

2014 Alzheimer's Advocacy Day

Message points

- What is Alzheimer's?
 - **Alzheimer's is a type of dementia that causes problems with memory, thinking and behavior.** Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.
 - **Alzheimer's is not a normal part of aging,** although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age. Up to 5 percent of people with the disease have early onset Alzheimer's (also known as younger-onset), which often appears when someone is in their 40s or 50s.
 - **Alzheimer's worsens over time.** Alzheimer's is a progressive disease, where dementia symptoms gradually worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment.
Alzheimer's is the sixth leading cause of death in the United States. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years, depending on age and other health conditions.
 - **Alzheimer's has no current cure, but treatments for symptoms are available and research continues.** Although current Alzheimer's treatments cannot stop Alzheimer's from progressing, they can temporarily slow the worsening of dementia symptoms and improve quality of life for those with Alzheimer's and their caregivers. Today, there is a worldwide effort under way to find better ways to treat the disease, delay its onset, and prevent it from developing.
- What is the difference between Alzheimer's and dementia?
 - **Dementia** is a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 50 to 80 percent of dementia cases.

About the Alzheimer's Association

- Who is the Alzheimer's Association?
 - The Alzheimer's Association Oregon Chapter provides education and support for people diagnosed, their families, and caregivers. From offices in Portland, Bend, Medford, and Eugene, the Oregon Chapter reaches out to diverse communities by providing information and resources, 24/7 telephone help lines, local support groups and educational programs, an annual caregivers conference and a nationwide identification program, MedicAlert + Safe Return, for people with Alzheimer's disease who may wander and get lost.
 - **Our mission**
To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.
 - **Our vision**
A world without Alzheimer's disease.
 - Who funds you?
 - The vast majority (over 90%) of our funding comes from individual donations; the remainder comes from business sponsorships, and a small amount from grants.
 - We are a 501(c)3 tax exempt organization

Why we need to act now

- What is the impact of Alzheimer's in Oregon?
 - As of 2010, approximately 76,000 Oregonians are living with Alzheimer's disease. That's about the same as the entire population of Bend.
 - Currently, approximately 165,000 Oregonians are unpaid caregivers for people with Alzheimer's. Most of these people are family members
 - They provide unpaid care valued at over \$2.2 billion each year
 - The impact of caregiving leads to over \$90 million in higher health care costs due to factors including:
 - Stress
 - Depression
 - Physical impact
 - Alzheimer's costs state government a considerable amount.
 - Oregon's share of Medicaid that goes to serve those with Alzheimer's is estimated at about \$300 million a year
 - Oregon also spends \$9.5 million for Oregon Project Independence (OPI) which probably reduces Medicaid spending
- Alzheimer's dramatically increases the costs to Medicaid and Medicare in part because of inability to manage other conditions like high blood pressure or diabetes.
 - Medicaid is about 19 times higher (in part due to long term care being covered by Medicaid)
 - Medicare is about 3 times higher
- The number of people in Oregon with Alzheimer's is growing quickly – to 110,000 by 2025.

1. Protecting people with Alzheimer's who wander

Sixty percent of people with Alzheimer's disease will wander. People with Alzheimer's may not remember their name or address, and they can become disoriented, even in familiar places. If a person with Alzheimer's wanders and is not found within 24 hours, there is a 60 percent chance that person will die. The risk of death increases to 80 percent if the person is not found within 72 hours. Simply stated, it is dangerous when people with Alzheimer's wander. Thankfully, prevention strategies and services exist.

Language in a bill proposed by Sen. Tim Knopp, SB 1577, would require every Oregon police department and sheriff's office to adopt a formal policy on what to do in cases of people with dementia who wander. The policy must address training of officers, coordination with other agencies, and procedures for working with the media to help find the missing person. We support this element of SB 1577.

2. Creating an office of the Oregon Public Guardian and Conservator

Guardianship and conservatorship are court-ordered protections that are ordered for individuals who are not capable of protecting themselves. When a court finds that a person is incapable of making decisions about his or her own basic health, safety and financial needs such that serious physical injury or illness is likely to occur, a guardianship or conservatorship may be ordered. The basis for incapacity may stem from severe mental health conditions, developmental disabilities and/or age-related conditions.

The Oregon Public Guardian and Conservator will provide needs-based guardian and conservator services for Oregonians who:

- Do not have a friend or relative who is willing or able to assume the duties of guardianship or conservatorship and
- Are assessed to lack the financial resources necessary to obtain a private guardian or conservator.

At-risk adults who are unable to care for themselves are vulnerable to continued abuse or neglect, which can yield various negative consequences, including repeated hospitalizations, stroke, heart attack, malnutrition, commitment to a

psychiatric unit and premature death. To address this problem, many states have developed a “public guardian.” The Alzheimer’s Association supports legislation (SB 1553) to create this resource — and corresponding office — in Oregon.

3. Funding for services for families affected by Alzheimer’s

In September 2013, the Oregon Legislature held a special session that reined in a tax break, which led to about \$26 million in resources set aside for services dedicated to seniors and people with disabilities. We support using some of these funds to help Oregonians affected by Alzheimer’s in the following ways:

a. Caregiver training

- i. *\$1.6 million: Geriatric medication-competency training pilot*
- ii. *\$450,000: Specialized training for professional and family caregivers on best care practices for Alzheimer’s and related dementias*
- iii. *\$400,000: Specialized training for caregivers on challenging behaviors*
- iv. *\$500,000: Specialized first-responder training on Alzheimer’s and related dementias \$350,000: Enhancing access to caregiver training statewide*

b. Public Guardianship program

- i. *\$925,000: Expansion of State Ombudsman office to manage Public Guardianship program and increase legal assistance*

c. Data, research, pilot projects

- i. *\$30,000: Collection and analysis of data on cognitive impairment and caregiving via annual BRFSS report*