

December “Senior Sense”: The Hidden Costs of Alzheimer's Disease

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When Rick could not remember where he kept his trusted toolbox, and then forgot his computer passwords, Sandy—Rick’s wife of 40 years—initially wasn’t alarmed. Sandy misplaced stuff all the time and who can remember all those passwords anyway? But over time the signs became more ominous. Rick, a 69-year old retired truck driver with a GPS-like sense of direction, got lost driving home from the grocery store one day. Concerned, Sandy took Rick for a medical evaluation to figure out what was going on. Then they got the grim news: Rick had Alzheimer’s disease.

Currently an estimated [5.7 million Americans have Alzheimer’s disease](#) and 47 million people worldwide suffer from it. By 2050 these estimates are projected to triple and the direct cost to American society may exceed a trillion dollars—a price we will all pay in [one way or another](#). Although the disease does not discriminate, it disproportionately impacts women. Women are [twice as likely to suffer from Alzheimer’s and more than twice as likely to care for someone](#) with the disease.

Close to half of all family caregivers who help older adults are caring for someone with Alzheimer’s or some other form of dementia and they shoulder both a heavy emotional *and* financial burden. What do they do? They help with activities of daily living their loved ones can no longer manage on their own such as getting dressed, eating, bathing and going to the bathroom. In addition, families manage medications, prepare meals, pay bills and provide one of the most vital functions foundational to human existence: connection.

Don’t Count on Medicare

The type of care most often needed for those with dementia is considered “custodial” and not typically covered by Medicare. In Massachusetts, where Sandy and Rick lived, the average annual cost of a nursing home is over \$140,000 and the median hourly rate for in-home care is \$25. And that’s not atypical. People with dementia who need institutional or home-based care can incur enormous expenses that are often borne by family members, most often spouses. In some cases, a solution for someone in Rick’s position would be Medicaid, the primary payer of nursing home care. But Rick didn’t have Medicaid, either. He was considered ineligible because his total assets exceeded the \$2,000 limit allowed in Massachusetts.

Family caregivers for adults with dementia spend over \$10,000 annually on out-of-pocket caregiving expenses such as medicine, personal care items, transportation, co-pays and paid caregivers. That’s nearly twice the amount of out-of-pocket costs incurred by those caring for adults without dementia. This financial pressure is particularly intense for millennial caregivers, who have less earning capacity and savings, yet spend a larger proportion of their wages on caregiving expenses.

Prepare for the Unexpected Costs of Care

Harry Margolis, an elder law attorney and founder of [Elder Law Answers](#), urges families to plan in advance for long-term care. To be eligible for Medicaid, many people will need to transfer assets years ahead of time. There are also ways to “spend down” your assets toward “medically necessary” expenses that can qualify your family member for Medicaid. These may include medical bills not otherwise covered by insurance, medication costs, and even pre-paid funeral arrangements. Part of planning ahead is finding out whether your parent has funds stocked away to pay for care. As crude as it may seem, having financial resources—or not—may determine the type of long-term care your parent will ultimately receive.

With the help of an elder law attorney Sandy was able to eventually get Rick on Medicaid. This was crucial when Sandy made the difficult decision to move Rick to a memory disorder facility nearby as she could not have afforded the six figure price-tag. She knew that Rick would receive the 24-hour care he needed and she visited him every day. Sandy was no longer preoccupied with figuring out how she was going to pay for Rick’s care. Instead she could focus on what really mattered—spending time with the man she loved and finding ways to connect with the person who was still very much there.

[Jody Gastfriend](#) is vice president of senior care at Care.com and author of *My Parent’s Keeper: The Guilt, Grief, Guesswork, and Unexpected Gifts of Caregiving*. For caregiving support, information and resources contact a Senior Care Advisor at Care.com. We are master’s-level social workers specializing in adult and senior care. Call us today at (855) 781-1303 x3 or email questions to careplanning@care.com

