A Place for Dad

One Family's Experience of For-Profit Care

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I'm having a hard time manufacturing words right now.

Those were the first words Dad spoke to me over the phone when he found himself heavily sedated and physically restrained in the local Intensive Care Unit (ICU). He sounded drunk.

My father was diagnosed with probable Alzheimer's in 2007. He was 83 years old and had lived for the past 30 years or so on five hilly acres in a "quarter-million-dollar-fixer-upper" in Northern California with his second wife, my step-mother, Catherine.[1] Like many who receive the diagnosis, Dad's cognitive difficulties crept up on him. Never terribly precise, Dad's stories became even more vague and inconsistent. Then he developed "sundowning syndrome." Common among people with cognitive impairment, sundowning describes the exacerbation of symptoms in late afternoon or evening (Khachiyants et al.). Catherine noticed that Dad didn't know who she was when they sat down to dinner. He wouldn't ask her name outright but pestered her with questions: "Where are you from?" "Are you married?" By the next morning, the problem was gone.

Later, the loss of names and identities became more pervasive. Once I called the house while my brother was visiting. Dad took the phone into the bedroom and whispered, *There's some guy staying here. I can't figure out who he is. So, I go through the waste paper in his room when he's not around. I think I'll find an envelope addressed to him and figure out his name.* Dad's cognitive difficulties were more severe than I'd thought, but I marveled at his clever coping strategy.

Linda Clare examined the coping strategies of 12 older adults in the early stages of Alzheimer's. She described the tension between "developing a fighting spirit" and "coming to terms" (139). In Dad's relationship with Catherine he provided the fighting spirit. She managed the coming to terms: setting up a

1 | All names used here are pseudonyms.

strict regimen of vitamins and supplements designed to forestall the inevitable, removing the knobs from the stove controls so he couldn't burn the place up, cutting off electricity to the power tools in his workshop, hiding the keys to the car.

The tension between these two positions played out in their relationship. After my brother's stay, I went for a visit. Dad pulled me outside to their deck, overlooking a dry California meadow. He said, *You know … the funniest thing … I used to be married to a woman with exactly the same name as that one in there. But the one I was married to was younger and prettier.* I laughed, "Dad, you'd better not tell this one about the other one," and tried to persuade him that he was actually married to "that one in there."

Catherine's emails were peppered with reports of Dad's misbehavior. She brought in a live-in male caregiver, but Dad didn't like the guy. He called him *Stan the man*, swore at him, and threatened to key his car. I figured Dad was jealous. Then one day he picked up a two-by-four and chased Stan off the property. I came to dread emails with the subject line, "Your Father."

Catherine arranged a trip to Sedona, a town in Arizona they both enjoyed visiting. But the day before they were scheduled to leave, she wrote,

> Your dad begged me in tears to cancel the trip. He said he knew he was an old man and he wanted to spend all of his remaining days right here, in a place he loves, with the cats …

So the trip was cancelled.

Catherine hired a daytime caregiver, a woman named Marilyn, whom she located through Senior Network Services, a non-profit "community resource agency" that relies primarily on government funding provided under the Older Americans Act. Senior Network Services maintained a registry of home-help providers who had passed criminal background checks. Marilyn had recently lost her best friend to Alzheimer's and knew how to manage dementia.

Still, as I told my friends, "Early Alzheimer's is not that bad!" Catherine and I marveled that my Dad, who had accumulated more than his share of resentments in life, had forgotten all about them. He was gregarious and more pleasant than ever. Three years after diagnosis, Catherine was still coping fairly well. Marilyn came on weekdays to take Dad to appointments and exercise classes, and Catherine was even able to get some work done. In August of 2010 she reported,

> We just adopted two 5-month-old tiger kitties from the collection at the Farmer's Market. They're litter mates, one male and one female. I think their names will be Mickey and Mocha. Lively little critters … Ten days later, One kitty's name didn't stick. Your

Dad calls the little female "Spider," so I guess that's her name. Mickey is sometimes "Monkey," so maybe that's his name. Or Mickey the Monkey.

The last weekend in September, Catherine asked me to keep Dad busy so she could get some things done. He and I set out to plant some tired-looking bay trees that Catherine got for free from a nursery. We hauled trees and water up the hill in a wheelbarrow. I dug holes with the old post-hole digger while Dad watched and gave the same instructions he'd given 40 years before when we built a corral for our new goat. Dad set up a drip irrigation system so the trees would survive those dry autumn days.

The following week I was scheduled to teach a workshop in New Zealand. At San Francisco International Airport I checked my email to find a message from Catherine:

Your Dad: An Update
Early this morning your Dad fell after getting out of bed … I was in the other room and heard the crash. He was on the floor, breathing but unresponsive for a while, then did come around. I called the paramedics to come and lift him back into bed. He complained of a fierce headache, so I think he hit his head when he fell.
Later this morning Marilyn took him to Urgent Care to get a prescription for cough medicine (they wouldn't prescribe without seeing him again). Dr. Kim at Urgent Care said your Dad has worsening pneumonia, worsening mental state, lower oxygen level. Also, he is very unsteady on his feet, and has to be assisted to walk. This is all so unlike your Dad!

Only a few days before, Dad was hauling water up the hill and playing with his cats. Now he was being assessed for hospice care. Catherine did not plan to treat the pneumonia because Dad had signed an advance directive requesting that no heroic measures be used to save his life. "But," I said, "antibiotics are not heroic measures!" "Oh yes, they are." Catherine had shown me the directive when Dad was initially diagnosed. I even read it. But, contrary to the advice of experts (Brown), we never really discussed its implications. This set us up for a difficult conversation that culminated in Catherine saying, "Amanda, you are in denial. Your father is dying." My brother Daniel and my husband Lucas both agreed with her. So I got on the plane, fully expecting to be summoned back by my father's death. But Dad didn't die. He didn't even have pneumonia. Or, if he did, it must have been viral. No. Dad rallied, but his abilities were diminished. Catherine wrote:

Turns out your Dad's cognition took a serious hit. He can no longer find the bathroom by himself … At midnight last night he got up and was wandering around the house in his pajamas. He was carrying a pair of shorts in one hand and my watch in the other hand.

