The Magazine AARP

Click to Print

Love Is (Not) All You Need

By Mary A. Fischer, March & April 2010

To provide for loved ones who need long-term care, too many older Americans are resorting to extreme measures. It doesn't have to be this way

In 2004 Roberta H. and her husband, Alex, both 64, were living a contented life in a small town in western Massachusetts. Married for 39 years, with two grown sons, they had saved for years and were looking forward to traveling in a year or two, once they retired from their respective jobs—Alex was a college English professor, and Roberta was director of communications for a consortium of local colleges.

Then disaster struck. Alex was diagnosed with early-stage dementia and took early retirement from his job. Determined to care for her husband at home, Roberta paid a variety of people—at a cost of about $1,000 a month—to take him for walks, drive him to the YMCA, and prepare his lunch. She filled in the gaps by telephoning him several times a day.

As his dementia worsened, though, Alex needed full-time care, so Roberta found an adult-daycare center that could take care of him while she worked. For 18 months Roberta dropped off Alex in the mornings and picked him up after work, a routine that worked well until he had a medical emergency—painful urine retention—that landed him in the hospital. Medicare paid for Alex's stay, but after three days the hospital released him, even though he could barely walk. "It was such a stressful time," says Roberta, "and I had no time to figure out where Alex should go to get the therapy he needed."

"I felt terribly guilty about getting a divorce, but I felt I had no choice."

A flurry of phone calls later, she found a skilled nursing home that didn't have a waiting list, but there was a catch: Medicare would cover a total of only 100 days of skilled care and rehab. After the coverage ended, Roberta began drawing on the couple's savings, paying the nursing home $7,500 a month, plus miscellaneous expenses. Eight months and $75,000 later, the stock market crashed and cut the value of the couple's savings in half.

"I was so scared," Roberta recalls. "Not only was my husband disappearing, but our savings were, too. All I could think was, if something happened to me, there'd be nothing left and I'd be out on the street." At the urging of a financial counselor, she made an appointment with a respected elder-law attorney in the area. When he laid out her options, only one—divorce—allowed her to get care for her husband and hang on to their remaining savings. By divorcing Alex, the love of her life, he would become indigent, thus becoming eligible for Medicaid.

"I felt terribly depressed and guilty," says Roberta, "but I felt I had no choice." She received the final divorce papers on August 15, 2008, the day before the couple's 44th wedding anniversary.

Health

Love Is (Not) All You Need

By Mary A. Fischer, March & April 2010

Roberta and Alex are not alone. Like many older Americans, they find they must make gut-wrenching choices—to divorce a spouse or to file papers refusing to pay for an institutionalized spouse (a practice known as "spousal refusal")—simply to become eligible for government-subsidized long-term care.

The two existing national health insurance programs—Medicare and Medicaid—have, in part, created the conditions that have led people to take these drastic measures. Medicare, the health insurance program for those 65 and over, was designed largely to treat acute medical conditions and does not pay for more than 100 days of skilled nursing and rehab therapy.

Medicaid, the health insurance program for the poor, does pay for nursing home care but only after an individual has "spent down" his or her assets—that is, he or she has depleted all cash assets, including stocks, except for a nominal amount, usually $2,000. Spending down assets by transferring them to your children is not a viable option because Medicaid looks for gifts the patient made within the five years prior to applying for Medicaid, and then denies coverage for the number of months the gifts could have paid for nursing home care.

Transferring assets through a gift to children must be done five years before you need care—or Medicaid will delay its coverage.

The viable options can be bleak, however. If the patient is married, spending down assets to qualify for Medicaid often means that the healthy spouse is left with insufficient assets for his or her own retirement. (The "community spouse"—the spouse who doesn't need nursing home care—is entitled to keep the couple's home but just half their savings.) "Requiring people who have worked hard and saved all their lives to become impoverished before they qualify for long-term care through Medicaid is draconian, demeaning, and disempowering," says James Firman, president and CEO of the National Council on Aging, a Washington, D.C.-based nonprofit whose mission is to improve the lives of older Americans. "It is also terrible social policy and can't be sustained."

A look at the numbers reveals just how precarious the system really is. Americans who live to 65 have a 40 percent chance of entering a nursing home during their lifetime. The average stay lasts 2.5 years and costs about $175,000. In 2008, the most recent year for which numbers are available, 9 million older people required long-term care. That number is expected to reach 12 million by 2020 as the boomer population ages. Currently, only about 8 million Americans have private long-term-care insurance, leaving the government to underwrite care at an enormous cost to taxpayers.

Critics of asset transfers point to the staggering costs of Medicaid—$333.2 billion in 2007—and maintain that those who dodge their responsibility to pay for their own long-term care are gaming the system. But elder advocates say these practices go on because Medicare and Medicaid haven't done enough to support home- and community-based services. Medicaid, in particular, is overly focused on nursing home care, with far fewer resources allotted for home- and neighborhood-based care. "Powerful state nursing home lobbies make it very difficult to break the institutional bias in Medicaid," says Firman. "Medicaid spends 75 percent of its long-term funding on putting people in costly nursing homes rather than finding ways to keep people in their own homes and communities."

