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WHEN SOMEONE YOU LOVE HAS DEMENTIA, THE EXPERIENCE CAN BE HEARTBREAKING—AND THE EXPENSES ENORMOUS. HERE'S HOW TO MANAGE YOUR FAMILY'S FINANCES WHILE PROVIDING THE BEST CARE.

By **DONNA ROSATO**

Photographs by
CHRISTOPHER CHURCHILL

Dick Pell wants to be sure he can finance dementia care for his wife, Helen.

Dee Jimenez-Grohowski (right) cares daily for her mother, Theresa, and her father, Aurelio (inset).



Theresa Jimenez, 89 MIAMI
Dalila “Dee” Jimenez-Grohowski, 62
DAVIE, FLORIDA

THEIR STORY

After Theresa, a mother of five, was diagnosed with dementia two years ago, her daughter Dee’s life and finances were upended. Theresa became aggressive and anxious, says Dee, and now needs help with everything from eating to using the toilet. During the day a home health aide looks after Theresa and her husband, Aurelio, 97, a former airline executive. But seven after-

noons a week, Dee—a widow who quit her job as a tax accountant to care for her parents—drives 40 miles to their Miami condo to make dinner, get them to bed, and stay overnight.

Her parents can’t afford to pay for the aide and Theresa’s medications, so Dee splits the annual \$30,000 cost with her four siblings. But since Dee’s only income now comes from her late husband’s pension and the \$25,000 a year she collects in Social Security, she’s having trouble paying her share and other bills, like her property taxes. She has run up \$20,000 on credit cards and is tapping her \$150,000 retirement kitty. Says Dee: “My financial situation is dire.”

ADVICE FOR DEE

- ▶ **Tap home equity.** Instead of draining her own finances, Dee should help her parents set up a reverse mortgage on their condo, says Miami certified financial planner Glenn Downing. The \$200,000 home, now mortgage-free, could get them a \$140,000 line of credit, by one industry estimate.
- ▶ **Increase care.** Use that money, says Downing, to up the number of hours that the home health aide works. That will mean Dee has more time off from caregiving.
- ▶ **Go back to work.** With more time available, Dee can work part-time as a tax consultant—a job she thinks will net \$15,000 a year. With that money she can pay down her credit card balance and start saving again. “Dee won’t be good to anyone,” says Downing. “If she doesn’t take care of herself.”

THROUGHOUT THEIR 39-YEAR MARRIAGE, DICK AND Helen Pell have shared a love of the theater. And it was in a theater that Dick first noticed something wrong.

Rehearsing a skit in an amateur production four years ago, Helen had trouble remembering her lines. Soon she was asking Dick the same questions repeatedly. He took her to a doctor, who diagnosed Helen with dementia.

Today Dick, 82, and Helen, 79, still go to the theater. But Helen doesn’t act. In their one-story home she gets lost looking for the bathroom. She doesn’t know how to use a toaster, or even a light switch. “I get very sad when I realize I am losing my gal,” says Dick. “And it gets more apparent every day.”

Also apparent are the mounting expenses they face. Right now Dick is spending \$255 a week for 15 hours of help from a home care aide. A nursing home stay, which Helen is likely to need someday, will cost about \$6,000 a month. Says Dick: “You don’t have to be a genius to see that we’ll run out of money, depending on how long Helen will need care.”

If you are one of the estimated 15 million Americans caring for someone with dementia, you know that it’s a uniquely devastating disease. Dementia—the most common form is Alzheimer’s—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 totaled \$61,500—81% more 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, compared to about

20% of patients suffering from heart disease or cancer.

Driving the cost aren’t drugs or treatments, but 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. “The burden is on families to figure out how to pay for it,” says Amy Kelley, lead author of the dementia study.

In the pages that follow, you’ll find detailed guidance on how to address the financial challenges of caring for a parent or spouse with dementia—the most important steps you can take in each of the three major phases of the disease. You’ll also meet three families coping with the economics of dementia care and getting advice from financial professionals.

Losing a loved one to dementia is always painful. But learning how to handle the financial obstacles you’ll face can take some of the inevitable stress away.

STAGE 1

Facing a
Difficult
Truth

“senior moments” that naturally come with aging. It’s also because the condition can be so frightening. “All too often, I’ve seen denial by the spouse, the family, or the person themselves,” says Charles J. Fuschillo Jr., CEO of the Alzheimer’s Foundation of America.