He said he needed to poop … I led him to the bathroom, and waited for him, to guide him back to bed. But somehow he must have forgotten how to use the toilet, and apparently didn't pull down his pajama bottoms. So he dropped a large loose load in his pajamas and also urinated through them into the toilet. He wasn't aware he had done any of that … I'm seriously thinking placement.

Dad's cognition improved a bit, but as winter approached Catherine developed severe colitis, which her naturopath told her was stress-related. Then she tripped over one of the cats and broke her foot. Later, she explained that with these two events she "permanently lost the ability to pursue two of my major interests: hiking and cooking."

Dad's problems with incontinence continued, and his outbursts became more frequent. As an academic gerontologist, I knew the predictors of institutional placement: cognitive difficulties (particularly when accompanied by angry outbursts), lower functional capacity (particularly incontinence), and caregiver burden (Haupt and Kurz; Luppa et al.; Rozzini et al.). I set out to find a geriatric care manager who could help us make tough decisions.

Care managers are not licensed in the United States, but a non-profit association (NGO) called the National Association of Professional Geriatric Managers (now Aging Life Care Association) provides certification and maintains an online directory of its members. That's where I found Sharon Kenway, a registered nurse and certified care manager, who held an "advanced professional" membership in the association. Sharon did a complete assessment of Dad's status and facilitated several pleasant family conference calls that led to clarification of issues, but no decisions.

Decision

Rather than place Dad in a facility permanently, Catherine decided to seek a temporary respite placement for a couple of weeks. Sharon recommended an assisted-living facility called Munio:

If you are open to talking with Rachelle at Munio, it might be a good place to look and have a conversation so you then have a good idea of some of the special care opportunities to look for in the other care homes. Munio is a leader in memory care and Rachelle is well respected and has been in her position for an extended amount of time. I told her you might be calling.

But Catherine wanted to send Dad to Marilyn's home for a while. Dad had an excellent relationship with Marilyn and it was difficult to arrange for the TB test required by licensed facilities. Sharon did not approve:

I'm not saying that you cannot choose to do this, but I caution you to look closely. Is Marilyn available 24 hours/day and prepared for any confusion at night? Do you know that the meals are prepared appropriately, I would much prefer that you consider having Marilyn go with [Dad] to a licensed board and care home or assisted living facility … there … you know that bathrooms are safe for him and that he has appropriate sleeping arrangements.

So Dad moved in with Marilyn and her husband, and Catherine cut off communication with Sharon. This was the second time Catherine and I had disagreed about Dad's care (the first being on the question of antibiotics for his pneumonia). Despite our gratitude and affection for Catherine, I found it difficult to accept that as Dad's wife and as the first person listed on his medical power of attorney, she was in charge. Perhaps sensing my disapproval, Catherine advised me of her decision after the fact:

Subject: Your Dad is Asking About You
Your Dad is staying with Marilyn for a few days while I get some projects taken care of here. She says he would like to hear from you, just to know that someone is "checking up" on him (he thinks I'm away for a few days). So, if you get a chance, Marilyn's cell number is …
Thanks.

Initially, the arrangement worked well. Dad was cheerful and focused during our daily phone calls. He got along with Marilyn's husband, and Marilyn didn't mind his getting up in the night. At least that's what she said. Catherine enjoyed having the house to herself and catching up on her sleep. Then, one night, Dad decided to walk home. This was not uncharacteristic. He often took long walks through the hills of his neighborhood. But this wasn't his neighborhood. A rescue squad located Dad a few miles from Marilyn's house and brought him back perfectly cheerful and healthy.

Dad returned home and was there for eight months before Catherine once more needed respite. During this time, Catherine wrote:

As summer wanes the flowering plants on the deck bloom less. I do more deadheading to try to prolong their blooming, and I rejoice in the occasional late burst of color. But it all feels a tiny bit desperate and ultimately futile. Caring for your dad brings a similar feeling of desperation and futility, and also a similar rejoicing in any small sign of normality, of reblooming. Then I wonder if I am just interfering with nature's course, if I am out of step with the rumbling universe.

She described her conundrum as Dad's "care partner:"

The more I do to support your Dad's happiness and health and cognition, the longer I delay his inevitable decline; and the longer I delay his inevitable decline, the worse toll it takes on my health and wellbeing. Yet, emotionally and morally I cannot, and will not, do otherwise. This is my path, and I need to find a way to follow it with grace. I feel caught between a rock and a hard place, and it has been tearing me apart.

Catherine arranged to attend a week-long retreat in a nearby community. My brother and I would stay with Dad, and Marilyn would be available to help us during the day. As time for her departure drew near, Catherine prepared a 40-page book of instructions and emailed periodic addenda:

Oh, and one other thing: the coffeemaker is history. Twice your Dad almost started a fire with the carafe, so it's too dangerous to have around. You'll have to make do with manual drip, a la barista.

Our week with Dad was uneventful. We had coffee in the morning, walked down to pick up the paper, played with the cats, puttered in the yard. Dad and Daniel talked, and I took notes. We went out for ice cream and Dad remembered Catherine's birthday – sort of: *September 27 … that's somebody's birthday.* So we bought a card. Nights were disrupted by the motion-sensitive alarm in the bedroom, which buzzed whenever dad left the bed or a cat walked by.

