

**TESTIMONY OF MAX RICHTMAN, PRESIDENT AND CEO
NATIONAL COMMITTEE TO PRESERVE SOCIAL SECURITY AND MEDICARE**

**UNITED STATES SENATE SPECIAL COMMITTEE ON AGING
HEARING ON “ALZHEIMER’S DISEASE: A BIG SKY APPROACH TO A
NATIONAL CHALLENGE”**

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My name is Max Richtman, and I am the President and Chief Executive Officer of the National Committee to Preserve Social Security and Medicare in Washington, DC. The National Committee is a grassroots advocacy and education organization dedicated to preserving and strengthening safety net programs, including Social Security, Medicare and Medicaid.

In my current position and as a former Staff Director of the Senate Special Committee on Aging, I especially appreciate the opportunity to testify today. I commend Chairman Bill Nelson, Ranking Member Susan Collins, Senator John Walsh and other members of the Aging Committee for holding this field hearing on Alzheimer’s disease and related dementias. The Senate Aging Committee has a long history of highlighting the need to combat Alzheimer’s disease and to provide assistance to family members and friends who are caring for someone with this devastating illness.

Many of us are aware of the great human and financial costs of Alzheimer’s disease (AD) because we have family members or friends who are victims of AD or are caregivers for someone who is. The financial implications of Alzheimer’s disease and related dementias on our nation’s health care system, particularly the Medicare and Medicaid programs, which I have been asked to address, are also great. Without a cure for Alzheimer’s disease, the cost of providing services to this population has the potential to consume federal and state health care budgets. My remarks include a brief discussion of the rising prevalence and cost of caring for people with Alzheimer’s disease and related dementias, followed by recommendations for meeting these challenges.

Prevalence of Alzheimer’s Disease

The number of people suffering from Alzheimer’s disease or a related dementia is expected to skyrocket over the next few decades because people are living longer and the incidence of Alzheimer’s disease increases with age. According to the Alzheimer’s Association¹, currently

¹ Unless otherwise noted, the statistics referenced in this testimony are from the Alzheimer’s Association report: 2014 Alzheimer’s Disease Facts and Figures. http://www.alz.org/downloads/facts_figures_2014.pdf

there are over five million Americans, aged 65 and older (1 in 9), living with Alzheimer's disease or a related dementia. This number is expected to climb to as many as 16 million by 2050. It is estimated that by 2030, a person in the United States will be diagnosed with Alzheimer's disease or a related dementia every 33 seconds.

Montana will face a significant rise in the number of people with Alzheimer's disease. In 2014, there are 18,000 older adults living with Alzheimer's disease or a related dementia in the state. By 2015, this number is estimated to increase by 50 percent to 27,000 individuals.

The Cost of Alzheimer's Disease

As more people are diagnosed with Alzheimer's disease and related dementias, the cost to care for this population dramatically increases. In 2014, the cost of caring for people with Alzheimer's disease is estimated at \$214 billion; by 2050, it will reach \$1.2 trillion. This does not include the unpaid services provided by 15 million caregivers. In 2013, this cost for unpaid caregiving was valued at \$220.2 billion. In Montana alone, 48,000 caregivers provided 54 million hours of unpaid care to people with Alzheimer's disease and related dementias, valued at \$677 million.

The Medicare and Medicaid programs cover about 70 percent of the cost of caring for people with Alzheimer's disease and related dementias. In 2014, these two programs will spend an estimated \$150 billion for health, long-term care and hospice care for people who have dementia and related disorders. And it is important to keep in mind that even with Medicare and Medicaid, individuals with Alzheimer's disease and related dementias pay high out-of-pocket costs for premiums and cost sharing as well as for health services not covered by public or private insurance. Costs are especially high for custodial care, which is not covered by Medicare and is only covered by Medicaid for low-income individuals. The out-of-pocket cost for treating Alzheimer's patients in 2014 is estimated to be \$36 billion.

Medicare and Medicaid

Despite the fact that Medicare does not pay for custodial care, Medicare spending is impacted by Alzheimer's disease. It is estimated that Medicare spending per person is three times more (\$21,095 vs. \$8,005 in 2013) for beneficiaries with Alzheimer's disease and related dementias than for beneficiaries without these diseases. These additional costs are due to the fact that people with Alzheimer's disease have more hospital stays, skilled nursing facility care, home health visits and hospice care than other Medicare beneficiaries. In addition, individuals with serious medical conditions such as coronary artery disease, diabetes, chronic kidney disease, chronic obstructive pulmonary disease, stroke and cancer who also have dementia use more health care services than people with these medical conditions without dementia.

Twenty-nine percent of older adults with AD and other dementias are dually eligible for Medicare and Medicaid, compared to 11 percent for those without dementia. About 1.5 million

people with dementia benefit from the Medicare payment assistance with co-pays and premiums that Medicaid provides to low-income beneficiaries.

