Alzheimer’s disease is a devastating disease and a growing health crisis of the 21st century. It affects Americans in all walks of life and across all regions of the country. As many as 5.4 million Americans currently have Alzheimer’s disease and by 2050, 16 million will be struggling with it. (1) Alzheimer’s destroys a person’s memories, judgment, and independence. It robs families of their loved ones. It creates stress and hardships for caregivers and depletes millions of dollars annually from state and federal budgets. The Alzheimer’s Association has made a “call to states” to make Alzheimer’s a policy priority. Idaho does not currently have a public policy plan to address Alzheimer’s disease and needs to take action in order to reduce the burden of Alzheimer’s on patients, families, caregivers, and the government.

**Background**

**An Overview of Alzheimer’s Disease.** Alzheimer’s disease is the most common form of dementia among the elderly, but it is not a normal part of aging. Alzheimer’s makes it difficult for people to care for themselves. It affects thought, memory, and language. The cause is unknown, but the most important risk factors are age, family history, and heredity. One cannot change these risk factors, but can influence other risks, including high blood pressure, heart disease, stroke, diabetes, and high cholesterol. Evidence suggests that strategies for overall healthy aging may keep the brain and body fit and protect against Alzheimer’s disease.

Approximately 5.4 million Americans, including 26,000 Idahoans, have Alzheimer’s. (2) It can afflict younger people, but is much more common after the age of 60, and the risk continues to go up with age. One in eight Americans 65 and older has Alzheimer’s disease and
nearly half of those 85 and older has it. It is projected that by 2050, 16 million Americans will have Alzheimer’s disease. The influx of baby boomers who are just starting to reach retirement age account for this sharp increase. Two thirds of all Alzheimer’s patients are women. Most people live 4-8 years after an Alzheimer’s diagnosis, but some live much longer. There is currently no cure for Alzheimer’s disease. (1)

Cost to Individuals, Families, Communities, and the Government. Alzheimer’s disease exacts a high cost mentally, emotionally, physically and monetarily. Caregivers and patients both suffer. About three-fourths of people with Alzheimer’s disease live at home where friends and family care for them. (3) In 2010 there were over 73,000 unpaid caregivers in Idaho. Sixty percent of Alzheimer patient caregivers rate their emotional stress as high or very high and one-third exhibit symptoms of depression. (2) Common behaviors of persons with Alzheimer’s include aggression, threats (verbal and physical), sexual inappropriateness, paranoia, delusions and hallucinations. (4) Caregivers struggle to manage loved ones exhibiting these difficult behaviors.

The government, communities and families all bear the monetary cost of Alzheimer’s patient care. In 2011 Alzheimer’s disease cost Americans $183 billion. Of this, Medicare paid $93 billion, Medicaid paid $37 billion, citizens paid $31 billion, and other sources paid $22 billion. Americans will pay the skyrocketing cost of $1.1 trillion by 2050. (2) When caregivers become unwilling or unable to serve Alzheimer patients at home, state and federal budgets often pay the cost of long term care after the person with Alzheimer’s has exhausted their financial resources. About one half of all Medicaid beneficiaries with dementia are nursing home patients, costing an average of $70,000 per year per patient. (5) Treatment that delays the onset of Alzheimer’s by five years could reduce the government’s spending on Alzheimer’s patients by
Government sponsored support of caregivers could also reduce government spending as more Alzheimer’s patients are able to remain in their homes.

Families and the government are not alone in shouldering the rising cost of Alzheimer’s care. Businesses pay in lost productivity as many employed caregivers must miss work, reduce their work hours or change jobs. Caregivers are often at risk for losing their jobs, health insurance and long term financial resources as they struggle to manage the unpredictable burdens of caring for a loved one with Alzheimer’s disease. (7)

**Landscape**

Alzheimer’s legislation is relatively new on the national and state levels. It continues to gain attention and support with the increasing number of people diagnosed with Alzheimer’s disease and the notoriety of some of these patients. Sandra Day O’Conner, who left the Supreme Court in 2006 to care for her husband who was suffering from Alzheimer’s, explained to the Senate Special Committee on Aging, “Until you have actually stared Alzheimer’s in the face...you cannot truly understand the deep sense of frustration, fear, helplessness and grief that accompany it.” (8) The federal government has introduced three different pieces of legislation dealing with Alzheimer’s disease since 2010. More than 35 states either have Alzheimer’s plans in place or their legislatures are currently creating Alzheimer’s plans. Idaho is not one of these.

**National Legislation.** William Theis, the chief medical and scientific officer of the Alzheimer’s Association explains, “The discovery of effective treatments is the best hope to change the trajectory of Alzheimer’s.” (6) The National Institute of Health (NIH), the nation’s largest funder of biomedical research, annually spends approximately $6 billion on cancer research, $4 billion on heart disease, $3 billion on HIV/AIDS and only $480 million on Alzheimer’s research. (9) To address this disparity, Representatives Christopher Smith (R-NJ)
and Edward Markey (D-Mass) introduced The Alzheimer’s Breakthrough Act of 2011 which is currently in committee. It aims to strengthen and increase the federal government’s commitment to Alzheimer’s research by funding $2 billion annually at the NIH. (6)

