

Coping With the Costs of Dementia: The Middle Stage

Managing rising costs

This is the second of a three-part series on coping with aging's costliest challenge. Read [part one](#), on dealing with the early stages, and [part three](#), on preparing for the final stages.

If you are caring for someone with dementia, you know that it's a uniquely devastating disease. Dementia robs you of the person you love. It attacks memory, personality, language, and physical abilities. It can last for years, even decades. And it has no cure.

The financial toll can be nearly as large as the personal loss. Over the last five years of life, the average out-of-pocket cost of care for dementia patients was 81% higher than for people without dementia, according to a new study in the *Annals of Internal Medicine*. Nearly half of the dementia patients ended up on Medicaid, the government health care program for impoverished Americans.

Driving the cost are the years of care necessary to get a person safely through life's everyday activities. Medicare, the primary health insurance for people 65 and older, doesn't cover that long-term nonmedical care.

In the middle stage of dementia, which lasts about 1½ years on average, your loved one has trouble looking after himself. Your mother, for example, might forget to eat, wander off, or be at risk of physical harm from lapses such as leaving the stove on. Her personality might change too: She'll grow increasingly frustrated or angry with you and need help to reduce her anxiety. Her need for care will rise, but her symptoms may not yet be severe enough for long-term-care insurance or other help, so funding at this stage is often entirely out of pocket.

Arrange for help at home

In the early parts of this stage, Mom or Dad can continue to live at home, but you'll need to bring in help—nonmedical home care aides who can cook, run errands, keep your family member company, and provide personal care by helping with dressing or bathing. This will cost you the same as a home health aide—about \$20 an hour. For help finding local resources, you can consult the [Alzheimer's Association](#), which has 80 chapters across the U.S., and the [Alzheimer's Foundation of America](#), which has licensed social workers available for free by phone and Skype.

It's a good idea to join a local support group—not just for the company but also for the information you can get about local resources, experts, and facilities. The Alzheimer's Association has message boards, chat rooms, and meetings at local chapters across the U.S.

Get a greater level of care

For someone who needs more than a few hours' worth of help daily, one option is adult day-care services, where he can get meals and participate in exercise classes and other activities. Costing an average of \$70 a day, adult day care is best for people who are still able to engage socially and move around easily. To find a day-care service and other resources in your community, go to the [U.S. Administration on Aging's Eldercare Locator](#).

You should also have a backup plan for emergencies or if you need to be away. Some assisted-living and nursing homes will take people for overnight stays or even for a few weeks.

Whatever local service you use, interview caregivers to find out if they have specific dementia-care training, which includes creating regular routines and working with individuals to understand what calms a person or reduces anxiety. "It's a personalized approach and different for everyone," says Gina Kaurich, head of client care for FirstLight HomeCare, a national provider of nonmedical home care services. "Maybe it's taking them for a daily walk or talking about their years in the service or gardening."

Know your insurance coverage

If your loved one has long-term care insurance, you can start tapping it as his need for care increases and the cost of that care grows. Check your policy for what's covered—usually, multiple types of care, including home care, day care, assisted living, and nursing home stays.

You'll also need to know the policy's benefit caps—a daily dollar amount and a maximum number of years or lifetime payout. LTC policies also specify a certain level of physical or cognitive impairment that interferes with daily activities, such as eating and dressing unassisted, before they can be tapped. So be aware of the conditions under which a policy will start to pay.

Tap VA benefits

Are Mom or Dad veterans 65 or older? They may qualify for long-term-care benefits up to \$2,800 a month—covering home care, assisted living, or a nursing home—through the Veterans Affairs Aid and Attendance program. A vet must have served at least 90 days in the military and at least one day during a war. The paperwork is daunting, and as with Medicaid, there are strict caps on assets and income for qualifying. You'll have to document all of your long-term-care expenses to make sure you max out this benefit.

Get conservative with investments

As you start paying for care by drawing money from your loved one's investment portfolio, you need to reallocate it, says Stig Nybo, president of U.S. retirement strategy at Transamerica Retirement Solutions. If the money was earmarked for retirement and invested to grow over 20 or 30 years, it's likely to be heavily weighted toward stocks. "Now that you're planning for larger near-term expenses, you'll have to get a lot more conservative with the investments," he says. Nybo suggests putting money into different buckets to balance immediate needs with long-term growth. Put two years' worth of projected expenses—including for costlier care options, such as a nursing home stay—in cash or a money-market fund. Invest the next five years' worth of expenses conservatively, mostly in bonds, and invest the balance in stocks.

Tap home equity

For many people, their biggest asset—and the most valuable resource for funding dementia care—is their home. If other sources of money for your spouse or parent are scant, you can use his or her home equity to set up a reverse mortgage line of credit, allowing you to borrow roughly 50% of the value of the home. A family member with dementia, along with a spouse, can stay in the house as long as their names are on the deed. If, when the house is sold, its sales price is less than what was borrowed, you won't be on the hook for the difference. To see what you're eligible for, use a calculator such as the one offered by the [National Reverse Mortgage Lenders Association](#).

For more cash, you can sell the family home. If you go that way, consult a real estate agent for an estimate of the market value and an assessment of any repairs that might be needed before listing.

Juggle caregiving with your job

If you're managing the care of a relative with dementia, chances are you're feeling it at work. Between daily responsibilities and emergencies, one in five family caregivers of dementia patients have quit their jobs, and 36% say their career has been hurt by their caregiving duties, according to [Caring.com](#).

A starting point for protecting your standing at work is to explain the problem you're dealing with. "Be open with your employer about what's going on in your life," says the Dementia Society's Jameson, whose wife passed away last year after battling dementia for more than a decade. "If your wife or mother had cancer, you'd tell your boss. It should be the same with dementia."

Ask your boss if you can temporarily cut back hours or make arrangements, such as working at home more, that make it easier to provide care. You may be able to take advantage of the federal Family and Medical Leave Act, which allows employees at a company with 50 or more workers to take up to 12 unpaid weeks off a year for caregiving. Most workers are guaranteed to keep their jobs.

Start researching nursing homes

Even though the person you're caring for may not be ready for assisted living or a nursing home yet, this is the time to see what's available in your area. "Explore your options as early as possible, before you reach a crisis point," says MaryBeth Musumeci, an associate director at the Kaiser Family Foundation. Assisted living is expensive and usually not covered by Medicaid, so this may not be an option if you don't have funds to pay privately. Most nursing homes take Medicaid, but there are often waiting lists.