine Therapy facility, funded by this Charitable Fund. Twenty-two people living with Dementia and their caregivers participated in this interaction with therapy horses. Three more Memory Cafés are planned for 2020.

* * *

Accepting a New Normal

Janice M. Thew & C. Noelle Driver

Janice

We had just returned from celebrating Thanksgiving at Mom's house when she called to accuse my husband and son of stealing her car's hubcaps. Bewildered to have Mom make such absurd accusations of the son-in-law and grandchild she adored, I argued the ridiculousness of her claim. She added that she also saw my daughter (Noelle) sneaking around her bedroom, looking to steal her jewelry! I was stunned by the uncharacteristic nature of this phone call. Shaken and, to be honest, angry, I relayed this incident and other recent hallucinogenic episodes to my cousin, a nurse, who asked if Mom had ever been evaluated for dementia.

I took Mom to a neurologist and she was diagnosed with Alzheimer Disease. Though a little anxious about this, especially given the long driving distance between us, one brief conversation about the diagnosis and a pamphlet of resources was minimally helpful in understanding what was ahead. I had no comprehension of the disease course and a complete lack of preparation for how rapidly we would have to face life-altering decisions, how rapidly Mom's mind would deteriorate, nor how quickly she would become unsafe in her own home. What behaviors might have been casually attributed to natural aging before this, now seemed to accelerate with concern for Mom's poor judgments when operating her car, misplacing her keys, and forgetting how to get home from the mall.

I ignored the need to move more quickly until she called 911 for the second time in two weeks for no apparent reason. I planned no change in her living arrangements until the ER doctor refused to discharge her unless we took her directly to a nearby assisted-living facility. As my understanding of the disease evolved and it became clearer that her strange behaviors were attributable to it, I subsequently learned from her neighbors, hairdresser, and dentist of other bizarre antics and phone calls, which began around the time of that Thanksgiving hallucinogenic episode. Fortunately, she had not caused harm to herself or others before we finally took action.

Over the next few months, and after 30 years as a self-sufficient, independent, and hard-working widow, Mom's inability to take care of herself and her home became obvious, putting her safety at risk. So began the long, hard period of transition for Mom and me, reversing roles of parent and child, making hard decisions about her home, and overall, her life, almost always without her consent. By the following Easter, we had moved Mom to assisted-living, sold her home, and disbursed most of her belongings. While I was still working and managing a family with two active children, now and for the next five years, I added the responsibility of managing my Mom's life. Mainly, I tended to her well-being and bore anxiety over the quality of care she received by others.

I lived 70 miles from Mom, not close enough for short check-ins on the way to or from work, frequent visits, or nearby doctor appointments. Each trip to her assisted-living home for a doctor appointment or a visit to replenish clean laundry or meet with her care coordinator required time away from work and family, at least one day per week, and often on weekends. There were also phone calls with her several times throughout each day. Mom's emergency trips to the hospital were even more difficult since they required my immediate attendance. She exhibited declining comprehension of medical questions asked of her, and I needed to correctly provide information to assist her in receiving appropriate medical care. She was also bewildered outside of her familiar environment, and I often had to defuse her unruly or uncooperative behavior that generated poor responses from her healthcare teams.

I grew quite resentful of the whole situation despite having the most supportive and involved husband during this time. The resentment often spilled into short-temperedness, intolerance, and anger with Mom's repetitive questions, multiple daily phone calls, and occasional notification from the assisted-living staff. I was angry as I saw my own life being turned upside down, the lost freedom as I was responsible for her care and safety, even without her living with us. We felt we could not take any family vacations during these five years, so we would always be nearby for the unexpected event.

I was saddened by who my Mom had become, once strong and independent, proud to be nicely dressed, now refusing to change her clothes or give up her badly deteriorated shoes for the new ones I had bought for her. With the progression of her disease, there was also a change for the better. Mom experienced times of disorientation and unruliness from being in unfamiliar settings but was, for the most part, happy, very socially engaged at her living facility, and often expressed gratitude for me and my time. She told me often that she loved me—an uncharacteristic softness for members of my family.

Over time, I came to understand that she was not responsible for her repeated questions and odd decision-making. As painful as this process was, what had changed her eventually changed me. I came to accept it all and accept her without embarrassment or explanation to others. This was an important transformation of heart and spirit and one I wished I had reached sooner. Sooner to avoid the anger, the shouting, the tears, and the resentment. Sooner to spend more time playing games and doing crafts together, sharing meals and laughter, and spending quiet times at peace together. There was no more chance to learn about the past since there were few memories of it to share, but there was still time to share the present and to experience the warmth of a mother's love.

The behavioral and communication changes that occur in patients with Alzheimer Disease are sometimes sudden and distinct and perhaps more recognizable as manifestations of the disease. More often, however, the behaviors are subtle peculiarities that grow more and more abnormal, eventually leading to a search for the cause. Prior to understanding the disease wherein the patient loses self-control, the smaller behavioral oddities are often met with responses of negativity such as frustration, attempts to correct, intolerance, shame, and anger. The patient is vulnerable to becoming a victim of this frustration and anger. The responder may not accept that this is the new norm of their loved one's personality. I certainly had a difficult time with this transition.

Overall, there are two phases of the Alzheimer Disease manifestation when the patient is vulnerable to harsh and uncompassionate responses from others. The first is at the onset when their behavior and decision-making are inexplicable, absurd, and not normal as before. The second phase is when the realization sets in that as the patient's life is permanently changing, and the caregiver's life is also, by no choice or control of either of them. Until the full transition takes place, whereby the patient is adequately and safely cared for, and the caregiver's new role is established and accepted in their own mind, the patient is vulnerable to responses of frustration by the caregiver.

It is during these phases that a caregiver requires understanding, help, education, and oversight to meet their own growing emotional and physical setbacks. Community support, therapy groups, or social workers should be available, accessible, and affordable to all caregivers and families of patients with Alzheimer Disease. Workplace paid family leave for intermittent days off (rather than weeks or months at a time) should be available to alleviate the burden of caregivers forced to reduce their hours and pay. Most importantly, Alzheimer Disease education should be immediately recommended to the family by the medical community upon the first signs of the disease to educate and prepare them for what lies ahead for the patient and themselves of this irreversible disease. It would have been very helpful when Alzheimer Disease was diagnosed to have heard from the neurologist a strong recommendation to join a support group, or to have follow-up where someone could help explain what to expect and what decisions we would have to be making.

Fortunately for me, frustration, fear, and anger were transformed into love and acceptance. Since my mother's passing from Alzheimer Disease, I have witnessed many friends traveling the same road with a parent. I try, without intruding, to explain what is happening and that their loved one is not deliberately obstinate, forgetful, abusive, or even crazy, but that the disease is in control. I understand my friends' pain, anger, and frustration, and encourage them to avoid the tendency to be dismissive of their parent's situation. I try to help them understand that the disease does not get better and sympathize with their plight to find adequate and affordable care. With education leading to understanding, and support from siblings, other family members, friends, and community social services at large, perhaps these caregivers may arrive at peace with the circumstances sooner and for the betterment of themselves and their loved ones stricken with Alzheimer Disease.

Noelle

I was in middle school at the time my mother, Janice, transitioned into the role of caregiver for Grandma. I struggled less than my mother did with understanding that the disease was out of Grandma's control, but I didn't have as long of a relationship with her as my mother had. I had less life experience knowing Grandma as my caregiver, and therefore less difficulty seeing Grandma transition out of that role in my life.

After my mom and Grandma settled into the new normal of their roles however, I witnessed a tremendous amount of love and sacrifice from my mother to take care of Grandma. Whereas I would get frustrated at Grandma's repeated questions, and in my teenager impatience, think, "Why do we bother visiting if she doesn't remember?," my mother saw the value of being present in my Grandma's life, even if she didn't remember the specific visits. We grew patient by interacting with her, helping to direct the conversation to new topics, helping to keep her on uplifting subjects and things she could do or notice in the present moment. I created a scrapbook for Grandma with pictures of family members so she could look back and keep connecting faces to names. My mother was attentive to upholding Grandma's dignity, taking care of her laundry, and advocating for her at her doctor's appointments, hospitalizations, and assisted-living facility. Having noticed many of the residents of the care facility did not have family who visited often or at all, my mother befriended many of the residents. She helped to make connections for Grandma to have opportunities for socialization.

I encourage all family members of patients with Alzheimer Disease to embrace their loved one's new normal and find ways to include them in conversations and life events. The power of presence goes a long way to communicate love and build the best life possible for patients with Alzheimer Disease. The relationships remain valuable, even as memories fade.

Messages With and Without Words

Ashley Cleere

"Today, we're going to trade in the truck and get a car for you!" my husband, Ray, announced, showing me a scrap of paper with the mileage penned on it in his arcane handwriting. It was five months after he was diagnosed with Alzheimer's disease. In a year, he would be gone.

Ray's purchase of the Ford F-150 twelve months earlier delivered a big hint that something was amiss. On a Sunday evening, we decided to keep both his 20-year-old pick-up and his Lincoln Town Car. Monday morning, he went to the county DMV and renewed the two license tags. From there, he drove to the local Ford dealership, where he traded both vehicles in for the brand-new truck, a sharp reversal from our conversation the previous night, and his stop at the tag office.

Cars and driving were high on the list of what brought Ray pleasure. He spoke of past vehicles with a tone and affection similar to how one might recall a childhood pet or past love. As a result, the prohibition of driving was poignant for him, a restriction presented in tandem with the diagnosis of Alzheimer's disease, arriving when he no longer could understand the profound changes afoot. Initiating the trade-in suggested a modicum of acceptance after months of fierce resistance.

The sales team at the dealership welcomed Ray and me. Outside of my hearing, he explained that, due to his health, he could no longer drive. When he told me about the conversation, he laughed uproariously because the car dealers thought he had a heart condition. Although unequipped to describe his actual circumstances, he knew this explanation was inaccurate.

When he saw the Lincoln MKC on the lot, Ray lit up: "A Lincoln for you! You'll love it." While a crossover SUV was not what I had in mind, it was attractive and easy to drive. Moreover, the ride appealed to Ray, whose encounters with cars would now be as a passenger. Most days, Ray could not recall his most recent meal, but the instant Matthew McConaughey showed up on television commercials, he shouted, "Lincoln!" Two years after his passing, I feel as if he continues to look after my interests through the choice of a well-accessorized vehicle.

Perhaps unwittingly, Ray had accommodated his dementia amid his driving habits and in other ventures for many months before diagnosis. He adhered a return address label to his wallet, which I assumed was there in case he lost the wallet. However, one day when we stopped at a gas station, he told me that the pumps didn't work. Belatedly, I realized that the label was in his wallet to inform him of the zip code associated with the credit card.

When the monthly charges on the credit card we used exclusively for fuel purchases decreased, I imagined that Ray was spending less time on the road. But our stop at the gas station with the "broken" pump indicated that technology had become overly complicated, so he paid cash.

Ray was a seasoned problem-solver. As a higher ed administrator, he had set up his office suite with adjoining rooms enabling him to hold two or sometimes three concurrent meetings. Because crafting ways to supplement his mental capacity was customary for him, figuring out how to buy gas was a manageable challenge, even with dementia. He also knew to avoid activities that would be overly complex. Once a lively cook who assembled sumptuous stews out of whatever happened to be in the refrigerator, he started refusing my requests to prepare dinner. He turned the task of balancing the checkbook over to me so gradually that I didn't realize that he had stopped participating altogether. My missed observations and incorrect surmises, along with Ray's savvy, contributed to delaying the diagnosis. While I'm grateful that we preserved normalcy for as long as possible, the risks we overlooked give me pause.

My husband was the most resilient person I have ever known. Throughout his life, he tolerated criticism and unfounded personal attacks in deference to the needs of the institutions he led. Six months after his diagnosis, the swift acceleration of dementia carried me to the sad realization that he could no longer live safely at home. Ray participated in the decision to move to assisted living to the degree that he was able. On the day his belongings were transported to the apartment, this charmer, typically gregarious with service providers, was sullen and non-conversational. That evening, he apologized to me, saying, "I'm sorry. I'm just scared." Fear was new territory for our relationship.

I regret that Ray did not grasp that he would never return to the home we had established together. Early in the three months spent at assisted living, before moving to a skilled nursing center, he compiled lists of steps needed to move out and resume our life. The details were sketchy, but the topics appropriate: finances, medical care, real estate. He still was functioning as a problem-solver. Yet, on a trip to a doctor's appointment, we drove by a shopping area very near our house, and he showed no signs of recognition.

Ray did not abandon his administrative role while at the assisted living community. Senior staff invited him to accompany facilities personnel during routine tasks such as changing light bulbs and setting up for special events. He provided encouragement and direction thanks to the patience of those who graciously accepted his improvised leadership. Reminiscent of his profession, he monitored activities of students, a.k.a. his fellow residents, and expressed concern to me about safety procedures, worrying about what would happen in the event of a fire or tornado.

The extent of Ray's commitment to emergency preparedness was not fully apparent to me until after he died, and I was preparing our home for sale. I lost count of the number of propane lamps he had placed in various closets and crannies around the house, along with more than a case of refill tanks. Shoeboxes stuffed with emergency candles surfaced in both the kitchen and the garage, along with multiple flashlights, a lifetime supply of batteries, a drawerful of smoke detectors, and numerous fire extinguishers. Plus, I inventoried heavily stocked emergency kits that had resided in trunks of cars. It's plausible that Ray accumulated excessive quantities of these items during his pre-diagnosis season of dementia. The level of protection he sought despite or perhaps because of his diminishing abilities stirs me.

In addition to remaining true to his preferences and what he thought was important, Ray leveled opposition to activities that did not reflect his nature. The few times we played Bingo at the assisted living community, he was indulging me, rolling his eyes in resignation throughout the game. On the other hand, pursuits we previously had enjoyed bore comfort for both of us. Sitting next to each other, watching musical performances, even with one of us in a wheelchair, recalled life before Alzheimer's and sustained our sense of ourselves as a couple.

My husband's dignity was, understandably, a higher priority for me than for those employed to care for him and many others. I delayed the convenience of sweatpants as long as possible because Ray had been regarded as a sharp dresser and was particular about cuffs and pleats. On the day he returned to skilled nursing after a hospital stay, I found him in the common room wearing mismatched pajamas, a red plaid top with black and white checked bottoms, pleading: “Help me! Help me!”

Although attentive to his attire, Ray grew averse to hygiene. The nursing staff enlisted my participation in persuading him to go to the shower and be shaved. For practical reasons, showers required staff assistance in a vast shared space with limited privacy, counter to the soothing qualities associated with bathing. To the gentle request for a shave by a CNA, Ray shocked me by bellowing, “Back off!” A clean shave would have enhanced Ray’s appearance, but having others perform such a personal task disrupted his modesty.

Ray’s commitment to his dignity impacted his care. Following two major falls, Ray tucked himself back into bed. When he complained for two days about what turned out to be fractured ribs, staff were hesitant to be convinced that he had fallen because they had not seen him on the floor. In a subsequent fall, he startled care providers who found him in bed, bruised and bloodied, fortunately only minutes after the incident.

Hospital stays, ironically, were pleasant interludes during the difficult months of assisted living and skilled nursing care. Instead of stopping by a couple of times a day, I stayed in Ray’s room all day. Sharing meals and watching TV together without a lot of people around felt cozily familiar. At the care centers, Ray generally was disinterested in food; however, when I called hospital dining services, his perception was that we were ordering take-out. One night he ate pork BBQ with gusto and asked which restaurant made it. Twice when he was discharged after prolonged hospital stays, disappointment marred my relief. I didn’t want the togetherness to end.

Ray had been using a cell phone for decades and therefore maintained that ability until the traumatic fall that resulted in a brain hemorrhage and his death eleven weeks later. I have saved almost all of the voice mails he left for me from care centers and hospitals. Many open with him, saying, “This is Ray!” as if I wouldn’t recognize his voice. Most messages end with, “I love you!” In between, he offers garbled instructions about how to arrange a rendezvous or to get him home, or he tells of plans to take his daughter out to dinner. In some, he expresses concern about where the car is parked or the fact that he has no money in his wallet. One refers to finishing “a long conversation I had with myself.” Several are brief, merely making a connection: “This is Ray, just checking in.” Somehow, even with dementia, he organized people, made plans, and upheld his sense of responsibility for managing his life effectively, lovingly.

Toward the end, Ray spoke infrequently. When he talked, it was with emphasis. After I arrived ten minutes after the holiday party had begun, he declared, “I was waiting for you.” He also communicated without words. On another December visit, he kept pointing at the “Happy holidays!” banner draped around the nurses’ station as if to remind me that we needed to be decorating, shopping for gifts, sending out party invitations.

When the day came for Ray to move to the palliative care wing of the Alzheimer’s center, I propelled his wheelchair to the new area, which had a color scheme and layout identical to the setting he had just left. For many months, I had wheeled him to various places in the building, but never to this space. As soon as I sat down next to him, he gripped my hand extraordinarily tightly for several minutes. My dear spouse seemed to know where he was and why he was there. Two days before he died, the last full sentence I heard him utter emerged as a blossom in a desert of silence: “I love you.”

During the last two years of my husband’s life many things I adored about him vanished, I learned to cherish small gestures, nuances that reflected supreme effort. When the hospice chaplain called to offer condolences, I lamented that he had not gotten acquainted with Ray earlier. The chaplain responded, “He still reached out to shake my hand.” In his final days, although his mind and body were failing him, Ray managed to convey, “This is Ray!”

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Alzheimer's, Unfolding: An Intricate Dance Between a Mother-Daughter Duo

Sara Feldman

Gazing across the pond on a warm and muggy evening just before sunset, my grandmother and I sat hand-in-hand, in silence. The tranquil sound of nature, the buzz of crickets, and a light breeze blanketed me in warmth. As the sun disappeared behind the horizon, a dragonfly landed on my forearm, and my grandmother gently put her hand on my arm. She peered into my eyes, and during a moment of what seemed like pure lucidity, she said in a serious manner, "*Always follow the dragonfly*." Before I could respond, she looked away and was lost again to the confusion and ever-familiar state of dementia.

