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Elder-Care Costs Deplete Savings of a Generation

By JANE GROSS

To care for her ailing 97-year-old father over the past three years, Elizabeth Rodriguez, a vice president at the Federal Reserve Bank in New York, has borrowed against her 401(k) retirement plan, sold her house on Staten Island and depleted nearly 20 years of savings.

The money has gone to lawyers' fees (\$50,000) to win a contested guardianship. It has gone for home-care equipment like the mattress for his hospital bed (about \$3,000 in all) and for a food service to deliver meals (\$400 a month).

It has gone for a two-bedroom rental apartment big enough for herself, her dad and a home aide (\$1,600 a month more than a one-bedroom apartment in the same building), and for a wheelchair-accessible van to get him to doctors' appointments (\$330 a trip).

Asked to tally the costs, Ms. Rodriguez, 58, said she had no idea how much she was spending. "A shower chair, body cream with no alcohol, new shoes," she said. "You don't stop and calculate. You just buy what you have to buy."

Ms. Rodriguez is among the legion of adult children - more than 15 million, according to various calculations - who take care of their aging parents, a responsibility that often includes paying for all or part of their housing, medical supplies and incidental expenses. Many costs are out of pocket and largely unnoticed: clothing, home repair, a cellular telephone.

Adult children with the largest out-of-pocket expenses are those supervising care long distance, those who hire in-home help and those whose parents have

too much money to qualify for government-subsidized Medicaid but not enough to pay for what could be a decade of frailty and dependence.

The burden is compounded by ignorance, according to a study by AARP, released in mid-December, which found that most Americans have no idea how much long-term care costs and believe that Medicare pays for it, when it does not.

Families have always looked after their elderly loved ones. But never has old age lasted so long or been so costly, compromising the retirement of baby boomers who were expecting inheritances rather than the shock of depleted savings.

"There is a myth out there that families abandon their frail elders," said Dr. Robert L. Kane, a geriatrician at the University of Minnesota School of Public Health. "Instead, across the income spectrum, children are sacrificing to care for their parents to the limit of their means and sometimes beyond."

Researchers have documented the time spent by adult children, and others, caring for ailing relatives. But data is woefully inadequate on how much they actually spend, health economists say, because most people do not keep itemized entries as they write checks, use their credit cards or pocket money to meet the demands of the day.

"When you're in the middle of the forest, with so many things coming at you, you can't really see the trees," Ms. Rodriguez said. "But each one of those trees has actual dollars connected to it."

Costs are astronomical for long-term, low-tech care, the sort most often needed

by those who linger with Alzheimer's disease or are too frail to get around on their own. Medicare is of almost no help, since it covers only acute episodes like a heart attack, cancer or repair of a broken hip.

That means the elderly and their families are left to pay for assisted living (which averages \$35,000 a year), nursing homes (\$74,000) or home health aides. Only the very poor receive Medicaid, which pays nursing-home bills nationwide but home care in only a few states (New York among them), and nothing toward assisted-living rent.

Nor does Medicare cover equipment like grab bars for the shower and incontinence supplies, which alone can run \$2,000 a year, or travel expenses for an adult child responding to medical emergencies.

Marilyn de Leo, for instance, has made two trips from New York City to Los Angeles since September, when her mother fell in the bathroom and broke her neck and both ankles. Ms. de Leo, 62, an associate director in the development office of Mount Sinai Medical Center, spent \$800 on airfare for the first frantic trip, plus \$50 a day on taxis, since she had left her eyeglasses behind in a mad dash to the airport and therefore could not rent a car. Ms. de Leo has no savings left, and is \$5,000 in debt. When asked about her own future, she said, "I'll have to work till I drop."

Only one authoritative survey, in 2004, has even asked adult children how much they contribute to their parents' support. Half said they did, and the average monthly expenditure was \$200. Respondents who looked after their par-

ents at least 40 hours a week said they spent an average of \$324 a month.

But those figures were based on "quick, top-of-the-head estimates," said Gail Hunt, president of the National Alliance for Caregiving, which conducted the survey.

