

# State Plan for Alzheimer's Disease and Related Dementias in Oregon



July 2012



# Acknowledgements

**The SPADO Task Force wants to thank the hundreds of individuals from across Oregon who spoke their minds about the challenges facing them due to the impact of Alzheimer’s disease. Their input was critical in shaping this state plan.**

The Task Force thanks these elected officials and their staffs, who participated in the town hall meetings:

U.S. Congressman Earl Blumenauer  
Rep. Betty Komp  
Rep. Gene Whisnant  
Rep. Lew Frederick

Offices of:  
U.S. Senator Jeff Merkley  
U.S. Senator Ron Wyden  
U.S. Congressman Peter DeFazio  
U.S. Congressman Greg Walden  
U.S. Congressman Kurt Schrader

The Task Force also thanks the people who helped make sure the town hall meetings, including the telephone town hall, were a success:

Mary Jaeger  
City of Beaverton  
Bend Senior Center  
Melissa Lande  
Donna Peterson  
Kay Metzger  
Joy Kilishek  
Ruth Cohen  
Naomi Tillery  
Center 50+ in Salem  
East Portland Community Center  
Wendy Davis and Nick Unger at VocalFi

Fred Miller  
Pam Norr  
Nancy Webre  
Adele Tiberius  
Liz Von Wellsheim  
Don Bruland  
Pat Gillette  
Kathy Belcher  
Shari Ridings  
Smullin Center in Medford  
Campbell Center in Eugene

# Acknowledgements

This plan was reviewed by many stakeholders around Oregon, and we would like to thank them for their helpful input:

Bob Joondeph, Disability Rights Oregon  
Ruth Gulyas, LeadingAge Oregon  
Elizabeth Eckstrom, Oregon Geriatric Education Center  
Matthew Bartolotti, The Oregon Health Authority  
The Oregon Medicaid Advisory Committee  
Deborah Jacques, The Oregon Hospice Association  
Mike McArthur, Association of Oregon Counties  
Ellen Garcia, Providence ElderPlace  
Nicole Palmateer, Oregon Association of Area Agencies on Aging and Disabilities (O4AD)  
Robin Moody, Oregon Association of Hospitals and Health Systems  
Kerry Gonzales, Oregon Academy of Family Physicians  
Brian Little, Oregon State Hospital  
Joe Greenman, Oregon Health Care Association  
Carlos Barrios, Endear for ALZ  
Members of the Governor's Commission on Senior Services

A special thanks to Steve Robinson of Decision Metrics for providing economic analysis of the recommendations and building the fiscal case for the need to take action. And thanks to the Alzheimer's Association, Kristrún Gröndal, Jason Hess, Anne P. Hill, LeadingAge Oregon, and the Oregon Health Care Association for providing the funding for this work. Thank you also to Steven Foldes for his contributions.

We also want to thank Jennifer Mead and Jason Hess for co-chairing the SPADO Task Force and Jon Bartholomew for staffing the effort. Thank you to the writing team of Ann Bartholomew, Jon Bartholomew, Nicole Easley, Anne P. Hill, Ann McQueen, and Jennifer Mead for their hard work. Thank you also to Evan Stewart for design and layout of this plan.

# State Plan for Alzheimer's Disease in Oregon Task Force and Workgroup Members

Roger Anunsen, mindRAMP & Assoc.

Jon Bartholomew, Public Policy Director, Alzheimer's Association Oregon Chapter

Holly Berman, LCSW, Consultant

Kevin Call, President/Owner, Adeo In Home Care

Margaret Cervenka, Deputy Director, LeadingAge Oregon

Lynda Crandall, Board Member, Alzheimer's Network of Oregon

Don Crites, President, Oregon Driver Education Center

Penny Davis, Attorney At Law, The Elder Law Firm

Rep. Michael Dembrow, Oregon State Legislature

Nicole Easley, Administrator, Marquis Centennial

Lee Girard, Community Services Manager, Multnomah County Aging & Disability Services Division

Kristrún Gröndal, Program Director, Alzheimer's Association Oregon Chapter

Theresa A. Harvath, PhD, RN, CNS, Director, John A Hartford Center of Geriatric Nursing Excellence, OHSU

Ken Hector, Silverton Hospital

Jason Hess, Chief Executive Officer, Elite Care

Anne P. Hill, Author, Speaker, Consultant

Kathy Irwin, Oregon Department of Public Safety Standards and Training

Katherine Jimenez, Regional Vice President of Sales, Serenity Hospice

Jan Karlen, CBC Policy Analyst, DHS-Aging & People with Disabilities

Dr. Jeffrey Kaye, Professor of Neurology & Biomedical Engineering; Director, Layton Aging & Alzheimer's Disease Center; Director, Oregon Center for Aging & Technology, Oregon Health & Science University

Tiffany Kirkpatrick, Co-Leader/Co-Founder of PreSERVE Coalition

Jeannette Launer, Caregiver

Glenise McKenzie, Assistant Professor, OHSU School of Nursing

Ann McQueen, Gerontology Faculty, Portland Community College – Sylvania

Jennifer Mead, Health Promotion Coordinator, DHS-Aging and People with Disabilities

Sen. Laurie Monnes Anderson, Oregon State Legislature

Dr. Maureen Nash, Medical Director, Tuality Center for Geriatric Psychiatry

Tim Nay, Attorney at Law, Law Offices of Nay and Friedenberg

Ana Potter, Deputy State Long-Term Care Ombudsman, Office of the Long-Term Care Ombudsman

Mary Ruhl, MAIS, Education Core, Layton Aging & Alzheimer's Disease Center, OHSU

Bandana Shrestha, Director, Community Engagement, AARP Oregon

Fred Steele, Senior Policy Analyst, Oregon DHS

Steve Winegar, Trainer, Oregon Department of Public Safety Standards and Training

Catherine Zimmerman, Gerontology Instructor at Portland Community College and Geriatric Care Manager at Cognitia Care





JOHN A. KITZHABER, MD  
Governor

Many health issues face our state, but Alzheimer's is especially challenging for Oregon families, communities, and health care providers. With the number of Oregonians with Alzheimer's expected to rise over the next decade, we must ensure we're prepared to respond with appropriate and compassionate public health resources.

This plan represents forward-thinking strategies to address the impacts of Alzheimer's for patients and the people who care about and for them. Like so many of the issues we're addressing in our efforts to improve Oregon's health care system, there are no quick fixes to transform how we care for Alzheimer's patients.

However, by gathering the expertise of diverse stakeholders, adopting a long-term perspective, and moving forward together, we can accomplish the larger goals outlined in this plan while taking immediate steps to increase awareness and optimize care and health provider coordination. As Oregonians, we know that we're so much stronger working as a team than we could ever be on our own.

Sincerely,

John A. Kitzhaber, M.D.  
Governor

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# Executive Summary

This is the State Plan for Alzheimer’s Disease and Related Dementias (ADRD) in Oregon. It is the product of professional expertise, personal experience, and public input from across the state.

The plan provides:

1. A starting point for an ongoing effort, coordinated with other efforts, to address related community needs. It should be revisited and updated regularly to ensure that we are meeting expected outcomes.
2. A guide for the engagement of public and private sector stakeholders to improve the state’s response to community needs associated with Alzheimer’s disease and related dementias.

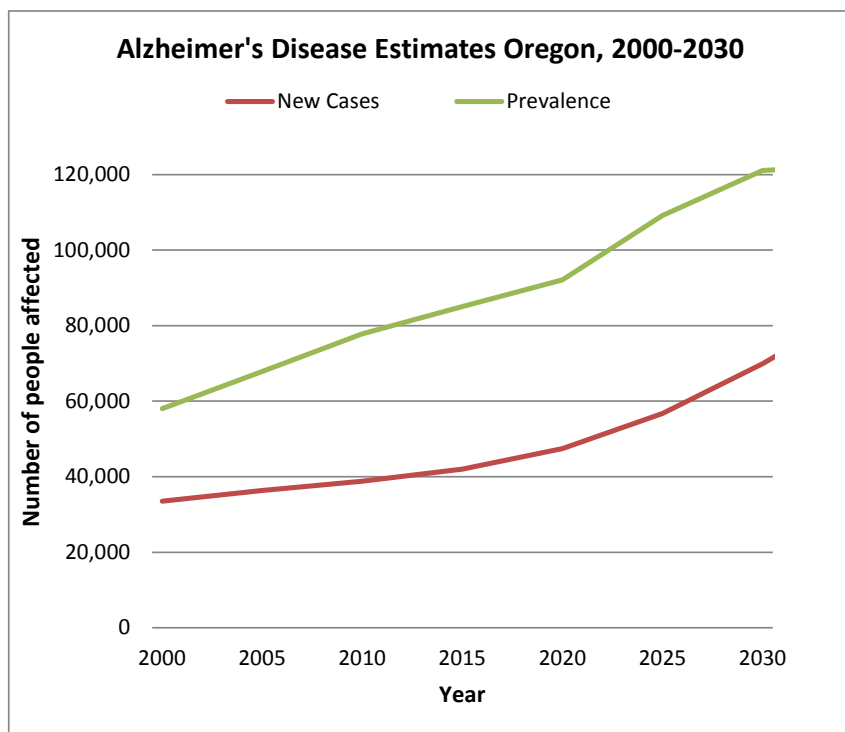
## Rationale for this plan

This plan was developed to ensure people with Alzheimer’s disease and related dementias (ADRD) and their caregivers have the information and support they need, and services are delivered as effectively and efficiently as possible. Alzheimer’s is a devastating disease that causes changes in one’s memory, behavior, and ability to think clearly.

### All Oregonians

No segment of our communities is untouched by Alzheimer’s. It is a disease that affects everyone in Oregon, directly or indirectly. Therefore, it requires coordinated effort to address this public health crisis.

Unless the disease can be effectively treated or prevented, the number of Oregonians with ADRD will increase significantly in the next two decades. Currently, about 76,000 Oregonians live with Alzheimer’s – and this number is expected to increase to 110,000 by 2025.<sup>1</sup>



**Source:** Alzheimer’s Association. 2012 Alzheimer’s disease facts and figures. *Alzheimer’s and dementia: The Journal of the Alzheimer’s Association*. March 2012; 8:131-168.

# Executive Summary

## Families

Alzheimer's places enormous emotional and financial stress on individuals with the disease and their family members. Informal caregivers, such as family members and friends, provide the majority of care for people with ADRD in the community. Over 165,000 unpaid caregivers in Oregon provide over \$2.2 billion worth of unpaid care each year. The intensive support required to care for a person with ADRD can negatively impact the caregiver's health and well-being.

## Healthcare

While death rates from heart disease, cancer, and stroke are gradually declining nationally, the number of people dying of Alzheimer's disease is growing. People with ADRD often have other chronic health conditions, and the costs associated with managing those other conditions in people with ADRD are higher as a result of cognitive impairment.

## Long-term care

Long-term care costs for individuals with dementia are significantly higher than for those without dementia. While most people with dementia live at home and receive unpaid help from family and friends, older adults who have ADRD are twice as likely to receive paid care as those without ADRD, and they make up a large proportion of all people who receive home care, adult day center services, assisted living, and nursing home care.