I grew up with a keen awareness of dementia and the Alzheimer disease type in particular. From my earliest memories, I remember stories of my maternal great-grandmother, whom I never had the privilege of meeting, and her "problems of memory" during her last years of life. As my grandmother was diagnosed with Alzheimer disease (AD) the year after I was born, my moments with her were, as a result, ever-changing and increasingly shallow. I frequently compared the stories of my great-grandmother's memory loss to what I had witnessed in my grandmother and, to me, experiencing memory loss in later life was, as far as I knew, normal.

Yet as I grew older and began to understand the gravity of my grandmother's condition, alongside her disease progression and institutionalization, I grieved. I saw my grandmother, an older woman who had a deep belly laugh and a love of decorating her face in makeup, sink further and further into the unknown and into a state where she seemed unaware of everything around her. Unsettled by her long decline, I promised my mother at the young age of thirteen that I would do everything possible to avoid putting her in an institution if her health ever declined in a similar way. A selfless thought—putting my mother's needs first—took priority.

Fast forward eighteen years later to the year 2017, when my mother was diagnosed with Alzheimer disease. This condition has now affected three generations of my family: my great-grandmother, grandmother, and now my mother.

The years leading up to my mother's diagnosis of Alzheimer disease

Over the past several years, my mother's cognitive capacity has slowly yet progressively declined. Prior to her diagnosis, early symptoms of cognitive decline were evident for years. She forgot to pay the bills, close the doors to the house or car, turn off the stove after cooking, and go to appointments she had scheduled. She failed to remember details of conversations, was unable to retrace her steps to find recently used items, and frequently put things in odd places (like a bowl of soup in a sock drawer).

In the year prior to her diagnosis, several significant events occurred. My mother was fired from her teaching job after multiple incidents of misplacing things and later blaming others for taking those misplaced items, not showing up to work, and walking out from the middle of lectures she was giving without giving an explanation or returning to class. I also remember vividly checking the mail one summer day, opening an official letter of notice indicating a lien would be placed on our home within 60 days unless action was taken, due to five years of her federal and state taxes not being filed or paid. And her driving went from being unsafe to having multiple at-fault car accidents, one in which her car was totaled, and all eventually leading to her losing her license.

Caring for my mother

Being a caregiver involves a multitude of tasks. Beyond preparing meals, providing transportation, managing financial matters and accounts, promoting social and community engagement, assisting with daily hygiene, searching for things she's misplaced, comforting her at 2 am following a nightmare, the most important part is simply being there. Being with my mother, physically and emotionally, is critical. Physical contact and sitting near to her are comforting. Exchanging stories and engaging in conversation enable her to feel heard and connected. This is what providing care to someone with Alzheimer's is really all about. Being present. Providing comfort. Reassuring her when everything around her is changing and becoming unfamiliar. It's enjoyable and rewarding, and yet it carries a continual, heavy presence.

Knowing dementia is progressive, and seeing my mother's needs increase over time, I try to proactively think ahead to avoid having to reactively cope with situations and circumstances gone awry. Given the ever-changing nature of dementia, this is hard. Yet thinking of potential 'what-ifs' is critical and has been a core component of maximizing my mother's sense of autonomy, while also ensuring her safety and easing my worried mind.

I've often criticized my caregiving and wondered where I failed and what I could have done better. After my mother forgot to close the door to the refrigerator repeatedly for more than a year, and after losing countless amounts of food due to spoiling again and again, alongside coping with copious amounts of frustration, I installed locks on the refrigerator and freezer. While doing so saved me a lot of money and frustration, I also grappled with significant guilt. Was I doing the right thing? How could I lock my mother out of our refrigerator? Yet my statements of "Mom, you left the fridge open" and her replies of "Oh sorry" or "I'll do better next time" weren't making the situation better, and likely made it worse, as acknowledging over and over where she went wrong only focused on her mistakes and reemphasized her *inability* to remember. Bright pink and orange signs that read 'PLEASE CLOSE FRIDGE DOOR' didn't work. Alas, what was the solution?

What I've come to know is that caregiving requires continual conversations with the person with dementia, a lot of patience, and a bit of innovation. My mother now has her very own minifridge, which promotes her autonomy. After forgetting how to use a phone—let alone find it—I got her a smartwatch so she can see the date and time and feel better oriented. Added benefits including being able to call her—and she can call me—at any time with a simple press of a green button, and the GPS component is helpful and comforting knowing that I can locate her if her whereabouts were unknown. I also installed a keypad on our front door that I can set individual codes for people to enter—something I intend to use more when further homecare and formal support is necessary.

Again, there is no right or best way to go about providing care, and what is best now may not be best tomorrow.

An ever-present sense of loss

I have come to develop an intimate and intricate relationship with Alzheimer disease. It is a relationship filled with celebration and loss, gratitude and selfishness, selflessness, and tolerance. Watching my mother, whom I currently care for, live with this disease is often heart-wrenching and emotionally intensive, particularly knowing that I lose more of her with each passing day. I grieve my mother's loss every time I am with her, and it pains me to even say this. There are moments I am sad, afraid, and frustrated, and other times I feel simply exhausted and defeated. Sadness comes with her loss of skills, interests, attention span, short term memory, curiosity, personality, and identification of friends and family. Fear and frustration come from the continual and impending sense of loss, of unknown change, and my inability to make any of it better. None of these are surprises, but they are surprisingly significant.

Caregiving is also one of the quietest, loneliest, and most challenging experiences. People around me grow up, move forward, start families, and engage in community activities that I just can't be part of at the moment. Certainly, the grief and loss I experience are not only associated with that of my mother's deterioration.

However, having the opportunity to provide support and care, and to be with my mother—my partner and best friend—is one of the best opportunities I've ever had the privilege to be part of. No matter how hard caregiving is, and no matter how much pain, lost sleep, stress, and grief there are, I wouldn't have it any other way.

Caring for myself

“How are you taking care of yourself?” asked one of my mentors a few months after I took on my caregiving role. I sat in silence and thought, “What do you mean, care for *myself?*” After all, I wasn’t the one who needed care. And yet—I really did.

Caregiving naturally put me in a position to think about my mother’s needs, and put her needs first, even before mine. The focus of my life had shifted to being present for my mother. In the beginning, I didn’t know how to be a caregiver and full-time employee and friend and partner and person connected to the community—all in one. I dove into caregiving mode, and I became exhausted, very quickly.

There is no one-size-fits-all definition for self-care. For me, caring for myself involves advocating for and talking about my needs. Journaling and writing, meeting other caregivers, talking about the joys and the hardships with people I have a close relationship with, and finding ways to share my story are helpful to me. It also involves me asking for help and allowing myself to be vulnerable. As a sole caregiver, my mother’s needs are completely dependent on me—and yet balancing caregiving with everything else in life requires help. Asking for help is not about being *unable* to do something—it’s about reducing my load and burden, and results in me delegating caregiving and non-caregiving tasks and accepting offers of support. I’ve also changed the way in which I communicate with others. I no longer include phrases such as “I don’t want to burden you” in my vocabulary and have instead replaced them with “thank you for your support,” because people inherently do care and find satisfaction in helping. I know—*it takes a village.*

I also no longer say, “Yes, I’ll be there” to commitments, meetings, and events. Rather, my commitments come with a disclaimer and compromise—again with the goal of making my life easier. Now, I say, “Yes, I’ll meet if circumstances allow me to *and* if we can meet at my house [or you come half-way to me].” Selfish it may seem, and yet it is okay to do what is possible to *make life easier*, amidst very challenging circumstances.

Building a network of people who care and who are willing to help is absolutely pertinent and necessary to sustain caregiving long-term.

Finding meaning and purpose

Since my grandmother’s last words spoken to me—*always follow the dragonfly*—I have held them close and hadn’t applied meaning to them until I became a caregiver for my mother. The dragonfly, integral in several cultures, is symbolic of change, transformation, adaptation, and perseverance. Naturally, I persevere, move forward, and have a ‘keep going’ mindset amidst hardship. I have learned to embrace the unexpected and ongoing detours in life and throughout my caregiving trajectory. However, the underlying meaning in transformation, and in transformative change, is emotional and mental growth, wellness, and grace following hardship.

My caregiving experience is one that goes both ways—it is a journey of caring for my mother and myself. I have chosen to be vulnerable and accept help. I choose to invest in my health and wellbeing, and my mother’s. I choose to view this disease, often viewed with extraordinary negativity and stigma, as an opportunity and gift. I have chosen to allow my mother’s, grandmother’s, and great-grandmother’s experiences with dementia define, in part, who I am and the career in Alzheimer disease and caregiving research that I have chosen to embark on.

When life hands you lemons, make lemonade . . . I’ve just followed the dragonfly.

* * *

The Miracle

Karen Klaus

My grandmother—a loving, generous, strong, spirited woman—had Alzheimer’s disease. After a feisty time with her at the beginning of her disease, my grandma became as sweet as a kitten. She, who had shown me the most love I had ever received in my life, went through a period when her disease started to kick in, where she would waver back and forth between asking for my help and challenging me, or looking at me with dagger eyes. Once she got settled into a nursing home, where she received round-the-clock care, she also eventually settled into her illness, becoming the sweetest person on this planet, full of the love I had always known, every time she saw me.

After a rough beginning, the joy on her face whenever I visited her was heartwarming. Once, when I came to visit her at the nursing home, there was a concert there, with about 100 people in the audience. I scanned the room, looking all over for my grandma. I finally spotted her—front row, center. That was my grandma, alright!

She was a hip kind of grandma who always made sure all of her grandkids had wonderful experiences. She was a "lake girl" who taught me (and all my friends) how to water ski, and when we came back into the house after a big day on the water, sun-drenched and waterlogged, she would have the air conditioner cranked with a big pot of piping hot chili waiting on the stove. That's just one example of the kind of grandma she was. When I was a kid, she made sure I had hullabaloo go-go boots with fishnet stockings every color of the time—shocking pink, neon green, etcetera. She even bought us matching paper mini dresses!

She drove a car at 12, hitchhiked to St. Louis at 14, had my mom at 17, became a keypunch operator, and worked her way up to managing a big office at IBM. All while being the most loving person I've ever known in my life! My hero—my role model.

With her disease, I was blessed that she always knew who I was. Our bond was incredible. I'd crawl in bed with her at the nursing home, and we'd hold hands and watch a football game together (not really watching)—just being together. Two peas in a pod.

A few years after living in the nursing home, I got a call that my grandma had a stroke and was in the hospital. She could not talk, eat food, or swallow, but was still able to show love. In the time she was there, every time I came to visit, she would make a sound—ooh!—she was always so happy to see me. She would take the one arm she could move and hug me tight and pat me on the back.

All along while my grandma was in the hospital, I played this little game with her, because every time I did it, it was new to her, and it brought her so much happiness. I'd walk into her room, saying to her, "Guess what, grandma? Devon (my daughter) is graduating high school next week!" My grandma would make a happy "*Ooh*!" and smile in awe and excitement. I'd immediately go around the corner, pop out, and do it all over, again and again, getting the same reaction—seeing her joy. With her disease, it was new every time!

I also had to make tough decisions about her care and her life. One was to get a feeding tube. When I filled out her healthcare directive, I did it with a nun. I wanted to make the right decisions, and it was very difficult. I imagined a person totally out of it—not someone who could still show love. I didn't want her to experience pain or suffering. I wanted her to be comfortable. I learned it was best to keep her hydrated because otherwise, it would be a very painful experience for her.

I felt like she received a mixed bag of care at the hospital. For instance, once I called for a nurse asking for assistance in swabbing her mouth because she was so dry and her lips were cracking—she couldn't swallow but needed moisture. I received a response, "we come in every 4 hours," to which I replied, "well, I've been here six hours and no one's come in." Then I'd get a great nurse who said, "I'm going to make your grandma so comfortable," as she fluffed up her pillows and strategically placed them to make her body feel good. The bottom line is she needed me to be her advocate, and I was happy to do so for this special person who helped to shape the person I am.

Regarding the decision to get a feeding tube, someone who worked at the hospital actually said, "well, she's lived a long life." (Actually, I heard that a few times.) Like I should just throw in the towel and give up. In desperation and sadness, I sat down with a candy striper who said, "well, I know what I'd do if it was my grandma." Finally, I felt like it was alright to say yes to the feeding tube, like I finally had permission.

After I made the decision and told the hospital to put in a feeding tube, I went into my grandma's room to play our little game—"Guess what, grandma? Devon is graduating high school next week!" Instead of the "*Ooh*" this time (remember she couldn't talk?), she actually burst into excitement and said, "Wow! Oh, my God!"

She didn't live long after that. It was the only thing she said before she passed a few days later. However, I knew I experienced a miracle. I am 100 percent confident that God let me know I made the right decision.

I cry as I write this. The tears are bittersweet. I'd like to share with those caring for someone with Alzheimer's that decisions are tough to make. Inform yourself, trust yourself, and remember to always go with your heart. I wish you all miracles and blessings.

* * *

Living With Alzheimer's Disease: A Shared Caregiver's Story

Catherine M. Politi

It started with simple statements like these: "I know I forget things. It's tiring. Every day, when I wake up, I feel like I'm starting all over again."

Over time, Mom started asking us questions like: "When am I going home?" ("Mom, look around. Here's your furniture, your clothes, your photos on the piano. This is your home," we would respond.) "Why don't my sisters and brothers visit anymore? When will I see them again?" (I thought, but never said, "Soon, Mom, very soon. But not on Earth.")

One day, when we were walking in her yard, she said, "You see that tree? It's a metaphor for how I feel." It was a tree in the woods that had uprooted, but it was leaning on another tree and didn't hit the ground.

My mother began exhibiting symptoms of memory loss in her mid 80's. By age 89, my siblings and I recognized she needed intervention for her care.

Mom was widowed at age 48. There were five of us: my older brother had just returned from Army basic training. I was in college, I had two sisters in high school, and a younger brother in 7th grade. She did her best to keep our lives as normal as possible while we all grieved our Dad's sudden death due to cancer. She stayed up well past anyone should in order to pore through paperwork, bills, and complete household tasks. She made sure we completed homework, socialized, visited with family, and went about our normal days. So to say we were devoted to our Mom would be an understatement.

As we each married and had our own children, Mom guarded her independence with ferocity. She frequently visited our homes and watched her grandchildren, but would never consider living with any of us, even when one of my sisters offered to purchase a home with independent space for her. She relished hosting dinners and holidays in her home through her 70s, even though we increasingly took on more responsibilities for grocery shopping, table setting, and cleanup. Whenever someone stopped in to visit her, she was always ready with a cup of coffee, tea, and a plate of cookies while we talked at her dining room table covered with a special tablecloth that rotated according to the season or upcoming holiday. Thus, as her decline began, her wish to remain in her home, the central place of gathering for so many, was paramount.

Mom's health care was always shared by all of us. One sister took her for eye exams and cataract treatment. One brother and I handled her checkups by an internist, cardiologist, and otolaryngologist. At age 77, she had cancer of the parotid gland, and my sisters and I shared driving her to her radiation appointments, timed around our work hours. Maintenance of her home when she became unable to care for it independently was also arranged by us, and even handled by our husbands, her grandchildren, or any of the large family network she had built and cultivated.

Once Mom's cognitive slips became noticeable, my siblings and I held a meeting. We decided that we had to slowly ease her into allowing help from a home health aide. One brother and sister began the process of applying for health and senior benefits for her, and another sister visited with a "lesson plan" to stimulate her brain. I applied for and obtained coverage for her very expensive drugs to slow her cognitive decline. Another brother, an attorney, prepared her living will and wishes for who would be legal and medical proxy before her Alzheimer's disease worsened. And he played the piano while she sang. Remarkably, she continued to play piano and said as she aged, "you know, I just can't play with my left hand anymore."

We hired someone to be with her from 9 AM to 1 PM so that her breakfast and morning pills would be supervised, and her lunch would be prepared and supervised. One of us (on a rotating schedule) would have dinner with her each night, give her evening pills, and would stay with her until her bedtime. At first, she was resistant to having an aide in the house, and made comments like, "I have five children, and you have a stranger staying with me?" But we knew we had to do what was best for her, and we couldn't be there enough. Eventually, she came to respect and even enjoy the aide's company.

Despite our best intentions, we made mistakes. I put Mom's daily pills in pill counters and hid her bottles so she wouldn't take a medicine twice. (In addition to her Alzheimer's medications, she was on diuretics, blood pressure medicines, and vitamins). Unfortunately, one day, one of us found her confused, discovered she had moved the pill counter, and she had taken two days of pills in one day. So we changed the medication routine. Another day, she left a pot heating on the stove and fell asleep. The aide who came that morning rescued her and disconnected the stove.

This routine worked for a while until she was hospitalized for pneumonia. A social worker would not let her go home without full-time care. For the next three years, she had a certified health aide living in her home Monday through Friday, and we rotated staying Saturday and Sunday until the aide returned Monday morning. We bought the groceries for the household, visited often, drove her to medical appointments, and found a geriatric specialist for her. We applied for physical and occupational therapists to help Mom as her coordination and brain slips worsened.

Eventually, even the weekends became difficult for us. I had breast cancer one year; another sister was widowed. Each of us had our own families, jobs, and sometimes we needed to be away on vacation or work trips. We realized we needed someone to come on Saturday or Sunday, even if just for a few hours. We briefly considered moving her into one of our homes or to a nursing facility, but then we would quickly talk ourselves out of it, given her staunch wishes to remain in her own home.

Despite the challenges balancing all of this care, we would not change our approach. We did our best to honor our Mom's wishes of remaining in her independent home, while making sure she was safe and cared for. We were fortunate that we had five of us living close enough to her home that we could rotate being with her, and that her health benefits covered large parts of her medical needs. Eventually, we had to share the cost of the aide's salary for the last year or so.

