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Woman steps into caregiver role after husband diagnosed with Alzheimer's disease

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CHARLESTON, W.Va. -- A recent report found that one in three seniors in the United States dies with Alzheimer's disease or dementia.

The sobering statistics help highlight what is now the sixth leading cause of death in this country, and what is becoming a challenge for more and more West Virginians.

Among them is Letha Goode, 65, of South Charleston. She's the primary caregiver for her husband, Steve, 64, who was diagnosed with the neurological disease more than two years ago.

"I noticed symptoms before that point, but I didn't really know what it was. I expressed to my family physician that I suspected something was going on.

"The doctor said, 'What are you going to do if he does have it?' I said, 'Isn't there medicine to slow it?' He said, 'No medication out there works,'" Letha said.

"But I took him to Morgantown to be tested, and I told that doctor what he said. The doctor said it's true and the drugs are expensive and only work for a very few people. But he asked me, 'How can you not try them? You don't know if your loved one is going to be one of the ones they help.' So he's on two different medications that are supposed to work together."

"I really can't say if they're helping . . . It seems like he's progressing pretty quickly," she said.

Letha, who continues to work while caring for Steve, said he is at the point where "he can't really do anything." He can feed himself and use the restroom if he's told. He'll watch TV if Letha turns it on for him. He isn't steady on his feet. His motor skills are regressing.

"I have to have someone come in during the day while I'm trying to keep my job so I can keep insurance. He isn't old enough for Medicare," she said.

Her day starts with waking him, fixing his breakfast and giving him a shower before preparing herself for her long day of work ahead.

"It's one of the most difficult and trying things I've ever experienced. It's so sad to just look in his eyes and see the emptiness," she said. "You can actually see. People have said, you look in his eyes and there's nothing there."

The couple has been together for almost a half-century.

"They don't have a filter for things; they don't show compassion. They don't understand. My mother passed away; my father passed away recently. He had no compassion for me. He couldn't be there for me. After 42 years. And we dated five years before then. There's nothing there," she said.

"They said that sometimes traumatic changes can make it worse. He had two brothers who passed away in one year. One was two years older than him and had a massive heart attack, and he was his last living family member. That pushed him over the edge a little bit. . ." she said.

One in three seniors dies with Alzheimer's or another dementia in the United States, according to the Alzheimer's Association 2013 Alzheimer's Disease Facts & Figures.

West Virginia has more than 48,000 people living with Alzheimer's disease, and the number continues to rise.

"West Virginia is about standard for the amount of people living with Alzheimer's disease compared to states with similar demographics to ours, as we have a higher than normal aging population. But as of now, the state falls in the normal range," said Laurel Kirksey, the director of constituent relations for the Alzheimer's Association, West Virginia chapter.

The report also shows that deaths related to Alzheimer's disease increased 68 percent from 2000 to 2010, while deaths from other major diseases, like heart disease, HIV/AIDS and stroke continued to decline.

Currently, Alzheimer's disease is the sixth leading cause of death in the United States and the only leading cause of death without a way to prevent, cure or slow its progression.

Alzheimer's was the underlying cause of death for 83,494 people in 2010. The Alzheimer's Association 2013 Facts and Figures estimates that 450,000 people in the United States will die this year with Alzheimer's.

"One of the things we struggle with is people citing Alzheimer's as the cause of death. Even if people living with Alzheimer's disease die with pneumonia or heart disease, it is because of the Alzheimer's disease. Their organs are failing because of Alzheimer's disease," Kirksey said.

"The true number of deaths caused by Alzheimer's is likely to be somewhere between the officially reported number of those dying from and those dying with Alzheimer's," according to the release.

Dr. Todd Goldberg, who specializes in geriatric medicine at Charleston Area Medical Center, said Alzheimer's is receiving increased recognition and diagnosis, and that has led to it being listed more often as the official cause of death.

"Alzheimer's is indeed a progressive and fatal condition but not any more so now than in the past," Goldberg said.

"Some of the other top five causes of death do have better treatments in recent years so there are slightly less deaths from those causes relatively speaking.

"More people are dying at home and in nursing homes and hospice due to Alzheimer's rather than in the hospital or ICU where they are more likely to be labeled as dying from heart or respiratory failure or septic shock.

"So, there are 68 percent more deaths labeled as Alzheimer's since 2000 rather than other causes, but not really more people dying or getting Alzheimer's except in proportion to the population getting larger and older."

According to the association's report, among 70-year-olds with Alzheimer's disease, 61 percent are expected to die within a decade. Among 70-year-olds without Alzheimer's, only 30 percent will die within a decade.

Alzheimer's also places a burden on the caregivers. In 2012, more than 15 million caregivers provided more than 17 billion hours of unpaid care valued at \$216 billion.

In West Virginia, that translates to 108,000 caregivers providing 123 million hours of unpaid care valued at \$1.52 billion, according to the report.

"It's running rampant. It's everywhere," said Letha Goode, the South Charleston woman who is caring for her husband.

"So many people have it, and it's very sad. After two and a half years, I'm getting to the point where I can talk about it without crying. I'm usually in tears every time. I want to do everything I can.

"I have two sons, and I'm worried to death about them because it's an inherited disease. My husband's father was diagnosed around the same time as him — 62. I want them to find a cure. I know it won't be in time to help my husband, but hopefully it can help them by that time. And you all."

To find an Alzheimer's support group near you, visit http://www.alz.org/wv/in_my_community_support.asp.

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