Several months later, when Catherine decided to go on another retreat, she asked Marilyn to stay with Dad. This retreat was not so restful, as Catherine wrote:

What happened that triggered the colitis was that the Sunday before I was to go [on retreat] your Dad experienced what seemed almost like a psychotic break. We were without electricity most of that rainy day, so our normal routine was off … He was unusually irritable at dinner, wouldn't take his supplements, and I made the mistake of arguing with him about it. Whereupon he collapsed on the table with wracking sobs, saying he was lost. The rest of the evening he varied between loud anger at me and such devastating unhappiness that at one point he collapsed in my arms and I had to lower him to the floor. So the whole time I was away I worried about him.

Catherine put Dad on the waiting lists of several assisted living facilities (they are called Residential Care Facilities for the Elderly or RCFEs in California) that met her criteria: activities to keep Dad busy, a pleasant setting that was convenient to their home, and the availability of organic food (though she eventually compromised on the food). Munio was not among them. Two weeks later, a room became available at a nearby facility, and Catherine put down her deposit. She was required to furnish the room and provide linens and blankets.

Dad would need a TB test, and Marilyn would take him over there. Catherine expected a smooth transition:

> When we visited there today your Dad seemed to have a good time chatting up the old ladies, and they gave him ice cream after lunch, so he was a happy camper. I think this transition is going to be harder on me than on him.

Context

The United States is sometimes described as having not one, but fifty different health-care systems. It might be more accurate to describe it as a "blended" health-care system, in which federal and state governments interact with the private market. Our residential care system includes very few facilities that are operated directly by the government.

This was not the case prior to 1935 (when Dad was 11 years old). Almshouses, largely populated with older adults, were funded and operated by local governments. Charitable groups, eager to ensure that their own elders never had to live in these wretched facilities, established small private facilities that were more like what we now know as group homes – small residences with 16 to 20 older adults. Although the quality of almshouses was improving, the federal government sought to encourage private facilities, and in the 1920s it prohibited payment of Old Age Assistance (OAA) to residents of public almshouses. These payments were available to residents of private homes, however; and many of these added nursing staff and call themselves "a private home with infirmary." The 1935 Social Security Act continued this tradition, and a private nursing-home industry grew up with minimal government regulation (Schell). With the 1965 advent of Medicare and Medicaid funding, the industry grew exponentially.

But there were growing concerns about the quality of care provided by these nursing homes, and in 1987, Title IV of the Omnibus Budget Reconciliation Act (OBRA) instituted sweeping reforms. In order to receive payments from Medicare or Medicaid, nursing homes were required to meet federal requirements, including:

- uniform certification standards, a revised inspection process, and expanded sanctions for noncompliance;
- regular evaluation of residents and formal care plans;
- staffing levels for nursing services, social services, rehabilitation, pharmaceutical care, dietary services, and a full-time social worker; and
- competency evaluation and a minimum of 75 hours of training for nursing aides.

In addition, the law established rights of nursing-home residents to:

- remain in the nursing home (except in cases of non-payment, dangerous behaviors, or significant changes in medical condition);
- be free from abuse, mistreatment, and neglect;
- choose a personal physician and access medical records;
- be free of unnecessary physical and chemical restraints;
- manage their own financial matters; and
- receive visitors and access a private telephone. (Wiener et al.)

The subsequent title of OBRA addressed energy regulations, and a comparison of the two led some to observe that, in the United States, nursing homes are regulated more strictly than nuclear power plants (Franklin). Later those regulations were expanded and clarified by additional legislation, which set the stage for assisted-living facilities.

The Rise of Assisted Living Facilities

In the 1990s, growing concern about the over-medicalization (and the high cost) of nursing homes led U.S. gerontologists to advocate for the expansion of community-based alternatives to establish a "continuum of care." Then along came assisted-living facilities. These alternatives to nursing homes expanded rapidly during the 1990s, particularly in the West, where they were widely touted as the "new model of long-term care" that "dazzled with its promise" (Hawes et al. 1; Wilson 18). Indeed, the California Advocates for Nursing Home Reform (CANHR) reported that "over the past twenty years, residential care/assisted living has become the fastest growing component of long-term care" (CANHR 3).

Assisted-living facilities were (at least in theory) "designed to accommodate individual residents' changing needs and preferences; designed to maximize residents' dignity, autonomy, privacy, independence, and safety; and designed to encourage family and community involvement" (Assisted Living Quality Coalition 4). They cater to "private pay" residents, who do not rely on the federal subsidies available through Medicare and Medicaid; therefore, they are not subject to federal regulations associated with those subsidies. Instead, they are defined, licensed, and regulated by the states.

In 2014 the Centers for Disease Control and Prevention (CDC) reported that there were 15,600 nursing homes in the United States, of which most (70 per cent) were owned and operated by for-profit organizations, 24 per cent by non-profits, and 6 per cent by government and other entities. At the same time, there were about 30,200 assisted-living and similar residential communities, housing one million residents. Among them, 82 per cent were for-profit, 17 per

cent non-profit, and one per cent government and other entities (CDC 2015). Whereas 16 per cent of nursing homes were located in the West, 42 per cent of residential care communities were located there; and the vast majority of both were located in major metropolitan areas. A minority of both nursing homes (15 per cent) and residential-care facilities (12 per cent) operated separate dementia-care units.