One fond memory we all cherish is her last birthday party. She turned 94. It was in her own yard, with my siblings and me, sisters-in-law, many grandchildren and great-grandchildren, her sister-in-law, and two nephews and nieces in attendance. Inside the house, she opened her presents, read her cards aloud, and made humorous comments as she did so. She kept her personality, sense of humor, and desire to host family gatherings through to the end.

Two months after her birthday, her physical health declined precipitously. Mom was deeply religious. I had been bringing her communion, but now we called a priest twice. It was time.

On her final days in this world, we all had visited with her, holding her hand, talking about everyday things and good memories. We played music for her, and even Christmas carols (she passed on Dec 17). The few who lived out of state skyped with her. Remarkably, she showed recognition and smiled.

We knew she appreciated it. We were fortunate that she knew all of us to the end, even her 16 great-grandchildren.

Mom often used to say that she was "never the star of the show, but always a great producer." As we looked around at her memorial Mass filled with family and loved ones—her five children and spouses, her 15 grandchildren, her 16 great-grandchildren, and countless cousins and relatives—we knew she had done a great job "producing" and cultivating connections as the central figure in many of our lives for years. But perhaps, even in a small way, we were able to help her feel like the star of the show in her final years.

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Caring for A Parent with Alzheimer's

Marsha Roberts

Who knew that Santa could get Alzheimer's? My dad, Jack, looked and acted so much like Santa, he was hired to be Santa at a large mall in Las Vegas. He had a faithful following of families who would stand in line to get their pictures with him year after year as their children grew up. But as the years went on, my dad began showing signs of cognitive decline.

As my dad's symptoms progressed, it became necessary to have someone with him at all times, and our family members stepped up to make that happen. Family from different states took time off from work and traveled to take numerous turns caring for my dad.

One of the joys of caring for someone with Alzheimer's disease is the amount of time you get to spend together. Most might not consider this "quality time," but in many ways, it is. You're forced to slow down and do simple things together. We walked outside together every day. I took my dad for his first pedicure during this time, and he loved it with a child-like glee. When we went grocery shopping, his job was to push the cart, and my job was to fill it up; it was a great arrangement for us both! He thoroughly enjoyed couples dancing to 50's music in the living room, sitting on the patio swing watching the sunset, and eating apples.

Early on in the disease process, we received a phone call from my dad because he couldn't find his car in the parking lot, and again from a neighbor when dad couldn't find his way home from a walk. On Thanksgiving Day, we were all busy in the kitchen preparing dinner and buzzing about when someone noticed that dad was missing. We looked all over the house for him, and he was gone! We went outside and looked around in all directions. He was nowhere in sight, so we jumped in our cars and eventually found him a good mile from the house. He was confused and had no idea where he was or where he was going. It was a turning point for our family. We realized then that dad was a flight-risk and needed close supervision.

Dad was fast. Even though we knew he was a wanderer and we needed to keep a close eye on him, he still managed to slip away from us a few times. Once while we were in Target, my mom and I wanted to go look at clothing, so I asked my husband to watch Dad and browse around the store with him. About 10 minutes later, I spotted my dad walking down the aisle alone and happy as can be, but my husband was nowhere in sight! Shortly thereafter, my husband rushed up in a panic because he had lost my dad. Another time after my dad and I had done the grocery shopping and put the groceries in the trunk of the car, I asked him to take the cart back to the cart storage area right up by the entrance to the store. I got in the car and waited for my dad to return, but he didn't. So, I got out to look for him and found him pushing the cart through the produce section as if to start the shopping trip all over again.

As his disease progressed, my dad had hallucinations and became anxious at times. My brother bought him some headphones and played relaxing music that really helped calm my dad. We even used the headphones while driving in the car and while around larger groups of people with lots of conversations going on. It was a struggle for my dad to keep up and participate in conversations, which made him anxious, so having the headphones helped relieve that stress for him. Another source of comfort for my dad was touch. Simply holding his hand or putting an arm around his shoulders would help to reduce his level of anxiety. When my dad had hallucinations, we would sit with him and listen to him describe what he was seeing. Calmly listening, consoling, touching, and using soothing music all helped to make him more comfortable during this time and throughout the disease process.

Like a lot of Alzheimer's patients, my dad eventually stopped performing self-care. He couldn't shave his own beard, he didn't want to shower every day, and he didn't want to change his clothes. His toilet skills also declined, especially if he had to get up and relieve himself in the middle of the night. He was disoriented and uncoordinated, which resulted in missing the toilet. This became a nightly issue that had to be cleaned up every morning. Not fun.

What surprised me most about the end stage of Alzheimer's was the rapid decline in motor skills. My dad became a fall-risk because he couldn't maintain his balance. It was a frustrating experience for him and for us, his caregivers. He was used to being up and active, and he couldn't understand why we had to keep him seated in a recliner or chair at home. We struggled with the logistics of how to prevent Dad from falling without restraining him. We ended up gently tying a sheet around his waist while he was seated so that if we couldn't be right next to him, at least this arrangement slowed him down a bit. Unfortunately, he ended up falling numerous times, which led to a few trips to the local Emergency Department. My dad also had seizures that increased in frequency and duration as his disease progressed, which was surprising. If you've never been around someone having a seizure, I can tell you it's a very scary event, and there's not much you can do to help except keep the individual from biting their tongue or physically hurting themselves.

While caring for my dad felt like an emotional rollercoaster at times, I was fortunate to have had the opportunity to help care for him throughout his journey with Alzheimer's. My hope is that these stories will help you, the reader, to know that you're not alone, and there are many others who have shared this same journey with their parent.

* * *

Our Journey with Alzheimer's Disease: A Love Story

Scott Weikart

My late wife Jo-Anne was diagnosed as having Mild Cognitive Impairment (MCI) in 2007, at age 60. She was diagnosed as having very mild Alzheimer's disease (AD) in 2009, at age 62; 10 years later, she died of late-stage, severe AD (in 2019, at age 72), at home in her own bed.

At the time of her MCI diagnosis, Jo-Anne was overweight and pre-diabetic. I did a lot of research and told her that a better diet and more exercise might slow the disease process; luckily, Jo-Anne accepted that recommendation. With a change in diet (more fruits & vegetables, less saturated fat and refined carbohydrates) and much more exercise, she was able to lose 35 pounds in 4 months (and kept them off), and her fasting glucose fell into the normal range.

Jo-Anne got AD so young because she had the highest genetic risk factor (ApoE-4/4). This turned out to be a bit of a blessing. Jo-Anne was otherwise quite healthy. I was old enough to be wise and emotionally resilient, but young enough to be energetic. This made it possible for me to take care of Jo-Anne at home, mostly by myself. (In retrospect, it probably would have been better for both of us if I'd hired someone to help care for Jo-Anne, plus be a companion.)

Amazingly, Jo-Anne's personality, values, sociability, upbeat-outlook, initiative, interest, or appetite didn't change. She had no delusions, agitation, aggression, etcetera. She recognized, loved, and appreciated me (and her best friend) almost to the end. I think all of this may be rare. I don't know if the relatively positive course of her disease was mostly due to intrinsic factors, or was also affected by the way I chose to care for her. I'll focus on the two aspects of my caregiving style that probably had the greatest impact.

Staying active and engaged

My general approach was to avoid restricting Jo-Anne's life and freedom, to always look for creative accommodations, and to try to enable her to live as full a life as possible. I realized that the best perspective was "let's live in the present" and "enjoy life to its fullest." The future was unpredictable (and bleak), so there was little benefit in dwelling on it.

When Jo-Anne was diagnosed with MCI, I chose to drop from working very long hours to working 3/4 time (the minimum needed to qualify for benefits). Soon after, I switched to working 10–20% time (made much easier by the PPACA coming into effect, with its protection for our pre-existing conditions). I made the implicit decision to start spending my savings: spending time with Jo-Anne was worth more than a luxurious retirement.

The main way Jo-Anne got more exercise was bicycling (and walking in the earlier years, when she loved taking pictures). When Jo-Anne's short-term memory started to fail, I got us both iPhones to track Jo-Anne. Jo-Anne always wore a "fanny pack" to carry her camera; I'd added her charged phone. I would work remotely from my home office while she was away, and periodically check her location. If she strayed into dangerous areas, or she was bicycling away from home as sunset or dinnertime approached, I would hop on my bicycle (putting my iPhone in a handlebar-holder), and chase after her.

Jo-Anne once left the house without me realizing it, and the police didn't find her until 8 hours later (one of my most stressful experiences; I literally jumped up and down to try to burn off the excess adrenaline). I bought inexpensive door alarms from the hardware store and mounted them at the top of the door. Whenever Jo-Anne opened a door, she would immediately close it when she heard the alarm.

One day, after Jo-Anne had transitioned to moderate AD, she went out for a bicycle ride but walked home. I bought a small pouch that attached under her bicycle seat and put her iPhone in that pouch; I put her iPad Mini tablet in her fanny pack. Now I could track Jo-Anne and her bicycle independently. (After Jo-Anne started taking memantine, she no longer forgot she was on a bicycle ride.)

Jo-Anne started to ask strangers to help her get home. If we'd lived in a rural town where everyone knew each other, I might not have worried about that, but we lived in a small city, so this felt unsafe. I started taking long bicycle rides with her, instead of letting her bicycle alone. I didn't mind the time, because I listened to podcasts as we bicycled.

The nearby big city had a wonderful nature museum, with lots of live fish and birds and reptiles; we got a one-year membership and visited the museum at least monthly. We would bicycle to the commuter train, then bicycle from the main train station to the museum.

When I'd go to events or get together with friends, I'd take Jo-Anne with me, since she liked the company and conversation. We started flying to visit my sister regularly since she was really great with Jo-Anne. We'd visit Jo-Anne's best friend (by bicycle and train) a few times a year. Whenever we traveled, I'd have Jo-Anne wear a "name tag" that said "I have Alzheimer's disease," so people would know why she wouldn't respond.

I started attending a weekly caregiver support group at Rosener House, during which Jo-Anne would participate in their Adult Day Services. As we left, I would ask Jo-Anne if she had fun (she always said "yes"), and if she'd like to attend more frequently: she said "no" after the first three visits, then said "yes." So she started attending every other day: we'd bicycle there in the morning; I'd pick her up at the end of the day, and we'd take a long bicycle ride home.

As Jo-Anne progressed to severe AD, she started having trouble following me on her bicycle: she would periodically stop. So I got us a tandem bicycle. We continued bicycling back and forth to Rosener House. (I was able to ride the tandem bicycle even when Jo-Anne was not on it.)

The time came when Jo-Anne could no longer attend Rosener House: she started having bowel incontinence, then started sleeping so long that we couldn't fit a visit into her day. We signed up for a Mon Ami companion; she was able to get Jo-Anne walking again (with the help of a walker), and put together a playlist of songs Jo-Anne liked. Eventually, Jo-Anne started sleeping most of the day on an erratic schedule, which made scheduling companion visits impossible.

I realized that Jo-Anne was sleeping so long that galantamine ER made no sense, so I switched her to regular galantamine. Then I realized that taking her galantamine on an empty stomach after waking would make her bowels move (she'd sit on the toilet until the galantamine took effect), mostly eliminating her bowel incontinence.

We got Jo-Anne a Hasbro robotic cat that she loved. I'd strap her iPhone to her arm and give her the robotic cat; she'd wander around the house with the cat in her left arm and pick up and study familiar objects with her right hand. (In the last, distressing week of Jo-Anne's life, I'd put her to bed with the robotic cat in her lap and the cat "set" to move around but not make noise, and I'd put Jo-Anne's hand on the cat's head. I'd put a favorite stuffed animal in her other hand, and nestle it against her neck.)

When a neighbor asked if she could "babysit" for Jo-Anne, I asked her to take Jo-Anne for walks instead. As soon as Jo-Anne would awake, I'd text the neighbor with a prediction of Jo-Anne's schedule, and the neighbor would tell me if she'd be available for a walk. Jo-Anne progressed to walking 12 blocks with very little assistance.

In her last few months, Jo-Anne lost the ability to walk "naturally." It took a lot of concentration to control her muscles, and she had to stop every 20 feet (primarily to rest her brain). Her physical therapist taught three neighbors and me how to safely take Jo-Anne for walks with her walker. Jo-Anne couldn't walk more than a block and a half before getting so worn out that we'd have to wheel her home on the seat of the walker. But she loved the walk and would walk until she could barely stand. She'd study flowers and pets if I turned her head toward them so they'd catch her gaze. And on days that Jo-Anne took walks, I noticed that she was more cognitively intact in the evening.

Jo-Anne's day was so short that she had to go to bed soon after eating, so she had to sleep sitting at an angle so she wouldn't aspirate her food. Now that she no longer slept on her side, she had to sleep at a 60-degree angle to avoid sleep apnea. So I had to use a lot of wedge pillows to simulate a hospital bed, then climb into bed and pull her into position. In the last month, I had to use a Hoyer lift to get her into and out of bed and her wheelchair. As I was doing things for and around Jo-Anne, I would narrate my actions. I'd occasionally make a silly mistake and would say, "I'm an idiot, I just did X?!" Even in her last month (when she rarely talked), this would often elicit a laugh, so I knew she still understood language (similarly, she laughed at ironic jokes when we listened to podcasts while eating).

Staying connected, and in love

In the two decades before Jo-Anne died, our relationship slowly evolved: Jo-Anne transitioned from wise friend and lover, to friend and lover, to loving companion, to teenage daughter, to young daughter. Early in this transition, our little personality quirks became less of a problem, and our love became stronger.

As Jo-Anne transitioned from moderate to severe AD, she'd often have a little cry in the morning. I'd tell her: "I'm sorry you're feeling sad. You often feel sad in the morning because of your Alzheimer's disease, because you don't feel like yourself. You'll feel better after you get up and walk around, your brain will work better, you'll remember things better." She'd usually stop crying after I said this; if she continued to cry, I'd say, "I'm sorry you're feeling sad right now," and hold her hand and stroke her face.

As she progressed to severe AD, she'd occasionally lose the ability to respond to simple requests (especially as she transitioned to a qualitatively more impaired cognitive state), which often made me quite frustrated. We had a history of being emotionally open with each other, e.g., recognizing that the other person wasn't "mad at me" but was just feeling frustrated. But, occasionally, my emoted frustration would make Jo-Anne wince. I'd say, "I'm really sorry, sweetie. I'm not mad at you; I'm mad at your Alzheimer's disease. You, I love, but your Alzheimer's disease drives me crazy sometimes." She accepted this.

During Jo-Anne's last year, as soon as she awoke each day, I'd say: "Good morning, sweetie! I'm Scott, your husband. You sometimes have trouble remembering me in the morning because of your Alzheimer's disease, but you'll remember me better after you wake up. I'm Scott, your husband, and we love each other. We're an old, married couple; we've lived in this house for 30 years! And you're the love of my life; I will take care of you 'til death do us part, you can count on me. I'm Scott, your husband, and we love each other." Until her last month, this would elicit a big smile; in her last month, she'd often be a little alarmed when she woke up, and this greeting enabled her to relax, visibly less worried. This greeting was also for me, a daily reaffirmation of our love for each other.

In the final months of her life, Jo-Anne rarely spoke phrases, usually giving single-word responses. Three months before she died, I went into our bedroom to see if she was awake. She gave me a big smile, and said, "I was waiting for you!".

* * *

Radical Awakenings

Pringl Miller

"WTF is going on with my mother?" I thought. My mind was racing; my heart sank deep into my gut, knocking the wind out of me as I struggled to breathe. Just breathe. Stay calm, don't panic. This isn't a trauma code activation . . . or is it? My observations and cognitive interpretations were being rapidly internalized as stressors, which led to a series of visceral responses because I knew they portended badness. I was experiencing a real-life reflex arc and entering the slippery slope of being a daughter who is also a medical doctor. Navigating the personal with the professional is often a challenge for clinicians. There was going to be a reckoning ahead; however, immediately, I found myself fighting back the emotions and impending sadness to diagnose the problem. I was on vacation in my mother's home and I had some serious work to do.

Reflecting on my last visit with her, everything seemed fine . . . normal. "At baseline," as we say. But now, in retrospect, these new observations would explain her recent comment to me that she was dropping things and didn't know why. How could I have blown off her comment? Why hadn't I realized this SOS was significant? I had failed the test of being on high alert as a doctor for my aged mother, and now I was learning that she was seriously ill, and it all felt so ominous.

While absorbing my mother's new state of affairs on the first day of my visit, I noticed subtle differences in her behavior and personality as well as dramatic changes in her physicality. For example, she was less engaging. It was as though her disposition was muted. The vibrant and inquisitive, in-your-face, "I want to know everything that's going on with you" mother was MIA. Similarly, when I looked into her beautiful grey-green eyes, they cast an absent quality that was eerie. I associated this void with what I imagined a zombie projects because it was as though my mother was no longer present in her own body.

Also disturbing were uncontrollable subconscious upper extremity jerking movements that occurred in synchrony with a weird facial grimace, giving the appearance of being possessed. Later, I would learn these spells were faciobrachial dystonic seizures or FBDS, a pathognomonic feature of Voltage-Gated Potassium Channel (VGKC) autoimmune encephalitis. It was noteworthy and somewhat reassuring that these FBDS and everything else that was disease-related went seemingly unnoticed by patient number one except for her report that she was dropping things, which didn't seem to faze her.

Another profoundly abnormal sign that she was not herself—she was no longer as vigilant about order and control. This 180 was unsettling to observe and accept in a woman who had always been highly aware, independent, and in control of herself and her surroundings. I felt strangely alone and uncomfortable holding onto this new information because nondisclosure didn't feel respectful, and yet I reasoned there was mercy in her not knowing to spare any associated distress.

The red flags kept accumulating and had me concerned, but I felt relieved that she was actually "ok" living in her body and in a safe place. Nothing catastrophic had occurred during the interim of time between the onset of these symptoms and my visit. I continued my assessment and started to formulate my management plan while she was pleasantly busy with something to read. It's always important to provide a complete history to the doctor, so I started inspecting the house looking for more evidence of trouble while also hoping to assuage my fears. Unfortunately, what I discovered suggested that her disability had been longer-lasting than I might have otherwise thought. Multiple entries in her checkbook dating back several months were illegible because of a combination of micrographia and incomplete notations. How long had this illness gone unrecognized? Were her bills paid? So many questions and the answers felt increasingly unwelcome and overwhelming.

