Aging baby boomers are about to push Alzheimer's disease rates sky high

Kristen Jordan Shamus, Detroit Free Press Published 9:24 p.m. ET May 4, 2019 | Updated 9:36 p.m. ET May 4, 2019

DETROIT – She had researched Alzheimer's disease and its effects on the brain for years, but it wasn't until her own mother's memory began to slip (https://bit.ly/2PCLCgE) that Dr. Eva Feldman, a University of Michigan neurologist, truly grasped how devastating the disease is.

Margherita Feldman was 88 when she moved in June 2017 to the memory care unit of an assisted living home in Saline. And although her memory loss wasn't as acute as some of the other residents, it's when the cruelty of the disease – now the sixth-leading cause of death in the United States – and the scope of America's Alzheimer's crisis became clear to her daughter.

"I learned more about dementia and Alzheimer's disease spending lots of hours in that memory care unit than I did as a long-standing, practicing neurologist," said Feldman, who is the director of the <u>University of Michigan's Program for Neurology Research & Discovery</u>
(https://www.pnrdfeldman.org/). "The people in the memory care unit, some were very violent. Some were very passive. Some were very young with really severe memory loss with early-onset Alzheimer's. You could see the whole myriad of presentations and you could understand what an enormously difficult disease that it is for the patient, but also for the families."



Dr. Eva Feldman and her mom, Margherita Feldman, pose together for a photograph in December 2017. Three months later, Margherita Feldman, who had Alzheimer's disease, died. (Photo: Feldman family photo)

In her work, but also while visiting with her mom, Feldman considered the <u>enormity of the Alzheimer's problem (http://act.alz.org/site/DocServer/2012_Costs_Fact_Sheet_version_2.pdf?docID=7161)</u>: About 5.8 million Americans now have the disease, according to the Alzheimer's Association. That number will climb to at least 13.8 million by 2050, a 138% rise, and as many as 1 in 3 people who live to be 85 in the United States will die with Alzheimer's disease.

"We are really in an epidemic," Feldman said, driven largely by baby boomers (those born between 1946 and 1964), who are growing older and coming to an age when the disease most commonly strikes.

What is Alzheimer's disease?

Alzheimer's disease is a form of dementia. Little is known about specifically what combination of factors causes Alzheimer's disease, though scientists say genetics, lifestyle and environmental exposures most likely play into it.

Dr. Rebecca Edelmayer, director of scientific engagement for the Alzheimer's Association, explained that three specific brain changes define the disease:

- A protein called amyloid beta builds up in the brain, forming plaques.
- · Another protein called tau also accumulates and forms tangles in the brain.
- · As this happens, the brain's nerve cells die and the brain actually shrinks in size.

The most commonly recognized early symptom is a memory problem, said Jennifer Lepard, the president and CEO of the <u>Alzheimer's Association</u> <u>Greater Michigan Chapter (https://www.alz.org/gmc)</u>, but the disease doesn't always initially present that way.

"Before memory loss, it can even be what we would call an effect on your executive functioning, so it's your ability to process information, make good decisions on complicated factors, planning," she said. "One of the best examples of that is sometimes people begin to have trouble with finances. People who have always paid the bills, run the household budget, all of a sudden can't.

"One of the reasons it's not always easy to see the memory issues up front is it's not always the earliest and most prevalent sign, but also because people that have what are called high cognitive reserves – people who have a lot of education, who maybe had done very demanding jobs in the past and really utilized their brain a lot – are sometimes very good at hiding symptoms and overcompensating. A lot of times, they know they're having some memory issues and some problems, but they are pretty good at making sure that you don't see it."

More: <u>Algae toxin may be causing Alzheimer's in dolphins. Illness could signal risks for humans (/story/news/nation/2019/03/29/common-florida-algae-causing-alzheimers-disease-in-dolphins/3314048002/)</u>

As the disease progresses, there can be confusion about time and place, difficulty speaking and writing, poor judgment, changes in mood and personality, aggression and agitation and being unable to recognize loved ones, according to the Alzheimer's Association. Eventually, people lose the ability to speak, walk, sit and even to swallow.