## State and local government

Oregon spends significant resources on care for and support of people living with ADRD and their families. Oregon's Medicaid cost alone is about \$300 million a year. Oregon public resources will be crippled unless we recognize and address the impact ADRD has on our communities.

## Employers

Oregon's employers are also impacted by the costs of ADRD. ADRD costs businesses nationwide \$61 billion a year in healthcare costs and lost productivity.

# Executive Summary

## **Potential impact of this plan**

Through implementation of this state plan, we expect to have a positive impact for all stakeholders in Oregon, from caregivers to government. Studies indicate that early interventions can be extremely cost-effective, taking into account not only the well-being of a person with dementia, but also their caregivers. Planning now will help prevent escalating costs as our population ages. Implementing this plan in the context of Governor Kitzhaber's ten-year budget process and state work to transform health care will lead to improved services while reducing state costs.

## **Plan development process**

The State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force, which developed this plan, includes state legislators, non-profit organizations, state government agencies, academic researchers, issue experts, physicians, care providers, and family caregivers. Five workgroups focused on different aspects of the impact of ADRD – Education and Public Awareness, Public Safety, Continuum of Care, Legal/Financial, and Medical/Research.

The SPADO Task Force gathered public input from a variety of sources, including seven town hall meetings and an online survey. This input informed and validated the recommendations crafted by the SPADO workgroups.

This state plan is complemented by the National Alzheimer's Plan, as directed by the National Alzheimer's Project Act. The national plan provides a guiding framework for all Alzheimer's plans around the U.S. It addresses certain identified needs that go beyond the capacity of any state's plan, such as increasing resources for clinical research to find a cure or effective treatments for ADRD. The national plan also relies on states to create their own plans that address local needs and find creative solutions particular to that state.

# Executive Summary

## Recommendations

Based on identified needs, review of other state plans, and guidance from each workgroup, the Task Force developed the following five goals and ten key recommendations:

### Goal 1: Enhance Public Awareness and Engagement

- A. Increase public awareness about Alzheimer's disease, and how to access resources that help those impacted by the disease.
- B. Create a website that provides a single entry point to link to existing information and resources on Alzheimer's disease and related dementias.

### Goal 2: Optimize Care Quality and Efficiency

- A. Develop and implement quality standards and measurable outcomes for dementia care in Oregon's long-term care and hospital settings and measure success of existing standards for memory care.
- B. Ensure that Oregon has a dementia-capable licensed health care workforce.

### Goal 3: Protect Individuals with Dementia

- A. Require that all Oregon guardians, both family and professional, receive training on dementia, as well as on the responsibilities and ethics of representing a person with dementia.
- B. Expand capacity to protect the safety and well-being of individuals with dementia.

### Goal 4: Improve Access to Quality Care

- A. Develop appropriate care settings and services for persons with dementia who require a higher level of expertise and staff in helping manage their significant behavioral needs.
- B. Increase access to medical care providers who serve those with Alzheimer's and related dementia.

### Goal 5: Comprehend, Prevent, and Effectively Treat Dementia and its Impact

- A. Establish a coordinated data system to improve Oregon's ability to plan for and provide effective resources regarding Alzheimer's disease and related dementias.
- B. Expand existing dementia research and participation in Oregon research efforts.

# State Plan for Alzheimer's Disease

## State Plan for Alzheimer's Disease and Related Dementias in Oregon

This is the State Plan for Alzheimer's Disease and Related Dementias in Oregon. It is the product of professional expertise, personal experience, and public input from across the state. As new needs arise or new resources become available, it should be amended to reflect these changes.

The plan provides:

1. A starting point for an ongoing effort, coordinated with other efforts, to address related community needs. It should be revisited regularly to ensure that we are meeting expected outcomes.
2. A guide for the engagement of public and private sector stakeholders to improve the state's response to community needs associated with Alzheimer's disease and related dementias.

## Rationale for this plan

This plan was developed to ensure people with Alzheimer's disease and related dementias (ARD) and their caregivers have the information and support they need, and services are delivered as effectively and efficiently as possible. Alzheimer's (see box) is a devastating disease that causes changes in one's memory, behavior, and ability to think clearly. It is the sixth-leading cause of death in America, and the only one for which there is no way to cure, prevent, or even slow its progression. From 2000 to 2010, the number of Oregonians with ARD increased 33 percent, with numbers expected to increase as our population ages. Currently, about 76,000 Oregonians live with Alzheimer's – and this number is expected to increase to 110,000 by 2025.<sup>1</sup>

# What Is Alzheimer's?

Alzheimer's is the most common form of dementia, which is a general term for loss of memory and other intellectual abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 60 to 80 percent of dementia cases. In this plan, we use the term "Alzheimer's" or "ADRD" to refer to Alzheimer's disease and related forms of dementia. Related dementias include Lewy body, frontotemporal, mixed, and vascular dementia.

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. Alzheimer's is not just a disease of old age, however. Up to five percent of people with the disease have young-onset Alzheimer's (also known as early-onset), which can appear in people in their 40s or 50s. This population has a set of needs different than those over 65, and those affected often experience difficulty accessing accurate and timely diagnosis and needed services due to their age.

Alzheimer's and most types of dementia are progressive diseases in which symptoms gradually worsen over time. In the early stages of Alzheimer's, the most well-known symptom is mild memory loss, although other symptoms may be apparent and initially subtle, causing confusion or concern for family and friends. Other symptoms can include word finding problems, trouble performing tasks like paying bills, personality changes or emotional symptoms of depression, anxiety, or irritability. By late-stage Alzheimer's, individuals lose the ability to carry on a conversation, respond to their environment, and care for themselves in every aspect of their daily lives.

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 cure at this time, but treatments for symptoms are available and research continues. Although current Alzheimer's treatments cannot stop the disease from progressing, they can temporarily slow the worsening of dementia symptoms and improve quality of life for some people 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.

*Adapted from materials produced by the Alzheimer's Association.*

# Impact of Alzheimer's in Oregon

Every segment of our community is touched by Alzheimer's. It is a disease that affects everyone in Oregon, directly or indirectly. Therefore, it requires a coordinated effort to address this public health crisis.

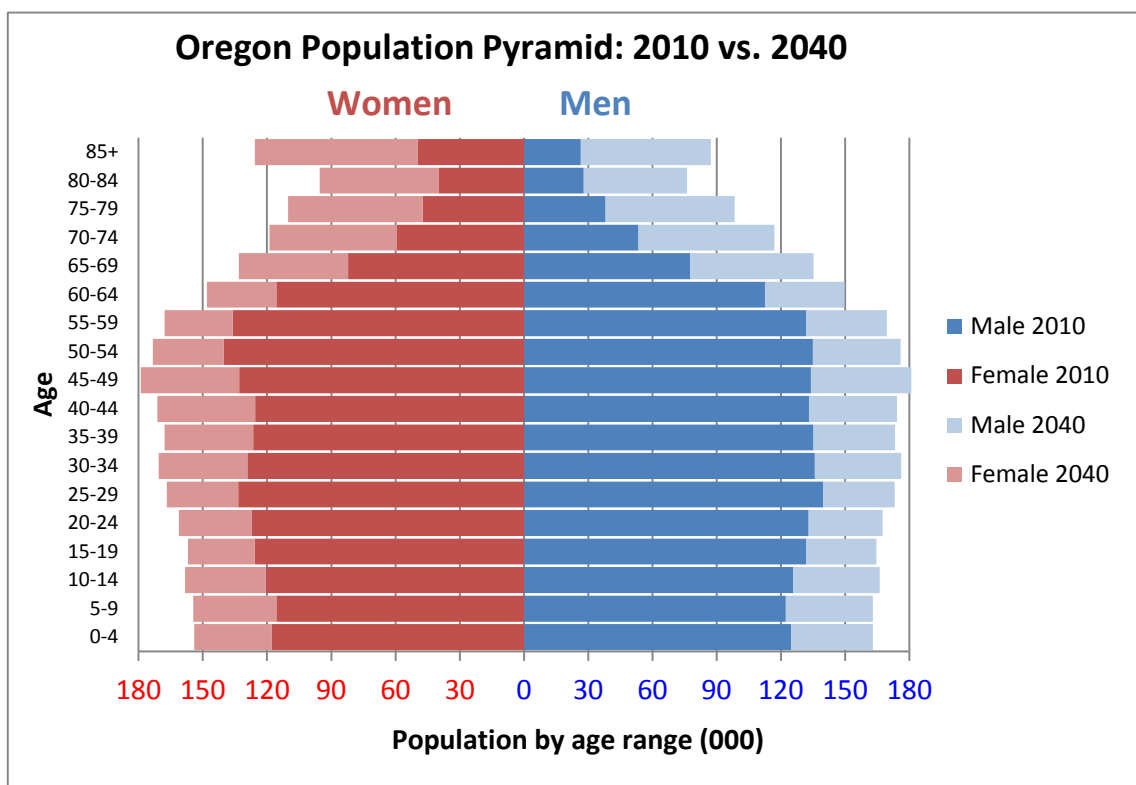
## All Oregonians

Unless the disease can be effectively treated or prevented, the number of Oregonians with ADRD will increase significantly in the next two decades. As the Oregon population ages, we are guaranteed to see a dramatic increase in the number of Oregonians impacted by this devastating disease – the seventh-fastest increase in the United States.<sup>2</sup> The first baby boomers started reaching 65 years of age in 2011. Although Alzheimer's disease is not a normal part of aging, age is the greatest risk factor for the disease, and the prevalence of people with ADRD doubles for every 5-year interval beyond age 65.<sup>3</sup>

**“[My mother with Alzheimer's] has lived with me for one year. I am sacrificing my health, time with my children and husband and my career for this disease. I am tired. There has got to be a better way.”**

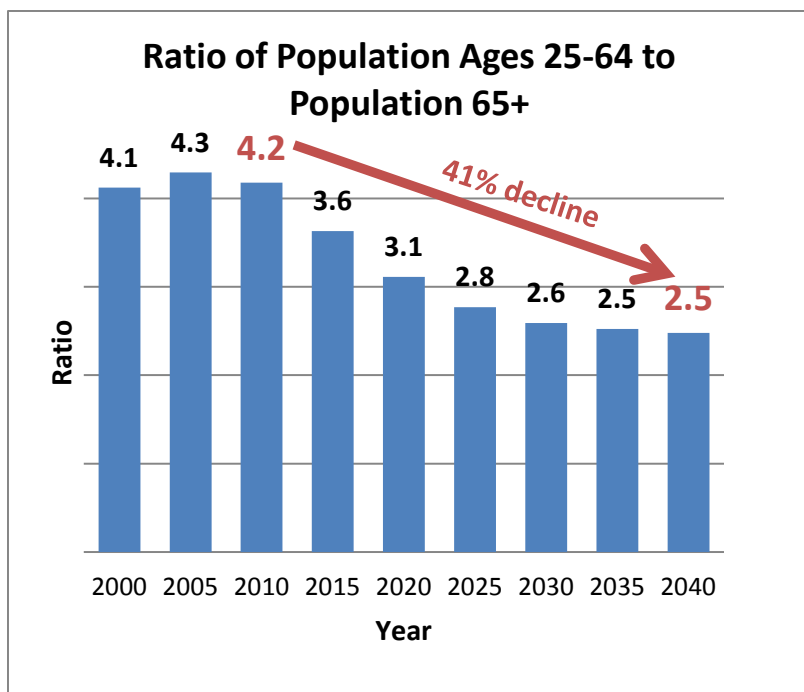
**– Janet in Beaverton**

This population pyramid shows how the population over age 85 will increase about 180 percent between 2010 and 2040, while younger age groups will also more than double.<sup>4</sup> Nearly half of all people over age 85 have AD. While about twice as many women as men are in this group, the Alzheimer's Association reports that this merely reflects the differing life expectancies, and there is no difference in risk by sex.