Upon confirming something was terribly wrong, I phoned my brother and relayed my concerns. I suspected we were about to embark on a journey none of us were expecting or prepared for. Although it wouldn't be the first time that he and I had received bad news about our mother's health. Ten years earlier she had been "misdiagnosed" with pancreatic cancer. In true form our mother had refused all "potentially curative" allopathic treatment recommendations and decided to treat herself with naturopathic tinctures discovered through her own research on the internet. This chosen course of action was antithetical to both my brother and my medical training and any hope for a cure. She heard us out, but we were ultimately schooled on the principle of parental autonomy and the natural right of our mother to live and die on her terms. She refused to be cut open, re-plumbed, and infused with toxins. I understood that, but a part of me wondered why she would "give up" so easily. My surgical training had definitely conditioned me to believe action is the foundational key to all success. An uneventful year sailed by and we knew it wasn't going to be pancreatic cancer that killed her. Eventually, we came to the same conclusion (again) that "mother knows best" because either her pancreatic cancer diagnosis was a mistake or those tinctures, with time, cured her. My mother's strong will and self-determined decisions were a testimony to her mental fortitude, commitment to a healthy lifestyle, and her personal philosophy about life and death. She would later tell me, "that something was going to have to kill her." Today, more than ever before, I admire her strength, wisdom, and willingness to go against the grain and accept death as a natural part of life. It turns out, she would live long enough to be misdiagnosed with another terminal disease, this time a rare, universally fatal neurologic condition, or so we thought.

Unlike with her pancreatic cancer diagnosis, this clinical course was relentless and worsened with a cruel pace. During her bout with pancreatic cancer, she had maintained decision-making capacity, relieving my brother and me from making major healthcare decisions for her. With this sneaky, unnamed, rapidly deteriorating dementia, her personhood and decision-making capacity were brutally stripped away. Within days of my arrival, she was in a minimally conscious state and admitted to a prestigious regional neurological institute for a work-up. I had the benefit of accompanying her and taking on the role of her primary caregiver. She did not exhibit any distressing symptoms and for this we were extremely grateful. All we had to do was keep her comfortable and process the information that was being relayed to us. After several days of evaluation, while she was in a vegetative state, she was diagnosed with Creutzfeldt-Jakob disease (CJD) and given a six-month prognosis. With very little left unanswered about her diagnosis and prognosis, my brother and I, as her legal agents, decided to enroll her in hospice and moved her into my home in the San Francisco Bay Area. I suppose it's true that "the apple doesn't fall from the tree," because within days, my research on CJD revealed that one of the world's experts was UCSF faculty and that he was enrolling patients into CJD research trials. Although not exactly aligned with my mother's preference for naturopathy, the idea of contributing to research to advance science would honor her. The additional built-in benefit was a second opinion by an internationally known leader in this area. During her clinic evaluation with Dr. MDG, he was not convinced she had CJD and recommended she be admitted to the hospital for additional testing. WTF—another wrong terminal diagnosis? How could we be so stupid? If we were medically educated and trusting of medical professionals, what did that mean for all the other families out there with no medical knowledge or connection to adequate healthcare? We were in expert hands, but clearly vulnerable nonetheless.

Looking back on the events that ensued after her admission and the resources expended, I am both grateful and in disbelief at the extreme measures taken to disprove the CJD diagnosis. Admittedly, I was guilty of succumbing to drastic measures during a moment of crisis at the end of my mother's life. Revisiting those decisions, I now recognize many were driven by being her daughter putting the medical doctor aside. My brother and I vacillated between the rational and the emotional, and to her benefit, we didn't always cycle together, making for a more reasoned long-term approach to care. Ultimately, we consented to a brain biopsy in order to exclude CJD from being her diagnosis. Remarkable—the decisions we are willing to make for a loved one, especially when hope is dangled in front of us. Our mother would live twelve more years because of that particular decision, a decision not easily forgotten because every time we looked at her forehead, we could see the scar. When all the results were interpreted, her diagnosis went from terminal CJD to an even rarer and potentially treatable VGKC autoimmune encephalitis, now known as LGI1-antibody encephalitis. How often is one person misdiagnosed with two terminal diseases in one lifetime? This mother of two accomplished medical doctors was.

Within 24 hours, she was treated with high dose intravenous corticosteroids and, shazam, we witnessed her first radical awakening. Marion W. Miller was back in living color—she shocked us all. We watched in amazement as she emerged out of a vegetative state and back into herself—into the complete person we knew her to be. She was *all* there, save some physical deconditioning from being bedbound. She never missed a beat on the re-entry because as soon as she woke up, she was full of questions trying to understand where the time had gone. Many questions and attempts at explanations later, we disenrolled her from hospice and looked beyond the precipice of death into her future life.

What came next was a roller coaster ride that no one could have predicted. She was never enrolled in the CJD study to help advance science, and instead, her contribution was that she became an index case for the diagnosis of LGI1-antibody encephalitis. In time, she was treated with all the common immunosuppressive therapies available to patients with autoimmune encephalopathy to keep her disease in remission. She tolerated treatment fairly well, except for the cushingoid side effects people experience from the long-term use of corticosteroids. Eventually, her disease was refractory to the current treatment, and she slipped into another minimally conscious state. Over time, we had watched her age with and without the impact of LGI1-antibody encephalitis. Unfortunately, aging with one condition does not offset or prevent others from occurring and accumulating. These cumulative insults get harder and harder to recover from until eventually there is a threshold moment when one must consider the quality of life over quantity of life, and to this end, whether the benefits of disease-directed therapy still outweigh the burdens. My brother and I had circled around this concept many times over the years with respect to our mother and also as each other's legal agents. What would she want? And what would we want? We never knew when remissions would end, and relapses would begin, and, more importantly, we never knew from one relapse to another, with other ailments in the mix, whether our mother would rebound to some self-proclaimed acceptable quality of life.

The repetitive episodes of uncertainty were challenging, to say the least, even though they became our new normal. Each relapse posed a unique set of decisions because of the cumulative hit and anticipated dysfunction that lie ahead. We had run versions of the final scenario over in our minds; as doctors, this wasn't too hard for us to do. But she always surprised us and bounced back. Would we know when enough was enough?

On this day, she hadn't gotten out of bed and was somnolent like she often was at the beginning of a relapse. She wouldn't even eat blueberries, her favorite. Dr. MDG suggested treating her with Rituxamab, our hail Mary. Rituxamab was experimental at that time and would have been approved under the pharmaceutical company's compassionate use protocol. This was one of those times when my brother and I were not cycling together. For one of us, enough was enough, and for the other, it would be enough after Rituxamab failed. Thankfully, through the genius of Dr. MDG, and our mutual decision to try it, Rituxamab was infused that day. She left my brother's house in a minimally conscious state, ostensibly on her death bed, and returned as herself after a second radical awakening. Not only did she return home as good as new that afternoon, but she played chess with her caregiver and won.

Our mother was eighty-six years old when she died a peaceful death at my brother's home with hospice care, twelve years after she was diagnosed with LGI1-autoimmune encephalitis. I'm not really sure what she thought about all her lost time during relapses and acute illness. Her grace with life and illness allowed her to accept what was, how to move on, and how to let go. It was hard to see her vulnerable, dependent, and losing self, and yet I imagine it might be more difficult with dementias that don't include amnesia. My brother and I were blessed to support our mother through her illnesses, never having to bear witness to the panic and pain of known loss of her personhood. She essentially remained herself during the periods of lucidity and was amnestic to everything else until her last four months.

During her last four months—she was dysarthric, lethargic, and bedridden. She was no longer the independent, quick-witted smart-ass I knew her to be, even though there were still glimmers of her personhood that shone through. She wasn't able to verbally express herself, but I could feel her love and she could still communicate. Miraculously, her times of illness and becoming non-decisional did not seem to violate her own sense of autonomy or impinge on her personhood in part because of how this disease manifested, and in part because we worked hard to honor her preferences.

* * *

Lessons from the Elsewhere-Elsewhen

Caitlin Leach

It all began gradually about five years ago: the diagnostic tests, the acetylcholinesterase inhibitors, the prognosis, the inversion of my role as her daughter.

I expected most of these things from her diagnosis. As a healthcare practitioner, I knew to expect the embodied consequences of amyloid plaques and neuronal degeneration.

But I did not expect the embodied lessons on love that my mother would teach me over the next several years.

In caring for my mother and watching her progression of Alzheimer's disease affect her speech, I have learned that while my mother can no longer speak of love, she communicates it to me every day. Her love is embodied in unexpected smiles, laughs, brief glances, and momentary eye-contact. Her love is communicated through the nourishing gestures of feeding and being fed, of bathing, and being bathed. Her fundamental kindness is expressed in her gentle disposition and these habituated bodily gestures. Since we are no longer able to communicate verbally, I pay much closer attention to her body now.

I look at the lines across her face and think about how I never noticed them before. I never really took time to notice her hair, her skin, her eyes, her legs, her feet. And now I can't stop noticing. Without words to dictate my impression, I rely on her body for signs of comfort. And I wonder, was she comfortable before? What have I missed in my overreliance on her mind as the site of her self?

We often rely too heavily on conceptions of the self that privilege cognition over the body, as if the mind is somehow separable from our bodies as we live them. My mother is no longer able to articulate a sense of who she is, but she exhibits familiar characteristics that I recognize as *fundamentally her*, as fragments of herself that still exist and often show up as bodily memory. This bodily memory is offering me food when I am feeding her, running her hands through her hair to help me wash her, reaching out to me across a table, catching my eyes, and smiling suddenly, fleetingly. In these moments, she reminds me to stop being a disembodied body, to check in with the bodily aspects of our relationships with ourselves and others. I hold on to these embodied fragments of my mother, but I cannot pretend that I decipher them fully. Nor can I ever claim to speak for her, only of her. And I am often left wondering what she would say if she still used words rather than this vocabulary of movement.

Kristin Zeiler's analysis of embodiment in dementia care has been essential in helping me think through my experiences. Writing about them, however, has been another challenge. I struggle so much with language in writing about Alzheimer's disease. I use the word "recognize" above, from the Latin *recognoscere*, to 'know again, recall to mind,' as well as the word "remind." Surely knowledge and memory are not relegated to the mind. The limits of our language highlight how difficult it is for us to conceive of concepts like our sense of self and memory as embodied phenomena. There must be a better way to talk about this. Alzheimer's disease shows us that the self is embodied, even if this self only comes to us in fragments.

More recently, I have begun to imagine that my mother's fragmentation is the result of her newfound ability to move seamlessly between the present world and a future world in which neurodiversity and disability are valued as integral aspects of human experience. This future world is reminiscent of what Alison Kafer refers to as the *elsewhere-elsewhen* in her work, *Feminist, Queer, Crip*. We place so many normative demands on our cognitive and bodily abilities that it often prevents us from treating ourselves and others with compassion when we cannot meet these demands. In the early stages of her diagnosis, I remember how nervous my mother used to get ordering meals at restaurants or asking others for assistance. She would often forget her request halfway through and become embarrassed and ashamed that she could not remember. In the beginning, I, too, would become embarrassed and sometimes try to finish her sentence before she forgot so I could save us both the trouble. But how would we have handled things differently if we were not so committed to rigid conceptions of 'normal' communication or 'normal' cognitive functioning? Now, when my mother whispers things that are unintelligible to me or laughs at a joke that is not articulated in a way I can understand, I like to think it is because she is bringing lessons from this other place to me. She is bringing lessons from Kafer's *elsewhere-elsewhen* to the here-now. She is trying to teach me how to engage in care work that challenges these inflexible, and frequently violent, notions of normativity.

I return to her embodied lessons on love and what she has taught me about imagining differently. I look at her hands, always in the same place, clutched together tightly against her chest. I look at her feet, permanently turned inward, fixed there. For a while they subjected her to rigorous stretching exercises to unclasp her hands, to turn her feet outward. We can recognize the caregiving utility of such exercises. But I like to imagine that she is trying to hug herself. Why are we trying so hard to stop her from hugging herself?

I look at the translucent gray film that now coats her eyes. Perhaps some have decided her eyes have seen all they're going to see. But I like to imagine she is simply trying on a new lens. A lens that colors her world differently, magnificently. A lens unavailable to those of us exclusively residing in the here-now, to those of us who often look without seeing.

In imagining differently, I am not trying to minimize the profound sense of loss I feel for my mother. After all, there are aspects of this disease that are nothing short of haunting.

I remember the day she drove to work and ended up in a parking lot in the middle of nowhere.

I remember the recurrent voicemails left for me at 3 am, begging me, "Please help me. Come get me. They won't let me go," while my dad and I slept upstairs.

I remember the night I came up to her bedroom to find her panicked, with every dresser drawer open, with clothing thrown everywhere because she couldn't remember how to get dressed.

I slowly helped her put her clothes back on. We cried. She said, "I'm scared." I said, "Me too." She said, "You'll be a good mom one day."

I was 25 years old. I could not comprehend the possibility of losing my mother, much less watching her lose herself.

So no, I am not interested in minimizing the loss or trauma that this disease can inflict. But I want to recognize that my mother is not *gone*. She's here and *elsewhere;* she's present and *elsewhen* simultaneously. Most days, no amount of imagining differently can alleviate the distress of caring for a loved one with Alzheimer's disease. But then, every once in a while, I find comfort in holding on to the speculative.

I also do not want to minimize the emotional and physical toll of care work. Caring is work. Caring is hard work. And caring for someone who struggled with accepting care is especially hard work.

My mother took her independence very seriously. She often vocalized the importance of being independent and expressed an immense fear of becoming a burden on our family. What is it about our notions of independence that frame dependence as necessarily burdensome? I wonder how valuing interdependence, rather than independence, would have helped my mother come to accept her diagnosis differently. I often wonder about the ways in which notions of independence fail us and how an interdependent conception of our bodies can change our approaches to care work. After all, I depended on my parents to provide for me when my care needs were drastically asymmetrical in childhood. Why must caring for each other at any other life stage bring the stigma of burden? Dealing with the diagnosis of Alzheimer's is challenging enough, and my mother should not have also had to feel ashamed of her care needs.

Instead, we need to develop an appreciation for bodily interdependency. And we need to appreciate the asymmetrical dynamics of this interdependency. We need to be capable of loving ourselves and others when our contributions to care networks are imperfectly reciprocal, operating according to what is possible for our differently-abled bodies on any given day. My mother often spoke of her fear of us growing resentful of caring for her, but this fear doesn't need to hold if we take seriously the value of caring for each other. Yes, care is work, but it is meaningful work. Importantly, this work is only sustainable if caregivers are properly compensated—that is, if caregivers are cared for themselves.

In *Care Work: Dreaming Disability Justice*, Leah Lakshmi Piepzna-Samarasinha talks about the importance of imagining a future of radical, collective care webs that attend to and appreciate asymmetrical care needs. She encourages us to focus on questions such as, "what is possible for you today?" In asking this, we are choosing not to focus on our different abilities as *lacks* but as *possibilities.* This distinction is important.

I wish I had this question with me in the early stages of my mother's disease. I like to think that instead of becoming frustrated that we move slower now, we would have cultivated the possibilities offered by slowing down. Instead of getting embarrassed by the figurative mess of sentences or the literal mess of incontinence, we would have been able to appreciate these moments as messes of possibility. The possibility to communicate differently, radically, bodily. The possibility to love differently, radically, bodily.

Mom, I ask, what is possible for you today?

While my mother can no longer speak of love, she communicates it to me every day. Her love is embodied in unexpected smiles, laughs, brief glances, momentary eye-contact.

In these fleeting moments, I look at her and she looks back. She doesn't know my name, but she knows me.

I feel her. She feels me. And I imagine a world where this is enough.

* * *

Deception, Dementia and Moving a Parent: A Daughter Ponders the Places and Meaning of Care

Sharon R. Kaufman

> *"The content and scope of care is always an open question."*
>
> Arthur Kleinman, The Soul of Care

My journey to care for my mother began with a phone call at 9:00 am, a Sunday in December. It was my stepsister. Her voice and the horns of Tel Aviv evening traffic poured into my California living room, fracturing my calm surroundings. "Dad is dying, probably tonight," she said. "You have to come and take care of your mother." Thirty-seven years before, my mother, Shirley, at age 50, had divorced my father and left San Francisco to move to Jerusalem and marry Bill. Jerusalem had become her beloved home. Now 87, she had early to moderate dementia. Bill had been holding everything together—a common scenario.

The plane carried one of my sisters and me to our losses. My mother's losses were her husband, memory, and the life she had built—mine, a decidedly care-free relationship with her. What I didn't know was that I would deceive my mother twice, once in life, once in death. Those deceptions, born from love and care, would haunt me for a long time.

Family discussions of dementia are loaded with poignant and often unrelieved anxiety about what to do when a parent or other loved one can no longer manage daily tasks. Families worry about how or whether to honor what the person wanted before the disease took hold. Would they want to be hospitalized when ill? Remain at home, no matter what? Avert death's arrival with medical technology? As my journey with my mother unfolded, this question of identity coherence—and its relationship to care—is what preoccupied me. Would I be honoring her late-life choices?

My mother and Bill had been living together in Jerusalem since 1973. As her memory loss progressed (with an initial diagnosis of vascular dementia) and his heart failure became more severe, my two sisters and I visited more often, sometimes three times a year, feeling the tug of responsibility getting stronger with each visit. We saw things our mother couldn't see or didn't reflexively understand. She couldn't make a shopping list. Then, she couldn't put together a salad. She got lost taking a walk in her beloved neighborhood. But she hadn't lost her rootedness in Jerusalem, her deep connections to friends, family, and life there, or her elemental knowledge of being at home.

The Funeral

"This is a dress rehearsal," I said to my cousin as we walked away from the grave after Bill's funeral. The next time we come back to this place with its dual plot, I remarked, it will be for my mother.

