



# A Daughter's Story

By HOWARD GLECKMAN

**M**argaret (who asked that we not use her real name) is one of 10 million family members in the U.S. caring for a loved one with dementia. She has been the primary caregiver for her dad through years of his slow cognitive decline. And she has been doing it while juggling her roles as a wife, mother to three now-teenage boys and her job in the Catholic health care ministry.

Helping improve care for patients and residents with cognitive issues, and encouraging government to develop policies that will improve care for those with dementia, are part of the ministry's mission. But for Margaret, as it has for many others, dementia care has become part of her life.

Margaret's dad James (not his real name) is 82. A former college basketball player and retired public relations official for NASA, James lived alone for many years in an independent living facility, not far from Margaret and her family. But about a decade ago, he began showing signs of cognitive decline.

Margaret doesn't really know exactly when it began because James — like so many in the early stages of dementia — was so good at masking his symptoms. For a long time his family missed the signs. So did his doctors. "He was very good at faking it," Margaret remembers.

Her first real clue came when James started having trouble paying bills. Then, he'd forget Margaret was going to pick him up for doctor's appointments, so she'd call first, often leaving a voice mail message. After a while, he lost the ability to use his answering machine. Then, Margaret began leaving sticky notes as reminders. Soon, he could not comprehend those messages.

As his dementia progressed, James' behavior

became unpredictable — sometimes calm, sometimes aggressive. "I never knew when he was going to be happy, passive Dad; angry, agitated Dad; or crying Dad," Margaret recalls.

She tried to hire private-duty aides to help out, but, she says, "He wouldn't let them in the door."

Finally, two years ago, Margaret and her family realized her dad could no longer stay in his independent living apartment. At first, she considered moving him into her home, but realized the toll that would take on her husband and kids. So she made the painful choice to move James to a dementia-only, assisted living facility.

When I ask what she thinks of the place, Margaret pauses for a long moment: "I think their intentions are good. The concept is great." But, she says, the facility may be too quick to medicate her dad when he becomes agitated or aggressive.

Margaret visits at least once a week, and as James' advocate, she has worked hard to build relationships with the staff at all levels. Her dad can no longer describe what activities he has been doing, who has visited him or how he got a bruise on his hand. So Margaret asks.

"I ask how I can be helpful, and I sometimes ask forgiveness for him," Margaret says. But, she adds, "You pay attention to everything. You listen closely to all the things you hear from the RN, the



activities director, the CNAs, the care assistants and the housekeeping staff.”

When something goes awry, she says, “You raise it with the staff as a member of the team caring for your parent. You do it in a nice way, not in an accusatory way, and show you’re concerned about the caregivers. You acknowledge how difficult their work is, but let them know you are paying

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attention to how your parent is being cared for, even when he is difficult.”

Margaret is, in many ways, a typical caregiver for a family member with dementia. More than 8 in 10 are women. About 40 percent are adult children. Most work.

Studies show that assisting a family member with dementia can take an enormous physical toll on caregivers. According to a 2011 survey by the National Alliance for Caregiving, as their loved one’s dementia worsened, so did caregivers’ own health status. Their self-rated health scores declined significantly over 18 months. And they were twice as likely to have to visit a hospital emergency department for their own acute medical problems.<sup>1</sup>

Getting good information and guidance about how to care for someone with dementia is an enormous challenge. Although Margaret’s work made her generally aware of dementia care, she constantly is surprised at what she doesn’t know and has had to learn — often by trial and error.

She gets some help from the Alzheimer’s Association website and other online resources, and, unlike most caregivers, she can ask her colleagues in Catholic health care for advice. But unfortunately, and all too typically, her dad’s primary care doc-

tor has offered her very little guidance. He never discussed the likely progression of her father’s illness, and he never provided any suggestions for how she could care for James.

The doctor’s focus was on treating James’ high cholesterol, hypertension and heart disease, not on the kind of social care that is so important to a dementia patient and his family. And sometimes, she couldn’t even get useful information about basic medical care. For example, no one told her that her dad needed — and could have access to — a podiatrist to trim his toenails, a potentially serious problem for frail elders.

No one ever suggested she consult with a neurologist, much less one with expertise in geriatric issues. So while the physician prescribed drugs to try to slow the cognitive decline, her dad’s form of dementia never has been diagnosed.

When James was hospitalized, she was never told she could request a sitter to be with him. Because, like so many people with dementia, James was extremely agitated in a hospital environment, Margaret felt she could not leave him. For James, as for many older patients, a hospital stay can be “horrific,” Margaret says.

Sometimes, medical interventions were even counterproductive.

For example, early in her dad’s disease, his primary care physician administered a standard cognitive test: Did he know the date or the name of the president? Could he answer some simple math questions?