"Anyone with a brain, when they get older, is at risk of developing Alzheimer's," Lepard said. "There are a number of people that think, 'Well, it wasn't in my family, so I'm sure I don't have it.' And that is not the case."

Although the majority of people who get Alzheimer's disease are 65 and older, Feldman said it's also important to understand that Alzheimer's is not a normal part of aging, and it does also sometimes occur in younger people. About 200,000 Americans under the age of 65 have early-onset Alzheimer's disease, she said.



"Other risk factors include your family history (especially if a first-degree relative has had Alzheimer's disease), type 2 diabetes and obesity, high blood pressure, previous brain trauma, and your APOE-e4 status – this is the first risk gene identified and remains the gene with strongest impact on risk," Feldman said.

Women, too, are at greater risk. As are people of African American and Latino descent.

Alzheimer's costly toll

The average person with Alzheimer's disease will live four to eight years after diagnosis, said Lepard, and about 40% of that time, the person will be in the most severe form of the disease, which requires around-the-clock care.

Dr. Eva Feldman, a University of Michigan neurologist, professor and director research for the university's ALS Clinic. (Photo: Scott C. Soderberg, University of Michigan Photography)

"So, if you take a person who lives eight years after diagnosis, for three of those years, that person will be in the most severe aspects of the disease and will need 24-hour care and have lost most of their ability to keep up with the activities required in daily living," Lepard said.

The intensity of care that people need when the disease has progressed that far is often beyond what their loved ones can handle, she said. Plus, families quickly see how expensive long-term care can be. The average cost to

Medicare for a single person with dementia in 2018 was \$27,244, according to the Alzheimer's Association.

Caring for people with Alzheimer's disease and other forms of dementia will cost \$290 billion this year alone. But by 2050, that cost is expected to rise to \$1.1 trillion annually. It's the most expensive disease in America – with care costing more than cancer and heart disease, the Alzheimer's Association reports.

"We really see this bankrupting Medicare at some point," Lepard said. "When we talk to members of Congress about the situation and why we need to invest in more research, it's because people cannot afford long-term care.

"Many people, until they are in the situation of needing long-term care, really don't understand how it's funded. They think well, if I have Medicare, I'm sure it's going to cover it all. That's not really how long-term care is paid for."

The cost goes far beyond dollars and cents, Feldman said.

"That's a drain like you can't imagine," she said. "There's an economic drain, a drain on those individuals' ability to work and be productive in society, a medical drain in terms of the cost to take care of the patient. But then, in my mind having lived it – and it's not quantifiable necessarily in terms of dollars – is the emotional toll that it takes not only on the patient but on the family.



Dr. Eva Feldman is photographed with her parents, George and Margherita Feldman. (Photo: Feldman family photo)

"I saw whole families fall apart in that memory care unit. I saw other families come closer together. I think most families ... take care of their loved one absolutely as long as they can ... because you see the essential spirit and essence of the person, but they're missing that one piece, the memory.

"It is the loss, really, of the person that you know right in front of your eyes, and to see what that did to wives and husbands was eye-opening to me. It is cruel, and it is very, very difficult as the primary family member to lose the person you know."

More: <u>Alzheimer's, dementia and caregiving: 5 ways to manage stress, avoid family strife (/story/news/nation/2018/10/25/families-battling-dementia-alzheimers-stress-tips-coping/1730576002/)</u>

Rising numbers, more research dollars needed

Although the number of Americans with the disease is rising, Alzheimer's true toll still may be underestimated. The Centers for Disease Control and Prevention (https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm) reports that often when people with Alzheimer's disease die, the cause of death listed on their death certificates may be pneumonia, heart attack or stroke; it sometimes isn't noted that the patient also had Alzheimer's disease.