In this early stage of dementia, which lasts an average of two years, your out-of-pocket costs won’t be burdensome.

Dementia comes on gradually, so you can easily miss the first signs of it in someone you love, especially if you live with that person or see him or her on a regular basis.

That’s partly because the early symptoms of dementia are often confused with the

But you’ll need to plan for more expensive care later on, and move quickly, since your husband, wife, or parent has a limited window to participate in financial decisions and sign any necessary legal documents before cognitive abilities fade. “When people don’t recognize dementia earlier,” says Fuschillo, “it costs you more in the end.”

KNOW WHAT IS NOT NORMAL AGING

Be on the lookout for subtle but distinct differences from typical signs of aging, says Ruth Drew, director of family and information services for the Alzheimer’s Association. Forgetting names or appointments isn’t a big deal. More alarming is asking the same questions over and over or forgetting how to do familiar tasks like preparing a favorite recipe. You might also notice your parent or spouse misplacing things that turn up later in unusual places, like a phone in the re-

frigerator. (Visit alz.org for more tip-offs.) If the person you're concerned about doesn't live close by, enlist friends and neighbors to alert you to any troubling incidents, advises **Kevin Jameson, president of the Dementia Society.**

ADD A DOCTOR TO THE MIX ... GENTLY

Bringing up the subject of dementia is an emotionally loaded conversation, and you don't want to put your loved one on the defensive. Pick a time when the person is relaxed. Start with a general question like, "How's your health? What has the doctor been saying?" Then raise your specific concerns. Andy Cohen, CEO of the caregiving information website Caring.com, suggests filtering your conversation through your own thoughts and feelings, along the lines of "I've noticed some behavior changes in you, I'm concerned, and it would make me feel better if you checked in with your doctor." A precipitating event—say, getting lost or bouncing checks—will make it hard to dismiss the problem, says **Jameson**, but if your loved one gets defensive, enlist a neutral third party, like a trusted friend, to bring up the issue. Offer to make the doctor's appointment and go along.

APPOINT KEY DECISION-MAKERS

Once you have a formal diagnosis in hand, ask for a family meeting to figure out who will be the point person, or persons, for managing your loved one's condition. As the dementia progresses, dozens of decisions will need to be made about care, housing, and finances—decisions that Dad, say, will be increasingly unable to make alone. Talk it through: Who lives the closest? Who has the most flexible schedule? Who is most comfortable with handling financial matters? Whoever ends up managing Dad's finances doesn't have to be the same person taking the lead on health care, but if it isn't, the two of them should be people who get along well enough to work together.

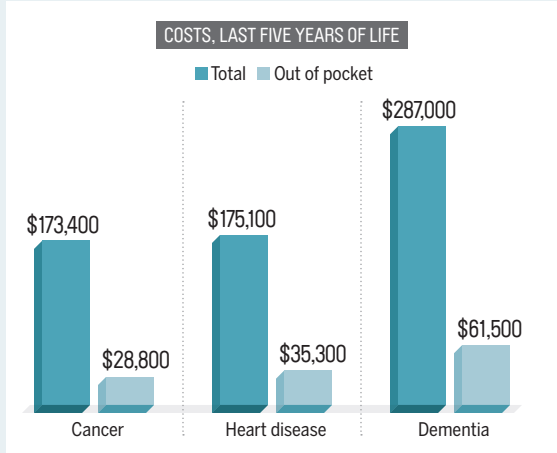
At the same time, sort out what will be needed in terms of relatives' money and time, and reach an agreement about who can contribute what. Even a long-distance relative can be of assistance by sending money or taking on tasks like paying bills online or handling taxes. "In the beginning the biggest cost is time and stress," says **Jameson**. "But those incremental costs can start to snowball quickly, so you need to always be thinking about the next steps."

GATHER THE PAPERWORK

Along with a will, you'll need to have at least two key documents, says Shirley B. Whitenack, a lawyer and the president

The Expense of Dementia

The end-of-life cost of caring for a person with dementia far outweighs the expense of treating people with cancer and heart disease.



