Senate Special Committee on Aging
Alzheimer's Disease: A Big Sky Approach to a National Challenge

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Good morning Chairman Walsh and distinguished members of the Senate Special Committee on Aging. I am Patricia Jay Coon, MD, a physician who has practiced geriatric medicine for nearly thirty years, the majority at the Billings Clinic in the frontier state of Montana. I also serve as co-chair of the Montana Alzheimer's/Dementia Work Group. A state-wide work group established this year with the goal of improving the lives of individuals in Montana with Alzheimer's disease and other dementias and to provide better support for their families and caregivers. It is an honor to be here today to discuss our efforts and the challenges we face caring for individuals with this devastating disease.

Framing the Dialog: The Alzheimer 's Disease Epidemic

Alzheimer's disease is likely one of the most significant public health crisis of our generation. It is a progressive and ultimately fatal neurologic disorder and is the sixth leading cause of death in the United States. It is the second most feared disease, second to cancer. But unlike the other top 10 leading causes of death in our country, e.g., heart disease, cancer, diabetes, Alzheimer's disease is the only one without a way to prevent or cure it. There are no effective treatments at this time. Yet, at present, federal funding for Alzheimer's disease research is substantially less that that for cancer and cardiovascular research. As a health care provider and a resident of the U.S, this is very concerning to me for the following reasons.

Alzheimer's disease is already a common medical condition but the number of Americans with the disease is rapidly growing. Currently more than 5 million Americans are living with this incurable condition. This number is estimated to triple by 2050. In Montana, 11% of our seniors live with the disease and by 2025 the number of individuals is expected to grow by 50%. Given the slow, insidious nature of this disease, on average individuals with Alzheimer's survive four to eight years after diagnosis; but some live as long as 20 years. Much of this time is spent with significant mental and physical disability and dependence.

Not surprisingly, Alzheimer's disease takes a significant toll on caregivers and families - physically, emotionally, and financially. Former President Ronald Reagan's daughter, Patti Davis, described losing her father to Alzheimer's disease as "The Long Goodbye". Families and friends say goodbye to an individual slowly over time as the disease gradually steals aware his/her memory and cognitive functioning. In the most severe stage of the disease, nursing home placement is almost inevitable given the high cost and resources needed to keep someone in their home.

The financial burden of Alzheimer's disease and other dementias is high at an individual, family, state, and national level. Alzheimer's disease is one of the costliest chronic diseases to our society. According to the Alzheimer's Association, the national cost of caring for people with Alzheimer's and other dementias will reach $214 billion in 2014. Of these costs, it's estimated that Medicare and Medicaid will pay $150 billion (70%) for health care, long term care and hospice. The average per-person payments for health care services, e.g., hospital, nursing home, health care providers, are higher for Medicare beneficiaries with dementia than for those without dementia. The out-of-pocket spending for individuals with dementia and their families is expected to be $36 billion this year.

The national annual cost for caring for these individuals is rapidly increasing and is projected to reach $1.2 trillion by 2050. Unless we change the trajectory of Alzheimer's disease, the economic burden of this disease stands to overwhelm us all. I applaud the steps the federal government has taken in recent years to address this, including Congress passing the National Alzheimer's Project Act which led to the creation of the *National Plan to Address Alzheimer's Disease* by U.S. Department of Health and Human Resources in 2012. The Plan is designed to help those with the disease, their families, and caregivers today and work toward changing the trajectory of the disease in the future. But more is needed if we, as a nation, want to prevent and effectively treat the disease by 2025.

Meeting the Needs of Individuals with Alzheimer's disease, Families, Caregivers, and Providers in Frontier Montana.

