

GOOD TO KNOW

Dementia costs weigh on relatives

If Denis Winter suffered from heart failure, cancer or almost any other deadly disease, his family could rest assured that his care would be largely covered by insurance.

But Winter has Alzheimer's disease. So the extraordinary cost of his care — \$8,500 a month, or \$102,000 a year — is borne entirely by his wife, Linda. It is quickly draining their savings.

"It is terrifying," said Linda Winter, 64, of Orinda, California, who has so far spent more than \$350,000 and could be left destitute by the illness of her 65-year-old husband, who no longer recognizes her. "Could I end up in old age under a bridge in a cardboard box? That is my fear."

Medicare is a lifeline for seniors and the disabled, paying for "medically necessary" costs such as hospitalization, surgery, chemotherapy, transplants, medications, pacemakers and other interventions.

A dementia diagnosis demands none of that. What it does require, however, is round-the-clock custodial care, such as help with eating and dressing, and constant supervision. That's not covered by Medicare. And it's extraordinarily expensive, according to a report recently released by the Alzheimer's Association.

Families' out-of-pocket costs for a patient with dementia are 80 percent higher than the cost for someone with heart disease or cancer, according to a 2015 study in the medical journal, *Annals of Internal Medicine*.

COSTLY FOR EVERYONE

"The costs were high for everybody, but among those with dementia, they were astronomical to the point of impoverishing the spouse, with many years still ahead of them," said Dr. Amy S. Kelley, a geriatrician at Icahn School of Medicine at Mount Sinai Hospital in Manhattan and lead author of the paper.

Families will spend \$60 billion for the care of their loved ones in 2018, according to the Alzheimer's Association report. In the United States, about 200,000 people have early onset Alzheimer's, the organization says.

The average lifetime cost of care for a person living with dementia was \$341,840 in 2017, with 70 percent of this cost borne by families through out-of-pocket payments and care.

The price tag for Denis Winter, a professional classical musician with a doctorate in music who was diagnosed with early onset Alzheimer's eight years ago, at age 57. The average patient survives 8 to 10 years, but those with early onset of the disease can live for another two decades.

Denis Winter, a former professor of music at the University of Central Arkansas, worked all his life, saving for



Linda Winter visits her husband, Denis, at an assisted-care facility in California.

retirement with a 403(b). He taught for 30 years and played trombone and euphonium — a large baritone horn — with the Arkansas Symphony Orchestra, the U.S. Coast Guard Band and at Michigan's prestigious Interlochen Center for the Arts.

Friends and colleagues remember his warmth and talent. "He was ambitious, energetic and inquisitive during the years that I knew him as a doctoral student," said Don Little, professor of tuba at the University of North Texas College of Music, where Denis Winter earned the university's first doctorate in euphonium performance.

Linda Winter, a singer and conductor, was his teenage sweetheart while at Cleveland Heights High School in Ohio; he charmed her by helping carry her books home after class. But their lives took separate routes. She earned a masters in business administration and is now director of sourcing, managing suppliers and purchasing strategies at San Francisco's Pacific Gas & Electric.

They were thrilled to rediscover each other in their early 50s, falling in love after a date at the San Francisco Symphony. Then, only six years into their marriage, Denis Winter developed mystifying symptoms. He had trouble keeping rhythm. It took longer for him to read music. Always punctual, he was often late for students' lessons and programs. He got lost while driving home after an evening's performance.

For several years, Linda Winter cared for him at home, but it proved exhausting. She brought in caregivers to help from 7 a.m. to 7 p.m. but was alone at night. Over time, she sickened, developing infections, high

blood pressure and pre-diabetes.

"He'd get up like a Jack-in-the-box in the middle of the night and start walking around," she recalled. "He'd cry out, 'Hello, who is there?' whenever you're in the bathroom or shower."

MEMORY CARE IS 24/7

The cost of hiring in-home caregivers for round-the-clock care is high, especially for those with skills to help dementia patients and strong enough to pick them up if they fall. "No family can do that. Memory care is 24/7," said Ruth Gay of the Alzheimer's Association of Northern California and Northern Nevada. "We see caregivers going down before the patient does."

Now at a Danville, California, facility, Denis Winter is well cared for, so Linda can earn income and keep her health insurance. He speaks only a few words. Although he's safer than he would be at home, he's still at risk of injury, sometimes walking into windows because he doesn't recognize glass.

Despite her near-daily visits, Linda is a stranger to him. So she welcomes him with a warm smile, a hug and an introduction. "Hello!" she says. "I'm Linda, your wife!"

Divorce is unthinkable for Linda Winter. Their savings will last only another three to four years. She hopes to keep working as long as possible and has cut costs to make their money last.

"He has a disease you can see in the MRIs," she said. "Just because we can't cure people, doesn't mean you don't care for them. 'I am responsible for his care, even if it financially ruins us,'" she said. "That is the constant worry. How am I going to do it?"



NY estate tax doesn't match federal laws

I was advised that New York State has raised its estate tax exemption to equal the current \$11 million federal exemption. Is this true?

No.

Let's begin with some background. Your estate is the dollar value of everything you own when you die — e.g., your house, retirement accounts, life insurance policies, jewelry, etc. That value is theoretically subject to federal and state estate taxes. But in fact, only estates that exceed an exempt amount are taxed.

The amount exempt from federal estate tax has long been greater than that exempt from the New York tax. But under current New York law, the state exemption has been increasing annually. Starting next year, it was intended to equal the federal exemption. But the federal Tax Cuts and Jobs Act — passed after the current New York law was enacted — increased the federal estate tax exemption from \$5.6 million to \$11.18 million per person. As a result, a married couple can now leave up to \$22.36 million free of federal estate tax.

But New York's law is tied to the previous federal exemption, says Alan E. Weiner, a Melville tax accountant. This year, the state's exempt amount is \$5.250 million. In 2019, it will be \$5.6 million plus the still-undetermined 2018 increase in the Consumer Price Index. Moreover, New York taxes an entire estate if its value exceeds 105 percent of the exempt amount, notes Eric Kramer, a Uniondale estate lawyer. For example, if a New York state resident dies this year, leaving an estate worth more than \$5,515,500 (105 percent of the current \$5.250 million exemption) his entire estate is subject to the New York tax.

THE BOTTOM LINE

A New Yorker's estate can be free of federal estate tax, but still be subject to the state's estate tax.

MORE INFORMATION

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