In the absence of nationally agreed upon definitions and standards for assisted-living facilities, conditions vary. California, with more assisted-living facilities (or RCFEs) than any other state, uses this definition: "a voluntarily chosen housing arrangement where residents are 60 years of age or older and where varying levels of care and supervision are provided, as agreed to at the time of admission or as determined at subsequent times of reappraisal." (U.S. Department of Health & Human Services, 1998)

In 2013 there were 7,500 licensed RCFEs in California, serving over 174,000 people. The vast majority (over 90 per cent) were owned and operated for profit, and most had six or fewer beds (CANHR). The licensing regulations for these facilities are 28 pages long; Mississippi's, by contrast, take only four pages. They specifically prohibit admission of someone with "active communicable tuberculosis" (hence the dreaded TB test). Facilities are allowed to issue 30-day eviction notices for nonpayment or failure to comply with facility policies, or if the resident has a need that was not previously identified. Further, assessment is required to address functional capacity, mental condition, and social factors. Admission of persons with dementia requires annual medical assessment, adequate supervision, enhanced physical-plant safety requirements, and an appropriate activity program.

The state also specifies training requirements for administrators and direct service staff. Those who provide direct care with Activities of Daily Living must receive at least 40 hours of documented training in their first month and 20 hours per year thereafter. Staff who help with administration of medication must complete 10 hours of initial training in smaller facilities and 24 hours in those with 16 or more residents. These staff are required to complete eight hours of annual training in subsequent years (NCAL State Regulatory Review). As a comparison, in California, nail technicians are required to complete 400 hours of training before they are licensed *(California Board of Cosmetology Licensing Requirements)*.

Moving Day

Dad moved into a small RCFE called "Casa de la Felicidad," on 11 January 2012. Tai, the owner of the facility, encouraged Catherine to tell Dad an acceptable fiction that would explain the move:

I'll tell your Dad that we have to have the house tented for termites, so we all have to vacate for a few days. Marilyn will tell him he can't stay with her because her mother is visiting. And I'll tell him that I will be taking the cats with me to stay at a friend's house. That's our story! If you talk with your Dad before he moves, please keep it in mind. This weekend we are doing some heart-wrenching "lasts," though of course he doesn't know that.

Tai also advised her to stay away for a couple of weeks, so Dad could adjust. Apparently, this is fairly common advice in "the industry." After moving day, Catherine wrote:

Amanda, it was more difficult than I anticipated. He hated the place, disliked the people, and resented having no choice in the matter, even though we said it was only for a few days "while the house is tented for termites." Seemed to me there were more high-functioning residents there, and more staff, when we visited before. I came away thinking I'd made a huge mistake … I couldn't stand for your Dad to be miserable there, and if that's what happens, we'll have to make some changes.
Now I must enter withdrawal. Your Dad anchored my life, the last few years took it over completely. Now I am adrift, with no clear idea who I am any more. Close friends have moved away, or distanced themselves in other ways. For so long I have been mainly the dispenser of pills, the provider of meals, the meeter of needs, the foil to your Dad's remaining and repetitive attempts at repartee. What now? An empty house, a sore heart, only kitties to feed, no one to hold me while I weep. I'll get through it, but please keep me in your thoughts tonight.

A few days later, things were "so far, so good." Marilyn visited Dad on weekdays and he seemed to benefit from the continuity. The manager of the facility said it was alright for me to visit, but not Catherine. Less than two weeks after Dad moved in, Catherine wrote:

Amanda, this rollercoaster is driving me crazy. Every day I get a call from Tai about your Dad's bad behavior, then later I get a call from Marilyn about what a good day he had! Tonight I got a second call from Tai, and he does want your Dad out of Casa de la Felicidad, because he frightens the staff. Tai gave me the name and number of a relocation specialist who found an appropriate place for the last resident they kicked out (the one whose room your Dad was waiting for). Her name is Betsy Sheehan, and her phone number is … Tai encouraged me to involve her to make sure we get the best fit for your Dad, which might or might not be Munio. I called her number and left a message.

Tai said Dad had removed his leather belt and threatened the staff with it. Catherine explained that:

Apparently he had fallen asleep in the living room, and they were trying to get him to get up and go to bed. They locked themselves in the kitchen and called the owner, who came and calmed your Dad down, then called me.

I imagine Dad was growling. He used to slowly take off his belt and growl at us when we were kids. But he never, ever hit us. Dad was a small, wiry man. But the aids were smaller, softer, Latina women. He could have scared them. And, given Marilyn's calming presence, it's entirely possible that he had a good day while she was there and behaved badly when she was not. My response to Catherine:

Yes, it does sound maddening. Bottom line is they want him out … I'd like to know what Betsy Sheehan's background is, and who pays her. Apart from that I guess ideas are welcome – confusion's not. We have plenty of that!
It'll work out – and I do think we'll be able to get Dad settled and reasonably happy eventually… he might outlive us all! See you Saturday.

And so it went. Tai said Dad was trying to jump over the fence and escape. Marilyn said he was just inspecting the fence and didn't try to go over it. She saw Dad as a happy camper and Tai saw him as "combative." Tai nagged Catherine daily. He wanted Dad on an anti-psychotic called Seroquel, but Catherine learned it was contra-indicated for people with dementia. She hated to see him drugged, and said, "Here we go, 'chemical restraint.'" But soon he was on Seroquel and Tai was urging increased dosages. I called the long-term care ombudsman, who told me dad had a right to 30 days' notice. Then I called Betsy Sheehan, and reported back to Catherine:

She refused to give me references or a list of facilities she uses and has no training in elder care. She's a marketing person who gets a finder's fee [The receiving facility pays her half of one month's rent, about $ 4,500.] if she places him, regardless of how long he stays there …

Against all advice, Catherine began to consider taking Dad back home. She spent an hour on the phone with Betsy and found her "very helpful." Betsy explained that Tai can "get emotional at times." Ultimately, Tai threatened to call 911, and told Catherine that would make Dad "very hard to place." Betsy suggested a facility called Crescent Lodge, which was over an hour's drive from home during those rare times when there was no traffic. I wondered whether Tai would get a kickback if she placed him there. I made an appointment with Rachelle (whom Sharon had recommended), and she agreed to go to Casa de la Felicidad and do an assessment of Dad. I called the Veterans' Administration's

Extended Care Liaison to see what help they could give (none). Within hours, I received an email from Catherine:

Subject: I'm picking up your Dad tomorrow.
Tai called tonight to say your Dad was threatening the resident in the next room. I can't take any more of this so I'm going to go get him tomorrow.