Donna T., 41, vividly remembers the day in 2008 when she broke the sad news to her father that his family could no longer afford to care for him in his home. Already partially disabled at 63 by a stroke, Donna's father had suffered a painful obstructed bowel, which landed him in the hospital for ten days. The rock of their family, he had worked for nearly 40 years in the shipping business and had retired early so he could stay home and take care of his diabetic wife and his mother, who suffered from dementia. But now, barely able to walk, he couldn't take care of himself, let alone them.

Donna had hoped her dad could recover at home, but the financial obstacles proved overwhelming. At 64 he was still a year away from qualifying for Medicare, and his private health insurance didn't cover long-term rehabilitative care. Neither Donna nor her siblings could afford the $400-a-day rate for skilled nursing care, and the roughly $7,000 a month for a nursing home would wipe out her parents' savings in nine months. The vexing question became: How do we care for Dad without putting Mom out on the street?

Medicaid was the only answer. Summoning up her courage, Donna informed her father that he had to spend down his half of her parents' assets in order to meet the Medicaid asset poverty level of $2,000. "I've done everything right in my life," he told his daughter, "and now I have to be poor?"

There was more bad news. For Donna's father to get the rehabilitation therapy he needed, Medicaid required that he move into a nursing home; six months later he died. "It broke my heart," says Donna. "My father died in that nursing home thinking he had nothing. He hated living there. But it was the best we could do, given the financial circumstances."

Print Email Page 1 | 2 | 3 »

Health

Love Is (Not) All You Need

By Mary A. Fischer, March & April 2010

Advocates for the elderly have long argued that Medicare and Medicaid should devote more resources to keeping people in their homes and communities as long as possible. Likewise, AARP research shows that nine out of ten Americans prefer to remain in their homes as they age. And though funding for home- and community-based services has increased (from $17 billion to $38 billion from 1999 to 2006), according to the Kaiser Commission on Medicaid and the Uninsured, those dollars are still dwarfed by the $60 billion that Medicaid spent on institutionalized care in 2006.

Some advocates see Medicaid's complicated spend-down policies (which vary from state to state) as part of the problem, and want to get Medicaid out of the long-term-care business altogether. "The disadvantage of Medicaid's funding long-term care is that it is a poverty program that has limited public access and fragmented services," says Steven P. Wallace, Ph.D., associate director of UCLA's Center for Health Policy Research. Others have proposed that Medicare provide long-term care as a benefit, in much the same way it provides the Part D drug benefit today. "If long-term care became a standard Medicare benefit," adds Wallace, "it is likely that the broad visibility of the program would engender more oversight, better coordination, and an adequate benefit package." Still others want a national long-term-care insurance program, something like the CLASS Act proposed by the late senator Edward Kennedy.

Meanwhile, back in Massachusetts, Roberta still wrestles with her agonizing decision to divorce her husband so he could qualify for Medicaid. "Married couples risk losing nearly everything when one spouse needs long-term care," explains Hyman Darling, Roberta's attorney, "and it shouldn't be that way."

Roberta has found some peace in the realization that "marriage means more than a piece of paper." Her love and devotion to Alex have not diminished; she visits him every day in the nursing home, giving him the latest news about their children and sometimes bringing flowers. Totally incapacitated now, both physically and mentally, Alex will never improve or return home. But Roberta is grateful for the time they do have, as well as the peace of mind that comes with knowing her own future is secure. "I'm grateful I still have my home and enough savings so I won't be dependent on my children," she says. "But the real question is, why should health care have to end up in the divorce courts? What kind of a system is that?"

A Practical Solution

The Community Living Assistance Services and Supports Act, also known as the CLASS Act, has received widespread support in both houses of Congress as part of the health care reform bill. The CLASS Act would essentially set up a government-run insurance program to help pay for long-term care in the home or elsewhere. As proposed, participants would pay a monthly premium that could be $120 to $150, and in five years they would be eligible to receive a modest daily cash benefit of at least $50 that could be used to pay for in-home care, including help with bathing, eating, or medication monitoring.

Many consumer-advocacy groups, including AARP and the National Council on Aging (NCOA), lobbied to include the CLASS Act in any final health care reform legislation, arguing that it would reduce

Medicaid spending on nursing homes. At press time, provisions of the CLASS Act were included in both the House and Senate versions of the health care reform bill.

Critics argue that the CLASS Act would increase costs over the long term, since only those who are disabled or sick would sign up. But advocates agree it's a good first step.

"It's not a total solution," admits NCOA president James Firman, "but the CLASS Act would be a giant step forward and provide the missing 'third leg of the stool' that would complement Medicaid and private long-term-care insurance."

Mary A. Fischer wrote about chronic illness in the January-February issue of AARP The Magazine.

Print Email Page 1 | 2 | 3