



Alzheimer's: Role Reversal for Adult Children

Millions of boomers are caring for parents afflicted with a disease that steals minds and memories. What life is like when your mother doesn't know you, or her own name.

By Barbara Kantrowitz and Karen Springen

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June 18, 2007 issue - A man is sitting next to her. She knows his name is Frank, but that is all she knows. She doesn't remember that when they met, she was head cheerleader and he was considered the best-looking guy in town. She doesn't remember that they've been married nearly 63 years and have raised two daughters, Michel Webb, 55, and Melinda Proza, 46. She doesn't know that her daughters and Frank, 85, try to watch her constantly because they're terrified she will wander off. She doesn't even know her own name. It is Helen Erskine. She is 81 years old and she has Alzheimer's disease—a devastating diagnosis. "Only people who have this in their family could possibly understand what we're going through," says Webb, a Dallas banker. With other diseases, she says, "there's usually a progression, a treatment, and you're hopeful for a positive end. With Alzheimer's, there is no positive end."

That is the constant sad reality of life with Alzheimer's, the most common type of dementia. It is an emotionally wrenching journey that millions of baby boomers share now that so many of their parents are living past 80, the age when the incidence of all types of dementia rises sharply. Alzheimer's currently afflicts more than 5 million Americans and 70 percent of them live at home, where they are cared for by many millions of daughters, sons and spouses. Caregivers can be younger or older, but demographic reality means that the weight of work is falling largely on those born between 1946 and 1964. As they watch their parents' inevitable decline, boomers can't help but see a disturbing glimpse of their own potential future. By 2050, the number of Americans with Alzheimer's and other dementias could soar to 16 million. The grim prospect of impending dementia has turned many caregivers into activists urgently pushing for research funds. "It's a coming crisis in health care," says Harry Johns, president and CEO of the Alzheimer's Association, whose own mother had Alzheimer's and died in April. The human cost is crushing, says Johns: "It's emotionally, physically and financially draining."

The time between diagnosis and death can be more than a decade, with each day bringing new heartache for overwhelmed families. Although Alzheimer's is always fatal, the course of the disease is unpredictable. In some cases, decline can be sudden; a mother will be able to recognize her daughter one day but not the next. Other patients stay at a relatively functional level for years before deteriorating. Mary Mittelman, who runs the Alzheimer's support program at New York University, says that living with uncertainty is a major reason that "the stress is so much worse than caring for someone with another disease." The skills a caregiver learns in the early days, when memory loss is minor, are of "very little use" in later stages, when behavior and physical problems become much more severe, says Mittelman. Coping with issues like incontinence or periods of screaming can undo even family members who vowed never to put their parent in a nursing home.

Support groups can help, but many caregivers say they don't have the time or energy to participate. They're balancing their parents' needs with the ongoing demands of work and, often, raising their own kids. Many report significant symptoms of depression as well as frequent anxiety, frustration and anger, says Stanford psychologist Dolores Gallagher-Thompson, who studies caregivers. "They tend to have recurrent negative thoughts about themselves," she says. "They don't feel they're doing a good enough job." Those emotional problems as well as the intense physical demands of caregiving can have serious health consequences. Caregivers are more likely to neglect their own medical care and show high levels of stress hormones and diminished immune response—all of which lead to an increased risk of heart disease and cancer.

Even with the very best of intentions and resources, families constantly struggle. Tim Kidwell, 56, cares for his mother, Grace, 78, who was diagnosed with Alzheimer's a year ago, and his father, John, 80, who has leukemia. His parents live in an apartment near his house in St. Louis, and caring for them has become so time-consuming that he recently quit his job as creative director at an ad agency and is freelancing. "You do what you feel is most important," he says.

The strain of nursing an ailing parent often exacerbates long-simmering family tensions. Sons or daughters

who never got along with their parents are the most likely to feel trapped by their obligations. "You're going to have a much harder time caring for somebody who never met your needs," says social worker Darby Morhardt, a professor in the Alzheimer's disease center at Northwestern University. Sibling relationships can also fray—especially when one son or daughter lives nearby and others are far away. "The sibling who lives far away doesn't appreciate the challenges, so they think Mom or Dad is doing better than the other sibling believes," says psychologist Elizabeth Edgerly, chief program officer for the Alzheimer's Association in Mountain View, Calif.

Often one son or daughter shoulders the heaviest burden, and that breeds resentment. In 2004, Pinky Holloway left her job in Chicago to move home to Atlanta. She wanted to care for her mother, Essie, now 78, who had been diagnosed with Alzheimer's a year earlier and was then living in a nursing home. Holloway, 56, doesn't regret her decision even though she says that looking after her mother is a "24-hour-a-day job." At first, it bothered her that she wasn't getting as much help as she wanted from her siblings. "After a while," she says, "I had to start thinking in terms of 'I can change myself but I can't change anyone else.' For whatever reason, they have chosen not to participate as much. I cannot change that." Coming to that realization helps, she says. "I'm thinking they'll do it when they're ready."

But in many families, that's unlikely. As the disease progresses, caretaking becomes even more difficult. The common public impression of Alzheimer's and other dementias is that they are characterized by a slow, quiet slide into permanent forgetfulness. In fact, it's rarely a gentle fade to black. Changes can be so profound that it often seems as if an alien spirit has invaded the body. Patients frequently act out—often because of frustration with their limitations. Caregivers, the people most likely to be nearby, are also the most common victims.

Financial issues can aggravate an already stressful situation. In almost every family, money disputes eventually surface. Siblings frequently disagree over how a parent's assets should be used. When a mother's or father's bank account runs low, the next generation has to kick in, and not everyone is equally willing or able.

