

Navigating the Local Eldercare System: A First Person Account

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BY ANN COCHRAN



Author Ann Cochran knew she had to find help for her elderly father, Gene Peters. Photo by April Witt.

I FIRST STARTED TO realize that my dad's mind was in decline when he began having trouble with the concept of time. He was 88 years old and residing close to our home in Cabin John, at Victory Terrace, a lovely Potomac apartment building for seniors living independently. I'd ask him to come over at noon, and he'd come at 11, or 10. Since he was always early, I thought he was anxious about missing something.

His cognitive unraveling happened over the course of a year, starting about two years ago. When he showed up at our house at 4 a.m. one morning, he insisted that he was supposed to be there. Unfazed by our blaring security alarm, he said we asked him to come for breakfast. True, but at 9.

He hadn't driven at night for a year. Neither the empty lobby of his apartment building, nor the deserted streets on the drive over, nor our dark house alerted him that something was off. Soon after that night, Dad agreed to sell his car.

Looking back, I realize now that I resisted adding up the signs, like the discovery that he hadn't refilled his prescriptions in weeks, or seeing that he had rubbed toothpaste all over his face, or the deterioration in his cooking. My father, Gene Peters, always loved to cook. Dad was known for his Christmas beef bourguignonne as well as eggplant parmigiana. His homemade biscotti graced dessert tables at the weddings of both of my sons, and his recipe was featured in *Relish*, a Sunday newspaper magazine.

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After a half-day outing together last summer, I walked Dad into his apartment and found a pot of cooled chicken soup on his stove. Despite my many warnings about food safety, he didn't understand why this could pose a problem. Gradually, his dishes weren't what they used to be. He could no longer make even the most familiar meatloaf.

My solution was to take each problem as it came and figure out a way to resolve it. In January 2013, worried about what he was eating when he wasn't at my house or my brother's, I called Meals on Wheels. Volunteers began delivering lunch and dinner Monday through Friday. For about \$200 a month, we had peace of mind.

But even with the daily deliveries, he saved milk and food and let it go bad. I now regret my impatience in dealing with the situation. "Come on, Dad," I'd say, "can't you see this milk is expired? Here's the date." My intention was instructive encouragement: You can do it! Realistically, I'm afraid I only badgered him.

Reasoning that all he needed were better strategies, reminders and tools, I bought him new calendars, clocks, watches and a phone with oversize numbers. I also started to call him well in advance of when I planned to pick him up. I'd call again when I was leaving my house, 10 minutes away. Sometimes it worked. Other times, his concerned neighbors would notice him sitting for an hour in the lobby or outside on a bench.

In the fall of 2013, Dad had an accident at my house. I should have put him in the shower —instead, I cleaned him up while he sat on our powder room toilet. My husband, Chuck, and one of my sons were around, but this was my responsibility. I hoped Dad would continue to clean himself up while I ran to get sweatpants from Chuck's closet, but when I returned, I saw that he didn't have the dexterity or strength to do much. I held my breath and my tears and got to work.

Shortly after that, while I was putting away groceries at his apartment, I asked him to heat a frozen meal. Watching him struggle with the microwave was painful. I had put dots of red nail polish on the "start" and "2 minute" buttons, but I finally realized my strategies were futile.



Cochran's father, Gene, now resides at J' Rose Assisted Living, a group home in Aspen Hill, where he shares a room with Victor, one of the home's caregivers. Photo by April Witt.

MY RELATIONSHIP WITH MY father is complicated. My mother died suddenly of a brain aneurysm when she was 50, leaving all of us traumatized. Having worked as an accountant for RCA his whole career, my dad sought a transfer overseas after my mom died. Even from

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Israel, Dad stayed close to my brother and me, and to our children. We vacationed together in Israel, Italy and Spain. But when he remarried just after he retired, he got wrapped up in his new life and we didn't see him very much.

When Dad moved to Maryland about eight years ago, it was in part to separate from his wife and in part because my brother, my husband and I had encouraged him to be near us as he aged. Although I was doing right by him, I resented his indifference over the previous two decades, and I felt burdened by his need for financial support. He admitted that he had lost money in several real estate transactions, and soon after we started to help pay his bills, we discovered that he had let his excellent health insurance lapse. Prayer and determination eventually helped me transition from serving him out of obligation to caring for him with love.

I've heard stories from friends and neighbors about their elderly parents fighting help. That was one area where we were lucky—Dad never questioned or resisted anything we did to help him. Due to a heart problem he had years earlier, my brother, Phil, and I already had the necessary legal documents in place: a power of attorney for financial matters, a power of attorney for health care decisions and an advanced medical directive.

Attorney William Fralin, president of The Estate Planning & Elder Law Firm, P.C., which has offices in Bethesda, says having those documents helps caregivers avoid the need to petition for guardianship. "That last resort process can cost \$2,000 to \$5,000," he says. "No one wants to go there if they can avoid it."