Source: Oregon Office of Economic Analysis

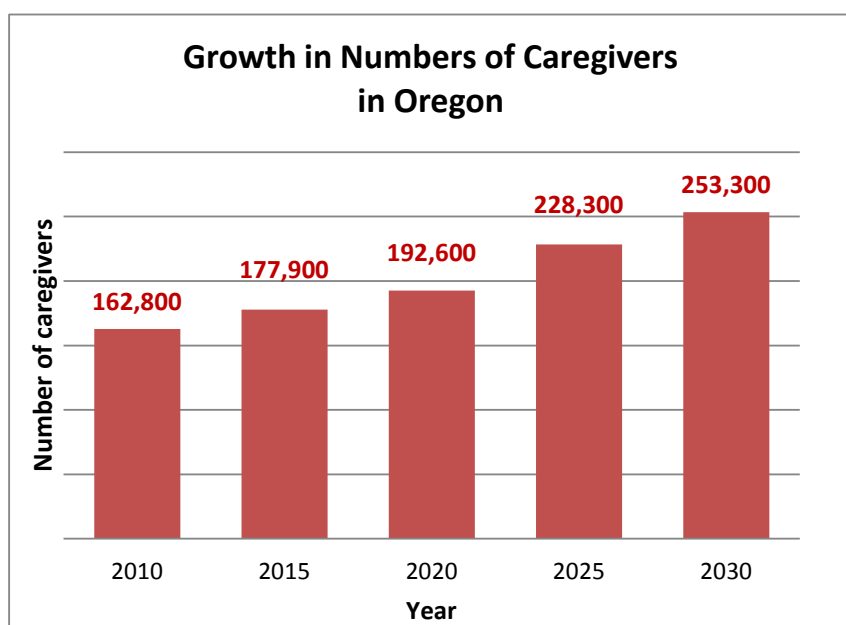
# Impact of Alzheimer's in Oregon



Source: Oregon Office of Economic Analysis

## Families

Alzheimer's places enormous emotional and financial stress on individuals with the disease and their family members. Informal caregivers, such as family members and friends, provide the majority of care for people with ADRD in the community. Over 165,000 unpaid caregivers in Oregon provided over \$2.28 billion worth of unpaid care in 2011.<sup>5</sup> The intensive support required to care for a person with ADRD can negatively impact the caregiver's health and well-being. Informal caregivers are more likely to report symptoms of depression and anxiety,<sup>6</sup> and they have poorer health than their peers who do not provide such care.<sup>7</sup> The impact of caregiving leads to about \$91 million worth of higher health care costs per year for the caregivers in Oregon.<sup>8</sup> When a person with ADRD moves to a nursing home to receive 24-hour care, the financial cost to families is great: an estimated \$78,000 per year.<sup>9</sup>

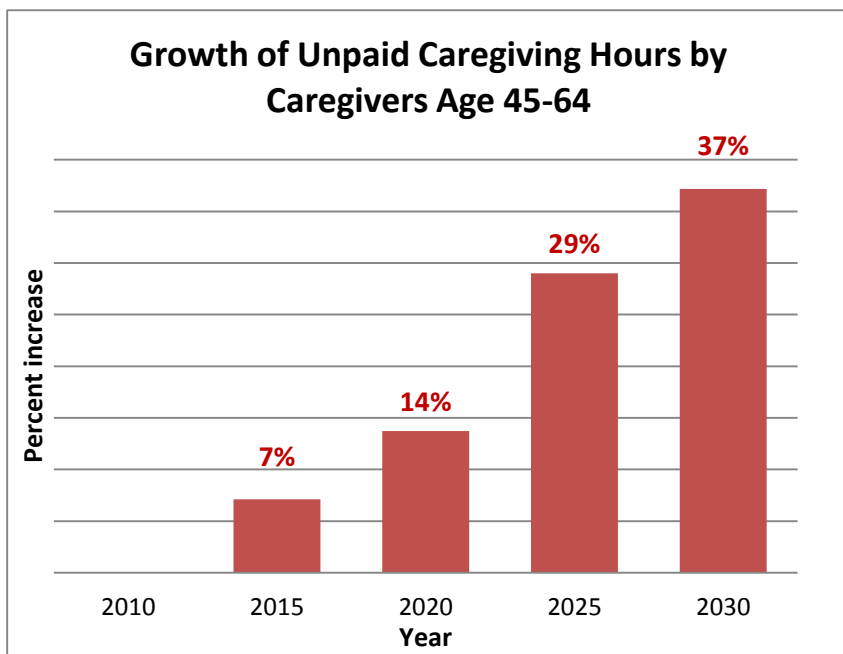


Sources: Created from data from the 2009 BRFSS, U.S. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, AARP, and U.S. Department of Labor



# Impact of Alzheimer's on Families

People between the ages of 45 and 64 provide 56 percent of the care to persons with ADRD. This younger caregiver population is not growing nearly as fast as the number of persons with ADRD. Thus, current trends indicate that the amount of unpaid ADRD care provided by the average person aged 45 to 64 will increase by 37 percent by 2030. This increased load will only increase the stresses on the the caregiver population, of whom 61 percent report high emotional stress and 43 percent report high physical stress, and large percentages suffered financial losses as well, such as reducing work hours or even leaving the workforce. In addition to the costs to the healthcare system, an average caregiver saw an increase of \$550 in his or her own health care costs. This out-of-pocket cost, coupled with increased health issues among the caregiver population, will intensify as the population of persons with ADRD increases relative to the main caregiver population.



**Sources:** Alzheimer's Association, 2012 Alzheimer's disease facts and figures. 2010 U.S. Census data

## Healthcare

While death rates from heart disease, cancer, and stroke are gradually declining nationally, the numbers of people affected by ADRD are growing. People with dementia often have other chronic health conditions, and the costs associated with managing those other conditions in people with ADRD are higher as a result of cognitive impairment.<sup>10</sup> Healthcare systems working to provide medical homes, reduce hospital readmissions, and ensure safe transitions between care settings face real challenges in providing these services to adults with cognitive impairment.

## Long-term care

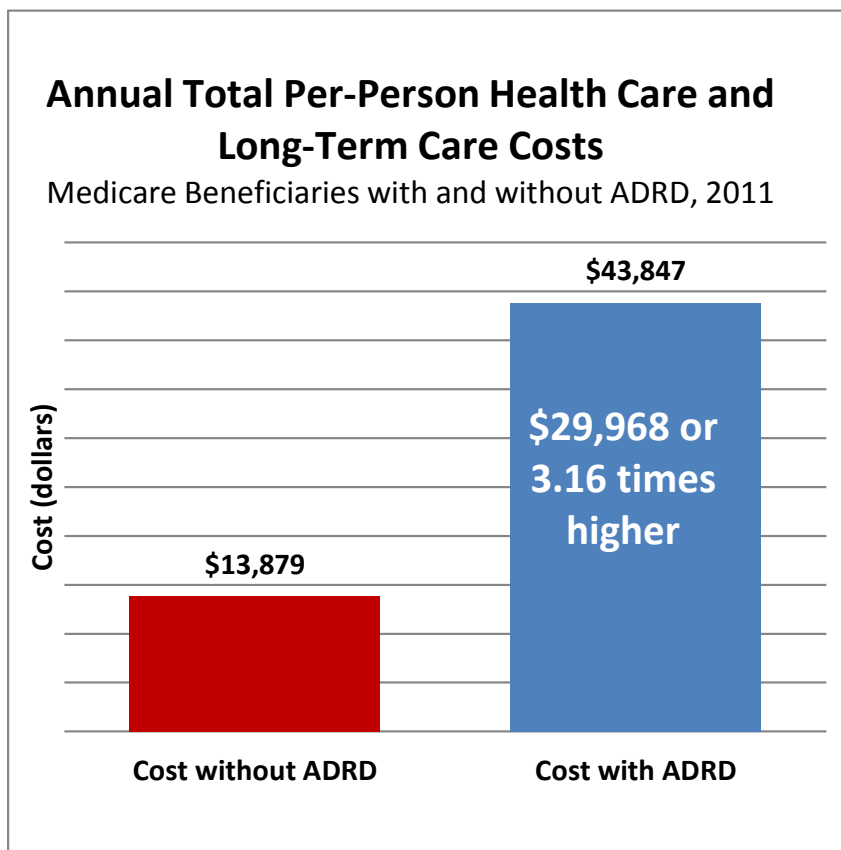
Nationally, 98% of older adults without ADRD live in community settings, compared with 60 to 70 percent of older adults with ADRD.<sup>11,12</sup> As with healthcare, long-term care costs for individuals with dementia are significantly higher. While most older adults who live at home and need assistance with activities of daily living, such as bathing, shopping, and managing money, older adults with ADRD are twice as likely to need additional paid care, and they make up a large portion of all people who receive home care, adult day center services, assisted living, and nursing home care.<sup>13</sup>

# Impact on State & Local Government

## State and local government

Oregon spends significant resources on care for and support of people living with ADRD and their families. Oregon's Medicaid cost alone is about \$300 million a year just for our share of Medicaid. Oregon's Medicaid program pays for long-term care in people's homes and in care communities as well as direct medical services for low-income Oregonians. In 2008, total per-person Medicaid payments for Medicare beneficiaries age 65 and older with ADRD were 19 times as great as Medicaid payments for other Medicare beneficiaries.<sup>14</sup> Oregon also uses \$9.5 million in state funds<sup>15</sup> through Oregon Project Independence (OPI) to provide services that help older adults who do not qualify for Medicaid stay at home and live with a higher level of independence. OPI also helps prevent many older adults from enrolling in Medicaid. Finally, there is growing national concern about the impact of an aging inmate population, and the impact of ADRD within the corrections system – an issue that will increasingly impact Oregon's local and state jails and prisons.

Oregon is seen as a national leader in providing care at home and reducing the need for more expensive forms of long-term care, and Governor Kitzhaber's Health Care Transformation explicitly aims to find efficiencies in care provision while achieving better health results. However, even with these existing efforts and systems, public resources will be crippled unless we recognize and address the impact ADRD has on our communities.



