



Why aren't doctors giving patients Alzheimer's diagnoses?

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Chicago, March 24, 2015 – The Alzheimer's Association's *2015 Alzheimer's Disease Facts and Figures* report, released today, found that only 45 percent of people with Alzheimer's disease or their caregivers say they were told the diagnosis by their doctor. In contrast, more than 90 percent of people with the four most common cancers (breast, colorectal, lung, and prostate cancer) say they were told the diagnosis.

"These disturbingly low disclosure rates in Alzheimer's disease are reminiscent of rates seen for cancer in the 1950s and 60s, when even mention of the word cancer was taboo," said Beth Kallmyer, MSW, Vice President of Constituent Services for the Alzheimer's Association. "It is of utmost importance to respect people's autonomy, empower them to make their own decisions and acknowledge that people with Alzheimer's have every right to expect truthful discussions with their physicians. When a diagnosis is disclosed, they can better understand the changes they are experiencing, maximize their quality of life, and often play an active role in planning for the future."

The 2015 Facts and Figures report also found that people with Alzheimer's or their caregivers were more likely to say they were told the diagnosis by their doctor after the disease had become more advanced. According to Kallmyer, this is a problem because learning the diagnosis later in the course of the progressive brain disease may mean the person's capacity to participate in decision making about care plans, or legal and financial issues, may be diminished, and their ability to participate in research or fulfill lifelong plans may be limited.

One of the reasons most commonly cited by health care providers for not disclosing an Alzheimer's diagnosis is fear of causing the patient emotional distress. However, according to the new report, "studies that have explored this issue have found that few patients become depressed or have other long-term emotional problems because of the [Alzheimer's] diagnosis."

Benefits of Disclosing an Alzheimer's Diagnosis

According to the Alzheimer's Association, telling the person with Alzheimer's the truth about his or her diagnosis should be standard practice. Disclosure can be delivered in a sensitive and supportive manner that avoids unnecessary distress.

"Based on the principles of medical ethics, there is widespread agreement among health care professionals that people have the right to know and understand their diagnosis, including Alzheimer's disease," said William Klunk, M.D., Ph.D., Chair of the Alzheimer's Association Medical and Scientific Advisory Council. "The findings from this report shine a light on the need for more education for medical students and practicing health care providers on how to effectively make and deliver an Alzheimer's diagnosis."

Dr. Klunk is a Distinguished Professor of Psychiatry and Neurology at the University Of Pittsburgh School Of Medicine in Pittsburgh, PA, where he also is Co-Director of the Alzheimer's disease Research Center.

The benefits of promptly and clearly explaining a diagnosis of Alzheimer's have been established in several studies. Benefits include better access to quality medical care and support services, and the opportunity for people with Alzheimer's to participate in decisions about their care, including providing informed consent for current and future treatment plans. Knowing the diagnosis early enables the person with Alzheimer's to get the maximum benefit from available treatments, and may also increase chances of participating in clinical drug trials that help advance research.

The Alzheimer's Epidemic and Its Impact

The 2015 Facts and Figures report provides an in-depth look at the prevalence, incidence, mortality and economic impact of Alzheimer's disease and other dementias – all of which continue to rise at staggering rates as the American population ages.

"Alzheimer's is a triple threat unlike any other disease – with soaring prevalence, lack of effective treatment and enormous costs. Promising research is ready for the pipeline, but there's an urgent need to accelerate federal funding to find treatment options that effectively prevent and treat Alzheimer's. Congress must continue its commitment to the fight against Alzheimer's by increasing funding for Alzheimer's research by \$300 million in fiscal year 2016, including increased federal research funding for better Alzheimer's diagnostic tools to increase the certainty of diagnosis," Kallmyer said.

Prevalence, Incidence and Mortality:

- According to the report, an estimated 5.3 million Americans have Alzheimer's disease in 2015. This includes an estimated 5.1 million people age 65 and older, and approximately

200,000 individuals under age 65 who have younger-onset Alzheimer's. Barring the development of medical breakthroughs, the number will rise to 13.8 million by 2050.

- Almost half a million (approx. 473,000) people age 65 or older will develop Alzheimer's in the U.S. in 2015. Every 67 seconds, someone in the U.S. develops Alzheimer's. By mid-century, an American will develop the disease every 33 seconds.
- Two-thirds (3.2 million) of Americans over age 65 with Alzheimer's are women.
- Alzheimer's disease is the sixth-leading cause of death in the U.S., and the fifth-leading cause of death for those age 65 and older. From 2000-2013, the number of Alzheimer's deaths increased 71 percent, while deaths from other major diseases decreased.
- Heart disease deaths decreased 14 percent; stroke deaths, 23 percent; HIV deaths, 52 percent; prostate cancer deaths, 11 percent; and breast cancer deaths, 2 percent.

Costs and Financial Impact:

- Alzheimer's is the costliest disease to society. Total 2015 payments for caring for those with Alzheimer's and other dementias are estimated at \$226 billion, of which \$153 billion is the cost to Medicare and Medicaid alone.
- Total payments for health care, long-term care and hospice for people with Alzheimer's and other dementias are projected to increase to more than \$1 trillion in 2050 (in current dollars).
- In 2014, the 15.7 million family and other unpaid caregivers of people with Alzheimer's disease and other dementias provided an estimated 17.9 billion hours of unpaid care, a contribution to the nation valued at \$217.7 billion (with care valued at \$12.17 per hour).

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Full text of the Alzheimer's Association 2015 Alzheimer's disease Facts and Figures report can be viewed at <http://www.alz.org>. The report will also appear in the March 2015 issue of *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* (volume 11, issue 3), at <http://www.alzheimersanddementia.com>.