Our first step was to find a caregiver. Fortunately, we didn't have to look far. A man who'd done similar work for a friend of ours was available. My dad knew both men well, and the instant comfort was worth \$25 an hour. We began with four hours of help three days a week. A cheerful soul, Pong took Dad shopping and on all kinds of errands, including some medical appointments, always ending with lunch at Corner Bakery Cafe or some other favorite restaurant. For additional help with medication management and meals, we increased the weekly pay of the trusted woman who had been coming to clean and do Dad's laundry ever since he moved to Potomac.

With those crucial documents in a folder and some caregiving in place, I started the search for a long-term plan. I discovered that we would have found support if we wanted Dad to remain in his apartment or move in with my brother or me. A nonprofit called The Senior Connection in Silver Spring matches seniors with volunteers who do food shopping and escort them to medical appointments free of charge. Volunteers also check on seniors by phone, make in-person visits and help pay bills. There are doctors and nurse practitioners who make house calls, and in Montgomery County there are 47 companies that offer home health care.

"The need is there and the demand is increasing," says Shaun Toomey of Capital City Nurses, the oldest home care agency in Maryland. Susan Rodgers, a registered nurse who established Capital City Nurses 40 years ago, says, "Having cared for my dad in my home, I experienced firsthand the physical and emotional needs of caring for a family member. It's not easy, no matter what your background is."

Financial planner Clark Kendall of Kendall Capital in Rockville often helps people determine the feasibility of aging in place. "If a senior stays in their home, you should factor in the cost of eventual full-time care," he says. "For 40 hours a week, that's about \$40,000 a year. Round-the-clock care at \$120,000 exceeds the cost of most assisted living and skilled nursing facilities."

For a while, my brother talked about having Dad live with him and his family in Falls Church. But because he and his wife travel often for work, it didn't make sense. I got an estimate for how much it would cost to make my lower-level bathroom handicapped-accessible, but I knew I didn't have the emotional makeup to care for my father. Guilt and shame piled onto my resentment.

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After weighing our options, Phil and I concluded that assisted living would be best for Dad and for us. Since our father had no assets left and only Social Security income, we thought he should qualify easily for Medicaid. Knowing nothing about the process, we made an appointment to tour the Methodist Home (now called Forest Hills) on Connecticut Avenue in Washington, D.C., which offers assisted living, long-term nursing care and memory care, which is the industry term for facilities for people with dementia and Alzheimer's.

The administrator was kind in the face of our ignorance. Medicaid is complex, but one thing is clear: It pays for skilled nursing facilities, but not for assisted living or help in the home.

Clearly, we needed some help navigating this process.



Cochran says she takes solace in knowing that her dad is in a good place, where the staff is cheerful and kind and he receives plenty of attention. Photo by April Witt.

The world of eldercare can feel like an Alice in Wonderland experience, and not in a fun way. I started attending a support group at my church, as well as lectures at Sibley Memorial Hospital in Northwest Washington and at local assisted living facilities. Each presented an opportunity to learn more and to ask questions as my dad's condition worsened.

One valuable lesson I learned is that I am, in fact, a caregiver. I'd thought that title (and halo) should be reserved for people caring for a family member in their home, not at a distance. I was wrong.

During a panel discussion about caregiving at my church, I heard about Debra Levy Eldercare Associates, a Silver Spring firm that helps family members navigate the complicated world of caring for older people. Owner Susy Murphy's hourly fee of \$145 was well worth it. She educated me on the basics of Medicaid and Department of Veterans Affairs (VA) benefits. Then she explained the typical cost of care in our area. Assisted living averages about \$3,400 per month. Usually, Medicaid comes into play when a person is already in a skilled nursing facility and is running low on money and assets. Although programs exist to offset the cost of home care or facilities for low-income seniors, the wheels of bureaucracies turn slowly, and nothing is clear-cut.

Murphy directed me to a regional VA office in Camp Springs in Prince George's County, where the director is known to be savvy and helpful. My dad, a World War II veteran, was eligible for a benefit called the Aid & Attendance Pension that was created to help wartime veterans and their surviving spouses pay for help with the activities of daily living. The VA estimates that it takes about a year to process an application, but the award is paid retroactively to the application date.

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Almost a year after I applied, the VA granted my dad a small amount of money, significantly less than he was qualified to receive. I made another long drive from Cabin John to Camp Springs for help in trying to correct the oversight.

A while back, a therapist friend recommended an attorney who charged \$2,000 for VA cases. That seemed exorbitant. Now, considering the time I've spent on the matter, I could kick myself for not scheduling that appointment.

Elder law attorneys, especially those accredited by the VA, have done hundreds of applications; I was doing one. "Having a file full of approvals means you've learned what is successful," says Fralin, the elder law attorney. "As the veteran's advocate, my goal is to get the application exactly right—on the first try."