Home

So Catherine took Dad home. She engaged his night caregiver to stay with him. The next morning, she wrote:

Your Dad seemed fine when I brought him home, we had a pleasant evening. But then in the middle of the night he became violent, and threatened both me and the caregiver with anything he could find to use for a weapon. At one point he tried to strangle me. [He also threw an Adirondack chair at her and was roving through the house looking for weapons when she called the sheriff.] It was like he was in a trance. He has never offered me violence before. I had to call 911, and now he's in the ICU at Dominican Hospital for safety.

I sent a message to my brother, "All hell has officially broken loose." I spent the rest of the day on the phone. Dad was in physical restraints in the Intensive Care Unit. They had put him on Haldol and expected to move him to the Medical-Surgery Ward. I jotted phone numbers, suggestions, questions and misspelled drug names in my journal:

5:30: Esther – napped a couple of hours, switched from Seraquel to Zyprex, olanzapine … Catherine – Dad's still in restraints … Seraquil? Geodon? Treatment plan? Zyprexa? No medical issue. Unstable. Restraints. Social worker: Do not let them discharge him to you. Must refer to psych. When will he be stable? Fran 6:15: Pleasant in AM, restraints in PM. Came in as observation patient. Social Worker: Medicare may refuse to pay. Look at RCF not SNF. Family must do that. How long? 24 hours. He has to be stable. Talk with nurse @ reversibility. 2nd opinion. Delerium, temporary condition, Infection?? On Diproxin now. Dr. Wilson: Great this morning. Medicine takes the edge off but can't help with the real challenges. Needs 24 hr. care. Meds help stay calm and not wander. Will get harder and harder until something else takes him.

The journal also has a long list of facilities and a note: "Rachelle at Munio says no. He's too fit." And a quote from Betsy Sheehan, "I feel your pain." I called the hospital before getting on the flight from Salt Lake to San Jose: 10AM: He's in critical care, nurses station "waiting for bed to open" – Urinary

infection – urinalysis fine, clear, Order says to be discharged today. Dr. Christianson on duty, call Ella in 45 minutes.

An email arrived from Catherine:

Subject: Your Dad is going to Crescent Lodge.
He'll be going there in his pajamas. I think I'll take a suitcase over to the hospital in the morning, and see if the social worker can make sure it goes with him.

While I was in the air, Dad was transported to Crescent Lodge. I arrived at the facility less than an hour after he did. Dad was in a large private room with a small twin bed and a separate bathroom with sink and toilet; pale and tired, but he wasn't in pajamas. I sat down at the edge of the bed, pulled off his socks, and rubbed his feet the way he used to rub mine while I drifted off to sleep. After I left, an aide called Catherine to say Dad had fallen in the hall and they wanted to know if they should take him to the emergency room. She said, "No." The next morning, I asked the administrator to please not bother Catherine. She said they had to call someone, so I gave them my cell number. For the next few days I got a call from a different staff person every night around 10pm. Either Dad was combative and they wanted permission to sedate him or he had fallen and they wanted to know whether they should take him to the Emergency Room.

The facility referred us to a doctor who served other residents, Ivanna Yeltsin. I sent Catherine an update:

Subject: Dad
It's hard to say how dad is. In a lucid moment yesterday he was talking about suicide and worrying about the tax bill when he died. Then he wanted to ask Helen [his deceased first wife] something and was distracted by ants he saw crawling across the carpet in his room. He complained of pain in his left knee, but didn't seem to remember the scrape he got on his elbow. He tired easily, but couldn't settle. Up and down, changing chairs (which was difficult because he has a hard time sitting down). He's weaker than he was on Saturday... It's hard to say what is meds, what is the challenge of adjusting to a new setting and what is grief and anger.
He's surrounded by people he doesn't know, some of whom act bizarrely. Dad tries to make conversation but most of them don't respond ... So he retreats into silence. There's a woman who shouts "honey!" whenever she spots a staff person. There's another with scary facial twitches who tries to talk but can't be understood. There's a Vietnam veteran named Jerry who talks a lot and sometimes makes sense. It's tempting to interact with him because he seems capable, but he doesn't always respond. I think a couple of the women have potential. One was throwing a bean bag from her chair during afternoon activity.

The staff vary. Roland, the guy from the Phillipines, is my favorite. He has a nice smile, seems kind and is alert to the needs of residents. There's a lovely black woman who likes to dance, but she seems to be assigned to only one or two of the residents. She doesn't circulate. There's Rico, a big guy with a grim expression. Chris is nice. Julie took care of Dad his first night, but I never saw her again. She's Asian and has a strong accent but a good vibe. They wear gloves when they serve food or touch the residents.
I ate two meals there today – the food is high on carbs, bland, low on fiber [hence the near-universal use of stool softeners] and (I imagine) vitamins. Dad enjoyed the ice cream dessert and the first night ate four servings. I bought him some fruit salads [at a nearby grocery] which he seemed to enjoy.

In my journal, I wrote some quotes from Dad:

I'm in the middle of the jungle. It's so loud and there's no real leader.
I need to get out of here pretty soon.

The administrator asked me to keep my visits short because Dad became disruptive after I left. She told Catherine to stay away for at least two weeks to give Dad a chance to "connect to the place without too many reminders of home." (Later, Catherine put a stuffed cat and some family photos in his room, but he didn't seem to notice.) I found it wrenching to leave him there. I'd linger, waiting for him to fall asleep after lunch. Then I'd sneak out, so discombolutated that I forgot the code to unlock the exit and had to wait for a staff person to come let me out. While I stood staring at the wall, I told myself that Alzheimer's was contagious.