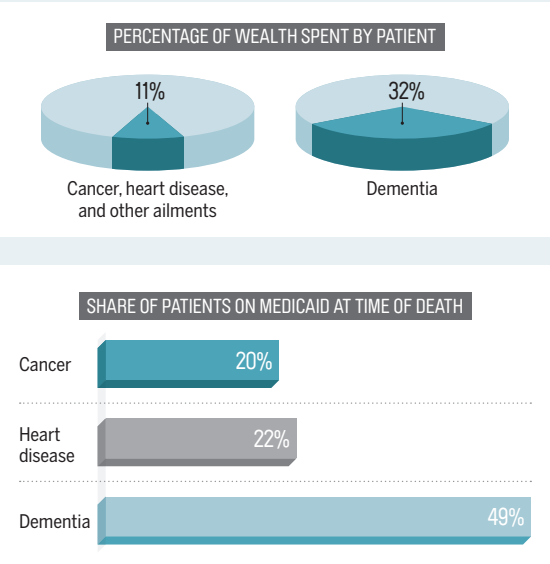
of the National Academy of Elder Law Attorneys (NAELA): a durable power of attorney, authorizing a person to make financial decisions for your family member, and a health care proxy, appointing someone to make medical decisions.

This, too, can be a tough subject to broach with a parent. Long-held roles are reversing: Now you're the one caring for Mom. Losing control can be scary and embarrassing for her, so make the conversation about you. You might say that you're getting your medical and financial paperwork together, so maybe she should too. Or you can say that you're worried and you'd feel a lot better if this paperwork were in place. You can draft these documents with the help of a local certified elder-care attorney who under-

stands the relevant state laws and regulations. Start your search for a lawyer at the websites for NAELA (naela.org) and the National Elder Law Foundation (nelf.org).

TAKE A FINANCIAL INVENTORY

It's important to get a handle on all the assets your family member has available for funding care, starting with money in the bank, investments, pensions, and Social Security. You also want to know if he or she has a long-term-care insurance policy in force. (Only 7% of the population does, and after a diagnosis of dementia it's too late to apply for one.) You'll also want to know the equity in the home, in case you might want to tap it via a reverse mortgage or sale. Such an inventory



NOTES: Cost figures are averages. Figures for spending as a percentage of wealth are medians. SOURCE: Annals of Internal Medicine, November 2015. Sources for additional statistics throughout article: University of Portland, Caring.com, GenWorth

may not be easy; when Theresa Von Vreckin (see profile on page 87) took over her father's finances, his investments turned out to be in more than a dozen different accounts. And your parent may not want to share this information with you for privacy reasons. If so, offer to make an appointment with a financial planner who can help sort things out. But that planner should get Dad's okay that the adviser can get in touch with you if he is worried about Dad's cognitive abilities—an increasingly common practice among financial planners.

If it's your husband or wife who has been diagnosed with dementia, you might want to do what Dick Pell has done for Helen: set up a special-needs trust so that if you die first, your assets will be earmarked for your spouse's care. Again, consult an elder-care attorney.

GET READY FOR MEDICAID

There's a substantial likelihood that your loved one may need to go on Medicaid for care: In the *Annals of Internal Medicine* study, for example, the share of dementia patients on Medicaid went from 21% to 49% during their last five years of life. You can start planning for that possibility now.

Medicaid, however, has strict rules limiting the assets a patient—and a patient's spouse—can own while qualifying for the program (see page 89 for more). One wealth-preserving tactic to keep in mind for now is for the patient to pay off any home mortgage. Because your primary residence is exempt for the purposes of determining Medicaid, that move will increase the amount of home equity you can tap later, if you end up needing those funds.

Another wealth-preservation tactic is to transfer assets of the person with dementia (again, plus the spouse's assets, if married) to someone else. There's a catch, though: Medicaid has what is known as a five-year look-back rule. If the dementia patient transfers the assets and then applies for Medicaid within five years, the patient will be expected to pay for caregiving equal in value to those assets. So if your mother impulsively gives all of her money to her grandchildren to spend down assets—but then needs that money for care within five years—you and other family members are going to have to figure out how to replace that money so she can qualify for Medicaid.

STAGE 2

Managing Rising Costs

At this stage of dementia, which lasts about 1½ years on average, your loved one has trouble looking after himself. You 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 per-

sonality 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 (alz.org), which has 80 chapters across the U.S., and the Alzheimer's Foundation of America (alzfdn.org), 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

“Explore your options ... before you reach a crisis point.”

