

A costly diagnosis: Alzheimer's disease takes toll on memories, and money too

November 27 2009, By Anya Martin

Alzheimer's disease takes a devastating emotional toll on families but it also is one of the most expensive conditions to treat because of its progressive nature, requiring increasing assistance with eating, bathing and other basic activities over up to 20 years.

However, financial planning at the disease's early stages can stretch available dollars and ensure that those afflicted with Alzheimer's receive the best care they and their families can afford.

Every Friday afternoon Ward Campbell takes his wife Peggy to happy hour. Often a local musician plays and the two sample appetizers. He has a beer or two and she sips a cola.

The location, however, is not a restaurant but Morningside of Charlottesville, Va., an assisted-living community operated by Newton, Mass.-based FiveStar Senior Living. Peggy is one of 20 residents in Morningside's [memory](#) care unit and most of the time she doesn't recognize Ward as her husband.

"There's a lot of guilt," Ward said. "Am I visiting her enough? Have I cared for her enough? Is she in the best place? Should I do more?"

Married for 46 years, Ward and Peggy Campbell, both age 72, had very different plans for their savings than \$4,600 per month for her care and board at Morningside.

"I'm skimping and saving," Ward said. "I'd hoped to pay \$4,600 on something else. It would buy a lot of trips, a lot of Porsches and a lot of fun."

Currently 5.3 million Americans live with Alzheimer's disease and someone new develops it every 70 seconds. Since the main risk factor is age, that number could accelerate to nearly a million new cases annually by 2050, when the youngest of the baby boomers turns 84. November is National Alzheimer's Disease Awareness Month.

In 2008, average yearly expenditures on health care and other long-term-care services for someone with Alzheimer's totaled \$33,007, more than triple the amount for other seniors 65 and older, according to 2009 Alzheimer's Disease Facts and Figures, an annual report by the Alzheimer's Association. Of these costs, Medicare covered a little less than half (\$15,145) and Medicaid about one fifth (\$6,605).

One reason why people with dementia face higher costs is that most also have one or more additional serious medical conditions such as diabetes or coronary heart disease, said Dr. Jae Pak, a geriatric psychiatrist at Healthcare for Seniors Center in Atlanta.

"Alzheimer's exacerbates other illnesses and vice versa," he added. "People may not take their medications correctly. Diabetics may forget to eat unless somebody is there to make sure that they eat."

Alzheimer's also is the sixth leading cause of death for Americans. In its final stages, complications include immobility, swallowing disorders and malnutrition -- all of which significantly raise the risk of developing pneumonia.

LOTS OF ASSISTANCE

Still the most challenging financial hit for patients and their families comes not from direct health-care costs but the increased need for assistance with just about every task of daily activity from getting dressed to using the bathroom as the disease progresses to its middle and late stages.

Because that care is not typically covered by government or private health plans, 8.5 billion hours of unpaid care valued at \$94 billion was provided by almost 10 million family members and friends last year. Many cut work hours or even quit their job to help loved ones.

But as the person with Alzheimer's becomes increasingly confused and requires 24-hour care, most families eventually require outside help. In 2008, the average home care rate for personal care and homemaker services was \$144 for an eight-hour day. Adult day care cost an average of \$64/day.

Specialized Alzheimer's care in assisted-living cost an average of \$4,267 a month or \$51,204 a year, while average nursing home rates run from \$191-\$219/day or from about \$70,000-\$80,000/year depending on whether one opts for a semiprivate or private room or is in an Alzheimer's special care unit.

Alzheimer's care in assisted living is typically completely private pay, although some states have Medicaid waiver programs that cover assisted living and at-home services. Low-income seniors may qualify to have Medicaid pay for nursing home stays, but coverage rules differ widely state to state. Because of the long duration of the disease, many people ultimately qualify for Medicaid because they have to spend all their assets.

A former staff manager for Bell Atlantic Corp. (now Verizon Communications, Inc.), Ward had invested well, accumulating a nice

nest egg since his 1991 retirement. To access money as needed for Peggy's care, he reallocated those investments from a heavily equity-based portfolio to more fixed income such as bonds. This move also helps inoculate savings against the stock market volatility, which shaved one-third off his net worth last fall although much of that value has come back now, he said.

For the Campbells, the process was step-by-step. Because Peggy enjoyed being around other people, Ward signed her up at a \$50/day adult day care center which offered activities five days a week.

"She preferred it there than being at home because there were lots of people and things to do," Ward said. "At home, there was only me and nothing to do."

Still while Peggy never displayed the aggressive behavior or tendency to wander that afflict others with Alzheimer's disease, she became increasingly restless at night to the point Ward could not get a good night's sleep.

However, 76-year-old Edith Vanderburg has no such safety net -- just a pension and her monthly Social Security payment and a loving 55-year-old son, Russell Patterson, who has moved into her Bronx home to care for her.

Patterson first suspected his mother might have Alzheimer's in 2003 when she started repeating the same stories to him during weekend visits. In 2005, she asked him to pay her bills and balance her checkbook.

Six months later after he found out that she had divulged her credit card number to a caller, he asked her if she would formally transfer the house to his name, give him power of attorney over her finances and write a

living will.

When Patterson was recuperating from his own surgery, he stayed with his mother and realized she had stopped using her stove and was living on pizza and Ramen noodles.

"To be honest, I was ready to go back to my house, but she just seemed better while I was there," he said. "She said I need you to be here with me."

An assistant manager for Federal Express Corp., Paterson sometimes has workdays that stretch to 14 hours, but his mother now requires 24-hour care. For a short while, he hired a home health aide for about \$25 an hour but found a more affordable solution when his cousin's daughter was laid off from her job six months ago and agreed to be a paid caregiver.

Patterson has not given any serious thought about how to pay for his mother's care should his cousin's daughter decide she no longer can handle the job, he said.

"Now, primarily, I'm just going day-to-day," he added.

AFTER A DIAGNOSIS

When you or a loved one is diagnosed with [Alzheimer's disease](#), the first step is to deal with the emotional impact of the news and develop a care strategy, said Beth A. Kallmyer, director of family and information services for the Alzheimer's Association.

"Reach out to family members," she added. "Because the disease goes on for such a long period of time and because it's progressive, it's important to have a care team in place which can include family, friends, doctor

and other medical professionals."

Next, while you are still at an early stage and can participate in such decisions, put in place a plan for how you want your finances handled and appoint representatives who will have the power of attorney to execute both financial and medical decisions, Kallmyer said.

"Because some of these decisions are tricky, sometimes families choose to meet with an eldercare attorney or financial planner that specializes in working with older people," she added.

If you have long-term-care insurance, this is also the time to review your policy carefully to understand what it does and does not cover, Kallmyer said.

Finally, caregivers should not forget to take care of their own mental and physical health and be honest with themselves about what care they can or cannot provide, Dr. Pak said. Numerous studies have shown that relatives who provide unpaid care for someone with Alzheimer's can experience high levels of stress and depression and negative effects on their own health, income and finances.

The Alzheimer's Association has many resources for patients and families including support groups in communities across the country, access to master's level clinicians who provide free consulting on how to break the news to key people in the patient's life, as well as a Carefinder resource to identify home health agencies, assisted-living communities, nursing homes, hospice services and other resources for dementia care in your community. Visit www.alz.org www.alz.org/ or call its 24-7 hotline, 1-800-272-3900.

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