Knowing the extent of these expenses might inform public policy, some experts say, calling attention to a gap in the government safety net for the elderly.

"Should this burden fall solely on the individual and the family?" asked Judy Feder, dean of the Public Policy Institute at Georgetown University. "And can we really expect this arrangement to keep doing the job as a larger and larger population comes to grips with it?"

Congress recently passed a poorly financed bill that would help family members who need a break to pay for substitute care of an ailing loved one. But the Bush administration, to date, has preferred a private sector solution, recommending long-term insurance and reverse mortgages.

For spouses, most expenses are tax-deductible if they exceed 7.5 percent of adjusted gross income. But children cannot claim parental expenses unless they pay more than half of a parent's support, which is often not the case when the parents are on Medicaid, like Ms. Rodriguez's father, or have savings, like the Schoengood family.

The elder Schoengoods, both 86, own a home in Yonkers and a condominium in Florida and have assets enough for round-the-clock care, which can cost \$100,000 a year. Still, their son, Matthew G. Schoengood, 49, vice president of student affairs at the Graduate Center at the City University of New York, has kicked in at least \$1,000 a month since 2005, when his mother had the first of two strokes.

Mr. Schoengood flew his family nanny to Florida, for example, to look after his father. Now that his parents are permanently up north, Mr. Schoengood orders their groceries online along with his own. "As a child, it's just something you do," he said. "Mostly you don't even think about it."

His father makes a half-hearted effort to pay him back, but Mr. Schoengood always says, jokingly, "I'll put it on your tab, Dad." Typical of their generation, his parents fret about every penny. His father asks, incessantly, "Do we have enough?" Mr. Schoengood tells him not to worry.

For sure, he hopes his own children will do for him what he is doing for his parents, but he cringes at the prospect of burdening them - one reason long-term care insurance is becoming attractive.

Mr. Schoengood's out-of-pocket spending is not sensible, elder-care experts say, but the result of the awkward minuet of preserving a parent's pride.

If families behaved logically, said Steven Schurkman, an elder-care lawyer in White Plains, all expenses would be paid from the parents' money, which if depleted would entitle them to Medicaid. "What most of us do isn't sound financial planning," Mr. Schurkman said. "But it's healthy for the family dynamic."

Carol Levine, director of the Families and Health Care Project at the United Hospital Fund in Manhattan, said that paying for her mother's needs required delicacy, even subterfuge. When Ms. Levine went shopping, her mother would say, "Take \$5 out of my purse." Her daughter would return with 10 bags of groceries, and both would pretend that was all she had spent.

Both Mr. Schoengood and Ms. Rodriguez say their out-of-pocket expenses will not ruin them. Others are not so lucky.

Take Patrice B., 47, who returned to her childhood home in Jacksonville, Fla., seven years ago to move in with her mother, 84, who has Alzheimer's disease, and her father, 86, who has congestive heart failure. (They requested that the family's last name be omitted so neighbors would not know their plight.)

In their African-American culture, Ms. B. said, putting her parents in a nursing home would have been shameful. Plus, they could pay for some home care out of pensions as well as military disability checks. She, on the other hand, after years of sporadic part-time work and untallied out-of-pocket expenses, is broke.

She has catastrophic health insurance, but it will not pay for the hysterectomy she needs. She has lost her credit cards after accumulating \$20,000 in debt. "Honestly," Ms. B. said, "I've got nothing anymore. I go from very angry to very depressed."

Kate Mesmer, a single mother in Northern California who had always worked for nonprofit organizations, was living paycheck to paycheck when her mother had a stroke in 2001. Ms. Mesmer took a tenant into her house so she could

contribute to her mother's \$6,000-a-month rent at an assisted living center.

Then Ms. Mesmer lost her job and had to move her mother to a board-and-care home. A second stroke forced her mother into a nursing home, where she qualified for Medicaid. That is where she died last year, with nothing left but an \$18,000 I.R.A. The State of California is seeking that, contending the \$18,000 should have gone toward nursing-home fees.

Given what she learned in the final years of her mother's life, Ms. Mesmer said: "I have a panic attack at least once a day. It's frightening to think about our generation and what's going to happen to us."