MARYBETH MUSUMECI

in your community, go to the U.S. Administration on Aging’s eldercare.gov website.

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.”

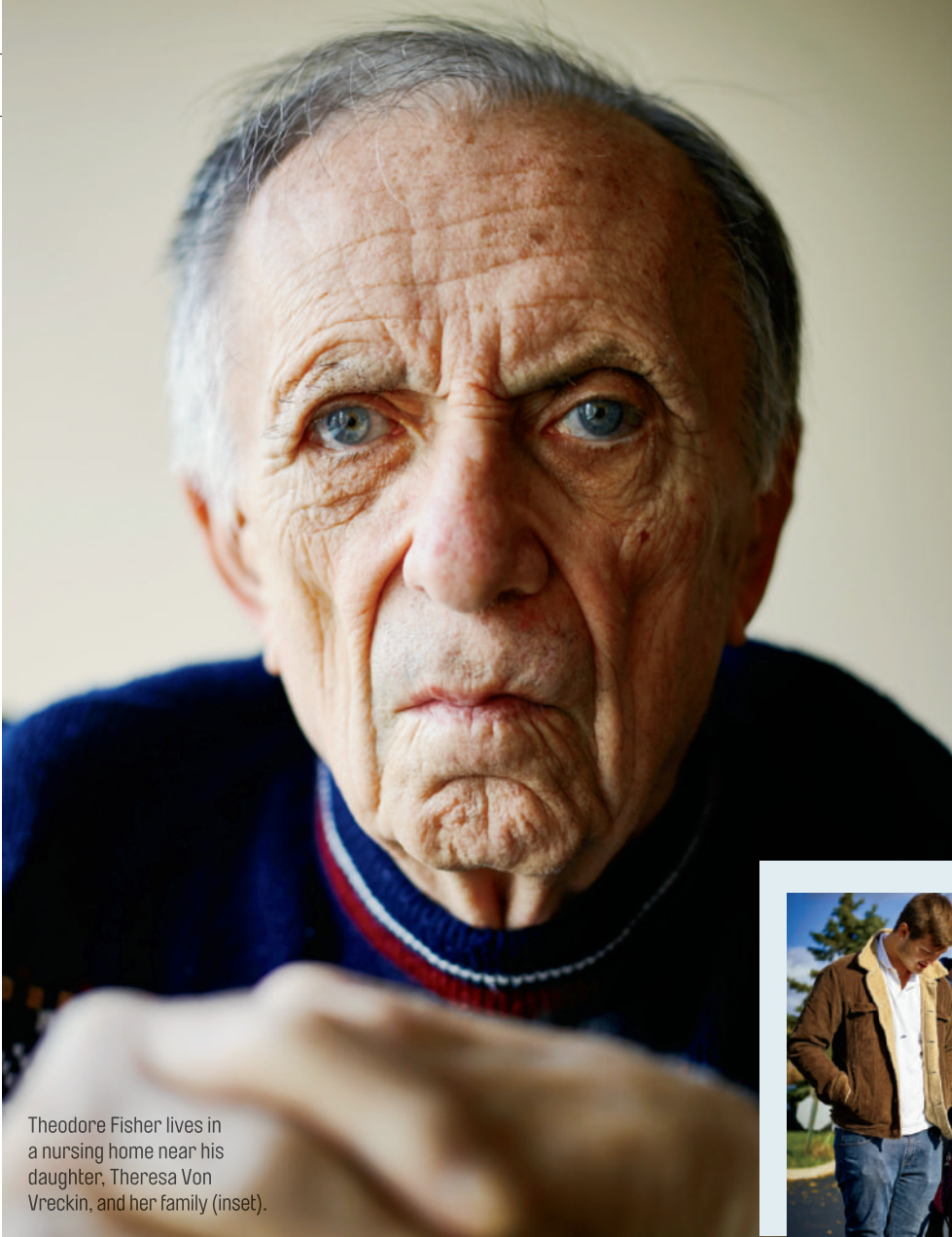
KNOW YOUR INSURANCE COVERAGE

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



Theodore Fisher lives in a nursing home near his daughter, Theresa Von Vreckin, and her family (inset).

