

Coping With the Costs of Dementia: The Final Stage

When someone you love needs round-the-clock care

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

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 final stages of dementia, which typically last four to five years, the need for care intensifies. Your spouse eventually will require around-the-clock assistance with most activities of daily living. Your toughest decision: whether to try to continue caregiving at home or move your loved one to an assisted-living facility or a nursing home. You may feel guilty at the prospect of putting someone you love in "a home"—that's common and understandable—but a setting where professionals are providing the intense level of care needed at this point is often the best path, especially if they're trained in the needs of dementia patients. That said, it's also the most expensive care option by far.

Act before the money runs out

Unless your loved one has enough assets to fund home care for years without a problem—or you do, without jeopardizing your own long-term financial security—you'll want to make the move to a nursing home sooner rather than later, because Medicaid won't cover 24-hour at-home care. And it's easier to get into a facility if you start out as a private pay patient, says Whitenack, because Medicaid usually pays only a fraction of what a family would pay. "Once you're in, they can't kick you out if you run out of money, but there's no law that a nursing home must take you in the first place," she says.

Aim for a home with memory care

A useful resource for finding a nursing home is the [Centers for Medicare and Medicaid's comparison tool](#). Use the site's checklist to judge facilities: For example, are residents clean, well-groomed, and -appropriately dressed? Does the staff wear name tags? Semiprivate rooms cost from \$50,000 to \$130,000 a year, depending where you live; go to [genworth.com](#) to find local prices.

About half of nursing homes have specialized dementia care services. The cost is greater than that of a standard nursing home stay, which GenWorth says averages \$6,600 a month for a semi-private room. In return, you get lower staff-to-patient ratios than traditional nursing home units, and greater attention paid to regular routines and other measures designed to keep residents calm and reassured. "People with dementia do much better when they have care that's tailored to them," says Ruth Drew of the Alzheimer's Association.

Tap assets strategically

Your money will probably last longer if you make withdrawals first from IRAs and taxable investment accounts before drawing on cash reserves, says Christopher Olsen, a certified financial planner in Lodi, Calif. That's because the taxes incurred by selling those assets can be offset by tax breaks on medical expenses. Currently, for people who are 65 or older, health care costs above 7.5% of their adjusted gross income are deductible, vs. 10% for younger taxpayers.

Whitenack recommends applying for Medicaid on your loved one's behalf once he is down to about \$50,000 in assets— enough to pay for care for about the next six months—since it can take a few months for Medicaid to determine whether a dementia sufferer qualifies. You'll need to gather five years' worth of financial documents, file the application in person, and give Medicaid time to review the paperwork.

Plan for your own future

Are you the spouse of a dementia patient going on Medicaid? You have to think ahead. If your spouse is to qualify for Medicaid, you're allowed no more than \$119,200 in assets, including any IRAs and 401(k)s but excluding a primary residence or car. You, the spouse, have no limits on your income, so one option is to liquidate investments and buy what is known as a Medicaid-compliant annuity. It's similar to an immediate annuity: You put a lump sum in and get a stream of income. The downsides: It can't be cancelled, you'll get lower payments than you'd get from a traditional annuity, and if you die, your heirs get nothing. Work with an elder-law attorney to buy one, because rules vary by state.

Caring for someone with dementia is emotionally exhausting and financially draining, but it comes with one particular satisfaction: knowing that you've done whatever you can to make the last years easier for someone you love. "The likelihood is that Helen will outlive me," says Dick Pell. "I want to make sure I am doing everything I can to protect her."