I didn't like Crescent Lodge. It didn't smell, but it was loud, especially when the activities director was using her microphone. The social spaces were small and crowded, and the staff were stressed out. Apart from a front lawn that residents couldn't access, there was no grass, just a concrete patio with a few container plants. Most of the residents were more demented and/or more disabled than Dad. Each day when I left Crescent Lodge, I went searching for a better option. Maple Creek had more space and less debilitated residents. It was quiet, but not better enough to merit the stress of moving. I wrote Catherine about my visit to Bayside Villa, where a friend of Marilyn's had stayed:

There I met Russ – a friend of Steve's. Steve is the owner at Crescent Lodge. I saw him there twice. The first time he explained to me that I should not hope for my dad to improve because he had Alzheimer's. The second time he walked past me as if I weren't there. There's a lot of that. I guess it's what people do when [they] have nothing in common but decrepitude. Bayside Villa was pretty awful, which made it easier to go back to Crescent Lodge and see Dad.

This is a strange industry, in part because those who work in it refer to it as "the industry." Russ and Steve both run what look to be mid-tier, old-style facilities. They face heavy competition from [newer] places like Maple Creek, which charges about the same rates. Of course, Russ and Steve have vacancies – Maple Creek doesn't. At least not now. So no wonder the old guys are nervous.

As I searched, I learned more about the industry. For instance, the base rate of $9,000 per month is not the only charge. You pay extra for continence and dementia care, for transportation, for medical equipment, for oxygen, for special dietary needs, and so on. You never know what the bill might come to in any given month, so you'd better keep a credit card handy. But Dad adjusted quickly. As I told Catherine:

On Saturday I would have said Dad did not belong at Crescent Lodge. When I saw him Wednesday I would have said he was incapable of living outside a facility of this kind. Now, he seems to be settling in – adjusting his behavior to its ambience. This is clearly easier for the staff, and probably for him, as well. He's safely warehoused and, as Bill [the owner] explained, there's not a lot to hope for.

I puzzled over the lack of a care plan. I wondered what it would take to get Dad a morning newspaper, whether he could take care of a few plants. I talked with a nurse who attributed Dad's agitation to my presence. Seems they had "another guy" who showed agitation until they reduced family visits. I explained that Dad had no family visits over the weekend, and yet last night he was more agitated than ever. I asked why Dad was taking Zyprexa, which is contra-indicated because it causes elevated risk of stroke. She said, "A lot of doctors don't like to prescribe Zyprexa," and suggested that Dr. Yeltsin might wean Dad off it. Then the driver arrived to transport Dad to Dr. Yeltsin's office. When I called to ask the doctor to begin weaning Dad off the Zyprexa, the woman who answered the phone said the doctor had just left to go to Crescent Lodge to go see Dad. I said that was unfortunate because Dad had just left Crescent Lodge to go see her. The woman came back to say Dr. Yeltsin was actually in the exam room with Dad.

When I finally got the doctor on the phone, her first question was "Why is he taking Lithium? I never prescribed Lithium!" I had no idea, but I gathered she was concerned about medication interaction with the Lorazepam. She wanted him to go on Depokote and just take Zyprexa at bed time and as needed. She said Atarane was not so good. For some reason I wrote "benzodiazapene" next to it in my journal. She asked about blood work, and I told her the hospital did check for Urinary Tract Infection (UTI) and might have looked for other things but I didn't know. She agreed to "wean him down" off Zyprexa and put him

on a mood stabilizer. She gave the name, but I couldn't understand her accent very well.

During the following two weeks, I took charge of Dad's care, so Catherine could get some rest. I spent as much time with him as I could, and when I wasn't in the facility I searched for alternatives, studied up on pharmacology, and attempted to orchestrate the various providers. Marilyn was present most weekdays, charming staff and administrators and calming Dad. Most of the staff thought we were sisters. Here are some notes from my journal:

- Me: "How are you?" Dad: "Hoping to pass inspection."
- This morning Marilyn said when she got there Dad was unresponsive. She could not wake him up. Staff said he was agitated and they gave him something. He didn't wake up at all. Liz [nurse] called doctor, said would discontinue. It's what he took at 8 AM.
- Dad: "The phone's unsatisfactory but it'll do. It calls some places, but not home. 1-2-3-4 there's quite a few people here. They're all talking. How can they find things to talk about?"
- Last night he was up when Marilyn called. He was alert, lucid.
- Julie [aide]: very good today. Last night not too bad – 12–4 slept up @ 5 picking up things from the floor
- Dad: "I'm going to bend their rules and go up to the mountains."
- Anna [Doctor's Admin Person] will call back when she finds medical records. No lab results just CBC [complete blood count].
- Dad: "I'm anxious to see Hawaii. It's so cold today. I want a ticket to Honolulu."
- Called Anna and told her about bloodwork and kidney stones. Can we have a conference call?
- Dad: "Left or right, there's no choice. People here in California are used to choice."
- Marilyn said a visiting nurse came in the other day and noticed red spots on his tummy. His left eye is red and legs are swollen. She says swelling is a side effect of the medications and wants him on a salt-free diet. Ointment is needed for dry skin and wounds, tear drops, and change laundry soap. She ordered a walker. Depakote, 30 mg and at lunch, Zyprexa 30 PRN. Took him off some because he was unresponsive. She'll be back Wednesday.
- Dad: "Just saw a cat go out the door. Cat food. Got to get some good cat food."
- Can't get Dad's shoes on because his feet are swollen.
- They took his belt away. Catherine ordered some elastic waist jeans.
- Lynne called. Walker will be delivered, but Medicare only pays 80 per cent. Gave my credit card for remaining balance, about $ 20.
- Can Dad have a private phone? What would it cost?
- Dad, looking at his reflection: "I have an animal in the mirror."