I was sure of that.

My mother knew it was unlikely we would visit often, and even less likely that her American grandchildren would visit a grave near Jerusalem at all. "Maybe some of you would visit my grave once in a while," is all she said. Her choice of burial location affirmed her later-life identity as an American-Israeli Jew, whose deliberately chosen home was Jerusalem, and who wanted to be laid to rest there, next to her husband of thirty-seven years. There was no question that she sought to complete the narrative of her life in a particular way. She chose an ending that would incorporate her remains into her beloved landscape and thus perpetuate her true self into our remembrance. She had made it hard for us to ignore that, and not yet realizing that Bill's funeral had already set the stage for both my betrayals, I wanted to honor her wish. My betrayal would be about her place of belonging and self-making, and that included the place of her burial.

"Absorbed with Place"

My mother, the poet Shirley Kaufman, had dementia for many years before she died in 2016 at the age of 93. She was exquisitely attuned to language and the power of words to evoke interior life and imaginative horizons. In a magazine interview 30 years after her move to Israel, she reflected how her life was marked by dislocation. Her poetry reflected that sensibility:

> *In a way, my life has been changed not only by tragic wars but by dislocation, a nagging feeling of not belonging anywhere . . . In Israel, I've been absorbed with place . . . and what happens in time, especially as I grow older, moving between my childhood home in Seattle, my life in San Francisco, and my home for thirty years in excessive and unmanageable Jerusalem. Looking forward with eyes in the back of my head facing the past with the future breathing down my neck.*

My mother's creativity, like so many writers, concentrated on claims of rootedness and rootlessness, identity and the desire to belong in a place. It focused, as well, on both mythical and ordinary time. Her particular place of belonging, Israel/Palestine, is, of course, a fraught homeland. It's creation for dislocated Jews after the Second World War instigated the displacement of Palestinians from their homes and homeland. The place is burdened with meaning for all who live, or want to live there.

My mother felt those dislocations acutely. That may be why from the moment Bill died, I too became absorbed with place—with this place of so much meaning, with her place in the world, and with my understanding of what that meant to her and to me. That absorption was the touchstone for my years of care for her and my preoccupation with how to remember her after she was gone. Without realizing it, I had taken a cue from her, and that made what came next both ironic and appalling for me. I would become the source of her final two dis-locations, both of them against her wishes.

I shouldn't have been surprised by my obsession with my mother's place in the world. I am an anthropologist who writes about aging and identity, dementia and death, memory, time and place. I am steeped in these topics. Yet in the aftermath of Bill's death, the significance of belonging in a *place* confronted my own life and family, demanding attention in a new way.

Connections Among Place, Memory and Care

Our family traveled to Israel twice in the 1960s, and my mother mused on these occasions, before meeting Bill, that she could live in Jerusalem. It called to her, thick with Old Testament stories that seemed alive to her there, the Jewish homeland millennia before and immediately after the Holocaust.

Raised in a secular household, nothing in my mother's childhood home was Jewish. But in 1943, while she was a college student, she went to a Zionist leadership training summer camp. That experience was a turning point in her life. She learned about traditional observance, arguing Jewish texts, and the kibbutz movement. She read the Bible and Jewish history. "*It was there*," she noted in an interview, "*by an idyllic lake in the mountains of eastern Pennsylvania, that I first heard the incomprehensible horror stories from the ghettos and camps.*" But she was "never comfortable," she wrote, with religious affiliation.

After she visited Jerusalem many years later, the tragedies of the Second World War were joined in her imagination with the three thousand years of myth and history emanating from the hills, forest, and desert around the city, the crumbling ancient walls, burial grounds and towns. That rich past was alive for her in the ghosts of religious leaders, patriarchs and matriarchs—Abraham, Sarah and Hagar, Moses, King David, Jesus, Mohammed, and their descendants and believers—and the paths they walked, from Jerusalem to Jericho, village to village, still there. All that resonated deeply with her own secular Judaism and connected her to that holy and fraught landscape. This was not abstract.

From 1973, when she was anchored in daily life in Jerusalem, she (and sometimes I with her) walked those ancient paths. My mother's self-awareness drew on the timelessness of the place while she also absorbed mundane routines. She brought biblical women into the present as she explored the mythic beginnings of Judaism and Islam and the millennia of struggle that followed. That struggle, she felt, began with Abraham's wife Sarah and his concubine Hagar, the founding matriarchs of Judaism and Islam, respectively. As she witnessed the wars, deaths, and daily insults surrounding her, she brought those two women to life as she knew it in Jerusalem. She linked myth to her own feminism and Jewish identity, and she imagined their emotional lives, their relationship with each other, and with Abraham, the father of two sons and two religions.

From *Deja Vu*
. . . One day they meet at the rock
where Isaac was cut free
at the last minute. Sarah stands
with her shoes off under the dome . . .
where Mohammed flew up to heaven.
Hagar is on her knees
in the women's section praying.

They bump into each other at the door . . .
Sarah wants to find out what happened
to Ishmael but is afraid to ask.
. . they walk out of each other's lives . . .
Not telling
that the boys are gone . . .

Sarah is in her cool villa . . .
She brings the food to the table
where he's already seated . . .
Guess who I met she says, dipping
into the hummus.

Hagar shops in the market . . .
Thinking . . .
I got what I wanted
from the old man. . . . (from Claims, 1984)

My mother's poems revealed her attachment to the mythical or real people who had dwelled in the place where Abraham brought Isaac, his son with Sarah, to be sacrificed and where the long history of Jews and Muslims, Israelis and Palestinians began. In her work and life, she placed herself in both mythical and mundane times. Her home, as for many others, was imagined and real, geographical and historical, personal and collective.

In his 1979 article, "Space and place: Humanistic perspective," cultural geographer, Yi-Fu Tuan describes attachment to place similarly, as though he had read my mother's poem, "Déjà Vu". He writes . . . *places are locations in which people have long memories, reaching back beyond the indelible impressions of their own individual childhoods to the common lore of bygone generations*" Places are "*fields of care*," he writes, in which human emotions "vibrate" across time.

My mother's fields of care were located on the same paths Sarah and Hagar walked. After decades in that landscape, her American-Israeli experience was woven with the ancient past. It was woven, too, with the contemporary anxieties shared by everyone in that place considered home by Arabs and Jews and all who lived there. My mother had absorbed the emotions that vibrate in that place of long memories. Dementia disrupted my prospects of caring for her *identification* with those fields of care.

At home In Jerusalem, my mother was embedded in a large community of friends, artists, writers, and family. She lived through wars, air raids, and suicide bombings. She mourned for the children of friends and all the others killed in the perpetual fighting that penetrated life and landscape. She worked with feminist Palestinian poets, hoping that, together, the poets could interject some sanity and peace into the region. In addition to the biblical women poems, she wrote others about the desert, the hills, the stones. Everything was personal and political. The long memory held in the ancient stones that characterize the landscape, along with the pervasive weight of history, lived also in her own home as she watched the doves on her windowsill.

from *Roots in the Air*
. . . On the sill the dove sleeps
over her two damp birds.
She built a nest in the pot of geraniums
and yesterday they hatched,
little homemade bombs.
They are not Jews or Arabs. (from Roots in the Air, 1996)

In addition to its location beyond the skin, the sense of being at home, of belonging *somewhere,* exists as an interior landscape, a landscape of feeling and imagination, intimate and embodied. My mother had learned *to appropriate* that landscape, including the characters who had dwelled there. She thought and acted with the landscape. The moods Jerusalem evoked in her were an essential existential fact.

Leaving the dual burial plot and the cemetery full of friends that day of Bill's funeral, I was already imagining my mother's funeral there, in her fields of care.

During the week of Shiva, the seven days of ritual mourning after a death, the bereaved family opens their home to friends and family. My second sister arrived that week. We had never been to an Israeli version of this. It started in the late afternoon and continued well into the evening. Scores of people came. Seven nights of food, drink, talk crowding the spacious living room and kitchen. It was lively, upbeat, not sad at all, and everyone was concerned about Shirley.

That week, without explicitly talking with our mother about it, my sisters and I began preparing to bring her to *our* hometown, San Francisco, her former home, the place we grew up. *That's where she belongs, near us, near where we live,* we told ourselves. Our caretaking future was pressing in on us. We began repeating to her that we would bring her to California, just for a visit. She agreed. A benevolent deception.

Four social workers arrived together one afternoon during the Shiva. Bill had taken my mother to a senior day-center a couple of times to see what it was like for her. The first time she visited, my mother unexpectedly led a poetry group, reading and discussing her poetry and the poems of others. Bill was amazed, as were the social workers. My mother did what she had done for years. She led a creative writing workshop. She figured out what her role should be in that place and enjoyed herself. This is not entirely atypical. Others have described the person-in-dementia who remains extraordinarily competent in a long-practiced sphere, yet who cannot function in daily routines. But the next time Bill took her there, she hated all that structured group activity. She didn't want to go back, and so they hadn't returned.

At my mother's apartment during the Shiva, the social workers remembered her beautiful performance and wanted her to return regularly now that Bill was gone. They could "work with" her, they told us. If we took her back to where *we lived*, they threatened, her dementia would progress faster than if she remained in Jerusalem where they could nurture and supervise her in their day center, not to mention they'd have a creative, well-known poet in their midst.

The social workers had not considered that we sisters, now the caregivers, lived 10,000 miles away, but they did raise some important topics for geriatrics. The social workers presumed my mother would thrive by attending the Jerusalem day-center. The critical thing for us, in contrast, was to sustain and support her continuously.

Predicting a quick or slow progression of dementia is tricky if not impossible. The social workers were concerned with the negative effects of our planned dislocation on my mother's disease progression and state of mind. It was a reasonable concern.

There would be no way to compare the speed of her decline and its effects on her mood, cognitive abilities, and physical health between the two places, the two strategies for care. We knew we could not care for her from so far away now that Bill was gone. What we didn't anticipate was what the rupture from home would entail, not only for her, but for us.

My sisters and I shared a broad view of care. We wanted and needed to be part of our mother's life, and for her to be part of our lives as the end of her life approached. We envisioned our care for her as care for us as well, truly family-centered. The Jerusalem day-center was not a solution for us.

Each afternoon before the Shiva guests arrived, and while my mother napped, I walked in an attempt to escape the planning and my anxiety. I took different routes from her apartment through town. My favorite was on the paths through Sacher park lined thick with rosemary, snaking through the Valley of the Cross. A Fifth Century Greek-Orthodox

Monastery sits at the bottom of the valley, built as a fortress, and still used as a church. It is the mythical site of the tree that was used to build the cross of the crucifixion. The church was destroyed, repaired, haggled over and rebuilt through the centuries, by Romans, Crusaders, Mameluks. Today it is a site for visiting Christian pilgrims. Peaceful.

My mother knew those paths, the Monastery, and its history well. Leaning against the cool, ancient stones of the church connected me to my mother's evocation of the landscape's myths. But I could not claim them as part of my own sense of self, though I sometimes tried. I could not enter her feeling of long memory, and that made me recognize the gap in my ability to care for her fully.

Re- location

We brought our mother to California six months after Bill died, knowing full well she would live near us for the rest of her life, though we had no idea how long that would be. We found assisted-living housing and selected an airy apartment. We wanted her new surroundings to seem familiar to her and pleasing to us to ease the potential shock of the move for her and to cover up somehow, the betrayal of the move.

My mother was delighted to be with us from the moment she stepped off the plane, and she was pleased by the move to what we told her was a senior hotel. That our deception had worked was irrelevant from the day of her arrival. Her version of the journey—to stay only two weeks—quickly vanished.

There are all kinds of deceptions. My sisters and I engaged in both small and large deceptions. Our little ones used both reality and non-contradictory approaches. The ruse of a two-week visit, and then, naming her surroundings as a "senior hotel," worked well for all of us.

These were not the important deceptions, however. Removing her from her beloved Jerusalem home and later, choosing her final resting place away from that home were far more momentous. They felt manipulative, a betrayal of her trust, and of her identity. But they were essential acts of care. I felt that I was re-shaping the narrative of her life, upending its coherence, and organizing future memories about her in a way that suited me, not her.

She lived in assisted housing for five and a half years, and for five and a half years, nothing remarkable happened. She slowly declined. We monitored her and the ever-changing institution staff constantly. We brought friends and grandchildren to visit. We celebrated the annual cycle of holidays and birthdays with her. I cried after each visit with her—about her changes, about my loss of our old relationship, and most of all, in response to the way her face lit up in happiness every time I walked into her rooms.

By her second year with us, my guilt faded, in tandem with her own seemingly disappeared memory of Bill and of Jerusalem as home. My queasy awareness of an open-ended dementia became my primary concern, and it was joined in my gut by the not quite looming question of where her final resting place would, or should, be.

Claims of the Dead: Caring for Memories

I grappled with the significance of burial place for her, for me, for my sisters and for our children. The decision would have multi-generational weight. How would the place of burial speak to the memory of our mother into the future? At first, one sister and I wanted to honor her wish and bury her next to Bill. My other sister told us from the outset that she wanted our mother buried in California. I was paralyzed by the impossibility of making a decision.

Over a period of months, I conducted an informal survey among a scattering of friends. Where is your mother or father buried? Who chose the gravesites? Do you visit? Among the friends I asked, mine was the only family that went to the graves of our relatives annually, located near our homes, in Colma, founded as a necropolis, just south of San Francisco.

After our mother had been in California four years, after she had stopped writing, lost her vibrancy, spoke less often and became more passive, I felt even more strongly that I wanted her to be buried where the next generations could easily visit, though I felt she didn't belong in Colma. My care for her in life included my concern about enabling succeeding generations to evoke memories of her, which, I thought, would be easier to do if they could stand by her gravestone.

To bury her in Israel, I knew, would be to give priority to her connection to everything that ancient, troubled, holy landscape signified for her—its claims, wars, traditions, and a life well-lived. It would reflect her existential self at the prime of her life. On the other hand, to bury her in foggy Colma entrusted the living memory of her to our children and other relatives. I wanted our choice to *look forward with eyes in the back of my head* as she had said so astutely about her own life in Jerusalem. I was in agony about the irreconcilable choice. But my guilt was softened by my concern about *memory into the future,* which was becoming an important form of care for me.

Grave Displacements

We buried her in Colma, in the family cemetery. The final deception of place and belonging. I had reconceptualized my idea of care to include the memory-keeping and memory-making of future generations of our family. Was it the right place? Can we ever know? What does our choice of location reflect about her, her hyphenated identity, and the life she had made? What does it say about us, her children, and our care for her? These remain my unanswerable questions as her daughter.

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Commentary
What Stories of Dementia Teach

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Abstract. This commentary focuses on 12 narratives written by caregivers of people living with Alzheimer's Disease and other types of dementia. While each narrative is distinctive and particular telling, common themes woven throughout the narratives include: embarking on a journey; I changed and they changed; feelings elicited; the hardest and best parts; understandings and acceptance; intersections; and what the future holds. This commentary shares these common themes and how they play out in the lives of people caring for loved ones with dementia. The last section connects the narrative themes to bioethical inquiry, with a focus on discerning moral boundaries. The boundaries touched on relate to justice within families, caregiver self-respect, and the persistence of persons and personal relationships over time.

Keywords. Caregiving, Dementia, Alzheimer Disease, Justice, Respect, Self-Respect, Empathy, Emotions, Narrative, Families, Personal Relationships, Gratitude, Filial Duty,

With advances in public health and modern medicine, the narratives of old age have changed. Gawande notes that in the not too distant past, later life was typically like a roll of the dice, with a person puttering along and then the bottom would drop out (Gawande, 2014). Today, by contrast, an aging person's descent more often resembles a long journey down a hilly mountain, a journey that involves living for extended periods with chronic conditions such as heart disease, cancer, respiratory illness, stroke, or dementia. Along the way, although "we may not be able to stave off the damage . . . we can stave off the death . . . ," making it possible for an older adult to make it home—weaker and more impaired though (Gawande, 2014, p. 27).

When individuals live well into their seventies and eighties, they are more likely to suffer from chronic disease and spend their last stage of life dependent on family members for help with activities of daily living. Longevity has resulted in family relationships that are not only stretched to new lengths but transformed. Parents and children, spouses, and others who are navigating this experience are charting new terrain.

For many grown children, parents once stood out as larger-than-life figures. Fonts of some of our strongest early emotions, parents can evoke feelings that range from safety and refuge to angst, from love to loathing. Parents can be the most important people in our lives or the bane of our existence. Strong feelings often linger well into adulthood, gradually diminishing only as adult children witness parents grow old. When a parent develops dementia, this can knock a parent off the pedestal a child might have placed them on. Whether a parent was loved or loathed, they are toppled. Any lingering perception of a parent as commanding and authoritative is laid to waste. A parent is no longer larger-than-life, but human, like me.

A different course unfolds when the caregiver of a person with dementia is a spouse. While a parent with dementia might be knocked off their pedestal, a spouse's dementia can feel too close for comfort. A spouse is typically not older or other, but a peer, perhaps perceived as part of one's self or, as the adage puts it, "one's better half." Reckoning with a dementia diagnosis for a partner can bring home a deeply personal realization. A debilitated spouse is a blunt reminder that we are all creatures that decay and die. With a spouse's decline closeup and personal, our usual defense mechanisms to avoid dwelling on decline and death break down.

Common Themes

Sharing stories of dementia can teach many lessons about what might be in store for us as individuals, offspring, and spouses. From the twelve NIB narratives of dementia, we learn about individuals moving from a mostly intellectual comprehension that a person close to them has dementia to a fuller appreciation of what this means. For some, the narrative includes a wish for a loved one's death; for others, the narrative is a love story. All the narratives express an effort to find meaning or something redemptive, yet for some, there is neither.