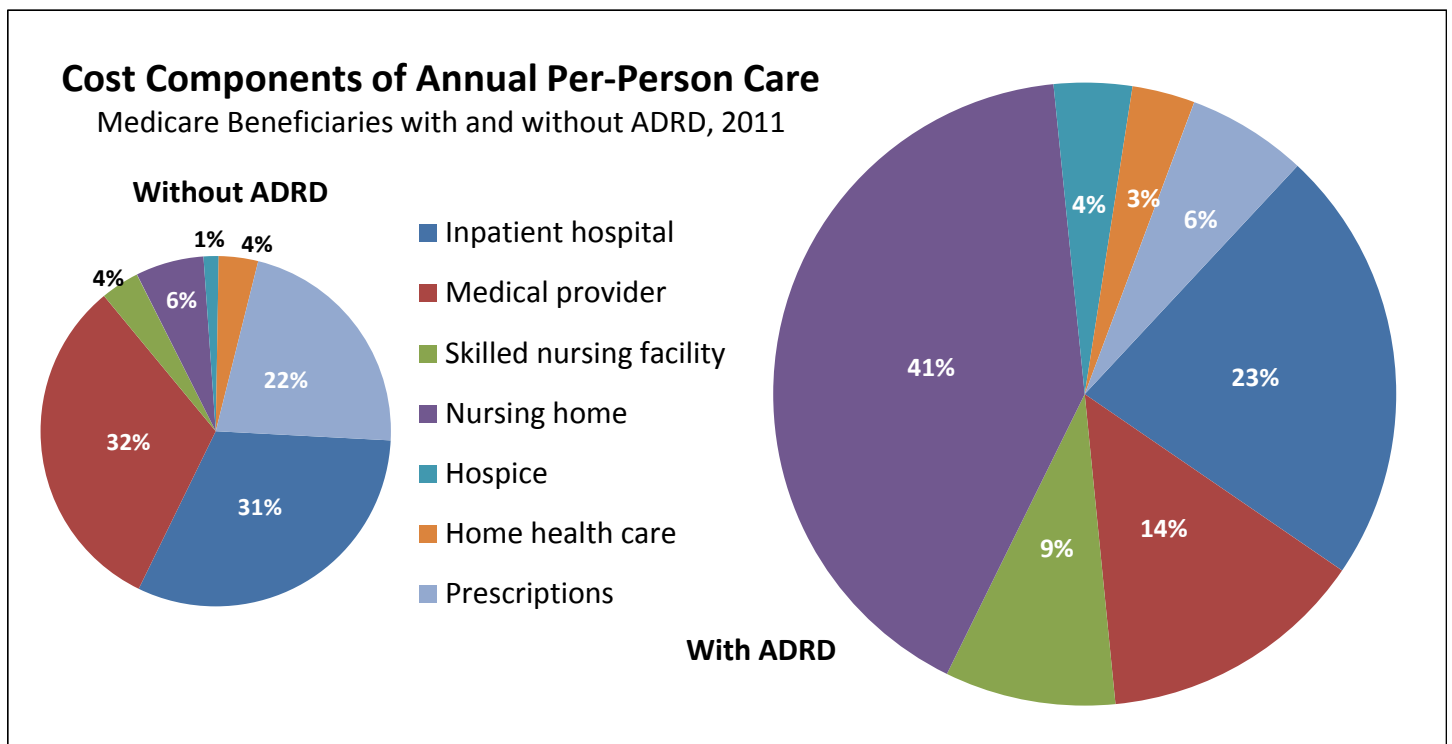
Of the nearly \$30,000 in higher annual health care costs for persons with ADRD compared to other Medicare beneficiaries 65 and older, about \$22,000 is paid by Medicare and Medicaid. Another \$7,100 is out-of-pocket cost to the family, with private insurance and other payers picking up the remainder. Because of the long-term costs incurred by those with ADRD and their families, which eventually deplete savings even for those who have planned and saved, 29 percent of persons with ADRD qualify for Medicaid, compared to only 11 percent for those without ADRD.<sup>16</sup>

**Source:** Alzheimer's Association. 2012 Alzheimer's disease facts and figures.

# Impact of Alzheimer's

## Employers

Employers are also impacted by the costs of ADRD. ADRD is estimated to cost businesses nationwide \$61 billion a year. About \$24.6 billion of this is directly related to costs associated with ADRD care (e.g., health, long-term and hospice). A further \$36.5 billion in costs to businesses is due to factors such as lost productivity related to employees providing care for individuals with ADRD.<sup>17</sup>



**Source:** Alzheimer's Association. 2012 Alzheimer's disease facts and figures.

## Diverse Communities

National data indicate that older African-Americans are about twice as likely to develop Alzheimer's as older whites,<sup>18</sup> and Latinos are about one and one-half times as likely to develop Alzheimer's as older whites.<sup>19</sup> Individuals with Down's syndrome are at extremely high risk for developing Alzheimer's due to a genetic link between these two conditions. Language and cultural differences lead to barriers in accessing resources for some populations. Alzheimer's does not discriminate, but the needs of different communities require constant consideration in crafting solutions to the problems they face.

# Plan Impact

## Potential Impact of this Plan

Implementing this state plan will help Oregon better plan for and reduce the growing costs associated with this disease. Some examples include:

- Increased public awareness of Alzheimer’s disease (Rec 1A) and access to a single entry point website (Rec 1B) will more quickly link individuals to available resources and support, which can enable families to keep those with dementia in their homes and communities longer, delaying or avoiding the need for high-cost care that occurs when families reach a crisis.
- Required training of guardians (Rec. 3A) is expected to reduce abuse of guardianship roles, which results in costly abuse investigations, and in costs to families and to state and county legal systems.
- Development of appropriate community-based care settings for individuals with serious behavioral needs (Rec. 4A) is expected to provide a more cost-effective alternative to the current use of the Oregon State Hospital.
- Development of a more coordinated system to track existing costs, using data to guide policy, and funding to identify and implement cost-effective approaches to Alzheimer’s care (Rec 5A) will enable Oregonians to identify emerging strategies that can improve care and reduce escalating costs for the state’s health and long-term care systems.

Both the National Alzheimer’s Plan and this Oregon Plan recognize the need for cost-effective approaches to addressing Alzheimer’s disease. Oregon has a good start: an innovative, nationally recognized long-term care system; nationally recognized researchers; and federal funding to pilot evidence-based community interventions. But the Task Force urges that Oregon needs to do more.

While there is need for increased research on the return on investment of specific interventions and approaches, the proposed recommendations are designed to help slow the growth in costs associated with this disease, while improving the quality of life for those with ADRD and their families.

## Emerging Research & Promising Practices

A study<sup>20</sup> by Mary S. Mittelman, DrPH et al at NYU School of Medicine found that a “support intervention for spouse caregivers” that involved individual and family counseling combined with group and telephone support significantly improved caregiver mental and physical health, while improving the quality of care they provide and delaying admission to residential facilities. The study followed 406 subjects for up to 17 years, and found an average delay of 18 months to institutionalization.

Admission to an assisted living, memory care or skilled nursing facility is expensive, ranging from \$4,200 to over \$7,000 per month. Using a (conservative) average cost of \$5,500 per month, if such a program had the same kind of results in Oregon as it did in New York, **cost savings of \$300 million per year** (rough estimate) would be possible. The intervention is now being piloted in Minnesota in community-based social service settings.

Three counties in Oregon are piloting the STAR-Caregivers program (STAR-C).<sup>21</sup> Developed by the University of Washington School of Nursing,<sup>22</sup> STAR-C is a behavioral intervention to decrease depression and anxiety in individuals with ADRD and their family caregivers. Like the NYU study, it includes in-home counseling and telephone follow-up sessions.

Furthermore, a number of healthcare systems and aging service providers are piloting evidence-based approaches to support care transitions for older adults, including adults with cognitive impairment, which research has indicated can help reduce hospital re-admissions and emergency department use.

Best practices that improve the lives of people impact as well as provide cost savings will continue to be considered as this state plan is revisited and updated.

# Plan Development Process

## Plan Development Process

In late 2010, the Alzheimer's Association Oregon Chapter brought together numerous community partners in Oregon who share a concern about the impact of the disease on our communities. The State Plan for Alzheimer's Disease in Oregon (SPADO) Task Force was formed and includes non-profit organizations, state government agencies, academic researchers, issue experts, physicians, family caregivers, care providers, and state legislators. The Alzheimer's Association Oregon Chapter provided staffing for the SPADO Task Force. Each of five workgroups focused on different aspects of the impact of ADRD – Education and Public Awareness, Public Safety, Continuum of Care, Legal/Financial, and Medical/Research. The workgroups helped craft questions for an online survey, participated in public input sessions, and drafted recommendations to address the most critical needs of people impacted by ADRD.

The SPADO Task Force heard public input from a variety of sources. This input informed and validates the recommendations crafted by the SPADO workgroups.

- During August 2011, the task force held town hall-style meetings in Beaverton, Bend, Eugene, Medford, Portland, and Salem. Over 200 members of the public attended these events, which were also attended by state legislators, Congressman Blumenauer and representatives from Oregon's other congressional offices.
- Over 600 people responded to an online survey in August and September 2011, which asked questions about their experiences and recommendations in dealing with ADRD.<sup>23</sup>
- The Alzheimer's Association Oregon Chapter asked for open comments from the public through its website in 2011, generating dozens of comments.
- Over 100 people also participated in a telephone town hall meeting in November 2011 that had participants from Brookings to Burns and Portland to Pendleton.

**“My mother passed away in 2007 after 10 long years of suffering from Alzheimer's. She was a loving and giving person her whole life and did not deserve to end her remaining days trapped in the misery of it. If there is any disease that America needs to find a cure for this is the one.”**

**– Lisa in Portland**

This state plan is complemented by the National Alzheimer's Plan, as directed by the National Alzheimer's Project Act ([napa.alz.org](http://napa.alz.org)). The national plan provides a guiding framework for all Alzheimer's plans around the U.S. It addresses certain identified needs that go beyond the capacity of any state's plan, such as increasing resources for clinical research to find a cure or effective treatments for ADRD. The national plan relies on states to create their own plans that address local needs and find creative solutions particular to that state. Oregon's plan adds to the more than 25 existing state Alzheimer's plans around the nation, all focused on ensuring coordination between public and private partners to plan and prepare for the growing impact of ADRD.

# Key Issues & Recommendations

## Key issues and summary of recommendations

The town hall meetings, online survey, public input, and the five workgroups identified a wide range of challenges and needs. Based on identified needs, review of other state plans, and guidance from each work group, the task force developed the following five goals and ten key recommendations:

### Goal 1: Enhance Public Awareness and Engagement

- A. Increase public awareness about Alzheimer's disease, and how to access resources that help those impacted by the disease.
- B. Create a website that provides a single entry point to link to existing information and resources on Alzheimer's disease and related dementias.

### Goal 2: Optimize Care Quality and Efficiency

- A. Develop and implement quality standards and measurable outcomes for dementia care in Oregon's long-term care and hospital settings and measure success of existing standards for memory care.
- B. Ensure that Oregon has a dementia-capable licensed health care workforce.

