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THE LONG GOODBYE

Alzheimer's in the Living Room: How One Family Rallies to Cope

By JANE GROSS

After his retirement as a New York City carpenter four years ago, and before he faded into the incoherent fog of Alzheimer's disease, Christopher Dillon and his two grown sons renovated a bathroom in the basement of the family's Queens home.

It would be the last multigeneration home-improvement project for the Dillons. But the tiny room with its stall shower would soon become center stage in a family's determined effort to care for a failing loved one at home.

Giving Mr. Dillon, 66, a shower is unbearable for his wife, Kitty, 63, despite her long experience working in a nursing home. She has only to lay out towels, washcloth and soap and Mr. Dillon becomes agitated, sometimes shoving her or pulling her hair, she said.

So the task falls to her strapping boys, Chris, 36, a sanitation worker, and David, 34, a police officer. The National Guard, Mrs. Dillon calls them, riding to her rescue each evening with stores of patience and good cheer that she, as the primary caregiver, feels seeping away.

"It's overwhelming, worse every day," Mrs. Dillon said recently, wincing from stomach pain and steadily losing weight. "I don't have any life. Whatever happened to the golden years? Both of us have been robbed of everything we worked for."

The Dillons' ordeal is familiar to families of the 4.5 million American men and women with Alzheimer's disease, which progressively destroys the cerebral cortex and thus the ability to think, communicate and comprehend. The number of afflicted will more than triple to 14 million by midcentury, according to health care experts and demographers. For their caregivers, life is a round-the-clock vigil, an act of stoic devotion that most families embrace as the antithesis of a nursing home.

"It's a myth that Americans dump their relative in long-term care," said Dr. Peter V. Rabins, a professor of psychiatry at Johns Hopkins University and co-author of "The 36-Hour Day," a groundbreaking guidebook first published in 1981, when Alzheimer's was not yet a household word. "When you look at the numbers, that is simply not the case."

Experts like Dr. Rabins agree that a substantial majority of Alzheimer's patients are cared for at home by family members; estimates range from two-thirds to 95 percent. This growing army of caregivers props up the nation's health care system with free labor, worth, economists and researchers say, more than \$100 billion a year, or more than twice the cost of nursing home and paid home care combined.

But these largely invisible caregivers, who buttress the nation's health care system, pay a terrible price. The architecture of the family is turned upside down, turning children into parents and parents into children. Emotional bonds and financial resources are strained, even in the most resilient households. Caregivers get sick from the stress.

A Test of Human Spirit

Alzheimer's disease is "a cataclysm" that "tests the human spirit" of caregivers like no other, wrote Sherwin B. Nuland, a physician and author of the best-selling 1994 book "How We Die," which describes without euphemism the most common causes of death.

With the baby-boom generation aging and life expectancy continuing to increase, Alzheimer's disease has become a ticking time bomb. The fastest-growing segment of the population is 85 and older. In Mr. Dillon's age group, 65 to 74, 3 percent have Alzheimer's; in the 85-and-over group, it is a staggering 47 percent, according to the National Institutes of Health.

But policy makers have ignored the inevitable, Dr. Rabins said. "As a society we're paying no attention," he said. "What you see is the coming together of a medical and social crisis that family caregivers alone cannot solve."

Each family has a different capacity for caring for an Alzheimer's patient, experts say, depending on its size, financial resources, location, competing obligations, social and religious support and approach to conflict resolution. According to criteria established by hospital groups for caregivers, the Dillons would score A-plus on all counts. Still, there are moments when the house seems to vibrate with silent tension.

Take shower time, typically among the worst for Alzheimer's families, because the patient's sense that his privacy is being invaded, and his inability to perform simple tasks, can provoke extreme reactions. Mrs. Dillon, on the rare occasion she tries to bathe her husband, pleads with him to cooperate. He can no longer follow instructions, she said, but is aware enough to be embarrassed and frustrated.

The result can be explosive. And having seen her once-gentle husband raise a fist or a stick in her direction, Mrs. Dillon was shaken last week when, the police say, another Queens man with Alzheimer's killed his elderly wife, who had been his caregiver.

Her sons have figured out not to reason or instruct. "Unless you really ruffle his feathers, he's easygoing 98 percent of the time," Chris Dillon said. But if necessary, the younger Mr. Dillon knows how to get the job done. "Not rough," he explained, "just slightly aggressive because it moves things along."

Mrs. Dillon is, by her own account, a perfectionist clinging to the last vestiges of control, so she often monitors the progress of the shower from the top of the stairs. She worries aloud that her sons might not wash Mr. Dillon thoroughly or might forget fresh underwear. They respond, "Ma, I know what I'm doing," or roll their eyes.