Embarking on the journey

Of course, an adult *knows*, intellectually, that a parent is just human. Yet in some salient ways, they don't really *know*. Some ways of knowing are gained only from living through experiences, such as the experience of a parent's decline or death. For some sons and daughters, the first sign that their parent is not invincible comes with noticing signs, such as wrinkles and gray hair, a stooped gait, a walker. For others, it is a parent's diagnosis of cancer. For the narrators of these stories, the path is marked by a fading mental state and an eventual dementia diagnosis. With dementia, signs and symptoms can arise as a dawning awareness that things are not right, or suddenly, like a jolt. Witnessing a parent's decline enacted forces a person's hand. It cannot be contested.

Yarbrough's journey bears this out. It began with a physician's pronouncement during a routine visit that "veered unexpectedly onto the caregiver path . . . I learned that Mom's cognitive changes were more than normal aging; they were the early stages of dementia."

For Chittooran, witnessing a parent's decline was like watching someone fall from a cliff. "My mother's symptoms devolved at an alarming rate into confusion, hallucinations, and delusions. She reverted to her days as a high-ranking government official's wife in India, with an army of servants at her disposal—she began to order people around, constantly asked who was coming to visit, and reminded me to 'tidy the house' and 'cook enough food for all our guests.'"

The lived experience was unmistakable for Pearson too, who describes an adventure his entire family embarked on several years into his dad's long course of Parkinson's Disease, "We set out to see the giraffe . . . he was starting to hallucinate but, in our stubbornness, we thought we could convince him the visions were not real." It was not that the family did not know; they did. But after the giraffe adventure, it could no longer be denied, tucked away for later consumption.

I changed and they changed

Each narrative depicts not just the arrival of something new, but the process of coming to terms with a life-changing truth. A common theme throughout was that a change was occurring not just in a loved one but in themselves. Ferguson muses, "Watching someone you love, someone who was so beautiful, intelligent, witty, and loving lose piece after piece of herself changed me; changed all of us who loved her. You don't come out of something like that the same as when you went into it."

Personal change sometimes grew out of sacrifice. Zerrenner relates career and lifestyle adjustments, which began when "I had to shut down my consulting business, as I could not travel . . . I had just landed a very lucrative consulting engagement with a large healthcare system and had to turn it down."

Referring to serving as her mother's caregiver, Thew asserts that "what had changed her eventually changed me. I came to accept it all and accept her without embarrassment or explanation to others. This was an important transformation of heart and spirit and one I wished I had reached sooner."

Feelings elicited

Accompanying the change were often a range of intense feelings. Binning recounts the "battle with anger" after living for over fifty years in a loving marriage and watching Alzheimer's drive "a sharp jagged wedge" into the life he had built with his wife.

Guilt and resentment loom large too. Chittooran describes the feeling that "as hard as I try, my caregiving goes unappreciated by my mother." For example, "When people tell my mother she's lucky to have me as a daughter, she rolls her eyes and smirks behind their backs. Recently, she commented, 'What exactly *are* you doing for me? I don't need you . . . '"

Worrying is the hallmark of Chittooran's caregiving experience, especially the incessant worry about "what will happen to her if something should happen to me . . . She'd have to move to an assisted living facility, something we wouldn't do unless it was the last resort because it would be a somewhat shameful thing to do in our Indian community."

The pain of others making comments that hurt was pronounced for Ferguson, who describes being on the receiving end of remarks such as, "'I'd never expect my kids to take care of me. I will go to a nursing home,'" with "[t]he subliminal message being 'your mother expected *you* to take care of her?'"

Feeling overwhelmed is also emblematic of dementia stories. Chittoran advises all caregivers "not to lose themselves in the act of caregiving, even though it is difficult to remember a life BC (Before Caregiving)."

The hardest and best parts

For many, the hardest part of caregiving involved a decision to place a family member in a nursing home. Pearson confesses, "I did not want to admit to myself that he probably was never coming back home. He would live in the nursing home . . ." For Binning, the nursing home was a trial of separation and a painful letting go of his life partner. The pain grew to new heights when nursing home staff directed him to come only two times a week in order to help his wife "adjust to her 'new home.'" This was followed by a moratorium on phone calls, because "Talking by phone only connected us together and made our separation worse." Scoring his visits on a scale of one to ten, Binning surmised, "There will never be a number 10; there will never be a perfect visit." It was torturous simply to hear his wife recite questions like, "'Are we ever going to be together again?'"

Some of the best parts were simple things. Pearson writes, "I began to appreciate the small but profound moments" and "these ancillary personnel . . . the assistants who gently turn him, change his wet diaper pad; the woman who tidies up the room." In a particularly poignant depiction of ancillary staff, Pearson says, "I watched the person who empties the trash can as she tied up the bags. When finished, she motioned toward my father, 'May I?' 'Sure,' I said, uncertain of her intentions. She walked over, spoke to him, kissed him on the forehead, and walked out to the next room. She did this every day." Pearson recounts daily scenes five or more caregivers who, embraced his dad. Some cried, others smiled. Pearson thinks, "We should all be so lucky."

Understandings and acceptance

Appreciation and gratitude for what remained was one path to understanding and acceptance for many family caregivers. For example, Pearson describes the value of mundane things, which matter because they are not mundane to the person with dementia: "[a] smile, a hand placed in another's," "presence," and "the dose of kindness."

Reaching acceptance for others meant mustering the ability to laugh. For Pearson, a surgeon, it was the fact that "Years later, we could finally laugh about my botched job of a shave." Yarbrough also recounts "Making a commitment to laughter" and to "Creating good memories." Pearson's good memories came from creating "a ritual beyond words. When I visited, I would cut his fingernails."

Binning found acceptance in the clarity of belief that he was doing the right thing even when there was stigma associated with those decisions. Referring to the stigma of having a spouse in a nursing home, Binning declares, "Let it be known and understood, we who are left will ask: 'Have we abandoned our life's partner?' The truthful answer is: It's imagined abandonment." Binning states that with his wife in a nursing home, he is "more than comfortable with the care my Soulmate is getting."

For others, such as We, there was little comfort. Instead, an acceptance of sorts came with the realization that the father who abused her and now suffered Alzheimer's would eventually die, but the death would not heal, just end, the narrative of their relationship. She writes, "closure is not a requirement of caregiving. When we can accept that not all stories from caregivers are caring, nor should they have to be, caregivers can finally begin to heal and speak their truth." Perhaps, We's best hope for closure is to finally be permitted to give testimony to her truth and to have it affirmed and accepted by listeners.

Intersections

The twelve narratives make clear that dementia does not take place in a vacuum, but in tandem with the rest of life. For example, Pearson's father broke his hip. So did Zerrenner's wife. Tumosa describes her father's ten-year battle with dementia coinciding with "the deaths of two wives and his oldest son, a serious tractor accident, hypertension, several transient ischemic attacks (ITAs), and cancer." Yarbrough reports life changed with "two small but utterly terrifying words, *breast cancer* . . ." Her mom "could not fully process the diagnosis and treatment options, so the decision-making was up to me."

For We, "the rest of life" included the ever-present history of domestic violence perpetrated by the father she cared for. Haunted by a history of "Pop Pop's" violence toward her, there was constant tension from the incongruity of the dual identities her father epitomized, as both a perpetrator of violence and an individual with Alzheimer's. Describing others' attempts to reconcile the tension in unkind ways, We describes their "chortles and phrases like, 'Well, he *was* your father . . . you must have loved him deep inside," or, "'You don't mean that. He *is* your father, after all.'" Repeated insistence that this duality was, indeed, her truth, were inevitably resisted. As she puts it, "each narrative of suffering repelled the other like two magnets of the same poll . . . no crossovers allowed." As a result, the complexities and contradictions that constituted her story was a truth she was forbidden to share.

What the future holds

The future for many caregivers did not look rosy. Anonymous cautions, "What's coming next is cognitive decline, choking, aspirating, maybe pneumonia, incontinence. Already social gatherings cause distress, and what's coming is harder . . ." Pearson warns that "families need to realize that further decline is inevitable" and advises those with loved ones in nursing homes to go on outings, bring them home, visit, celebrate holidays," a lesson he learned only after the window closed: "Perhaps this should have been obvious, but we really never gathered as a family in the nursing home until he was dying"

Chittooran confesses she does not know what to think: "I don't know whether to hope that the end is swift and merciful or that she will live many more years, even as her light gradually dims." She adds, "I pray for patience and understanding, for strength and courage, so that we can handle whatever the days ahead may bring."

Thinking about the future, some caregivers wish that their family member would die or that they themselves would. Anonymous, who has a life-threatening illness, states starkly, "[m]y advance directive is on file, but that is not enough. I need to finish my own end-of-life plan: get the 'No Code' tattoo, set aside money for a ticket to Amsterdam, and, just in case, order a copy of *Final Exit*."

Chittooran worries about what comes after her parent's death. "I worry about my own future if I too, should develop dementia. I tell my children that if I do, they're to walk me to the lake in our neighborhood and simply push me in. They think I'm joking."

Knowing that caregiving will one day end, Chittooran advises caregivers "to remember who they were before they became caregivers, and how important it is to maintain ties to the people they once were and to the lives they once had . . ."

Zerrenner speaks of opportunities that come with loss: "[t]here was no more chance to learn about the past since there were few memories of it to share, but there was still time to share the present and to experience the warmth of a mother's love."

Setting Moral Boundaries

Family caregiving raises bioethical questions related to moral boundaries in family relationships, which are often sidelined in scholarly literature. These questions emerge differently for adult offspring caring for aging parents compared to spouses caring for partners. A salient ethical concern for some offspring concerns the fair division of caregiving between them and their siblings. For both offspring and spouses, issues of self-respect, and the persistence of persons and relationships are central.

The fair division of caregiving within families

An issue Chittooran flags early on is the gendered division of caregiving. She wonders about "[h]ow it's all on me, not my dear brothers?" Chittooran is right to question the assumption that caregiving must fall only on her shoulders. Her experience points to the larger, gendered pattern of caregiving that has taken place since time immemorial.

Although longstanding prejudices about who ought to care can be difficult to budge, a just society ought to make reasonable efforts to support a fair division of caregiving not just within families but between families and the wider society. This includes protecting family caregivers against threats to their central life opportunities. A good place to start is by asking, do caregivers retain or lose the capability to create their own life narratives; be healthy; maintain bodily integrity; use senses, imagination and thought; express a range of human emotions; make and carryout life plans; affiliate with others; relate to nature; play and recreate; and regulate their environments (Jecker, 2020).

Absent minimal supports, family caregivers may find themselves in an uneasy place, where moral limits to what is asked of them fall to the wayside. Chittoran describes caregiving for her mother as teetering on the edges of moral boundaries when she refers to, "The most challenging aspect of being a caregiver . . . how it has consumed every minute of my time." Having cared for her husband before caring for her mother, she felt her life's time was not her own.

Culture is also interwoven into stories of filial duty. Thus, Chittooran explains that in "an Asian family . . . respect for, and obedience towards, one's elders is expected." Yet, at the same time, she steps back and reflects on the moral code she inherits, acknowledging "how important it is" for caregivers "to be kind to, and take care of, themselves, to accept support when it's offered and to ask for it when it's not."

Self-respect

The perception of a responsibility to care for a family member arises differently for children versus marriage partners. For adult offspring (Baxter, Bogdan-Lovis, Chittooran, Ferguson, We, Tumosa, Yarbrough, and Driver), the decision to care may be informed by a sense of moral responsibility that springs from gratitude for life or for being raised by a parent (Jecker, 1989). Yet it is widely held in moral philosophy that certain conditions must obtain for a debt of gratitude to arise, although the exact nature of these conditions is disputed.

One widely accepted precondition for gratitude is that the acts for which one is grateful were not performed in ways that violate the rights and dignity of the recipient. When they were, any assertion that one should be grateful is morally dubious. For example, We's childhood included violence perpetrated against her by the parent she now cares for. Since childhoods vary, a gratitude-based duty must be modulated by the nature of the acts for which one is grateful (Manela, 2019). In some instances, family history renders caregiving harmful and these harms are sufficiently weighty to establish that a person should forego caregiving. For example, if a person perceives caregiving to be tantamount to denying their own worth and dignity, a self-respecting person does not take on caregiving.

For some adult offspring of formerly abusive parents, a path forward arises out of the belief that a person with dementia is not the same person as the individual who perpetrated violence years before. Another path forward is the belief that the prior act of abuse does not entail that a person forfeits their dignity. Analogously, someone convicted of an egregious crime and sentenced to prison still retains a right to be fed, sheltered, and live under humane conditions. Similarly, a parent who was abusive to their child in the past does not forfeit all claims to help with activities of daily living, such as being toileted, bathed, and fed. Yet it might be argued that the duty to provide this cannot fall on an abused child, but instead rests with the wider society.

The persistence of personal relationships over time

For spouses (Binning, Anonymous, Pearson, and Zerrenner), the perception of a duty to care takes a different form. In contrast to a sense of moral responsibility based on gratitude, a sense of spousal responsibility may relate to the voluntary decision and commitment that initiates the relationship. Perhaps the most obvious basis for this perceived responsibility is the promise undertaken during marriage, which traditionally commits a person 'for better, for worse, for richer, for poorer, in sickness and in health, till death do us part.' Based on this, someone might reasonably expect that if a party to a relationship becomes the victim of a devastating disease, the other will stay by their side and care for them.

Yet, it is reasonable to ask if there are any moral boundaries to such a promise. Even if it is reasonable to expect a measure of spousal support, it might not be reasonable to expect that a partner will be there no matter what. A judicious interpretation of marriage might include that the literal vows spoken are not the same as the underlying commitment the vows speak to. One reasonable interpretation of marriage someone might hold is that the actual commitment made is to support and nurture a certain kind of valued relationship (Jecker, 1995). The question then becomes, when dementia advances to the point that a person no longer recognizes their spouse, and nothing is left of the former relationship, what, if anything, is left of the former obligation?

Another way to think about the relationship between husbands and wives is what carries it through tumultuous times are continuing bonds of love. Schoeman (1980) characterizes the ethics that love sustains as having its source in virtues, rather than duties. Virtues of loyalty reflect the fact that "We share ourselves with those with whom we are intimate and are aware that they do the same with us." It follows that "traditional moral boundaries, which give rigid shape to the self," do not apply, and that "talk about rights of others, respect for others, and even welfare of others is to a certain extent irrelevant" (p. 8). For Schoeman, what matters most in marriage is not that one vowed to stay by the other's side, but that, despite illness, love persists.

However, it could be argued that Schoeman's analysis does not preclude the possibility that moral limits remain in force between loving partners, and that these are properly expressed as rights and claims based on justice. The moral responsibilities that love can license are limited, first, because love does not warrant self-injury. For example, if a spouse with dementia endangers a caregiver's health or grows violent, it may violate the caregiver's self-regarding duties to remain in harm's way. Second, even if a caregiver feels love unconditionally, this does not show that they are morally bound under any and all conditions. Instead, relationships are circumscribed by moral considerations outside themselves (Jecker, 1993). Rather than exempting relationships from moral criticism or holding certain loyalties and allegiances unconditionally, we should instead impose constraints that ensure that each party is regarded as an ends, and each person's moral claims are upheld.

A guiding ethical idea should be the Kantian insight that persons have an ultimate value and worth, in contrast to mere tools, which possess a purely instrumental value (Kant, 1785). Admittedly, moral boundaries can be murky and challenging to set in dementia care. After all, the person with dementia cannot be held responsible for their present actions. When they lose their filter, bully, or behave aggressively, caregivers may feel (and be) trapped. In these instances, it can be morally incumbent upon the caregiver to protect themselves by exiting the caregiver role.

For both offspring and spouses, the test of doing caregiving well is variously described. According to Pearson, the challenge was "to listen and not discredit . . . no matter what." For Ferguson, it was recognizing "although sometimes it's difficult . . . there is still a person inside. A person who deserves the best of ourselves." Yet another test is respecting and caring not only for the care recipient but for oneself. When deciding to treat her mother's breast cancer or not, Yarbrough displays self-respect and a sense of her own moral worth when she affirms a commitment to live without regret, manifest as "the genesis of my central care question: 'what would she want; what do you want?'"

Yet, it is a genuine and difficult moral problem for many family caregivers to know their limits and to reach a decision to cease caregiving. Zerrenner says he knew, "It was time" to move his wife to a memory café (a living facility for older adults with dementia) when it "reached the point where I was stressed out, not sleeping well, and my own health was at risk . . . She was hallucinating at night and causing me to have sleepless nights."

For others, ending a caregiving relationship is not a live option because they perceive no viable alternatives. When this occurs, society has a positive duty to intercede. The alternative is morally tragic: refusing to care is tantamount to abandoning a loved one, yet continuing to care is self-injurious. A just state does not compel such choices; it does not leave families with care-dependent members in the lurch. Instead, it mitigates the financial, social, and emotional costs of caregiving by lending a hand (Brake, 2017).

Conclusion

In conclusion, this collection of narratives depicts humanity on the brink. It reveals human frailties and interdependencies, moral limits, and linkages between personal identity and relationships with others. As old age is stretched and family relationships last longer, these stories offer insights, if not always solace. By showing us how they gathered the wherewithal and courage to care, we can better understand our own stories and our shared human predicament.

References

Brake, E. (2015). Fair care: Elder care and distributive justice. *Politics Philosophy &Economics, 16*(2), 132–151. doi:10.1177/1470594X15600831

Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*. New York, NY: Metropolitan Books.

Jecker, N.S. (1989). Are filial duties unfounded? *American Philosophical Quarterly*, 26(1), 73–80.

Jecker, N.S. (1993). Impartiality and special relationships. In D. T. Meyers, K. Kipnis & C. F. Murphy (Eds.), *Kindred matters: Rethinking the philosophy of the family*. (pp. 74–89). Ithaca, NY: Cornell University Press.

Jecker, N. S. (1995). What do husbands and wives owe each other in old age? In L. McCullough & N. Wilson (Eds.), *Long-term care decisions: Ethical and conceptual dimensions*. (pp. 155–180). Baltimore, MD: Johns Hopkins University Press.

Jecker, N. S. (2020). *Ending midlife bias: New values for old age*. New York: NY: Oxford University Press, Incorporated.