While James aced the math, he could not answer the other questions. The doctor carefully went over the results with James, pointing out each of his mistakes. Margaret says her dad was humiliated and embarrassed. Yet, at every visit, the doctor would administer the same test, her dad would do poorly, and feel even worse. It got so

bad that James refused to go for regular checkups.

Finally, Margaret insisted the doctor stop the test.

“It took me a while to challenge what he was doing,” she remembers, “And he was kind of offended. But once he got over the initial shock, he was very nice about it.”

Besides being a strong advocate, what can a family member do to help a relative with dementia?

One of Margaret’s touchstones is something she learned from the Avila Institute of Gerontology in Germantown, N.Y.: If someone with dementia is agitated, there is a good reason. The key is to find out what it is, and change it. Often, it may be something like not wishing to be touched, or being troubled by noise or changes in light. People with dementia may not be able to describe in words what is bothering them, but they can use non-verbal signals. The key for caregivers — both aides and family members — is to learn to read those signals and respond to them.

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What gives Margaret’s dad joy, or at least calms him when he’s having a difficult time?

Big Band music from the 1940s and 1950s. Frank Sinatra. So Margaret ordered some CDs and has asked the staff to play his favorite music, espe-



cially when he seems out of sorts.

Ice cream, especially strawberry.

The company of children.

But what is most important to James? Preserving his dignity.

Margaret notes that this is a mantra in Catholic health care, but she only realized how powerful that goal is when she began caring for her dad.

“There is nothing more important to my father than not looking like a fool,” Margaret says.

“You don’t ever demand something of him,” she says, “you ask.” For example, if she is bathing him, she’ll always be sure to ask if it is OK to put water on his head, or whether he wants soap on the washcloth.

Sometimes, this may require a bit of fibbing. For instance, when he’s reluctant to take a shower, Margaret may tell her dad that he asked her to fix the faucet, and now that she’s got it working, would he like to try it out.

If he says no, Margaret says, she respects that. Once you get to no, she says, it is time to move on. “A little bit of dirt,” she says, “isn’t going to kill him.”

It doesn’t mean you always ask. Some choices can be hopelessly confusing for someone with dementia. For instance, when Margaret decided to move James to assisted living, they did not discuss it. She took him out for the day. Other family members moved his furniture and did as much as they could to recreate his old apartment in his new facility, and Margaret brought him to the assisted living facility without ever saying a word about the move.

“A couple of times he asked, ‘Is this home?’” Margaret remembers, “‘Yes, Dad,’ I told him, ‘This is home.’”

“You feel very bad. You want to consult with him, but you can’t. It would have been too traumatic,” she says.

Margaret has learned that it is essential to draw boundaries, in part to care for herself. Caregivers often burn

out by doing too much, and with her kids and her job, Margaret realized she could not do everything for James.

For Margaret, and for many family members who care so deeply for loved ones with dementia, the price for this is

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guilt. Margaret brings it up a lot: When she can’t visit as often as she’d like, when she has to end a visit, when she tells her dad a small fib.

This seems to be a perverse rule of caregiving: The more you care, the harder you work, the more guilt you feel for not doing it all. Or for making a mistake.

Margaret will tell you that caring for a parent year after year is hard. Very hard.

Now, James struggles to complete sentences. His mobility is limited. He remembers Margaret and sometimes her husband, but no longer seems to recognize his other children or his grandchildren. But there are also small, transcendent moments: One day recently, Margaret’s 4-year-old nephew was visiting his grandfather. The family brought along a small beach ball to keep the boy entertained. Suddenly, James began bouncing the ball back and forth with the child, showing more enthusiasm and engaging in more

physical activity than he had in months.

On one level it was no surprise: Margaret says her dad becomes “magically alive” in the presence of young children. But this much activity and enthusiasm? It was, she says, “just stunning.”

When you are caring for a relative with dementia, those moments help keep you going.

What else keeps Margaret going? The support of her husband and her boys.

Unlike many families, Margaret and her husband did not shield their children from her dad’s dementia. The boys visit regularly, and, Margaret says, it hasn’t always been easy. Sometimes they’ll ask about what’s happening, but often it is hard for her to know what they are thinking. They are, after all, teenage boys. But the visits are important for them — and for Margaret.

What else helps her get through the tough days? Her colleagues at work, who have been enormously supportive. And one other thing.

“Of course, faith,” Margaret says, when I ask her what helps the most. “There is solace in knowing that God has a plan, and you pray for guidance and strength to make it through.”

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#### NOTE

1. Richard Schulz and Thomas Cook, *Caregiving Costs: Declining Health in the Alzheimer’s Caregiver as Dementia Increases in the Care Recipient* (Bethesda, Md.: National Alliance for Caregiving, 2011).

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