- Wednesday: Lynne called and asked me to call the doctor. Dad is unusually sleepy. My sense is she needs help and doctor is refusing. She says we'll find a quiet phone near room 19.
- Dad: "You've got to dream up things to do with boats."

I grew increasingly frustrated with Dr. Yeltsin, and one of my children suggested I post a review on Yelp. A quotation from W.E.B. DuBois came to mind, "We must complain. Yes, plain, blunt complaint, ceaseless agitation, unfailing exposure of dishonesty and wrong – this is the ancient, unerring way to liberty, and we must follow it" (621). So I gave Yeltsin 2 out of 3 stars and wrote, "I think she's OK face-to-face, but she doesn't return phone calls and doesn't do conference calls." The next day the doctor called Catherine and told her she was "depleted" by my post, and that I had made trouble for her. She would not discuss Dad's care until I took down the post. Betsy Sheehan, the relocation specialist, sent me an email that echoed the threat and accused me of being "an angry woman." "You're damned right I'm angry!" I thought, as I took down the post. My father was dependent on these people, so it was time to suck up and take it. Catherine was furious with me. Her naturopath called to tell me I was giving her unnecessary stress and I needed to be more supportive. I was immediately relieved of responsibility for Dad's care.

I quit worrying about medical records, staff qualifications, and mealtime experiences, and spent time online ordering things for Dad: a monthly fruit basket, a plastic tool kit, puzzles designed for people with dementia, a fuzzy hat, flannel shirts, warm socks. Lucas and I took to visiting Dad once a month on weekends. I'd look around the room, but could never find the gifts I had sent. We would take Dad out for seafood and beer, bring him back late – often with his pants full – and turn him over to staff with a guilty apology. Eventually, Dad forgot how to walk. He still could, but his mind wouldn't tell his legs what to do. So whenever we needed to walk somewhere I held his hands and walked backwards just as Dad did when he taught me to dance. I repeated, "One, two, cha-cha-cha. One, two cha-cha-cha" while other pedestrians veered out of our way. Occasionally, and I sometimes thought surreptitiously, Marilyn would let me know how Dad was doing. She told me, for instance, about the time he was found passed out on the floor with low blood pressure and a slow heartbeat. They sent him alone to the ER, and he didn't know why he was there.

Eventually, Crescent Lodge was sold and the quality of care deteriorated. Dad developed frequent UTIs, and enough was enough. So Catherine moved him to one of the places we had both visited (separately) and liked better, City Square. It was a larger facility, with a locked dementia wing. Dad shared a room with another man, but he seemed to enjoy that and I felt better thinking of him less alone. On Saturdays we ran into other families and exchanged grimaces, but not words. We were all in our own, opaque bubbles bouncing against each

other, but seldom connecting. The place was better, but it was still hard to leave him.

By the time my brother and I took Dad out to celebrate his 90th birthday, he was no longer walking. He had his own wheelchair. The day was sunny and still, so we went to a café on the beach. As usual, Dad had fish and chips, but this time he didn't finish his beer. He just asked to be wheeled out onto the wet sand so he could feed the gulls.

Do Chapters Have Epilogues?

American enthusiasm for the private market is not entirely unfounded, but even Adam Smith, in *Theory of Moral Sentiments*, acknowledged that some parts of life must be kept safe from market influences. Capitalism can expand the pie. But when it does so at the expense of the vulnerable, we all suffer. The practical challenge for long-term care (as for other sectors in the American economy) is to strike an effective balance, to harness the incredible power of greed and, through appropriate regulation, direct it towards the good of humanity.

In their 2013 report "Residential Care in California: Unsafe, Unregulated, & Unaccountable," the CANHR attribute the incredible expansion of RCFEs in part to the absence of regulation. They note the increased frailty of residents in these facilities, and argue (as *Frontline* did in its 2013 documentary, "Life and Death in Assisted Living") that five years ago these elders would have been placed in nursing homes. The CDC's 2014 long-term care survey partially supports this view. For instance, it reports that a higher proportion of RCFE residents were 85 and over (53 per cent) than those either in nursing homes (42 per cent) or in hospice facilities (47 per cent). But whereas half (50 per cent) of nursing-home residents had Alzheimer's, only 40 per cent of RCFE residents did so. Likewise, 91 per cent of residents in nursing homes needed assistance with locomotion or walking, compared to 47 per cent in RCFEs (CDC). Perhaps it is more accurate to say that "some" of those in assisted living would have been placed in nursing homes. But the rest might, like Dad, experience significant declines in their functional ability during their time in residence. Certainly, these are among the nation's most vulnerable.

Our family was among the more privileged of consumers. Like Robert Kane (who recounts his family's experiences in *It Shouldn't Be This Way: The Failure of Long-Term Care*), we were well educated and possessed significant financial resources. Yet we struggled to get accurate and useful information to help us make decisions, and our experiences of care were far from ideal. We encountered facilities that were understaffed, and staff who were undertrained and overworked. Despite moments of incredible kindness by some nursing aides, the quality of care we were able to purchase was inadequate. Our experiences

also underscored an observation by the CANHR that "the chemical restraint of RCFE residents knows no bounds. Unlicensed and barely trained aides give out antipsychotic drugs to residents like candy, while often little or nothing is done to respond to the underlying causes of pain, illness, despair and distress" (11).