"It was very common – it's getting better now – that someone would be in the late stages of Alzheimer's disease and their body is not functioning," Lepard said. "They would develop pneumonia and die. Did they die because they developed pneumonia or did they die because they had Alzheimer's? Our argument is that they are dying because they had Alzheimer's disease.



Jennifer Lepard, president and CEO of the Alzheimer's Association of Greater Michigan. (Photo: Alzheimer's Association of Greater Michigan)

"More and more, it is being put on death certificates if not as the main cause, it might be listed as pneumonia as a result of Alzheimer's disease. We are pushing ... for that," she said, because it creates a more accurate picture of just how huge its reach truly is."

Without an accurate idea of the scope of the problem, health officials and public policy makers are less likely to give it the attention and research dollars needed to find new and better treatments, she said.

The National Institutes of Health allocated \$2.3 billion for Alzheimer's disease research this year, which is up significantly from the \$500 million that was awarded six years ago.

"That sounds like a tremendous amount of money, but it is still much less than NIH spends on AIDS, heart disease or cancer," Lepard said. "Of course, we do not want less to be spent on those diseases, but we do believe that so much progress has been made on those diseases because they have been investing the research money to do it. That's our biggest ask."

Although some treatments can help people with mild or moderate Alzheimer's disease in the short-term, no treatments have yet been discovered that are effective long-term in stopping brain degeneration or reversing memory loss. There is no cure for the disease.

"Just like every disorder, the more we can understand, the more awareness, and the more governmental input we can have and research dollars," Feldman said. "There are so many unanswered questions and we really do need to continually do active research in this area and try to develop therapeutics."

More: A blood test may detect whether Alzheimer's will develop 16 years before symptoms show, study says (/story/news/health/2019/01/22/alzheimers-could-predicted-up-16-years-ahead-symptoms-study/2651012002/)

Among them, Feldman said, is whether the disease could be treated earlier – before symptoms develop – with lifestyle changes, immunotherapy or a vaccine (https://www.medicalnewstoday.com/articles/323734.php).

The scientists in Feldman's lab are working to develop a breakthrough treatment using enhanced lines of human neural stem cells to reduce the buildup of amyloid plaques to improve memory and learning deficits.

"We recently received a grant from the National Institute on Aging to determine exactly how these stem cells impact (Alzheimer's disease) and improve memory," she said.

She is fascinated, too, by the power of music to stir remembrances in people who have Alzheimer's disease.

"My mother was born and raised in Italy, and toward the end, she wasn't really speaking a great deal," Feldman said. She'd speak to me and have conversations, but she was definitely declining."



Dr. Eva Feldman and her brother, George Feldman sit on the lap of their mother, Margherita Feldman. (Photo: Feldman family photo)

One evening, Feldman recalled taking her mother to a sing-along at the assisted living center. A musician sang many old-fashioned, well-known songs like "A Bicycle Built for Two."

"Since my mom didn't grow up here as much in her early life, she didn't know some of the songs the other residents knew," she said. But then, "the guy started singing a song in Italian. My mom's eyes lit up, and she sang the entire song with him. And I looked at her, and she gave me a big smile, and then she kind of went back" into herself, and the memory faded once again.

"I saw that many times with music among the other residents. ... So, you know, it's very interesting how music activates the mind. There are still parts of the brain that are working, and a lot of them still have their essential personalities. They just lost their memories. There are so many unanswered questions."

Feldman, whose mother died in March 2018, said it's hard to pinpoint what is most important moving forward.



Margherita Feldman was 18 when this photograph of her sitting on a bench in Italy after World War II. (Photo: Feldman family photo)

"As a doctor, I will tell you that early diagnosis, lifestyle intervention (diet/exercise), ensuring optimal care, safety and quality of life for the patient is the most important thing," she said. "As my mother's daughter, I will tell you that remembering that the person affected may have lost their memory, but not their spirit, or some would say, their soul."

Follow Kristen Jordan Shamus on Twitter: @kristenshamus.

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