### Goal 3: Protect Individuals with Dementia

- A. Require that all Oregon guardians, both family and professional, receive training on dementia, as well as on the responsibilities and ethics of representing a person with dementia.
- B. Expand capacity to protect the safety and well-being of individuals with dementia.

### Goal 4: Improve Access to Quality Care

- A. Develop appropriate care settings and services for persons with dementia who require a higher level of expertise and staff in helping manage their significant behavioral needs.
- B. Increase access to medical care providers who serve those with Alzheimer's and related dementia.

### Goal 5: Comprehend, Prevent, and Effectively Treat Dementia and its Impact

- A. Establish a coordinated data system to improve Oregon's ability to plan for and provide effective resources regarding Alzheimer's disease and related dementias.
- B. Expand existing dementia research and participation in Oregon research efforts.

# Call to Action

## Call to action

This state plan has identified approaches to meeting the needs of Oregonians impacted by ADRD that we can realistically expect to accomplish. The plan will not solve all the challenges facing people with ADRD and their families, but it will make a positive difference.

Now is the time to move forward. That means pursuing the proposed recommendations and committing to:

- Follow through with public-private partnerships
- Ensure oversight of efforts to pursue the recommendations
- Identify opportunities to improve our response to the continuing challenges of ADRD
- Integrate the state plan into broader efforts to address the needs of the aging and those with disabling diseases, including the Health Care Transformation efforts currently underway by the Oregon government

**“When my father was diagnosed, I felt all alone in Josephine County. I was unable to get help from my family doctor, including for stress of caregiving. My friends noted that other caregivers were ending up in the hospital and were worried for me. It has been the hardest thing in my life to take care of my dad.”**

**– Joy in Medford**





# Goal 1: Enhance Public Awareness and Engagement

**Recommendation 1A: Increase public awareness about Alzheimer’s disease, and how to access resources that help those impacted by the disease.**

## Strategies

1. Identify a marketing firm to develop a public-awareness campaign, coordinated with national efforts to focus on Alzheimer’s, to raise awareness of Alzheimer’s and where to turn for help.
2. Engage local and statewide organizations to disseminate information to their clients and constituents to raise awareness, with particular focus on reaching multi-cultural, low-income, and rural populations.
3. Ensure that Oregon’s Aging and Disability Resource Connection (ADRC) and other statewide organizations serving older adults and their families receive training about dementia and develop clear policies and practices to effectively assist and refer people with the disease and their families to appropriate services.

## Rationale

Alzheimer’s disease still carries a stigma that keeps people from seeking the resources and assistance they need. Oregonians need better information on ADRC, the resources available, and the importance of planning ahead. Organizations that provide services and information to older adults and their families must be able to provide appropriate information and referrals.

## Lead Organizations

Alzheimer’s Association Oregon Chapter and the Oregon Department of Human Services (DHS).

**“There is a need to overcome the fear of diagnosis – both by the patient and the doctor. My step-father experienced a lessening of difficult behaviors when it became a fact and not a fear. It then was much easier to deal with for my mother and the family.”**

**– Concerned family member in Lincoln County**

## Time Frame and Measurable Outcomes

- Marketing plan and messages to be completed by June 2013.
- Training and recommended referral systems for organizations serving older adults and their families to be available by June 2013.
- Anticipated outcomes include increased calls to the Alzheimer’s Association Help Line, increased hits to the proposed statewide Alzheimer’s website (see rec. #1B), and additional measurable outcomes to be developed as part of the marketing plan.

## Fiscal Implications

- No anticipated costs for strategies 1 and 2. Foundation and/or pro-bono support for marketing campaign (strategy 1).
- Training related to strategy 3 to be developed through existing organizations, with costs relating to staff time and possible travel for training.

# Goal 1: Enhance Public Awareness and Engagement

**Recommendation 1B: Create a website that provides a single entry point to link to existing information and resources on Alzheimer’s disease and related dementias.**

## Strategies

1. Establish a workgroup to develop and maintain a new ADRD information website that provides a single entry point linking the public and professionals to existing local, state, and national information relating to resources and education opportunities focused on ADRD. [See Appendix B for the initial information to be included on this website.]
2. Website should include up-to-date and culturally appropriate information on the various dementias, as well as local resources and services to support people with dementia throughout the disease process (including newly diagnosed individuals and those with young-onset dementia).
3. The workgroup should explore the possibility of including a wiki section of the website as well as a forum section to allow for the development of an online community.

## Rationale

The Internet is replete with information about ADRD, but often challenging to families looking for clear and accurate information and local resources. Participants in town hall events described difficulty finding information on available resources. Participants expressed frustration that physicians making a diagnosis of Alzheimer’s did not provide adequate follow-up information about the disease itself, specific information needed at different stages of the disease process, or available resources. This recommendation will not recreate the wheel, but create a central starting place to make it easier for families to access existing information from reliable sources and for professionals to find the latest information and resources for referrals.

**“A big problem is the lack of knowledge and understanding of just what our community resources are. We have a lot of great resources, but people don’t know what they are because they don’t need them yet.”**

**– Nancy in Bend**

## Lead Organizations

Alzheimer’s Association Oregon Chapter and Oregon DHS.

## Time Frame and Measurable Outcomes

- Creation of legal/financial resource page created for Alzheimer’s Association Oregon Chapter website by October 2012.
- Identification of existing web-based information and development of a system to create an umbrella/hub website by June 2013.
- New ADRD resource website online and accessible by January 2014.

## Fiscal Implications:

- Continued upkeep of existing websites by currently active organizations.
- Funding needed to develop umbrella/hub website to link to existing resources. Estimated costs are \$5,000 to develop the website, and \$120 annually to host it, which could be funded through various public or private sources. This site would not require much maintenance, but some costs would be required to maintain its freshness. Legal/financial page costs would be covered by existing resources at the Alzheimer’s Association. Information can be updated in part for free by use of the wiki model.

# Goal 2: Optimize Quality Care and Efficiency

**Recommendation 2A: Develop and implement quality standards and measurable outcomes for dementia care in Oregon’s long-term care and hospital settings and measure success of existing standards for memory care.**

## Strategies

1. Convene a workgroup composed of providers of various settings, advocates, and state-agency staff by December 2012 that would:
  - A. Review examples from Oregon and other states of standards and programs that support people with dementia, such as the recently adopted DHS rules for memory care communities in Oregon.
  - B. Analyze the level of success of DHS rules for memory care communities adopted in 2011.
  - C. Draw upon examples of best practices to develop and adopt quality standards for all long-term-care and hospital settings that incorporate person-directed standards and address the common characteristics of people with dementia. Standards and quality measures should address person-directed care and quality of life, as well as other key health and safety areas identified by the committee.
2. Educate providers, advocates, and state agency staff on the new quality standards and methods for implementation.

## Rationale

Over 60 percent of residents living in long-term-care settings in the United States have ADRD.<sup>24</sup> In addition to the traditional nursing home model of long-term care, Oregon has developed community-based care models. People with dementia reside in a variety of care settings, each with distinct licensing requirements for training staff to care for people with dementia. In some settings the requirements for dementia care training are either insufficient or nonexistent. Participants at town hall meetings expressed frustration that knowledge of the disease, as well as best practices in care, varied significantly between settings.

**“We need research and development of person-centered/directed care approaches and physical environments that assist memory-impaired individuals to retain as much autonomy/dignity as possible.”**

**– Rose in Medford**

# Goal 2: Optimize Quality Care and Efficiency

Development of standardized quality measures of dementia care across long-term-care and hospital settings would allow the public and providers the ability to measure the quality of care provided to people with dementia. A review of existing dementia-care training programs and standards would aid Oregon in developing such measures, thus leading to greater consistency between settings and improved care for people with dementia. In 2011, Oregon DHS created new rules for memory care communities through a thorough stakeholder process. These rules may serve as a basis for the standards for other care settings after an analysis of their impact.

## Lead Organizations

Oregon Health Authority and Oregon DHS. Other key partners: Alzheimer’s Association Oregon Chapter, Oregon Health Care Association, LeadingAge Oregon, Oregon Association of Hospitals and Health Systems, Alzheimer’s Network, and the Office of the Long-Term Care Ombudsman.

## Time Frame and Measurable Outcomes

- Convene best-practices workgroup by January 2013.
- Decide upon new standards by October 2013.
- Adopt any necessary legislation or rulemaking by April 2014.
- Disseminate new standards and measurable outcomes to all relevant parties in the state by June 2014.

## Fiscal Implications

Care settings adopting these standards will have additional costs for staffing, training, increased services to residents, and possibly environmental enhancements if the setting does not currently meet the standards. These costs may be offset by reductions in unnecessary hospitalizations and delays in accessing more expensive services.

**“The heart of Long Term Care is the caregivers. They are traditionally very low paid, under-educated, under-trained. This is the greatest resource to a person with dementia’s quality of life. Improvement in this are of long term care is vital.”**  
– Professional in Multnomah County

# Goal 2: Optimize Quality Care and Efficiency

**Recommendation 2B: Ensure that Oregon has a dementia-capable licensed health care workforce.**

## Strategies

1. Establish a workgroup to create a strategy to grow the provider workforce and improve its skill levels. This work group will:
  - A. Recommend ways to integrate basic dementia education into the curricula in all schools teaching healthcare-related subjects in Oregon, from trade schools through undergraduate and graduate schools.
  - B. Work with professional healthcare licensing boards and organizations whose licensees and members provide services to people with dementia and their families, to promote and include dementia-specific training in continuing education opportunities for their licensees and members. The work group will explore establishing ongoing requirements and incentives for continuing education about dementia at a determined interval for professionals in long-term-care settings and those working with the elderly in hospitals.
  - C. Recommend ways to increase the size of the workforce that provides services to people with dementia and their families, at all levels of care and service provision.
2. Promote statewide educational conferences and events about dementia to educate Oregonians. Encourage healthcare organizations to promote the availability of information about dementia by expanding the number and kind of places that organizations attend and distribute information and talk with Oregonians about dementia.

**“We need better education for health care providers. Some providers express frustration that there’s no cure. Well, we don’t have a cure for diabetes, but we treat diabetes all the time. We don’t have a cure for congestive heart failure, but we treat that all the time. We treat chronic diseases all the time. Alzheimer’s disease is diabetes without a blood test.”**

**– Dr. Gillette in Medford**

## Rationale

Oregon needs a workforce that is educated about dementia to meet the increasing needs of people with ADRD and their families. Very little formal education about dementia is available in schools in Oregon and no licensing board for health care professionals in Oregon requires training about dementia.