It's not always a parent who re-quires help; some boomers find themselves looking after spouses. When Darlene Jordan's husband, Charles, 57, was diagnosed with Alzheimer's six years ago, her old life vanished. Early-onset cases like his are not as common as the dementia that appears in old age, but the Alzheimer's Association estimates that approximately 500,000 Americans under 65 fall into this category. Like the Jordans, many of these patients still have children living at home. Darlene, 49, says their daughter, Lindsey, 13, initially tried to help. But about three years ago, "she got really scared because he yelled at her, and she thought he was going to hit her." Jordan suspects that her husband was upset that his child had to dress him and get him to the shower. Now Lindsey sticks to simpler tasks, like bringing her father a snack.

Charles Jordan's behavior has continued to deteriorate, his wife says. Early on, he compulsively stuffed batteries in his pockets. Now he's becoming increasingly aggressive. A few weeks ago he charged at the female driver of the van taking him to adult day care when she got out to help him. The driver ran into the Jordans' house screaming. Charles finally agreed to get into the van but then he started hitting another patient. Darlene is so frightened that at night, she and Lindsey sleep in the same room with the door locked to keep her husband out. "I still love him," she says, but she knows that he's no longer "the person I married and had all those hopes and dreams with. Once you accept that, it makes it a little easier."

Acceptance may make the day-to-day challenges easier, but caregivers are also fighting back—through political activism. Entrepreneur John Osher, 60, decided to make Alzheimer's his crusade after his 87-year-old father, Daniel, a neurosurgeon, died of the disease in 2003. "He was like a 5-year-old," Osher says. "He had deteriorated so much." Osher began working with the Alzheimer's Association, hunting major donors. Funding research now makes economic sense, Osher says. "It's the most expensive disease" for families, he says. "It's so many years, and there's so much care involved. The fact that it's going to cost us so much down the road is one of the biggest reasons we need more funding." It's estimated that by 2030, Alzheimer's will cost Medicare \$400 billion, almost as much as the entire current Medicare budget.

To increase public awareness, the Alzheimer's Association has been recruiting celebrities who have personal experience with the disease. "Frasier" star David Hyde Pierce, 48, signed up because both his grandfather and father had Alzheimer's. When his family heard his father's diagnosis, they were haunted by the fate of his grandfather. The last time Pierce saw him, the old man's arms were strapped to the sides of his wheelchair. When Pierce's father died of pneumonia before the disease had progressed that far, the family was thankful.

"Having seen my grandfather go the full route of the disease, we knew Dad was lucky to have been spared that," Pierce says.

Other activists are targeting lawmakers. Julie Baeza, 48, of Sterling, Ill., helps her father, Otto Null, 75, care for her mother, Margaret, 69, who has Alzheimer's. She visits her mother every day, even though she works full time for the city of Sterling's economic-development corps and has two high-school-age sons, including one with autism. "It's a very, very sad disease," Baeza says. "My mom was the memory of all of us." Now she is "this very old person who just sits there." Baeza worries that she, too, may someday suffer her mother's fate. "That's part of why I decided to start contacting our legislators," she says. She's trying to get support for two bills making their way through Congress: the Alzheimer's Breakthrough Act of 2007 and the Alzheimer's Family Assistance Act of 2007. The first bill would double funding for Alzheimer's research at the National Institutes of Health to \$1.3 billion from the current \$642.7 million. The Family Assistance Act would provide tax credits for caregivers. "This legislation is so important," she says. "It's so expensive to the caregivers to keep these families at home." Home health aides can cost more than \$20 an hour, and that's on top of special equipment like wheelchairs or adjustable beds.

For activists, the ultimate goal is to uncover the cause of Alzheimer's and prevent it. A century after the disease was first described, scientists are still trying to fully understand what causes the two hallmarks of an Alzheimer's brain—gummy brown plaques between neurons and tangles that look like bundles of tiny ropes inside cells. Drugs now available to treat Alzheimer's provide only modest, temporary relief. Researchers are currently pursuing new treatments intended to prevent formation of A-beta (the main constituent of plaques) or remove it from the brain. If they work, these drugs might be able to slow the course of the disease. (Research on several of these experimental compounds will be presented this week at the Alzheimer's Association conference in Washington.) Scientists are also looking for ways to detect the disease early in order to start treatment sooner. But at the moment, the best advice for preventing dementia is to eat a heart-healthy diet and stay mentally and physically active. Unfortunately, obesity rates are soaring—an ominous sign. "The more unhealthy things we do for our heart, the higher risk we have for both heart disease and brain disease," says Dr. Samuel Gandy, director of the Farber Institute for Neurosciences at Thomas Jefferson University in Philadelphia.

For caregivers, the most effective therapy is an ancient one. "Be patient," says Mashy Modjdehi, 52, of Plano, Texas, who is caring for her 85-year-old mother. Maliheh Shirvanya, Modjdehi's mother, was diagnosed with Alzheimer's more than five years ago, when she still lived in Iran. Modjdehi, a U.S. citizen, brought her to this country to get better treatment. Her mother has a green card but can't become a citizen for two years. "I don't think she's going to make it," Modjdehi says. Shirvanya needs diapers and cannot feed herself. She takes medication to stop hallucinations and is often so anxious that she paces incessantly. Most days, she doesn't recognize her daughter. But Modjdehi isn't deterred by these obstacles. "When we were kids, they cared for us," she says. "Now it's our turn." That kind of love is not just a memory.

With Anne Underwood

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