While working towards changing the trajectory of the disease in the future, we need, at a community-, state-, and national-level, to deliver better care and support to individuals suffering with Alzheimer's disease and their families and caregivers today. As a physician who has practiced geriatric medicine for nearly thirty years, I continue to see the devastating effects of Alzheimer's disease and other dementias on my patients and their families and caregivers. I've watched health care providers, hospitals, medical clinics, community nursing homes and assisted living facilities and patient advocacy groups struggle to provide the comprehensive quality care and services these individuals and families require and deserve. Given the slow, progressive nature of this disease with its associated cognitive and physical disability and psychosocial issues, "it will take a village" to accomplish this. We need to develop effective, dementia-capable systems at the health care organization-, community-, and state-levels and find new strategies to provide high quality coordinated care, services, and programs to these individuals and their families and caregivers.

To help achieve this here in Montana, a number of concerned and motivated individuals have formed the Montana Alzheimer's/Dementia Work Group. This state-wide "grassroots" effort consists of a diverse group of individuals from across the state representing multiple industries or stakeholder groups including the National and state Alzheimer's Associations, Montana Office on Aging and other government agencies, patient advocacy groups, patient advocates (caregivers), Assisted Living/Long-Term Care, senior services groups, regional healthcare organizations and providers, educators, and researchers.

The Work Group has tasked itself with identifying the challenges and gaps Montanans face when dealing with Alzheimer's disease and estimating its economic impact on our state. Using this information, over the next 12 – 18 months, we plan to develop a comprehensive Montana Alzheimer's Disease State Plan. This plan will serve as a state-specific roadmap to help inform our state government on critical dementia issues across the state. It will also provide a set of recommendations on how to improve and support Alzheimer's disease care and services and will outline what steps our state should take over a given timeframe to achieve key recommendations. Given the current and future impact of Alzheimer's disease on our state budget, e.g., Medicaid, we feel that developing and implementing a well-formulated state plan now will move Montana towards becoming a dementia-capable state and prepare us for the sweeping economic and social impact Alzheimer's disease will have on us all going forward.

To be prepared for the Alzheimer's disease public health crisis, Montana faces the same challenges as other states in the union. Alzheimer's can no longer be the "silent" or "hidden" disease. We need to increase public awareness about Alzheimer's and encourage early detection and diagnosis. We need to deliver community-based and residential dementia care services in an equitable, cost-effective manner. There needs to be better support for family caregivers to help alleviate their burden. Training programs for all health care providers, e.g., physicians, nurses, nurse practitioners, emergency department personnel, nursing home and assisted living staff, with a standardized curriculum need to be developed to ensure providers have the skills necessary to deliver coordinated dementia-capable care. In partnership with our federal and state governments and key stakeholders, we need to create "dementia-friendly" communities that locally provide high quality coordinated care, services, and programs to individuals with Alzheimer's and their families and caregivers.

Montana also faces unique challenges. Given its large land mass and small population, it is not only a rural state but also a frontier state. Rural and frontier communities struggle to recruit and retain primary care providers. They lack the community-based and residential dementia care services found in larger communities. For decades, one of our state's biggest exports has been its youth. This affects the availability of local family support to help someone inflicted with Alzheimer's. To ensure their care needs are met, many will need to be admitted to a local nursing home or leave their community to be closer to family. There is also a shortage of geriatric specialists across the state. Our work group and state will need to consider these unique challenges as we develop and implement an Alzheimer's Disease State Plan.

Conclusion

I would like to thank the Committee again for the opportunity to testify today and talk about our Montana Alzheimer's/Dementia Work Group initiative. I appreciate your interest in and efforts to address Alzheimer's disease going forward. It is clearly a prevalent, costly, devastating condition with high morbidity and mortality. If the trajectory of the disease is not altered, by mid-century the economic and societal impact of this disease will be overwhelming. Likely all of us and our children will be impacted by it. Working in partnership, we all need to do what is necessary to achieve the goal of the National Plan to Address Alzheimer's Disease – to prevent and effectively treat Alzheimer's disease by 2025. As a physician who provides medical care for these individuals, I look forward to the day when I can offer effective preventive treatment options to my patients and their families. Thank you again for your time.

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