Cochran visits her dad often. It's hard for him to have conversations with her, she says, but he enjoys looking at photos. Photo by April Witt.

WE DIDN'T HAVE time to wait for the VA to revise its decision, so we continued our search for a place for Dad. My brother and I and our spouses were splitting Dad's current expenses, bracing ourselves for what was coming.

In 2014, Rodgers, the founder of Capital City Nurses, opened The Cottage at Curry Manor in Bethesda. She calls it "refined residential living." Monthly fees range from \$8,500 to \$12,000; the daytime ratio is three staffers for every eight residents. I couldn't resist visiting, in case I won the lottery. I wish I could give Dad luxury like that: a gorgeous home, gourmet meals, art classes and monthly massages.

Given our budget, Murphy suggested that we look into group homes. In addition to offering the most affordable type of care, group homes provide stability and close attention in a homey setting; there are currently 160 in Montgomery County.

I knew most group homes wouldn't offer the activities of a luxury property or large facility, but Dad's interest in such things had become almost nonexistent. Murphy gave me the name of a referral agency called Loving Decisions in Bethesda. Based on Dad's condition, our budget and current availability, Loving Decisions recommended J' Rose Assisted Living in Aspen Hill, which I visited right before Christmas 2013.

I felt so good about it that I stopped there. The house was clean and cheerful, large enough, and the owner and staff exuded kindness. When we brought Dad, he told us he was ready to move in. I lamented that I hadn't taken this step sooner. When I left him there the first night, all I could feel was relief. It helped that Dad exhibited no anxiety. He was probably thinking that it was about time this happened. Although he never admitted he was struggling, he agreed he needed help from the minute I mentioned it.

Dad's \$2,500-a-month fee for a shared room is as low as it gets for assisted living in this area. The owner, Rose Jayaraman, hires kind and respectful people. Two caregivers are present at

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all times, and the house is licensed for a maximum of five residents. Dad's roommate, Victor, is one of the home's devoted caregivers, so we lucked out. The comings-and-goings of five families creates more stimulation and activity than Dad would have had in my home or my brother's. When we visit, we can be his daughter and son, not harried helpers trying to get things done.

More than a year ago, a neurologist diagnosed Dad with mild dementia and aphasia, a language disorder. He seems to know what he wants to say, but can't find the words. Conversations are difficult, but he loves looking at photos and videos and doing FaceTime sessions with his grandchildren and their children. He can't cook anymore, but he loves to eat, so our visits always involve food: We take him out when he is up to it, or we bring favorite foods in. My brother whips up breakfast some Sunday mornings, just like Dad used to do for us.

Although Dad's home does not provide dedicated memory care, geriatric professionals say group homes are a good place for seniors with dementia. "Small group homes provide constant, attentive, personalized care," says Carol Kaplun, nurse care manager at Iona Senior Services in the District. "You can't beat this level of assistance for moderate and advanced memory care."

J' Rose will likely be Dad's home until the end, unless he develops a medical problem or condition that requires nursing care, such as a feeding tube. If we have to move him to a skilled nursing facility, we will be facing expenses of \$7,000 or more per month.

The guilt I feel over not caring for my father in my own home, as my mother did for her parents, may never relax its grip entirely. But I take solace in knowing that he's in a good place. Whether my father is conscious of it now or not, I hope that on some level he feels good about putting his trust in us. I expect my husband and I will have strong opinions about where and how we grow older, and I hope our children and their spouses will be sympathetic.

Fralin calls people who have been through this heart-wrenching process "True Believers." He says most people who experience this firsthand with parents or in-laws make it a priority to get their own affairs in order.

"Preparing ourselves and our adult children for our senior years requires psychological as well as financial planning," Rodgers says. "Our generation firmly wants to be in control and not have decisions made for us."

My wise and sensible husband bought long-term care insurance for us when we were in our mid-50s. It gives us peace of mind, and it's a gift to our children. These insurance policies may seem pricey, but they can pay out more than \$1 million in benefits. Insurance broker Kim Natovitz, founder and president of The Natovitz Group in Bethesda, says a couple in their 50s should expect to pay an annual premium of \$4,000 to \$5,000; a couple in their 60s will pay \$6,000 to \$8,000 per year.

As another gift to each other and our children, Chuck and I set up a program with our banker, Chad Gerber at SunTrust, that automatically updates our investment and retirement accounts and stores insurance policies, wills, advanced medical directives and any other documents and instructions we want to include, such as my long list of computer IDs and passwords that my sons tease me about.

My dad was a loving father who always had a good job, but poor financial decisions in his older years had a major impact on him and his family. I learned a lot from him, but the final lesson is a sad one: I can't let my last act be this tough for my own children. Should something happen to my husband or me, all our kids have to do is open the Valentine's Day cards we sent them this year, in which we provided the SunTrust ID and password that will lead to all the information they'll need. This gesture may be financial and logistical, but it feels like love to me.