Representatives Christopher Smith (R-NJ), Edward Markey (D-Mass), Michael Burgess (R- Texas) and Jim McDermott (D- Wash) introduced The Health Outcomes, Planning and Education (H.O.P.E.) for Alzheimer’s Act (H.R. 1386) in April of 2011. If it passes, it will provide Medicare coverage for comprehensive diagnosis so patients showing signs of dementia can receive a formal diagnosis, helping to improve their care and reducing cost by providing information and resources. (10)

President Barak Obama signed into law The National Alzheimer’s Project Act (NAPA) on January 4, 2011. NAPA establishes the Office of the National Alzheimer’s Project and will create a strategic plan to address the rapidly escalating Alzheimer’s crisis. (11) Thousands of Alzheimer’s caregivers have turned out at public meetings and over 32,000 participated in a “telephone town meeting” sponsored by the Alzheimer’s Association in August of 2011, voicing their opinions of what should be included in the national plan. (12)

**State Alzheimer’s Plans.** The formulation of state Alzheimer’s plans is fairly new. Iowa became the first state to deliver a comprehensive state plan to confront Alzheimer’s disease in January of 2008. (13) Thirty-five states currently have plans in place or are working to develop plans to deal with the growing Alzheimer’s crisis. Colorado is the only nearby state with a functioning Alzheimer’s plan. (3)

Utah, a bordering state, enacted S.B. 48 on March 10, 2011. This bill created a 20 member task force to address Alzheimer’s and other dementias in Utah. The task force assessed
the current and future impact of Alzheimer’s disease in Utah and developed recommendations for a November 2011 report. (14)

The state plans address a variety of issues dealing with Alzheimer’s disease. Colorado identified the lack of dementia specific training for health care workers, facility staff and family care givers as one of their biggest concerns. (3) Other states, including Illinois and California, also tackled this issue in their plans. Illinois recommended the establishment and initiation of required basic specialized and periodic education and training for persons throughout the state whose responsibilities make it likely they will work with people with Alzheimer’s disease. These states concluded that dementia training is critical because of the unique nature of symptoms and management of Alzheimer’s disease. (4)

States also identified the need of caregiver support as one of their priorities. California established a comprehensive approach to support family caregivers, acknowledging and investing in them as vital participants in Alzheimer’s patient care. (7) Illinois is spending resources on adult day cares, respite services, support services and financial assistance for unpaid caregivers. (4) Colorado is increasing visibility and utilization of programs already available for Alzheimer’s patients and caregivers. They plan to collaborate with and leverage national Alzheimer’s Association public awareness campaigns through local radio and television programs. (3)

State Alzheimer’s plans tackle many other issues, including, but not limited to funding and promoting Alzheimer’s research at state institutions, creating statewide lists of attorneys willing to provide pro bono or reduced fee services to Alzheimer patients and their families, providing scholarship and loan repayment for students in geriatric programs willing to work in rural areas, and encouraging early diagnosis of the disease.
**Where does Idaho stand?** The Idaho State Legislature does not have an Alzheimer’s plan in progress; however, on March 30, 2011, The Idaho Alzheimer’s Planning Group (IAPG) made a presentation to Idaho’s House and Senate Health and Welfare Committees advocating that the state elevate Alzheimer’s disease and other dementia’s to a public policy priority. (15) With donated resources, IAPG is moving ahead to determine in general what an Alzheimer’s plan should look like. IAPG will work for several years to gather information and put together a proposal. When developed, their plan should provide legislators with concrete steps to move forward in developing a state Alzheimer’s plan.

Although Idaho does not have a state Alzheimer’s plan, the Idaho Commission on Aging (ICOA) administers state and federally funded services for the elderly, including Alzheimer’s patients. They plan and coordinate funds and monitor statewide programs to address present and future needs of older Idahoans. They receive federal funds through the Older Americans Act and state funding supported by Idaho Senior Services Act. Six geographically situated Area Agencies on Aging (AAA) plan, develop and deliver services throughout the state. ICOA oversees the programs that fund services managed by the AAAs then reports federally and to the Governor and Legislature on these programs. Each of Idaho’s AAAs is required to directly provide certain core programs: Information and Assistance, Case Management, Ombudsman, and Adult Protection. The AAAs contract with local community service providers to deliver other services. These services include, but are not limited to: Home-Delivered Meals, Congregate Meals, Family Caregiver Support, Transportation, Homemaker, Legal Assistance, and Respite.(16) Many of these services benefit Alzheimer’s patients and their caregivers.

ICOA is currently leading a statewide project to provide a free online 6 week training course to caregivers of persons with Alzheimer’s disease – the Building Better Caregivers
Program. The project has funded 9 community events in Idaho to raise awareness about Alzheimer’s disease, support IAPG member Dr. Troy Rohn in educating communities, and support the IAPG in gathering data. (17) Prior to this project ICOA lead a six year project serving persons with dementia, their caregivers, and families.

A Plan for Idaho? The number of people with Alzheimer’s disease and other dementias will continue to grow rapidly in the coming years. Idaho needs to follow the national and state trend to make an Alzheimer’s plan. A state Alzheimer’s plan will provide a comprehensive approach for dealing with the many facts of the Alzheimer’s crisis. It will create the infrastructure and accountability needed to confront the enormous social and economic impact of the disease. The legislature should support the IAPG in their efforts to research and develop a plan that will work for Idaho.

References