Medicaid, which is a joint federal and state program, provides health insurance coverage to multiple low-income populations, assistance to low-income Medicare beneficiaries, long-term services and supports to seniors and people with disabilities and support to safety net hospitals and health centers. Some states receive home- and community-based waivers that allow them to provide additional resources to help seniors live in the community.

Individuals with Alzheimer's disease and related dementias rely heavily on Medicaid services. This is, in part, because the majority of nursing home residents (about two-thirds) have some form of cognitive impairment. In 2014, per person Medicaid spending for Alzheimer's disease and other dementias is, on average, about 19 times higher (\$10,771) than Medicaid spending (\$561) for people without dementia.

In 2014, Medicaid will spend about \$37 billion for people with Alzheimer's disease and related dementias. By 2050, Medicaid expenses for this population are expected to climb by almost 400 percent, reaching \$172 billion in 2050. These costs are likely to overwhelm many state Medicaid budgets.

Senate Special Committee on Aging

In 1983, the Senate Special Committee on Aging held a field hearing entitled, "Endless Night, Endless Mourning: Living with Alzheimer's."² The focus of the hearing was on caring for people with Alzheimer's disease but the Senators and witnesses discussed the same wide array of issues we are grappling with today – the need for increased funding for Alzheimer's research, how to pay for custodial long-term care and education and training for professional and family caregivers, and social supports for Alzheimer's victims and family caregivers.

Thirty years ago, when this hearing was held, we knew very little about Alzheimer's disease. Since then, research supported by the National Institute on Aging and other organizations has deepened our understanding of the disease and improved diagnosis. In addition, support for families and caregivers has improved.³

While I acknowledge and commend the progress that has been made, we are still waiting for a cure and/or a way to prevent Alzheimer's disease. At the Aging Committee's 1983 hearing, then-Senator Larry Pressler of South Dakota stated, "The point is, if we could find a cure or a treatment for this disease, we could save a lot of money, besides preventing the tragic losses involved."

² U. S. Senate Special Committee on Aging, Hearing on "Endless Night, Endless Mourning: Living with Alzheimer's." New York, NY, September 12, 1983. <http://files.eric.ed.gov/fulltext/ED246344.pdf>.

³ Alzheimer's Disease Fact Sheet, Alzheimer's Disease Education and Referral (ADEAR) Center, National Institute on Aging, National Institutes of Health, U. S. Department of Health and Human Services. September 2012. http://www.nia.nih.gov/sites/default/files/alzheimers_disease_fact_sheet_0.pdf.

Without a cure for Alzheimer's disease and related dementias, millions of Americans will continue to suffer the devastating effects of these illnesses into the foreseeable future. Not only does this take a huge emotional toll on their lives, but it also places a severe financial burden on them and their families, and on the Medicare and Medicaid programs.

Recommendations

The National Committee to Preserve Social Security and Medicare urges Congress to adopt the following recommendations to help meet the challenges that Alzheimer's disease presents and to lessen the economic impact it has on families and government programs:

- **Invest more federal funds into Alzheimer's disease research to find a cure and/or a way to slow down the progression of the disease.** This would save millions of lives and curb rising Medicare and Medicaid costs associated with Alzheimer's disease and other dementias.
- **Build on the reforms in the Affordable Care Act (ACA) that contain costs and promote access to high-quality care.** This includes coordinated care, such as Accountable Care Organizations and medical homes, which improve care for beneficiaries with multiple chronic conditions including Alzheimer's disease. The National Committee believes we can strengthen Medicare's financing and improve the quality of care provided without cutting benefits.
- **Establish a long-term services and supports social insurance program.** People need assistance in paying for custodial care without having to impoverish themselves or their spouses.
- **Encourage states to expand their Medicaid programs under the Affordable Care Act.** Expansion would benefit younger seniors under age 65, enabling low-income people diagnosed with early onset dementia to receive Medicaid benefits.
- **Provide caregiver credits under Social Security.** Temporary interruptions in a person's participation in the labor force to care for an individual with Alzheimer's disease can result in a reduction of Social Security benefits upon retirement. Providing caregiver credits would help make up for the time family members are away from employment for their caregiver duties by increasing their Social Security benefits.
- **Boost Social Security benefits; do not cut them.** In addition to helping individuals, it is important to recognize the positive economic impact Social Security has on state and local economies, including Social Security payments that go toward helping pay the cost of in-home or institutional care that is not covered by Medicare or Medicaid.

Thank you for the opportunity to testify today on the important topic of combating Alzheimer's disease for both humane and financial reasons. These issues and all they encompass are critically important to the millions of members and supporters of the National Committee to Preserve Social Security and Medicare and to all Americans.