# Goal 2: Optimize Quality Care and Efficiency

## Lead Organizations

- Strategy 1 – Office of the Governor of Oregon. Other key partners: Oregon State Board of Higher Education, Alzheimer’s Association Oregon Chapter, Oregon Health Care Association, LeadingAge Oregon, Oregon Department of Community Colleges and Workforce Development, Oregon DHS, OHSU, Oregon Academy of Family Physicians, Oregon Medical Association, Oregon Academy of General Dentistry, licensed health professionals and regulatory boards
- Strategy 2 – Alzheimer’s Association Oregon Chapter. Other key partners: Oregon DHS, Oregon Medical Board, Western University of Health Sciences, Oregon Health & Science University (OHSU), Oregon Academy of Family Physicians, Oregon Medical Association, Oregon Academy of General Dentistry, and other organizations hosting conferences and educational opportunities.

## Time Frame and Measurable Outcomes

Workgroup formed by January 2013.

## Fiscal Implications

Schools should incorporate this training into their established programs, but adding an additional course would entail additional cost to the school, as well as a cost to the student to take an additional course. There may be an additional cost to licensees if licensing boards impose a requirement for training.

**“A lot of physicians don’t know what the community resources are. There’s a need to educate them about disease process more and how to keep people integrated in community.”**

**– Nancy in Bend**

# Goal 3: Protect Individuals with Dementia

**Recommendation 3A: Require that all Oregon guardians, both family and professional, receive training about dementia, as well as on the responsibilities and ethics of representing a person with dementia.**

## Strategies

1. Collaborate with a broad set of stakeholders to develop a comprehensive training package that includes dementia as one element of mandatory training for existing guardians and all new guardians appointed in Oregon.
2. Develop a pilot training on dementia and guardianship and provide it online as a voluntary training for guardians until a mandatory training package is established.

## Rationale

Many individuals with moderate to severe ADRD exhibit behaviors requiring psychiatric in-patient treatment and/or 24/7 placement in secure placement settings. Treatment centers are hesitant to hold individuals without civil commitment authority or legal guardianship. Families universally wish to avoid the stigma of civil commitment leaving guardianship as the best alternative to provide treatment and appropriate placement. Few families can afford to appoint a professional guardian. Family members are thus often appointed as guardians with no training or orientation regarding ethics or the required duties.

Currently Oregon guardians for incapacitated persons, including those with ADRD, are not mandated to receive any training. In order to be an effective guardian of someone with dementia, one must be informed about dementia, aware of the issues relating to how to care for a person with it, and the resources available.

## Key Partners

The Oregon Bar Association, Guardian/Conservator Association of Oregon, Oregon DHS, Probate Appointed Special Advocates (PASA), representatives of the judiciary, the Oregon Association of Area Agencies on Aging and Disability, Disability Rights Oregon, individuals currently serving as guardians, the Office of the Long-Term Care Ombudsman

## Time Frame and Measurable Outcomes

By January 2013, the training will be available online with a training manual. By January 1, 2015, training in Oregon will be mandatory within 90 days after appointment, and 90 percent of new guardians will have been trained.

## Funding Implications

Any cost to develop training may be funded by the Older Americans Act legal-services funds, or by a private grant. It is anticipated that training would then be made available online at little or no cost to participants.





# Goal 3: Protect Individuals with Dementia

**Recommendation 3B: Expand capacity to protect the safety and well-being of individuals with dementia.**

## Strategies

1. Increase transportation options for individuals with dementia by ensuring that the needs of individuals with dementia and their families are considered in planning decisions by state and local transportation agencies, and by expanding volunteer and state/federal options available to support their transportation needs.
2. Establish a stakeholder workgroup to determine how to protect residents of Assisted Living Facilities (ALFs) and Residential Care Facilities (RCFs) that terminate their Medicaid contracts from being negatively impacted by the contract termination.
3. Secure state and/or federal funding to expand the Gatekeeper Program statewide through existing Area Agencies on Aging or other aging-services partners in each community. Gatekeeper programs train identified community members such as letter carriers, meter readers, bank tellers, and trash haulers about ways to identify potential harm to at-risk older adults and how to alert existing services.

**“We need a much better plan for dealing with driving, especially because it means you lose independence.”**  
– Anonymous in Bend

## Rationale

Individuals with ADRD need additional support and protection to remain safely in their communities and care settings. Key issues identified through public input and workgroup efforts included:

- **Transportation** – Families and individuals face significant transportation challenges when driving is no longer safe for the person with dementia. Families need help in preventing a family member from driving and in finding alternative sources of transportation.
- **Avoiding unnecessary moves for residents of ALFs and RCFs who become eligible for Medicaid assistance after spending down their resources** – Low-income individuals need protection from the negative impacts of eviction from care settings that decide to no longer accept Medicaid payments without following a gradual withdrawal process that allows existing residents to remain.
- **Community identification and referrals of at-risk older adults** – Oregon communities need more Gatekeeper programs that enlist the help of utility, law enforcement, postal, and other service providers to help identify people in need of support. Currently, Gatekeeper programs are only available in Multnomah, Washington, and Clackamas counties.

# Goal 3: Protect Individuals with Dementia

## Lead Organizations

- Strategy 1 – Alzheimer’s Association Oregon Chapter. Other key partners: Oregon Department of Transportation, Department of Motor Vehicles, AARP, Area Agencies on Aging (AAA)
- Strategy 2 – Oregon DHS. Other key partners: Oregon Health Care Association, LeadingAge Oregon, Office of the Long-Term Care Ombudsman, Disability Rights Oregon, Oregon Association of Area Agencies on Aging and Disabilities (O4AD)
- Strategy 3 – Oregon Association of Area Agencies on Aging and Disabilities (O4AD). Other key partners: Oregon DHS, Association of Oregon Counties, League of Oregon Cities

## Time Frame and Measurable Outcomes

- Increased information online and through Alzheimer’s Association Oregon Chapter on driving decisions and transportation options for individuals with dementia by April 2013.
- By 2015, 80% of individuals with ADRD will have access to affordable transportation to vital resources at least once per week.
- Medicaid withdrawal workgroup formed by April 2013.
- Gatekeeper Program in place statewide by January 2016.

**“We need all the resources possible to find a cure. Now my father is 92 and he is starting to show signs of dementia and the terror of forgetfulness. Whatever we can do as a nation we need to do now at all costs.”**

**– Lisa in Portland**

## Fiscal Implications

- Individuals who can no longer safely drive are often forced to relocate to a higher-cost care setting if transportation options are not available, resulting in costs to themselves and the state. These costs savings would likely more than balance out any new costs associated with providing transportation.
- Gatekeeper Program estimated cost is \$50,000 per Area Agency on Aging (AAA); at seventeen AAAs in Oregon, this would cost \$850,000. Federal funding could be available for this purpose. Program could be self-supporting as participating businesses, organizations, and agencies pay for training to become “Gatekeeper-certified.”

# Goal 4: Improve Access to Quality Care

**Recommendation 4A: Develop appropriate care settings and services for persons with dementia who require a higher level of expertise and staff in helping manage their significant behavioral needs.**

## Strategy

1. Establish a workgroup to:
  - A. Evaluate existing settings and services that have traditionally supported individuals with ADRD who have serious behavior needs and identify the issues that prevent finding appropriate support or placement for them.
  - B. Review current models either within Oregon or from other states that have proven to be best practices and cost effective.
  - C. Develop proposals for model(s) to serve this population, including an economic analysis of the proposed models and suggestions on how to fund them.
  - D. Determine if there is a need for legislation, additional administrative rules or changes to current rules.

## Rationale

Some people with dementia in Oregon exhibit serious negative behaviors, which create barriers to appropriate care. Families have great difficulty finding long-term care settings with appropriate staff levels and available medical care for their family members with significant behavioral needs.

## Lead Organizations

Oregon DHS and Oregon Health Authority/Addictions and Mental Health (OHA/AMH). Other key partners: Office of the Long-Term Care Ombudsman, Oregon Health Care Association, Leading Age Oregon, Oregon State Hospital, Tuality Healthcare, Center for Geriatric Psychiatry, Alzheimer's Association Oregon Chapter, Alzheimer's Network of Oregon, Oregon Hospice Association, Providence ElderPlace.

## Time Frame and Measurable Outcomes

Convene the work group by January 2013 and have proposals ready for legislators, DHS and OHA management by June of 2014.

## Fiscal Implications

Any avoidance or delay in admissions to psychiatric facilities or Oregon State Hospital will create substantial savings to offset any implementation costs.

# Goal 4: Improve Access to Quality Care

**Recommendation 4B:** Increase access to health care providers who serve those with Alzheimer’s disease and related dementia.

## Strategies

1. Develop and maintain a statewide list on the central Alzheimer’s website of health care providers who serve those with dementia, including providers in primary care, geriatrics, psychiatry, and neurology.
2. Create a work group to identify ways to expand utilization of telemedicine and other technology to keep healthcare providers updated on current treatment developments, and increase access in rural areas to expertise in other areas.

## Rationale

Families and professionals often face challenges in finding medical care for people with dementia. No single comprehensive list exists of healthcare providers who have experience treating dementia in Oregon. Also, rural communities face additional barriers to services and finding providers with expertise, but new technologies could bridge that gap by allowing rural healthcare providers and their patients to consult with healthcare providers in other parts of the state.

**“We need more options for care when a Memory Care facility can no longer handle a person.”**

**– Advocate in Benton County**

## Lead Organizations

- Strategy 1 – Oregon Geriatric Society. Other key partners: Oregon Psychiatric Association, Oregon Medical Association, Alzheimer’s Association Oregon Chapter.
- Strategy 2 – OHSU Layton Aging and Alzheimer’s Disease Center; Oregon Center for Aging & Technology. Other key partners: Oregon Medical Association and the U.S. Department of Veterans Affairs VISN 20.

## Time Frame and Measurable Outcomes

- Healthcare provider list developed and posted online by January 2014.
- Workgroup established by OHSU to explore technology options by June 2013.

## Fiscal Implications

Costs and possible funding options for expanding technology into rural areas would have to be explored as part of workgroup. Expanding telemedicine and other technological tools can create cost savings and improvements in treatment to offset the cost of investing in these tools.

# Goal 5: Comprehend, Prevent, and Effectively Treat Dementia and Its Impact

**Recommendation 5A: Establish a coordinated data system to improve Oregon’s ability to plan for and provide effective resources regarding Alzheimer’s disease and related dementias.**

## Strategies

1. Create a work group of stakeholders to identify existing data, identify gaps, and design and implement a system that ensures data can be collected, analyzed, and reported to guide policy and funding decisions related to dementia care in Oregon.
2. Increase public-health surveillance and analysis of impacts of ADRD and caregiving in Oregon using the Behavioral Risk Factor Surveillance Systems (BRFSS) cognitive impairment and caregiver modules. Explore use of other existing data sources available that are related to state-funded medical and long-term care services.
3. Assess current capacity (including Medicaid-eligible) in licensed long-term care settings that serve people with dementia in Oregon to determine availability and potential gaps in this service statewide.

