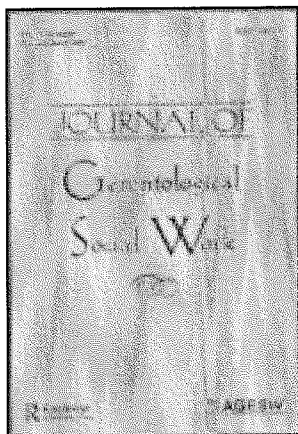


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Editorial

Long-Term Care Gets Personal

ONE FAMILY'S ENCOUNTER WITH THE INDUSTRY OF CARE

Weeks after the JGSW editorial team decided to devote issue 55(3) to long-term care my family joined the ranks of Americans living our country's long-term care nightmare.

My father, Gilbert, was diagnosed with Alzheimer's in 2007. His primary caregiver was his second wife, Carolyn. They lived on five acres in Northern California. Dad was highly skeptical of the medical industrial complex, an outlook shared by his wife. With consultation from her naturopath, Carolyn implemented a program of nutritional supplements: from 25 to 50 pills and liquids ingested on a strict schedule, five times a day, from morning to night. Carolyn arranged for daytime caregivers to come to the home Monday through Friday but was the sole caregiver most weekends. A male caregiver named Dan moved into the apartment downstairs. Never fond of the arrangement, Dad called him "Dan the man."

From time to time my brother David and I and our spouses would relieve Carolyn for a weekend or a week's respite. We enjoyed spending time with him, but Carolyn never felt we were competent to care for Dad. Consequentially, our efforts never gave her any true respite. Eventually, Dad's daytime caregiver, Mary Jo, agreed to take him home with her for one week a month. This arrangement worked well until Dad wandered off one night. The rescue squad found him miles down the hill, heading home.

As Dad's abilities eroded, Carolyn took measures to limit the damage he could do. His car "went out for service" and never came back. A lock was placed on electrical outlets in his workshop so the power tools wouldn't turn on. Burner knobs from the stove were removed and stored in a drawer. His weed-eater disappeared. I began to receive sporadic reports of misbehavior. Dad swore at Dan. He set the coffee pot on fire. He threatened to key the car of a visiting nurse. One day he picked up a two by four and chased Juan, a new daytime caregiver, off the property.

Did I mention that Dad was physically fit? A farmer for most of his life, Dad's favorite activity was puttering around the property, digging drainage

ditches and repairing things. On one respite visit he and I planted four bay trees on the property. We hauled trees and water up the hill from the house. I dug holes with the old post-hole digger, while Dad looked on and gave the same instructions he'd given 40 years ago when we built a corral for the new goat. The trees flourished.

When I told people my dad had Alzheimer's they usually said they were sorry. How sad that must be for us. "On the contrary," I assured them. "My father has always been a gentleman, and if anything the disease has improved him." For a long time this was true. Carolyn and I agreed that he seemed to have forgotten his old resentments and was more open and communicative. When he recovered from a pneumonia scare we said, "He'll probably outlive us all."

Dad enjoyed talking on the phone, so my husband Larry and I called him on the weekends, joking that with Alzheimer's you never wanted for a topic. The weather alone was good for hours. Dad loved to talk about the weather. A pattern developed. When Carolyn answered the phone we asked about the weather; "cloudy," "drizzly," "cold" came her answers. Then Dad got on, and he'd chortle, "Sunny and beautiful here in California. Where did you say you were? Salt Lake City is mighty pretty . . . but effing cold!" In retrospect the difference in their weather reports might have been a clue that caregiving was taking its toll on Carolyn's outlook. It was certainly taking a toll on her health. She developed colitis and other stress-related problems, all of which came to a head when she tripped over a cat one day and broke her foot.

Carolyn decided it was time to place Dad in an assisted living facility. David and I agreed, and soon he was on the waiting list for Casa de la Felicidad (pseudonyms for facilities and facility staff used throughout). It sounded promising. Just before Christmas I spent a few days with Carolyn and Dad. Placement seemed imminent and I was warned to stick with the story that would be used to get him out of the house: the exterminators were going to tent the place for termites and he couldn't stay there.

Our last weekend on the property, Dad and I walked out and checked on the trees. We drove to the marina to look at the boats and had a close encounter with two giant pelicans. We went into town and bought ice cream cones. We drove around to give Carolyn more time on her own. I slept on the couch, but my snoring kept Carolyn awake. "I'm sorry" just wasn't enough.

On Monday I made a stealth visit to Casa de la Felicidad. Carolyn didn't want to talk about it, so I borrowed a phonebook from a nearby convenience store, looked up the phone number, called for directions, and drove out. The setting was a beautiful agricultural valley, but the house was shabby and the staff unimpressive. The owner, Tai, was a former surfer with bleached blond hair and a hail-fellow-well-met style that just didn't ring true. In case we needed a Plan B I also visited a backup facility called Abri. Located on a

busy street, the place looked like a hotel, but the staff was professional. It might do, but would never feel like home. Moving day came quicker than I expected. Evidently a “female resident” had become “combative” so Tai had a “relocation specialist” move her out. I wondered what combative meant and what a relocation specialist had to offer.