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

Theodore Fisher, 77
Theresa Von Vreckin, 50, BUFFALO

THEIR STORY

Three years ago Theresa noticed her newly widowed father, Theodore, behaving oddly. He hallucinated, for example, that there were people living in his house and got lost driving to his home in Buffalo, though he’d lived there 50 years.

Soon afterward Theodore was diagnosed with Lewy Body dementia, the most common form of dementia after

Alzheimer’s. “My dad was a chemical engineer, a very intelligent man,” says Theresa. “Now there are times when I am not sure he knows who I am.”

Theodore is in a nursing home that costs \$13,000 a month—covered by his long-term-care insurance policy and pension income. Theresa is in charge of managing her father’s \$1.5 million investment portfolio and wants to fulfill his wish to leave money to his family. But she feels overwhelmed by the task, since his assets are spread out over more than a dozen accounts.

ADVICE FOR THERESA

► **Consolidate accounts.** To make managing

Theodore’s portfolio easier, Theresa should combine the \$640,000 he has in four IRAs into one account, says San Antonio certified financial planner Ben Gurwitz. She should consolidate his taxable accounts as well.

► **Sticks with stocks.**

The portfolio is heavily invested in stocks, but Gurwitz doesn’t recommend selling to reduce the risk—even though benefits from the long-term-care policy will expire in three years. Between Theodore’s pension and Social Security, his income is nearly \$7,000 a month. “I’m not concerned about him running out of money,” Gurwitz says. Selling long-held stocks in the taxable accounts would trigger a big tax bill now, but after Theodore’s death, that capital-gains liability will be erased for heirs.

see what you’re eligible for, use a calculator such as the one offered by the National Reverse Mortgage Lenders Association (reversemortgage.org).

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 **Jame-son**, 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 em-

ployees 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.

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

36% FAMILY CAREGIVERS WHOSE CAREER HAS BEEN HURT BY DEMENTIA CAREGIVING

STAGE 3

Getting 24-Hour Care

In the later 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 (medicare.gov/nursinghomecompare). Use the site’s checklist to judge facilities: For example, are residents clean, well-groomed, and appropriately dressed? Does the staff wear name tags? Semi-private 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 Gen-Worth 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.

\$220

AVERAGE DAILY COST
OF A NURSING HOME
SEMI-PRIVATE ROOM

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’

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.

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Dick Pell looks after his wife, Helen, at their Sarasota home.



Helen Pell, 79
Dick Pell, 82
SARASOTA

THEIR STORY

Helen and Dick met on a blind date in 1975 and married the next year. They ran several businesses together, acted in community theater, and traveled the world. “My gal was always witty and up for whatever crazy adventures I came up with,” says Dick.

Now, four years after Helen was diagnosed with dementia, she’s physically robust, but her mental abilities have declined. Dick wants them to keep living together at home, but given his own health problems—he has a heart condition—he foresees he won’t always be able to care for her. That would mean moving

Helen to a nursing home.

Helen has a long-term-care policy, and Dick has investments of nearly \$1 million—65% in U.S. stocks, the rest in corporate bonds from a single company. But he fears that’s not enough. The average cost of a nursing home with memory care is \$6,000 a month in their area, and the LTC policy’s benefit is capped at \$150,000. “The financing of her care is a constant worry,” he says.

ADVICE FOR DICK

► **Fix the mix.** Dick will soon have to draw on his investments to care for Helen, so he needs a more conservative portfolio, says Jacksonville certified financial planner Carolyn McClanahan. She advises he cut the

equity stake to 35% and diversify by adding international stocks. Dick should also be diversifying into bond funds or multiple municipal and corporate bonds. Those moves will help protect money he can use to put Helen in an assisted-living facility or a nursing home with memory care. If that money runs out, he can apply for Medicaid on her behalf. ► **Protect himself.** Dick might one day need care for himself, says McClanahan, so he should formalize his own wishes. Dick and Helen’s children from previous marriages think the couple should move to assisted living now, but Dick has pushed back. “We live on a beautiful lake. Life is still pretty good right now,” he says. “I am not ready to give this up yet.”

“Life is still pretty good right now. I am not ready to give this up yet.”

DICK PELL

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.” **M**



MORE ONLINE

Watch video and see more photos of the families in this story, and get additional resources at Money.com/dementia.