## Rationale

Oregon needs accurate data to measure the burden of disease, guide public-health priorities, target interventions, and set healthcare policy. Surveillance data help us understand who is affected by ADRD, what health behaviors may increase risk, and how this disease affects the person and his or her quality of life. Some data already exist, but there is difficulty accessing state and local data related to people with dementia, caregiving, and facilities and services for those with dementia. Town hall meeting participants raised concerns about a) shortages of space in dementia-specific long-term care settings in Oregon, and b) needing to be better prepared as a state to withstand the impact of this disease. Oregon-specific data on the prevalence of ADRD, healthcare costs associated with ADRD, service needs and utilization (including availability of long-term care) in specific regions, and caregiving costs would allow for better statewide planning and development of appropriate strategies for addressing dementia and its impacts in Oregon.

## Lead Organizations

OHA Public Health and Oregon DHS. Other key partners: Alzheimer’s Association Oregon Chapter and OHSU.

## Time Frame and Measurable Outcomes

- Create work group by January 2013.
- Identify existing Alzheimer’s-related data and data gaps, and improve access to existing Alzheimer’s-related data by December 2013.

## Fiscal Implications

- Staff time of partners involved to identify and make available existing data.
- Federal (CDC or Administration on Aging) or private funding to support any additional data collection and analysis.
- Cost of including Cognitive Impairment and Caregiver modules in BRFSS: approx. \$40,000 annually.

# Goal 5: Comprehend, Prevent, and Effectively Treat Dementia and Its Impact

## **Recommendation 5B: Expand existing dementia research and participation in Oregon research efforts.**

### Strategies

1. Create an online list of all current state and national dementia-related research in order to increase the number of Oregonians participating in Alzheimer's research trials.
2. Promote increased use of the state income tax check off through a publicity campaign.

### Rationale

Oregon has a mechanism for supporting new and emerging dementia research projects through the Oregon tax check-off fund included on the Oregon tax forms on rotating years. However, this program results in raising only small amounts each year,<sup>25</sup> and is only able to fund about half of submitted proposals.<sup>26</sup> These Oregon-specific projects, as well as nationally funded research, often face challenges in finding participants, while potentially interested individuals and families currently only have access to recruitment lists of federally funded research.

**"I frequently hear from families that the resources available are very limited. Families have difficulty finding geriatric providers who are accepting new patients. There is also a shortage of providers who specialize in Alzheimer's and other dementias."  
– Care professional, Lane County**

### Lead Organizations

- Strategy 1 – OHSU Layton Center for Aging and Alzheimer's Disease. Other key partners: other Oregon research programs, Alzheimer's Association Oregon Chapter, Oregon Medical Board
- Strategy 2 – Key partners: OHSU Layton Center for Aging and Alzheimer's Disease, Oregon Health Care Association, LeadingAge Oregon, Endear for Alzheimer's, Alzheimer's Network, Alzheimer's Association Oregon Chapter

### Time Frame and Measurable Outcomes

- List of state and national research compiled and posted online by March 2013.
- Twenty percent increase in participation in Oregon research projects by January 2014.
- Annual ten percent increase in amount raised for research through tax check off.

### Fiscal Implications

Costs for development of online research listing and promotion of tax check off may be covered by partnering organizations.

# Glossary of Terms

## Glossary of terms

**Caregiver** – The term “caregiver” refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help. Informal caregiver and family caregiver are terms that refer to unpaid individuals such as family members, friends, and neighbors who provide care. These individuals can be primary or secondary caregivers, full or part time, and can live with the person being cared for or live separately.

**Long-term care** – This term refers to a variety of services that include medical and non-medical care to people with a chronic illness or disability. Long-term care helps meet health or personal needs, such as assisting with activities of daily living (dressing, bathing, cooking, etc.). Long-term care can be provided at home, in the community, in assisted living, or in nursing homes.

**Medical Home** – A medical home integrates patients as active participants in their own health and well-being. Patients are cared for by a physician who leads the medical team that coordinates all aspects of preventive, acute and chronic needs of patients using the best available evidence and appropriate technology. These relationships offer patients comfort, convenience, and optimal health throughout their lifetimes. (American Academy of Family Physicians 2008)

**Person-centered care** – Person-centered care is a key concept guiding efforts to improve long-term care. Elements of person-centered care include personhood, knowing the person, maximizing choice and autonomy, comfort, nurturing relationships, and a supportive physical and organizational environment. An example is allowing a resident in a care community to have a daily bath at a time that is appropriate for her.

**Person-directed care** – Person-directed care is a process based on a set of principles of supporting an individual to direct his or her own care through developing a plan rooted in what is important to the individual, while taking into account all the factors that impact the individual’s life. Person-directed care promotes a positive relationship between the individual and staff, which is accomplished by staff being knowledgeable about the individual’s life story, routines, and habits, and incorporating that information into the individual’s daily care and activities.

**Wiki** – A wiki is a Web site that allows users to add and update content on the site using their own Web browser. This is made possible by Wiki software that runs on the Web server. Wikis end up being created mainly by a collaborative effort of the site visitors.

# Appendix A: Information about Alzheimer's

## 10 Signs of Alzheimer's

Memory loss that disrupts daily life may be a symptom of Alzheimer's, a fatal brain disease that causes a slow decline in memory, thinking and reasoning skills.

There are 10 warning signs and symptoms of Alzheimer's. Every individual may experience one or more of these signs in different degrees. If you notice any of them, please see a doctor.

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work or during leisure time
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood or personality

## 7 Stages of Alzheimer's

Alzheimer's symptoms vary. The stages below provide a general idea of how abilities change during the course of the disease. Not everyone will experience the same symptoms or progress at the same rate.

This seven-stage framework is based on a system developed by Barry Reisberg, M.D., clinical director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center:

1. No impairment (normal function)
2. Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease)
3. Mild cognitive decline (early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms)
4. Moderate cognitive decline (mild or early-stage Alzheimer's disease)
5. Moderately severe cognitive decline (moderate or mid-stage Alzheimer's disease)
6. Severe cognitive decline (moderately severe or mid-stage Alzheimer's disease)
7. Very severe cognitive decline (severe or late-stage Alzheimer's disease)



# Appendix A: Information about Alzheimer's

## Risk Factors for Alzheimer's

Scientists have identified factors that increase the risk of Alzheimer's. While the greatest risk factor is advancing age, many who advance even into their nineties do not have Alzheimer's disease. While family history and associated genetic influences are important predictors, many family members of those with Alzheimer's will not develop this condition. Thus, identifying other disease modifying factors is critically important.

Most experts believe the majority of Alzheimer's disease occurs as a result of complex interactions among genes and other risk factors. Age, family history and heredity are all risk factors we can't change. Now, research is revealing clues about other risk factors we may be able to influence through general lifestyle and wellness choices and effective management of other health conditions:

**Head trauma** – There may be a strong link between serious head injury and future risk of Alzheimer's, especially when trauma occurs repeatedly or involves loss of consciousness.

**Heart-head connection** – Growing evidence links brain health to heart health. Your brain is nourished by one of your body's richest networks of blood vessels. Every heartbeat pumps about 20 to 25 percent of your blood to your head, where brain cells use at least 20 percent of the food and oxygen your blood carries.

**General healthy aging** – Other lines of evidence suggest that strategies for overall healthy aging may help keep your brain as well as your body fit. These strategies may even offer some protection against developing Alzheimer's or related disorders. Try to keep your weight within recommended guidelines, avoid tobacco and excess alcohol, stay socially connected, and exercise both your body and mind.

## Related Dementias

Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. Physical changes in the brain cause it.

Alzheimer's disease is the most common type of dementia, accounting for 60 to 80 percent of cases. Other causes may include:

- **Vascular Dementia** – 2nd most common cause of dementia after Alzheimer's.
- **Mixed Dementia Abnormalities** – Linked to more than one type of dementia occurring simultaneously in the brain.
- **Dementia with Lewy Bodies** – Can include sleep disturbances, visual hallucinations and Parkinsonian movement features.
- **Parkinson's Disease** – A progressive dementia similar to dementia with Lewy bodies or Alzheimer's.
- **Frontotemporal Dementia** – Includes dementias such as behavioral variant FTD (bvFTD), primary progressive aphasia, Pick's disease and progressive supranuclear palsy.
- **Creutzfeldt-Jakob Disease** – The most common human form of a group of rare, fatal brain disorders affecting people and certain other mammals.
- **Normal Pressure Hydrocephalus** – Symptoms include difficulty walking, memory loss and inability to control urination. Caused by the buildup of fluid in the brain.
- **Huntington's Disease** – A progressive brain disorder caused by a single defective gene on chromosome 4.
- **Wernicke-Korsakoff Syndrome** – A chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). The most common cause is alcohol misuse.
- **Mild Cognitive Impairment** – A condition that causes a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. A person with MCI is at an increased risk of developing Alzheimer's or another dementia.

# Appendix B

The following is a list of topics and services to be provided through the proposed central Alzheimer's website for Oregon. This list serves as a starting point, and other ideas and topics will be considered for inclusion.

- **Information about**
  - Advance directives/guardianship/power of attorney/conservatorship and other legal issues
  - Financial planning
  - Care Options
    - In-home care options
    - Residential care options
    - Respite services
    - Adult day services
  - Safety Issues
    - Driving
    - Wandering
    - In-home safety
  - Facts about Alzheimer's disease and related dementias
    - Including culture-specific information
    - Including younger-onset information
  - Finding Oregon doctors specializing in diagnosis and care of dementia
  - How to participate in Oregon research projects and local clinical trials
  - Upcoming events and trainings
- **Connection to local resources such as**
  - Classes
  - Support groups
  - Caregiver respite programs
  - Adult day care
  - Counseling
  - Care managers
  - Family caregiver support programs
- **Links to**
  - Home care commission
  - Adult Protective Services
  - Long term care ombudsman
- **Online training for people serving as guardians in Oregon**
- **Information geared toward medical profession**
  - Latest care standards
  - Diagnosis criteria
  - Latest research info
  - Training opportunities

# Appendix C: Oregon Programs and Resources that Provide Alzheimer's Disease Support

The following list outlines some of the many programs and services that already exist in Oregon. While this is not an exhaustive list – and not all listed programs and services are designed specifically for people with Alzheimer's and related dementias – it provides an overview of some of the existing services.

## Information and Support

**Aging and Disability Resource Connection (ADRCs)** – ADRCs are being developed in Oregon to be a central source of information, advice and help in locating services or applying for benefits for older people and people with disabilities regardless of income. [www.ADRCofofOregon.org](http://www.ADRCofofOregon.org)

**Alzheimer's Association Oregon Chapter** – The Alzheimer's Association Oregon Chapter provides education and support for people diagnosed, their families, and caregivers. From offices in Portland 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. [alz.org/oregon](http://alz.org/oregon) 1-800-272-3900

**Alzheimer's Network of Oregon** – Based in Salem and serves Marion, Polk, Linn, and Benton counties with family caregiver training and resources, an early stage program, and on-line caregiver resources. [alznet.org](http://alznet.org)

**Area Agencies on Aging (AAAs)** – Oregon's 17 AAAs are supported with funding from the federal Older Americans Act, and provide information, nutrition services, family caregiver support, health promotion, legal services, and home support services. The Older Americans Act Family Caregiver Support program coordinated by each AAA supports caregiver services including information and support, respite care, counseling. [www.o4ad.org](http://www.o4ad.org)

# Appendix C: Oregon Programs and Resources that Provide Alzheimer's Disease Support

## Community Services and Programs

**Adult Day Services** – Provide health, social and related support services to private-pay and/or Medicaid clients in a protective setting during part of a day but for less than 24 hours per day. Specific services include assistance with activities of daily living, social services, activities, nutrition services, health care services, and assistance to arrange transportation to the program.