Kant, I. (1785). Groundwork of the Metaphysics of Morals. In J. Bennett (Ed.), *Groundwork for the Metaphysic of Morals*. Retrieved from www.earlymoderntexts.com/assets/pdfs/kant1785.pdf

Manela, T. (2019). *Gratitude*. In E.N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy*. Retrieved from https://plato.stanford.edu/archives/fall2019/entries/gratitude/

Schoeman, F. (1980). Rights of children, rights of parents, and the moral basis of the family. *Ethics, 91*(1), 6–19.

NARRATIVE SYMPOSIUM

Commentary
Patience, Presence, and Persistence: What It Takes to Be an Alzheimer's Caregiver

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Abstract. These stories convey the diversity of AD caregivers but also the similarities of the difficulties they experience over years of adjusting to the increasing challenges of the tasks. The authors vividly express both the toll caregiving takes; many also derive positive feelings from the experience. Among the bioethical issues raised in the stories are the failure of professionals to utilize caregivers' intimate knowledge of the person, the tension between lying to and comforting the person, choices at the end of life, and the still-emerging impact of genetic and biomarker information about the caregiver's own susceptibility to the disease. It is common for caregivers and professionals to characterize the relationship of caregiver and parent as "role reversal." This commentary calls for a new look at that framework, which fails to recognize the many differences between caregiving for a child and for a person with AD.

Keywords. Alzheimer's Disease, Lewy Body Dementia, Montreal Cognitive Assessment, Caregivers, Nursing Home Memory Care Units, Role Reversal, Terminal Care, Genetic Markers, Biomarkers, Bioethical Issues, Narratives

The first time I read Noël Ferguson's story in this series by caregivers of people with some form of Alzheimer's disease, I was puzzled by the title—"Was He Wearing His Good Suit?" These words were her mother's reaction to a daughter's gentle reminder that her husband had died 21 years earlier. As I read further, I learned that Ferguson was also confused. Only when she realized that her mother wanted to be reassured that at his funeral her husband was appropriately dressed for this solemn occasion—wearing his good suit—did she understand the depths of her mother's need to connect with her past.

In different ways, all the authors of these stories observe and recount details that only a family member could know and understand. They create portraits of the person living not only in the present, but also in the past, often at the same time. No matter how skilled doctors, nurses, and other professionals are in administering and interpreting validated tests and scales of cognitive function, these cannot substitute for the family member's intimate knowledge of the person. Unfortunately, professionals often do not ask the questions that would elicit this valuable information.

This gap is explicit in the symposium by an anonymous writer, who is caring for Peter, her ex-husband. (This relationship is not as unusual as it may seem. In my research about family caregiving, I have come across caregivers who are taking care of ex-mothers-in-law.) For Peter, an appointment to the doctor generally begins with the Montreal Cognitive Assessment, administered by the neurology staff. The test, the author says, is given "in notably inconsistent ways. One [staff member] rushes through the instructions for the first task, a task that involves alternating numeric and alphabetical sequences and points vaguely at the sheet of paper. Another speaks slowly and clearly, tracing the pattern shown on the paper."

The author, a college professor, says, "If I thought the results mattered, I might point out that demeanor and clarity affect Peter's ability to complete the tasks." She asks plaintively, "If the neurologist wants to assess Peter's cognitive function, why not ask us which tasks and situations have become harder? I spend hours with him every day, and I am sitting right there beside him." She is present in his daily life, unlike the professionals providing medical care.

Many of the authors echo this dissatisfaction. Doctors dismiss early signs of disease as inevitable signs of aging. When some form of dementia is finally diagnosed, often because of the family's persistence, doctors fail to provide critical information and referrals to aid in managing the disease. Even seasoned health care professionals encounter this gap. In his story, Scott Pearson, a surgeon caring for his father, says that medical students are taught about care at a superficial level. Care requires patience, and "biochemistry is easier to master than patience." Arthur Kleinman, a Harvard psychiatrist and anthropologist, described his frustrations in getting useful advice from specialists about how to care for his wife with early-onset Alzheimer's disease (Kleinman, 2020). Writing about her family history of dementia, Tia Powell, a psychiatrist and bioethicist, says that she is still angry about an uncaring cardiologist who insisted on installing a pacemaker, against her mother's and Powell's wishes as her health care proxy. The cardiologist said, "No one is allowed to die of a heart block." The pacemaker was canceled (Powell, 2019, pp. 14–17).

A few authors describe actions by professionals that I found ethically problematic. Sheri Yarbrough, 24 years old at the time, says that her mother's doctor told her she had to move back into her mother's home to take care of her. This advice—really an order—was issued presumably without discussing other options or the impact this would have on her life and her previous not-so-great relationship with her mother. (Would the doctor have said the same thing to a son? I doubt it.)

In another story, ER personnel told Janice Thew (writing with her daughter C. Noelle Driver), that her mother, who had called 911 for the second time in two weeks for no apparent reason, could not be discharged home. She had to go directly to a nearby assisted living facility. This order was given apparently without any discussion of whether the family agreed with the move, could afford it, or had any idea about how to choose the most appropriate facility.

Professionals may defend these actions as "patient-centered" without recognizing that the patient does not exist in isolation. Family members are not all willing, able, or prepared to take on the demanding caregiver role. These actions seem like risk avoidance; if the family does not follow the advice, it is their fault if something bad happens.

Who Are the Caregivers?

The authors of these twelve stories, like the estimated 47.9 million of their counterparts across the country providing care to adults, are diverse in many ways (National Alliance for Caregiving & AARP, 2020). Among the authors in this symposium, there are ethnic diversities (African-American, Latina, Indian, Korean). They have different relationships with the person in their care. Half are daughters taking care of their mothers, but there are also a daughter and son and a daughter and granddaughter in that role. A son is taking care of his father, and two husbands are taking care of their wives. As noted, one woman is taking care of her ex-husband. While most are middle-aged, two are millennial caregivers, a growing segment of the caregiving population in general.

They are taking care of people with a range of diagnoses—Alzheimer's (mild, moderate, severe), Lewy Body Dementia, vascular dementia, semantic dementia, and Alzheimer's with Parkinson's disease. Yet from the descriptions of everyday life, it is hard to say which person has which diagnosis. The brain scans may be different, but the behaviors are similar. Moreover, beyond the brain disease, most of the persons have other chronic or emergent conditions due to severe falls, cancer, or other medical problems that complicate their Alzheimer's care.

Even with all their differences, the stories in this symposium describe a similar narrative arc: early signs of memory loss or confusion, difficulty getting a diagnosis, progressive decline, need for full-time care at home or in a facility, and eventually death. (At the time of writing, half of the people described in the stories had died.) The authors write about incidents from the years-long process, which, for some, is still ongoing.

Several of the people with AD are in assisted living, nursing homes, in what is called "memory care units" or "neighborhoods." This terminology is presumably designed to avoid the stigma and negative reactions to "dementia" or "Alzheimer's disease," At best the care is kind and respectful, but will not change the trajectory of the disease. Focusing on memory loss as the signal event overlooks other losses that can be even more troubling. Among these, says Powell, are "wandering, agitation, and incontinence . . . Big problems also come with driving, sex, and money" (Powell, 2019, p. 215).

Despite their difficulties, many authors say that they not only survived years of endless tasks but had positive feelings about the experience. Many people who have not gone through this experience wonder whether these feelings are authentic or reflect the caregiver's unwillingness to present the person they are caring for or themselves in a negative light. Writing about her father, who abused his family, Sunnie Songeun We says, "What my family and I experienced was a type of burnout that lasted years beyond the period of caregiving—guilt and shame that stemmed from the societal pressure to perform artificially loving 'roles' to be perceived as *caring enough* for a patient who once inflicted trauma upon us." It is natural to want to derive some positive meaning from a life-changing experience. Yet caregivers should feel free to express the range of emotions without being criticized for the negative ones or praised as saintly for the positive ones.

Questioning the Concept of Role Reversal

The phrase commonly used to describe life as a caregiver of a parent with AD is "role reversal." Sara Baxter's story, which opens the symposium, is titled "Role Reversal in the Art of Caregiving." Mary (Rina) Chittooran uses the phrase to describe how the relationship between her and her mother has changed. This is particularly troubling in an Asian family, Chittooran says, "where respect for, and obedience towards one's elders, is expected."

My discomfort with the phrase is not in any way a criticism of these and other authors who use this phrase to encapsulate a complex relationship. The tasks that one does for children and for people with dementia are on the surface similar, as basic as feeding, safety, and toileting, and as complex as managing health care, keeping finances in order, and making life-changing decisions. Yet the life stages are different, bodies of children and older adults are different, and so are the relationships. Baxter recognizes this in her story, writing, "I redirect, distract, and yes, bribe. But unlike a stubborn toddler, I can't pluck her up and make her do anything she doesn't want to do." Like Baxter, Chittooran compares her mother's care to that given a balky two-year-old. But the two-year-old is growing and discovering her wide world; the 80-year-old in the last stage of life is seeing her world contract. She mourns and sometimes fights against her loss of independence and identity. It should, I believe, be possible to do intimate and often intrusive caregiving tasks while still acknowledging the primacy of the person's identity as a parent.

This way of looking at caregiving is by no means limited to family members. I have heard professionals chide a reluctant caregiver by saying, "Your mother wiped your bottom when you were a baby; now it's your turn." Looking for the source of this concept, I came across a reference to a 1988 Gerontological Society of America symposium on "Role Reversal: Is It a Valid Concept?" Two papers from the conference were published in *Gerontological Social Work.* Elaine M. Brody, a pioneer in gerontology and caregiving, titled her article, "Role Reversal: An Inaccurate and Destructive Concept," leaving no doubt about her stance (Brody, 1990). Similarly, Mildred M. Seltzer, a well-known social work researcher, called her article, "Role Reversal: You Don't Go Home Again" (Seltzer, 1990).

Both authors believe that the concept of role reversal, which originated in the psychodynamic literature of the 1960s, adds to the discredited notion of old age being a "second childhood." Seltzer says that role reversal emphasizes the deterioration of the old person and the stress on the adult child. Brody emphasizes the importance of giving older adults control over aspects of their lives. (This also comes up many times in the stories.) Both Brody and Seltzer are deceased, and I have not found any current writers continuing the discussion. Perhaps it is time for another symposium and another phrase that captures not only the differences in doing the actual tasks but also the complexity of the relationship.

Ethical Issues Raised by the Authors

Since these stories were written for a bioethics audience, what ethical issues do they raise? Several authors worried about lying to the person. They believe lying is wrong, yet being truthful is not necessarily always right. The authors manage this dilemma by indirection; without naming it, they are following Emily Dickinson's advice to "Tell all the truth, but tell it slant." Baxter provides some nice examples. When her mother says, "You never come to see me," she does not respond with, "I've been here three times this week." Instead, she says, "I know, work has been so busy. I will try to come more often." Reminding the person that her memory is flawed is not only counterproductive; it is unkind.

One issue that was missing in all but one of the stories was the financial implications of providing this care. The exception was Walt Zerrenner's story—a husband caring for his wife Aline. He was unusual in arranging in-home care for Aline early in the course of her disease, which allowed him to continue important aspects of his life. He was also unusual in having a long-term care insurance policy.

In 2014 he moved her to a memory care neighborhood, where she adjusted very well. The financial impact began when Aline had a mini-stroke and broke her leg, and their insurance company refused to pay for more than 13 days of rehab therapy. In addition, the memory care neighborhood required payment to hold her room for her return. After a second fall, which Zerrenner attributed to inadequate care, he moved her to a nursing facility. That costs $1,500 a month more than his long-term care insurance policy will cover. From May through December 2019, his out-of-pocket costs exceeded $40,000.

In the few other mentions of finances, the authors say that the parent had savings to cover expenses. No one mentions Medicaid, but perhaps the parent was eligible for this program, which covers nursing home stays. Maybe some authors felt that bringing up financial woes would distract attention from the story of loss and remembrance. But family caregivers need to know about the impact on their own retirement and current life choices.

End-of-Life Decision Making

Two stories discuss decisions at the end of life. To open her story, Elizabeth Bogdan-Lovis remembers her mother's plea years in advance of her dementia: "Lib, if I ever lose my mind, just get a gun and shoot me." Lib replied, "Mom, that's not an option." Yet, at the end of her mother's life, when she was suffering from terminal cancer and kidney failure, as well as AD, Lib, her mother's health care proxy, refused a last-ditch renal shunt proposed by a nephrologist. She was influenced both by her mother's prior wishes and the terrible experience restraining her mother when she had to have a tooth extracted, described in her story, "The Trip to the Dentist." Ed, her mother's partner but not her health care proxy, and Lib's siblings wanted to give the procedure a try, but Lib held firm. She refused IV fluids as well.

Her mother died four days later. "I didn't shoot her," she concludes, "but I did let her die." And she regularly revisits the decision, even with the passage of time. For me, the ethical issue is not the decision to forego treatment, which seemed only to prolong dying, but the lack of palliative care or hospice for the patient and counseling for the family.

The second example concerns Anonymous, who is caring for her ex-husband Peter. "As soon as I can gather the wherewithal," she writes, "I'm going to get a tattoo across my chest. In capital letters, this tattoo—my first—will read "No Code." To protect herself against doctors and first responders who might say that the tattoo might not reflect the person's current wishes, she plans to use a Sharpie pen to add the date every few days.

Her determination comes not from advanced age or frailty—she is 60 and a full-time college professor—but from what she has experienced as a caregiver and the health challenges she has endured as a result. Her title—"My Shattered Useless Fix-It Heart"—reveals the depths of her distress. She has had hours-long attacks of vertigo and vomiting from constant stress, and is losing the hearing in one ear, diagnosed as Meniere's disease. She worries about getting in an accident and not being able to tell someone that a man with Lewy Body Dementia is relying on her for care. She has an advance directive on file, but she does not think that is enough. Until she gets the "No Code" tattoo, she plans to set aside money for a ticket to Amsterdam, and "just in case, order a copy of *Final Exit*" (Humphrey, 2002).

A competent adult in the United States has the legal and ethical right to refuse medical treatment. Whether tube or even hand feeding should be considered medical treatment is still debated, particularly if the person is no longer competent. One view is that choice made in advance should determine the care of a person with AD. This view is countered by those who claim that the welfare of the person—especially if they do not refuse food and hydration—should override advance directives made at a time when they could not fully appreciate their needs. Legal scholar Norman Cantor argues that artificial nutrition and hydration, as medical treatments, can be withheld if the person's advance directive, made while competent, includes it. He believes that hand feeding and offering fluids are also medical interventions and can be declined in advance (Cantor, 2018). Rebecca Dresser, also a legal scholar, believes that the welfare of the person with dementia should sometimes take priority over earlier choices. The person may have adjusted to her situation and has changed her mind; her current views should determine care (Dresser, 2018).

But Anonymous does not take the next step. By alluding to her plan to save money for "a ticket to Amsterdam," she suggests that physician-assisted suicide would be an option. Depending on the state in which she lives, it might not be necessary for her to go abroad. Nine states and the District of Columbia have laws permitting physicians, under certain circumstances, to provide fatal doses of drugs to patients. This option would be available to her only if she met the eligibility criteria, which would likely mean being competent and having only six months to live. Legal rulings in other states have opened the door to this change. No jurisdiction in the U.S. has allowed a physician to assist in the death of a person with AD. If Anonymous develops AD, she would need that ticket to Amsterdam, where this practice is acceptable.

Biomarkers and Genetics

It has been known for years that AD runs in families. Yet in their stories, none of the daughters and sons express any concern about their own futures and what they might (or might not) learn from genetic testing or the newer science of brain biomarkers. If one were able to predict, with a high degree of accuracy, whether AD is likely to develop, would that change people's behavior and particularly their thinking about advance directives and end-of-life decisions? Would there be more thoughtful planning and discussion? Or would people choose early death rather than face what they may see as an unacceptable life?

The search for brain biomarkers is driven by the desire to find early signs of disease that can be treated and forestall or eliminate the risks of future disease. "Stopping the disease before it starts," the title of an article by Greg Miller, is the goal (2012). So far, the research has not achieved that goal, but the implications are already being debated. Rebecca Dresser's comprehensive article on this work describes the alternatives as: pre-emptive suicide, advance treatment refusals, advance refusals of food and water, and advance requests for physician-assisted death (2015). Palliative care is another option that would avoid these difficult choices.

Whether advance directives that specify that the person would not want medical treatment or food and water if they have dementia of any kind should be deemed ethical and lawful is a debate that will continue with passionate advocates on both sides.

For the Future

These stories were written before the onset of the COVID-19 pandemic and the discussions about who should receive lifesaving treatment when resources are scarce. Should old age be a criterion for having a low priority? What about mental deficits, whether in adults or people with dementia? Should advance directives include statements about declining treatment so that another, younger, more mentally fit person can benefit?

In another time, these would be just exercises in bioethics classes. Now they are real questions, even in a country as rich as the United States. Our future as individuals and as members of society depends on the answers.

References

Brody, E. M. (1990). Role reversal: An inaccurate and destructive concept. *Journal of Gerontological Social Work, 15*(1–2), 15–22. doi:10.1300/J083v15n01_04

Cantor, N. L. (2018). On avoiding deep dementia. *Hastings Center Report, 48*(4), 15–24. doi:10.1002/hast.865

Dresser, R. (2015). A fate worse than death?: How biomarkers for Alzheimer's disease could affect end-of-life choices. *Indiana Health Law Review, 12*, 651. doi:10.18060/3911.0004

Dresser, R. (2018). Advance directives and discrimination against people with dementia. *Hastings Center Report, 48*(4), 26–27. doi:10.1002/hast.867

Humphrey, D. (2002). *Final exit: The practicalities of self-deliverance and suicide for the dying* (3rd ed.): Delta Publishing.

Kleinman, A. (2020). *The soul of care: The moral education of a husband and a doctor*. New York, NY: Viking Press.