On January 12, 2012 Mary Jo dropped Dad off at Casa de la Felicidad.

E-mails from Carolyn hinted at trouble. “Your dad hates the place . . . Dislikes the people . . . Resents having no choice. Tai says he’s put on extra staff just for your dad, but the manager said the night went smoothly.” The next day, “Mary Jo visited. The manager says your dad’s OK, but confused. He keeps asking, ‘Where’s Mary Jo?’ The dermatologist said those lesions on his face were precancerous, but they’ve all been removed.” Then, “Tai called to say he has a great sense of humor.” One day I asked Dad how he was and he said, “Ready for inspection!” Carolyn moved back into the master bedroom.

Then came the escalation. Carolyn wrote, “Things aren’t going so well. The owner called to say your dad took his belt off and threatened staff with it. Evidently, he had fallen asleep in the living room and they woke him up and tried to get him to go to bed. Staff locked themselves in the kitchen and called the owner. He talked your dad down. Then he called me, but there’s nothing I can do in the middle of the night.” Tai wanted Dad on sedatives, so his doctor prescribed Seroquel, the first of many antipsychotics we would learn to pronounce. Later Tai called Carolyn. Dad was trying to climb the fences. Carolyn started to think about bringing Dad back home. She said she’d put him in a hospital bed in the guest room and hire a night nurse. We urged her to give it some time.

But Tai wanted him out. His staff couldn’t handle Dad. The Seroquel wasn’t doing much. Carolyn called Abri, but there was no male room available. Carolyn wrote, “Are we having fun yet?” Then Dad had a good day. He said the place was “bitchen” and limited his exit-seeking to fence inspection. No climbing. Carolyn visited the relocation specialist recommended by Tai, hoping she would help find the “best fit” for Dad. I thought of the army uniform my peace-loving father wore in Korea and wondered whether that was the kind of fit they had in mind.

I volunteered to call the relocation specialist—to check her out. When I asked about training and experience, she explained that she had no credentials or training. She had what she called “anecdotal experience.” She launched into a pitch about how she spent three years “in the industry” and realized she could help families better this way. I said, “I don’t want a pitch. Do you have references?” No references. No care experience. She did marketing for a facility. She wouldn’t provide a list of the places she worked with. But hey, it’s a “free service.” If she placed Dad, the receiving facility would pay her half of their monthly fee. But she wasn’t about money. She wanted to help families.

Meanwhile, Tai escalated pressure on Carolyn to get Dad out. He threatened to call 911 if Dad became combative. I called the long-term care ombudsman, Wade. In time I would make several calls to Wade and I came to feel he was the only person we could trust. Wade explained that Dad had the right to 30 days' notice—three if Tai could prove to a judge that Dad was a threat. Of course Tai could dial 911, but we could file a licensing complaint if we felt Dad's rights were violated. Wade explained that relocation specialists are part of "the industry" in California but they have no incentive to do careful assessments because their fees are based on making placements no matter how long they last. A registered nurse I consulted advised me to "run, not walk" away from relocation specialists.

That weekend, Larry and I drove to Santa Cruz for a day with Dad and Carolyn. On a brilliant, sunny Saturday we drove to a Mexican restaurant overlooking the ocean for a long two-margarita lunch. Dad chatted eagerly then fell silent, listening to the rest of us or daydreaming. We walked down to the beach. Larry and I flew home to Salt Lake that evening and woke Sunday to find an e-mail from Carolyn. At midnight on Saturday Tai had called to say Dad was threatening another resident. "I can't take any more of this so I'm going to go get him tomorrow," Carolyn wrote.

Monday morning there was a second e-mail: "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. 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 started a journal in my purple AGE-SW notebook. It lists an array of the medications, spelled as I heard them: Haldol, Seroquel, Geodon, Dipraxin, Olanzapine, Zyprexa, "something that begins with an R." In time I quit looking the drugs up on WebMD because they all had nasty side effects and some were contraindicated for older adults with Alzheimer's. I recorded the time he spent in physical restraints and noted the names of his nurses. Several days I wrote, "Treatment plan???"

One day Dad's doctor at Dominican returned my call. He thought Abri would be good for Dad. Medications would be necessary, but they could "handle him." "Your dad's on Dipraxin now, sleeping like a baby." This doctor offered the only explanation I heard of Dad's behavior: "He's frustrated and sad at all he's lost. Medication won't change the feeling, but it will take the edge off." Dad was shifted from observation to inpatient status.