"I don't think they always understand the whole scenario," Mrs. Dillon said, referring to the difference between visiting and living with her husband. She catches herself sounding critical. "There's a lot of pressure on my children and they never complain," she said. "Neither of them has a lazy bone in his body."

Chris and David Dillon, like their mother, can be annoyed one minute and admiring the next. They chide her for being stubborn or saying something that provokes their father. But they realize that they get to go home at night. "What we do is the easy part," Chris Dillon said. "She's there all the time."

Hiding the House Keys

Mr. and Mrs. Dillon both retired with good union pensions and health benefits. She spent 28 years working the 3-to-11 p.m. shift at the Dry Harbor Nursing Home, near the family's three-story attached Tudor-style home in Middle Village, Queens. Thus, she said, she "saw the writing on the wall" a decade ago when her sweet-tempered husband suddenly became "snappish over the smallest thing."

Her sons noticed only garden-variety forgetfulness. Mrs. Dillon did not tell them that the keys they thought had been lost had actually been hidden by their father behind the sugar in the cupboard, common hoarding behavior. She came home from work to charred food in the oven and the smell of gas throughout the house. Finally, Mr. Dillon had a seizure, an uncommon but not unheard-of symptom, in the middle of the night. It frightened her into forgetting her sons' phone numbers. At St. John's Queens Hospital, she said, it took eight nurses and four security guards to restrain him.

Last year, Mrs. Dillon took early retirement, with a smaller pension, to stay home with her

husband. Caretakers often do this when it becomes impossible to hold two 40-hour-a-week jobs, one in the office and the other at a sickbed, according to a study in April by the Caregiver Alliance and AARP.

A definitive diagnosis of Alzheimer's was not made until a few months ago.

"But I'd seen it in the home, so I knew I wasn't dreaming," Mrs. Dillon said.

The neurologists said her husband was in the middle stage of a disease that can last 20 years.

In conversation, Mr. Dillon drifts to his boyhood home in Ireland, the village of Ardee in County Louth. There, a pretty, bold girl named Kitty picked him to dance at a ladies'-choice 40 years ago. "Some days we're there pretty much all the time," Mrs. Dillon said, her voice girlish with the memory.

Soon came the wandering so common to Alzheimer's disease. Mrs. Dillon put an internal lock on the front door but once forgot to remove the key. Off her husband went, found by teenagers in the middle of the night in a snowdrift miles from home. He now wears an identification bracelet, with Mrs. Dillon's phone number and her sons'.

The door from the basement to the back garden remains easy to open so Mr. Dillon can spend time in his vegetable garden. He plucks green tomatoes because he can no longer distinguish them from the ripe ones. The garden opens to an alley. At dusk, children greet him as they ride by on bicycles and he kneels to pet the neighborhood dogs.

One recent day, when no one was looking, Mr. Dillon wandered from the garden. The creak of the door sent his sons racing after him. He had crossed the street to visit with a 97-year-old neighbor. The household breathed a collective sigh of relief. But was it time to lock the basement door?

The progression of this disease is inevitable. But each day brings change. Caregivers must be nimble, reconsidering what is possible, what is safe.

Mr. Dillon has lately gotten "lost" on the way to the toilet and used a wastebasket instead. How-to literature for Alzheimer's caregivers suggests positioning the bed within sight of the open bathroom door, painting the wall behind the toilet a contrasting color, running a strip of Day-Glo tape from bedroom to bathroom. Instead, Mrs. Dillon, a light sleeper, shares her husband's bed, waking when he stirs and showing him the way.

Both of Mr. Dillon's sons live close by and adore their father, who used to take all the neighborhood children on camping trips in the Poconos. They visit daily, inviting Mr. Dillon for a round of pitch-and-putt or a slice of pizza. When David Dillon, the police officer, had to work

straight through the Republican National Convention, his brother picked up the slack. The reverse will happen next winter when Chris Dillon is summoned for snowstorm overtime at the Sanitation Department. Both are insistent that caring for their father is a privilege, not an imposition. "It's not a burden at all," David Dillon said. "I never look at it that way. I've always loved spending time with him and I still do."

His wife, Colette, is equally devoted. "There are fathers and then there are storybook fathers like Christy," said Ms. Dillon, an executive with a commercial real estate firm. At the house one recent day, her eyes brimmed with tears and she tenderly held her father-in-law's hand. "To be asked to do something for him . . .," she said, her voice trailing off. "He would have done it for any of us a thousand times over."