Miller, G. (2012). Alzheimer's research. Stopping Alzheimer's before it starts. *Science, 337*(6096), 790–792. doi:10.1126/science.337.6096.790

National Alliance for Caregiving & AARP. (2020). Caregiving in the United States 2020 Retrieved from https://www.caregiving.org/wp-content/uploads/2020/05/Full-Report-Caregiving-in-the-United-States-2020.pdf

Powell, T. (2019). *Dementia reimagined: Building a life of joy and dignity from beginning to end*. New York, NY: Avery.

Seltzer, M. M. (1990). Role reversal: You don't go home again. *Journal of Gerontological Social Work, 15*(1–2), 5–14.

Commentary
Caring When Curing is Not an Option

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Abstract. These narratives provide intimate descriptions of the challenges, frustrations, and sometimes, the satisfaction of caring for a family member with dementia. They are presented by twelve individuals who want us to understand and possibly learn from their lived experiences. At the beginning of their journey, most describe a slow awareness that "something is seriously wrong." During the middle stage, their narratives are filled with examples of conflict and frustration as the authors try to respond with patience to behavior that "makes no sense." Finally, most learn to forgive themselves and accept 'the new normal' of this person, or their death. For some, the end of their journey is filled with regret and guilt, while others find acceptance and peace. We are privileged to be immersed in these stories, as such honest descriptions are rarely shared with 'outsiders.'

Keywords. Dementia, Alzheimer Disease, Guilt, Empathy, Forgiveness, Narratives, Bioethics, Aging

Introduction

Before proceeding with this commentary, I want to acknowledge the lens through which I 'saw' and heard these stories. I am a nurse, and for almost two decades, I have provided end of life counseling for persons seeking information about end of life options and choices. For the last several years, my work has focused on providing information and support to persons diagnosed with an early stage of dementia. Along with their family members, these individuals want to know how to take steps while still retaining the decisional capacity to potentially control the timing of their death in the future. They do so by completing a written advance directive that specifies which life-prolonging measures to limit in the future when their dementia becomes advanced (Schwarz, 2019). These experiences have undoubtedly influenced my response to these narratives.

I found it noteworthy that only one caregiver was appointed as a health care agent (Libby); one other became her mother's guardian (Janice), primarily to protect her financial assets. People with dementia often live for 8 to 10 years after diagnosis, and some live much longer. The disease is incurable, progressive, and without effective treatment. During the early stage of dementia (4 to 5 years), persons retain decision-making capacity and are cognitively able to complete an advance directive. Reports indicate a range of 36% to 60% of nursing home residents with dementia have completed an advance directive—the percentage increases with the severity of the disease (Tija, Dharmawardene, & Givens, 2018).

Thus my professional experience of persons with dementia (PWD) who choose to complete a directive to limit future treatments is quite different from the completion rate of the individuals at the center of these stories.

In addition to frequently occurring examples of emotional conflicts, several themes occurred in many of these narratives. The first theme involves conflicts around caring—having to make decisions and choosing how to care for the person with dementia. Many of these decisions were initially made with little guidance or information from health care professionals. The second theme encompasses the work of acceptance and mourning: learning to 'cope' with the new person while mourning what has been lost. Finally, expressions of regret, acceptance, and 'lessons learned' are present in most of these stories.

The Authors

Half of the stories are told by daughters who care for their mothers. Two male authors describe caring for fathers, and a brother and sister share caregiving responsibilities for their father. The remaining three narratives are written by spouses; two husbands describe caring for their wives, and one ex-wife became the exclusive caregiver for her former husband. This is consistent with national data that documents the 16.1 million family caregivers who provide 18.4 billion hours of unpaid care for PWD (Alzheimer's Association, 2020). Two-thirds of all family caregivers are women; most care-givers are elderly and experience significant emotional, physical, and financial burdens as a consequence of their caregiving (Alzheimer's Association, 2020). Most family members want to keep their loved ones at home, but eventually, most are transferred to an institutional setting once their care needs escalate beyond what can safely be provided in their homes.

Six stories were written after their family member died. I wondered how the passage of time might have affected what was forgotten—whether intentionally or lost with the passage of time. I also wondered about the process of deciding what to include or omit in these narratives. Writing after her mother's death, Noël notes a familiar song, "What's too painful to remember, I simply choose to forget."

In the Beginning of the Journey

Many of these narratives begin with a description of 'first signs' and the slow realization the behavior being observed is not 'normal aging.' Yet Libby begins her story with a powerful memory from several decades before her mother becomes ill and said, "Lib, if I ever lose my mind, just get a gun and shoot me!" That memory will haunt her.

Sara begins her narrative by recounting her 'prediagnosis' concerns. At first, she and her brothers are able to dismiss their mother's early symptoms and find ways to 'rationalize' it. Eventually, Sara realizes her mother can no longer safely manage alone. When she tries to discuss it, her mother firmly dismisses her worries and denies there is anything wrong, claiming "it's just old age," and all her friends are like this. Denial and 'workaround solutions' are a common response by those in the early stages of dementia, and several authors note a similar response by their family members.

Janice describes seeking advice from a cousin who was a nurse because, "Mom's acting weird," and her cousin responded by asking whether she had been tested for dementia. The neurologist who examined her mother provided no useful information aside from "one brief conversation about the diagnosis and a pamphlet of resources." Because she had no understanding of the disease, she was unprepared for how quickly her mother lost the ability to remain safely at home. She wanted to believe that her mother was "still self-sufficient, independent, and hard working." It was only after her repeated and inappropriate 911 calls that Janice was told by an ER physician her mother was at risk for harm and must be admitted to an institutional setting.

The initial attempts to normalize abnormal behavior breaks down in many of these stories. What arises instead is the recognized need to step in and decide *how* to care for this family member who neither requests nor welcomes such care. Taking this action requires a significant and often uncomfortable change in roles. Daughters become mothers to their mothers, and caregivers can no longer share decision making with spouses. In many of these stories, there was an effort to respect the autonomy of the family member and their self–determination—to honor their place within the family—but only as long as the person could be kept safe from harm. Sons told of decisions to 'take Dad's guns away," and others removed car keys to prevent accidents. Janice specifically speaks about her discomfort with this 'role reversal,' where she must take over and sell her mother's house, disperse her possessions, and move her into a care facility "all without her consent."

These caregivers rarely receive ongoing advice from medical professionals. Anonymous described her frustration about the absence of medical information regarding resources or support for caregivers of people with dementia. She notes, "each caregiver must figure out how to manage all of the necessary care tasks without any centralized, reliable source of information and referrals." Absent such information, planning for the future is extremely difficult. She describes how mechanistic and unhelpful most of the clinicians are when she and her former husband Peter, go for regular assessment of his steady disease-related cognitive and physical losses. She finds it upsetting that these interactions only add to Peter's pain and provide him little benefit.

Conflicts in Caring: Duty Versus Rights to Care

Generally, in bioethics, there is a reciprocal relationship between rights and duties. If a person has a right to receive something, like information to facilitate informed decision making, then someone else has a duty to provide that information. Sunnie's powerful story, which is unique among the narratives, shines a spotlight on the tension that can occur between duties and rights. Sunnie and family share a painful history of providing a decade of care for "a volatile, abusive father with early-onset Alzheimer and Parkinson's disease." Sunnie and Sunnie's sibling and mother all lived through years of trauma. Nonetheless, they are expected to provide loving care for the man who abused and humiliated them—because he is still 'family.' Whatever the cost to them, they are encouraged by others to realize their 'duty' to care.

By contrast, Mary grounds her story of caring for her elderly mother in the cultural roots of India and the expectations that guide their behavior. Diagnosed with dementia just a year ago, her mother "reverted to her days as a high-ranking government official's wife in India, with an army of servants at her disposal" Currently, the only available servant is Mary. Although she has two brothers, it 'is expected' that daughters provide the care for an ailing parent. When she occasionally complains about the burden of being the sole family caregiver, her mother responds, "It's what Indian girls do. It's expected. And I'm your mother. I looked after you." Her mother expresses a 'right' to receive the care that Mary has a 'duty' to provide, whatever the personal costs to her.

Even though her mother was diagnosed with an 'early' stage of dementia, her mother's physician told Sheri she 'had to' move in to provide her care. Because of their contentious early history, Sheri learned they got along best when physically apart. While she "willingly" moved back in with her mother to 'fulfill her caregiving duties,' their old patterns initially persisted. They squabbled for 18 months until her mother, at age 84, was found to have breast cancer. Then everything changed as Sheri became the 'decision maker,' and chose a treatment plan with a goal that her mother would "live life after cancer." I wondered how the cancer was found, and whether, at age 84, she was still receiving 'routine' mammograms.

In the Middle: Learning to Cope and Mourning the Loss

Although Sara said, "I can't make her do anything she doesn't want to," she learns to cope with her mother's new persona by applying what worked with her own kids as two-year-olds, "re-direct, distract, and bribe." While managing her mother's resistance, she mourns the loss of who her mother was. "My mother was a bright light. She was funny, smart, and brave. She raised four kids as a single mother . . ." She describes the day she had to 'trick' her mother in order to move her into the long-term care facility as "the worse day of my life." Bernie similarly laments now having to lie to his wife in order to leave after visiting her in the assisted living facility. He also feels uncomfortable describing his wife's dementia symptoms. He describes it as disrespectful of their previous long married life together when she always supported him.

The emotional conflict of having to 'bribe' or trick your beloved into behavior that *you* know is in her best interests is an example of moral distress. Moral distress is understood as a phenomenon in which one knows the 'ethically correct' thing to do but is unable or powerless to do it (Epstein & Delgado, 2010). It feels disrespectful and unethical to tell lies or trick adults in order to make them behave in a way we want them to—and yet, there may be no good alternative. There is an emotional cost to experiencing moral distress.

Sara describes the upsetting changes in her mother's personality. She becomes "another person" who is mean and physically combative. "It was a side of her I had never seen." While Sara knows none of this is her mother's fault, she acknowledges snapping at her when overwhelmed with frustration. Her coping skills improve following advice from an experienced nurse who tells her to stop arguing! "You will never win an argument with a person with dementia." She starts attending support groups and learns about the disease, both of which help.

Initially, Janice also felt overwhelmed and resentful of all the time she had to spend managing her mother's care because of the time it took from her husband and children. She was also annoyed that her mother would not accept any of the clothes she brought to re-place her dirty and disheveled outfits. She was embarrassed and ashamed by her mother's appearance. Two things changed her perspective—one was caused by her increased understanding of dementia and its symptoms, and the other was her mother's change in personality. Unlike Sara's mother, Janice's mother became loving and able to express gratitude for the care and attention she received from her daughter. While she wishes this 'transformation' had occurred earlier, Janice has learned to live in the present and enjoy the experience of her mother's love.

Libby tells an incredibly brave narrative filled with suffering. Several months after her mother was diagnosed with dementia, her complaints of 'stomach pain' led to the discovery of a tumor in her colon. Her cognitive deterioration dramatically increased following the surgery to remove the cancer, which had already spread to other parts of her body. Her longtime partner, Ed, was particularly devastated. They were told her condition was terminal.

It is not clear from the narrative whether the physician provided them with information about the clinical implications of a 'terminal' prognosis, specifically that death would likely occur within six months. Apparently, the surgeon did not suggest or make a referral for home hospice care for his patient, which sadly is not uncommon across America. Hospice support would have provided assistance to Ed in caring for his beloved partner and assure him and Libby that she would receive good pain management. Libby wrote that, "the cancer and dementia progressed in tandem, and she quietly sobbed through the waking hours of many days."

Ed was her caregiver on a 24/7 basis and while often over-whelmed, he was desperate to keep her home with him. Libby lived a seven-hour drive from her mother's home; they both lived in small towns with few medical resources. The next medical crisis was caused by a decayed tooth and fears about sepsis. Ed found a local dentist who provided an emergency dental extraction that was performed without anesthesia. It was a deeply traumatizing experience for all. She wrote that while she and Ed understood logically that the tooth had to be extracted, "At a gut level, it certainly didn't feel like we'd served her best interests. That episode subsequently and profoundly influenced my decision-making at the time of her death."

It is the responsibility of the health care agent to make treatment decisions as the patient would have wanted under these or similar circumstances. If the agent is not familiar with the patient's wishes or values, the decision would be made on a 'best interests' standard. This standard is based on weighing the expected benefits and burdens of the intervention and of alternative treatments, and the possibility of no treatment other than symptom management. Libby, with great honesty, acknowledges, "Whether it was avoidance on my part or simply the path of least resistance, I acquiesced to his (Ed's) wishes." Such awareness is often much clearer in hindsight. When one is in the midst of reacting to an ongoing series of calamities, it is almost impossible to step back and reflect about how best to prepare for and manage what might come next, particularly in the absence of any prior discussion about end of life wishes.

The Physical and Emotional Costs of Caring

Several authors described the stress-related physical and emotional toll that comes from caring for a family member with dementia. Walt resisted moving his wife into an assisted living facility until his own health began to suffer due to the escalation of her symptoms. Anonymous had several preexisting medical conditions including impaired hearing, and was the sole caregiver for her former husband whose symptoms of dementia were fast progressing. She recognized the association between the stress-related visits to future nursing home sites for Peter and her own escalating physical symptoms. She agreed to an injection to treat her increasing episodes of vertigo recognizing that doing so might cause further hearing loss. She wears a MedicAlert necklace around her neck—for his sake. It identifies her as the hearing-impaired caregiver for someone with Lewy Body Dementia. She wrote, "Somebody around here has to be able to drive. And if I get into an accident, somebody will need to know that a man with LBD requires care."

The Ending: Fears, Hopes and Lessons Learned

Rina said that if she could no longer care for her mother, her greatest fear would be the need to move her into an assisted living facility. In her Indian culture, that would be shameful—but she knows it would become necessary because neither her brothers nor her children could manage her care. She also worries about her own future and the possibility of developing dementia. "I tell my children that if I do, they're to walk me to the lake in our neighborhood and simply push me in. They think I'm joking." When she thinks about what she wants others to learn, she says, "I'd tell them how important it is to be kind to, and take care of, themselves, to accept support when it's offered and to ask for it when it's not . . ."

Sheri, who also cares for her mother in her home, has learned to focus on what her mother still can do, rather than on the literature's description of the further losses to come. She makes choices that they both can enjoy—focusing on what her mother (and she) want to do. In so doing, positive memories are created. She provides information and support for other new caregivers.

Anonymous knows the increasing deterioration that lies ahead for Peter and is trying to do all she can to ease the ending of his life. However, she has different end of life plans for herself. Based on what she has lived through with Peter, she states: "I won't prolong my own [life]. My advance directive is on file, but that is not enough. I need to finish my own end of life plan: get the "No Code" tattoo, set aside money for a ticket to Amsterdam, and, just in case, order a copy of Final Exit. So perhaps she intends to hasten her own death.

Sunnie remembers the disconnect between expectations held by the hospice caregivers caring for Sunnie's father and those of Sunnie's family. Reflecting on their caregiving experience after the death of their father Sunnie writes, "What my family and I experienced was a type of burnout that lasted years beyond the period of caregiving—guilt and shame that stemmed from the societal pressure to perform artificially loving "roles" to be perceived as caring enough for a patient who once inflicted trauma upon us . . ."

Sunnie wants readers to understand the frustration of *not* being heard. Sunnie tried to share both aspects of the caregiving experience in a single description. "I would come to understand that these two narratives—one of domestic abuse and the other of caring for a patient with dementia—would not be tolerated in the same room." Sunnie's conclusion is equally powerful: "There is a real need to recognize that different types of traumas and illnesses can simultaneously exist from all participants in a story, and that closure is not a requirement of caregiving. When we can accept that not all stories from caregivers are caring, nor should they have to be, caregivers can finally begin to heal and speak their truth."

And finally, the conclusion of Libby's narrative: After another medical crisis forced her mother back into the hospital, Libby did assume her role as health agent and refuse more interventions. When she said "No" to the additional interventions proposed by the physicians for this dying woman, Ed and her siblings questioned her decision. When she said 'no more' and refused IV fluids, her mother lingered for four days before she died. Libby said, "even with the passage of time, I regularly revisit and challenge that certainty. I didn't shoot her, but I did let her die." These are difficult decisions to make, even *if* a thoughtful discussion precedes the choice to stop life (or death) prolonging measures.

After her mother's death, Sara said, "I wish that I had had a conversation with my mother early on about her dementia so I could gauge how much she understood and what she was feeling." That might have been a good place to start a conversation that progressed to include whether her mother wanted to be resuscitated if her heart stopped, or have antibiotics or other life-prolonging measures used as her dementia progressed. These decisions must be discussed and documented during the early years of the disease so caregivers know how to respond in the future when decision-making capacity is lost.

Final Thoughts

These wonderful narratives are a gift to those who might one day be caregivers for a PWD. The authors speak about what they learned as they journeyed along with their family members; many spoke about their continuing efforts to help others who are just learning about the challenges and potential satisfactions of providing such care. Yet there were some significant omissions in their stories. The caregivers seemed unaware of the benefit of hospice support during the advanced stages of the disease, and with one exception, there was also no discussion about the cost of long-term dementia care. Only Libby was a health care agent, and none of the authors reported discussions about future interventions the person would or would not want. Having conversations about end-of-life wishes can be difficult, but even in their absence, decisions still have to be made. And for many family members, the greatest distress comes from *not knowing* what their loved one would want when they can no longer tell us.

References

Alzheimer's Association. (2020). Facts and Figures. Retrieved from https://www.alz.org/alzheimers-dementia/facts-figures

Epstein, E. G., & Delgado, S. (2010). Understanding and Addressing Moral Distress. *OJIN: The Online Journal of Issues in Nursing, 15*(3). doi:10.3912/OJIN.Vol15No03Man01

Schwarz, J. (2019). Lessons From New York's Dementia Directive and Applications to Withholding Oral Feedings. *The American Journal of Bioethics, 19*(1), 95–97. doi:10.1080/15265161.2018.1544308

Tjia, J., Dharmawardene, M., & Givens, J. L. (2018). Advance Directives among Nursing Home Residents with Mild, Moderate, and Advanced Dementia. *J Palliat Med, 21*(1), 16–21. doi:10.1089/jpm.2016.0473

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