Clearly, the situation calls for more effective regulation. Highly prescriptive regulations that limit staff initiative and divert resources from caregiving to paperwork can be counterproductive. But stringent regulations that determine the conditions of care such as staffing and funding levels, training requirements, and facility safeguards can support quality (cost-effective) care (Banerjee and Armstrong; Mukamel et al.). CANHR recommends the development of a three-tiered level of care system, with differential requirements based on residents' degree of disability. They advocate annual inspections, preferably unannounced; vigorous investigation and reporting of complaints; and penalties for violations.

Families need better information as they choose from the array of long-term care options so that they don't have to rely on marketing personnel, private "relocation specialists," word of mouth, or sporadic reviews on Yelp and Google. Long-term care ombudsmen need authorization and resources to maintain a registry of complaints and make it publicly available.

Finally, during Dad's time in residential care the Affordable Care Act passed. Tightly regulated exchanges were set up so that Americans could purchase health insurance and know exactly what they were getting. I wrote in my journal: "We need long-term care exchanges too."

Final Visit

Dad hands me a warm rose petal,
brown around the edges,
whispers
Huh. Soft. Feel that.

A withered woman asks,
Can you open the door for me?
But the aide says
No. She's not
allowed.

We'll shuffle
out
through a different
door.

We stop in the maple shade,
and he
murmurs
Trees, to me, are attractive.

Lately, I've been taking
photos of people.
I'll photo them
down
to nothing.

The almost spring
sun warms
his temple,
and he tells me

My end is –
I'm carrying it, I think.
I'll unload,
put something together,
and close up.

I don't really understand
as so often before
I just write down
what he's saying.

Works Cited

Assisted Living Quality Coalition. *Assisted Living Quality Initiative: Building a Structure that Promotes Quality*. ALQC, 1998.

Banerjee, A., and P. Armstrong. "Centring Care: Explaining Regulatory Tensions in Residential Care for Older Persons." *Studies in Political Economy*, vol. 95, 2015, pp. 7–28, reltc.appso1.yorku.ca/wp-content/uploads/2012/11/Centring-Care.pdf. Accessed on 15 Feb. 2017.

Brown, S. *Through the Valley of Shadows: Living Wills, Intensive Care, and Making Medicine Human*. Oxford University Press, 2016.

California Board of Cosmetology License Requirements. Beauty Schools Directory, 2015, www.beautyschoolsdirectory.com/faq/license_ca.php. Accessed on 28 Dec. 2016.

CANHR (California Advocates for Nursing Home Reform). *Residential Care in California: Unsafe, Unregulated & Unaccountable*. CANHR, 2013, canhr.org/reports/Residential_Care_in_California.pdf. Accessed on 28. Dec. 2016.

CDC (Centers for Disease Control and Prevention). National Center for Health Statistics, Nursing Home Care, 2015, www.cdc.gov/nchs/fastats/nursing-home-care.htm. Accessed on 28 Dec. 2016.

Clare, L. "We'll Fight It as Long as We Can: Coping with the Onset of Alzheimer's Disease." *Aging & Mental Health*, vol. 6, no. 2, 2002, pp. 139–48.

Du Bois, W.E.B. "The Niagara Movement." *The Voice of the Negro*, vol. 2, no. 9, 1905, pp. 619–22.

Franklin, D. *Nursing Homes Explained*. Algora Publishing, 2013.

Haupt, M., and A. Kurz. "Predictors of Nursing Home Placement in Patients with Alzheimer's Disease." *International Journal of Geriatric Psychiatry*, vol. 8, 1993, pp. 741–46.

Hawes, C., et al. "A National Survey of Assisted Living Facilities." *The Gerontologist*, vol. 43, no. 6, 2003, pp. 875–82.

Kane, R. *It Shouldn't Be This Way: The Failure of Long-Term Care*. Vanderbilt Press, 2005.

Khachiyants, N., et al. "Sundown Syndrome in Persons with Dementia: An Update." *Psychiatry Investigations*, vol. 8, no. 4, 2011, pp. 275–81.

"Life and Death in Assisted Living." *Frontline*, produced by C. Byker and A.C. Thompson, PBS, 2013, www.pbs.org/wgbh/frontline/film/life-and-death-in-assisted-living/. Accessed on 29 Dec. 2016.

Luppa, M., et al. "Prediction of Institutionalization in the Elderly: A Systematic Review." *Age and Ageing*, vol. 39, 2010, pp. 31–38.

Mukamel, D.B., et al. "The Effect of State Regulatory Stringency on Nursing Home Quality." *Health Services Research*, vol. 47, no. 5, 2012, pp. 1791–1813.

NCAL State Regulatory Review. California Department of Social Services, Community Care Licensing Division. NCAL, 2016, www.ahcancal.org/ncal/advocacy/regs/State%20Reg%20Review%20%20State%20Summaries/California.pdf. Accessed on 28 Dec. 2016.

Rozzini, L, et al. "Predictors of Institutionalization in Demented Patients Discharged from a Rehabilitation Unit." *Journal of the American Medical Directors Association*, vol. 7, no. 6, 2006, pp. 345–49.

Schell, E. "The Origins of Geriatric Nursing: The Chronically Ill Elderly in Almshouses and Nursing Homes, 1900–1950." *Nursing History Review*, vol. 1, 1993, pp. 203–16.

U.S. Department of Health and Human Services (1998). *State Assisted Living Policy: 1998. California*. https://aspe.hhs.gov/report/state-assisted-living-policy-1998/california. Accessed on 30 May, 2017.

Wiener, J.M., et al. *Twenty Years after the Omnibus Budget Reconciliation Act of 1987*. Henry J. Kaiser Family Foundation, 2007, kaiserfamilyfoundation.files.wordpress.com/2013/01/7717.pdf. Accessed on 28 Dec. 2016.

Wilson, K. "Historical Evolution of Assisted Living in the United States, 1979 to the Present." *The Gerontologist*, vol. 47, supp. 1, 2007, pp. 8–22.