The hospital social worker said this was good news. Dad received an official diagnosis. This, too, was good news. Delirium might be reversible. Then she repeated a threat she had mentioned to Carolyn. The hospital might have to discharge Dad. Medicare might refuse to pay and his costs

were running \$3,000 per day in the ICU. I said, "That's not going to happen," thinking of strategies for delaying discharge. We could ask for a review, file a licensing complaint, pay ourselves, talk to the ombudsman—anything to avoid a rushed decision.

I wasn't thinking clearly, and I couldn't insulate Carolyn from the social worker's pressure to discharge him quickly. Someone from Abri did an assessment and declared Dad unsuitable for their facility. He was too physically fit. He might get out. The Abri marketing director quit returning my phone calls. That was a blow, but I kept looking for alternatives. Meanwhile, the relocation specialist found a placement without ever meeting Dad. He would be going to Valley House, a facility more than two hours from his home—in his pajamas. They didn't want Carolyn to visit for two weeks, so she would send a suitcase with his clothes.

I booked a flight immediately and arrived at the facility minutes after Dad. At first I didn't recognize him. The man with whom I'd had a two-margarita lunch four days ago was gone. In his place was a gaunt "male resident" of an assisted living facility. The trauma of hospitalization, along with the antipsychotic drugs pumping through his system, left him aphasic and unable to walk without support. Given the sudden onset of this decline I insisted on believing it was reversible. The staff and owner of Valley House didn't think so. "It's the disease," they said fondly, as if Alzheimer's had been invented just for them. I think "the disease" is making some people rich.

I found myself up to the elbows in the jargon and the rules of what insiders affectionately call "the industry." One of the rules is that family must be called whenever there's an injury. During Dad's first week I received several such calls, each time with the threat of a visit to the ER. I learned to keep my cell phone close, thinking Dad wouldn't survive another hospitalization. Another rule, at least in the two facilities we dealt with, was that spouses were urged not to visit during the first two weeks. Indeed, facility staff urged all family members to keep our visits infrequent and short. One day Dad was unresponsive for several hours. A staff member said he had become "agitated," so they gave him a shot. I never learned which antipsychotic was in that shot. I did learn the justification for using antipsychotic medications like Zyprexa, with a high risk of stroke. "It's worth it." There's no sense asking for whom it is "worth it."

W. E. B. Du Bois (1903) said, "We must complain. Yes, plain, blunt complaint, ceaseless agitation, unflinching exposure of dishonesty and wrong—this is the ancient, unerring way to liberty, and we must follow it" (p. 621). So I complained. When the facility's doctor refused to hold a conference call with the family I posted a review on yelp.com (a technique I learned from my daughter). I gave her 2 out of 5 stars, and said, "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 Carolyn and threatened to withhold treatment from Dad. Carolyn quoted the doctor as saying she “couldn’t continue to care for him as long as the post was up.” The relocation specialist sent me an e-mail that echoed the threat and accused me of being “an angry woman.” It was meant as an insult, but I embraced the charge even as I removed the post. Yes, I am angry, but my dad is vulnerable and alone. Later the *New York Times* published an editorial, “The Web Is Awash in Reviews, but Not for Doctors. Here’s Why” (Lieber, 2012). I wondered whether I should write and tell them.

Colleagues, we must complain. The only social worker we encountered placed the hospital’s financial needs well above my father’s. The relocation specialist who chose my father’s placement never met him. The people who care for him now don’t have time to listen when I try to tell them who he really is. They aren’t paid to listen and they aren’t paid to care.

I’m sure my family is not alone in this quagmire, and as evidence I refer you to the book *It Shouldn’t Be This Way* (Kane & West, 2005). There is much work to be done, and I am proud that some of it is reported in the *Journal of Gerontological Social Work*.

INTRODUCTION TO THE LONG-TERM CARE ISSUE

The JGSW editorial team is proud to offer five articles in issue 55(3) that address the long-term care of older adults in the US, the UK, and Canada. First, Chengqiu Xie and colleagues (2012) at the University of Manchester draw upon results of a national survey to examine themes related to the personalization of social care in the UK. Then Jasmyne Rockwell (2012) from the University of British Columbia draws upon her qualitative study of staff in a residential care facility to identify barriers to personalization of care and notes the importance of meaningful relationships for resident well-being. Catherine J. Tompkins and her colleagues (2012) report on interviews with 29 residents of assisted living facilities, who reported their desire for greater contact with friends and family. Sara Sanders and her colleagues (2012) at the University of Iowa offer practical suggestions to help social workers in long-term care address the psychosocial challenges posed by urinary incontinence. The final article in this issue, by Jack C. Wall and Marcia K. Spira (2012), describes therapeutic approaches that can be used to help families make difficult decisions about the care of older adults. The issue closes with Kelly Mills-Dick’s (2012) thoughtful review of *Living Your Best with Early Stage Alzheimer’s: An Essential Guide*, by Lisa Snyder.

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Editor, JGSW

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