**Behavioral Coach Program** – Pilot program developed in Oregon in 2009 to reduce the frustration, injuries, stress, placement failures and crisis situations that result when persons who have substantial behaviors are not provided with the support that they and their caregivers need. The program uses behavioral coaches to develop supports in the person's environment and improve interactions with caregivers who work in long term care settings.

**Faith-Based Programs** – Faith communities have traditionally provided spiritual, emotional, and sometimes physical support to members. Parish nurses, Stephen Ministers, Faith in Action programs, and other services developed in individual faith communities are all resources that may be able to provide support for families dealing with Alzheimer's. [www.parishnurseministry.org](http://www.parishnurseministry.org)

**Gatekeeper Program** – This program, available in the Portland metro area through Area Agencies on Aging, trains community members on how to identify seniors and persons with disabilities who may need assistance, and who to call when they encounter someone in need. It trains community members such as postal workers, bank tellers, and utilities providers how to keep their eyes and ears alert for seniors and people with disabilities who are at risk, particularly those who are isolated, living alone and potentially in need of some type of assistance to maintain their independence.

**Gerontology Programs** – Oregon has a number of accredited community colleges and universities offering associates, bachelors, graduate, and certificate programs in aging and gerontology which include coursework and training related to cognitive impairment and Alzheimer's: Portland Community College, Clackamas Community College, Southwestern Oregon Community College, Portland State University Institute on Aging, Marylhurst University, Oregon State University.

**Home Care Commission** – The Commission is responsible for ensuring the quality of home care services that are funded by the Department of Human Services for seniors and people with disabilities. The Commission has a statewide registry of homecare workers, provides training for homecare workers and consumers, and serves as the "employer of record" for purposes of collective bargaining for homecare workers whose pay comes from public funds. [www.oregon.gov/DHS/spd/adv/hcc](http://www.oregon.gov/DHS/spd/adv/hcc)

**In-Home Care Agencies** – Are designed to provide essential supportive non-medical services that enable an individual to remain in his or her own home. In-home agencies are licensed, and services range from assistance with household tasks to assistance with activities of daily living, with services varying from a few hours per week to full-time.

**Medicaid** – A jointly-funded (federal and state) public program that supports long-term care services. To receive support, participants must be low-income and have significant care needs, including cognitive impairment/dementia. Under the Home and Community Based Care waiver, eligible participants can receive a variety of services in their home or in licensed facilities (see licensed facility listing below). In addition, Oregon offers

# Appendix C: Oregon Programs and Resources that Provide Alzheimer's Disease Support

several programs to allow Medicaid clients more control over the care they receive in their homes:

- **Client-Employed Provider Program (CEP)** – Allows Medicaid clients to select and hire their own care providers, called home care workers. Home care workers may be friends, neighbors or relatives, and they can provide services on an hourly or live-in basis.
- **Independent Choices** – A Medicaid program clients receive that allows clients to receive funds to directly pay for services by a home care worker or family member.
- **Spousal Pay** – Allows payment for services provided by a spouse of an eligible Medicaid client who has a progressive, debilitating condition which limits their activities of daily living and requires assistance in at least four areas. [www.oregon.gov/DHS/spwpd/ltc/inhome.shtml](http://www.oregon.gov/DHS/spwpd/ltc/inhome.shtml)

**Oregon Project Independence** – State-funded program for individuals who are not receiving Medicaid long-term care services, and who are 60+ years old or who have Alzheimer's disease or a related disorder. Participants may have to pay for services based on a sliding fee schedule. Possible services include; personal care, homemaker/homecare services, chore services, assisted transportation, adult day care, respite, case management, registered nursing services and home delivered meals. [www.oregon.gov/DHS/spwpd/ltc/inhome.shtml](http://www.oregon.gov/DHS/spwpd/ltc/inhome.shtml)

**Oregon DMV's Driver 50+ website** – Provides education and resources to help drivers age 50+ stay safe and mobile as they age, including information on transportation options and resources for family & caregivers. [www.oregon.gov/ODOT/DMV/50plus/index.shtml](http://www.oregon.gov/ODOT/DMV/50plus/index.shtml)

**Oregon DMV's Medically At-Risk Driver Program** – Provides voluntary and mandatory reporting guidance and FAQs, including information on reporting based on when cognitive and functional impairments affect driving ability. [www.oregon.gov/ODOT/DMV/pages/driverid/medical.aspx](http://www.oregon.gov/ODOT/DMV/pages/driverid/medical.aspx)

**Powerful Tools for Caregivers** – Six-week peer-led program developed in Oregon based on Stanford's Chronic Disease Self-Management Program that provides caregivers with skills and strategies to deal with the challenges of caregiving. [www.powerfultoolsforcaregivers.org](http://www.powerfultoolsforcaregivers.org)

**Senior Companion program** – A program of the federal SeniorCorps (along with RSVP and Foster Grandparents), this program provides adults 55+ with a small stipend to provide companionships and simple household assistance to older adults in their community. [www.seniorcorps.gov/about/programs/sc.asp](http://www.seniorcorps.gov/about/programs/sc.asp) and [www.oregonvolunteers.org/volunteer/seniorcorps/scp](http://www.oregonvolunteers.org/volunteer/seniorcorps/scp)

**Star-C** – This three-year grant-funded project uses trained case managers to provide a series of home visits and phone calls to family caregivers of individuals with Alzheimer's disease. The program is based on research from the University of Washington and is expected to result in a decrease in frequency of challenging behaviors, and severity of depression in caregivers. The project is being conducted in just three counties: Multnomah, Jackson and Josephine.

**Veterans Administration** – Care for Veterans with ADRD is provided throughout the full range of VA healthcare services. Depending on the Veteran's needs, services may include home-based primary care, homemaker and home health aide, respite, adult day health care, outpatient clinic, inpatient hospital, nursing home, or hospice care. Caregiver support is an essential part of all of these services. [www.va.gov](http://www.va.gov)

# Appendix C: Oregon Programs and Resources that Provide Alzheimer's Disease Support

## Licensed Care Settings

Oregon Department of Human Services is responsible for the licensing of long term care settings, including adult foster care homes, residential care, assisted living facilities and nursing home. These licensed settings provide assistance with activities of daily living (bathing, dressing, grooming, toileting), assistance with medication, meals, planned or individual activities, housekeeping, and either providing or arranging transportation. Retirement homes or communities are for people who are able to live independently, but do not want to maintain a home and are not licensed by DHS.

[www.drcoforegon.org/residential.php?t=Licensed Residential Care Facilities](http://www.drcoforegon.org/residential.php?t=Licensed%20Residential%20Care%20Facilities)

**Adult Foster Homes** – Provide personal and health care to people in private homes for five or fewer residents. Adult foster homes provide different levels of care depending on their license. And there are foster homes that focus on providing services to people with dementia.

**Assisted Living Facilities (ALFs)** – Are required to have private apartments that are equipped with a kitchenette and a private bathroom for an individual or a couple. ALFs provide health services and have systems in place to respond to the 24 hour care needs of residents. A registered nurse is not required to be on-site 24 hours a day, however facilities are required to have a licensed nurse who has regularly scheduled hours and who is available for phone consultation.

**Memory Care Communities** – Formerly known as Alzheimer's Care Units, these settings have an endorsement to provide services to people with dementia. Nursing, residential care and assisted living facilities can obtain an endorsement if they meet the requirements. These requirements are in addition to the licensing requirements for the facility type. Memory Care Communities are expected to provide a person-directed approach to care, to provide staffing that meets or exceeds their licensing requirement and that meets the needs of the residents, and to provide additional training specific to dementia.

**Nursing Facilities** – Provide nursing care on a 24 hour basis for individuals who need nursing or medical oversight including recuperation, rehabilitation and restorative services post hospitalization for a serious illness or injury. Nursing facilities are required to have Certified Nursing Assistants (CNAs) provide direct care to residents.

**Office of the Long-Term Care Ombudsman** – The Office of the Long-Term Care Ombudsman is an independent state agency that serves long-term care facility residents through complaint investigation, resolution and advocacy for improvement in resident care. The mission of the Office is to enhance the quality of life, improve the level of care, protect the individual's rights and promote the dignity of each Oregon citizen residing in a long-term care facility. Online at [www.oregon.gov/LTCO/](http://www.oregon.gov/LTCO/) or by phone at 800-522-2602.

**Residential Care Facilities (RCFs)** – The requirements for systems and services provided in residential care facilities are the same as for assisted living facilities; however, a residential care facility may have shared bedrooms and bathrooms, or residents may have their own apartment.

# Appendix C: Oregon Programs and Resources that Provide Alzheimer's Disease Support

## Medical Research and Trainings

**Layton Aging and Alzheimer's Disease Center** – Funded by the National Institutes of Health, this Center at OHSU focuses on dementia care and research.

[www.ohsu.edu/xd/research/centers-institutes/neurology/alzheimers](http://www.ohsu.edu/xd/research/centers-institutes/neurology/alzheimers)

**Oregon Center for Aging and Technology (ORCATECH)** – This OHSU Center supports research and development of technology to support independent living, aging-in-place research, and evidence-base for technologies supporting aging – and has included a large focus on aging supports for people with cognitive impairment including Alzheimer's. [www.orcatech.org](http://www.orcatech.org)

**Oregon Geriatric Education Center (OGEC)** – Based at OHSU and funded by the Health Resources and Services Administration (HRSA), this Center is focused on improving the care of older adults through interdisciplinary education and training of healthcare providers.

[www.ohsu.edu/xd/education/schools/school-of-nursing/about/centers/oregon-geriatric-education](http://www.ohsu.edu/xd/education/schools/school-of-nursing/about/centers/oregon-geriatric-education)

**Oregon Partnership for Alzheimer's Research (OPAR)** – Staffed by the Layton Center, this research fund to support new and emerging research on Alzheimer's is supported through a tax check-off that is rotated with other charitable efforts on Oregon tax forms in varying years. The check-off results in limited funds which allow for supporting 3-4 small projects in years when the tax check-off is listed.

[www.ohsu.edu/xd/research/centers-institutes/neurology/alzheimers/giving/tax-checkoff-giving.cfm](http://www.ohsu.edu/xd/research/centers-institutes/neurology/alzheimers/giving/tax-checkoff-giving.cfm)



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25. According to the Oregon Department of Revenue, in the last ten years, the largest amount raised was \$140,539 in 2004 when the check off was on the tax form. The lowest amount was \$12,330 in 2011 when it was not on the form.
26. The Layton Aging and Alzheimer's Disease Center at OHSU reports that since 2004, when they began administering the program, 38 proposals have received funds out of 63 applications. Grants are typically about \$25,000, although some have been as much as \$40,000.