Colette Dillon is also efficient. Without children, she has time to help. She is the one who found a support group for her mother-in-law, at Sunnyside Community Services. It was canceled last month when the center lost a federal grant. She is looking for a lawyer to help Mrs. Dillon put the remaining family affairs in order.

The cancellation of the support group was a terrible blow to Mrs. Dillon. "Hearing everybody else pouring out their souls, I didn't feel so alone," she said.

The last meeting featured a financial and legal expert. Some topics were familiar. The house had already been put in trust for the sons, and Mrs. Dillon had her husband's financial and medical powers of attorney.

But there is no plan in place if Mrs. Dillon were to get sick. Neither has the family taken the steps, entirely legal, to qualify Mr. Dillon for paid home care at Medicaid expense. "I never thought that was for people like us," Colette Dillon said.

Colette Dillon's mother, Beth Prior, takes care of Mr. Dillon three afternoons a week, calming him with her familiar brogue and jolly demeanor. She fixes him a sandwich and urges him to eat: "One more bite. Keep going. Good man!" Then she gives him his midday medication - drugs to slow cognitive decline, reduce anxiety and prevent seizures - and teases that she might sneak him some Viagra. He gets the joke, and that makes Mrs. Prior's day.

Sometimes they page through *The Irish Voice*, although Mrs. Prior is not sure if Mr. Dillon can read it. Sometimes they dance to Irish music or he helps her hang the wash. Their favorite activity is walking, generally to the park, where Mr. Dillon recognizes the smell of cut grass or the sound of distant thunder, coos at babies and pets dogs and looks forward to the ice cream truck.

Mrs. Prior holds his hand now, which did not used to be necessary, and stands sentry outside the public restroom if he is inside. But when they pass friends from the old country, fellow

retirees from the carpenters' union, he remembers them by name. "We saw the Neville boys, Kitty," Mr. Dillon tells his wife when Mrs. Prior takes him home. "You remember the Neville boys."

Remembering to Laugh

David and Colette Dillon marvel that humor lingers when so much is gone. Mr. Dillon accompanied them to the mall recently, where David was buying a suit. When his son was not paying attention, Mr. Dillon donned a Kelly green jacket, the kind that Bob Hope might wear. "Shuuush!" he told his daughter-in-law, apparently eager to keep his costume a surprise. "He knew it was funny," she said. "This is a good time in the disease because we can still connect with him."

But Mrs. Dillon's good humor is fading. One day he will not know her. "Look after yourself; you can't take care of him if you don't take care of yourself." She hears this daily from well-meaning relatives and friends. But like so many other spouses in her situation, she often refuses relief.

Her eldest son took a two-week vacation after Labor Day to free his mother to go to Ireland for a family wedding. She balked. "You just have to get on the plane, Ma," Chris Dillon said. "You're not flying it."

Mrs. Dillon was awaiting the results of a sonogram for her stomach pain, she said. Also, she said, "I don't have the energy - mental, physical or emotional - for getting organized and packed."

Chris Dillon suggested a weekend in Amish Country instead. Mrs. Dillon agrees, if her husband can join them. "You need dynamite to move her," Chris said. "I might as well be talking to a wall."

Mrs. Dillon acknowledges that she is neglecting herself. "At the rate I'm going, I'll be gone before him, dead and buried," she said.

A while back, she tried adult day care for Mr. Dillon. Restless and screaming, he lasted only a day before she and her sons were called to take him home. She would like to try again, since the progression of the disease has made him less aware of his surroundings.

Mrs. Dillon is also researching respite care, small settings where someone with Alzheimer's can stay for a limited time while a caregiver rests and regroups. She suspects that one son will object, interpreting it as a slippery slope to a nursing home.

That prospect is the conversational third rail for the Dillon family. Mrs. Prior said her sister-in-

law, who also had Alzheimer's, was put in a nursing home when she still knew what was going on and quickly died. In a whisper, she added, "That time will come for Christy," but only after he is oblivious.

Colette Dillon said she reacted to vague inquiries about the future as if the family were being hurried in that direction. "Is it 10 years away? Is it 20?" she asked. "You don't know. How long does this stage last? It's hard to look past today when we know we're making him happy. As long as Christy can be here at home. . . ."

Her husband interrupted in midsentence. "This," David Dillon said, "is the best environment he can be in."

Mrs. Dillon sat very still in a straight-back living room chair, exhaustion etched in her face. It was time to head for Mass at Our Lady of Hope.

Would someone take Mr. Dillon upstairs and help him change from shorts to long pants? It would surely be a struggle, perhaps not worth the bother, she said. But he shivered so in the air-conditioned church.