

Washington State Plan to Address Alzheimer's Disease and Other Dementias

Executive Summary
January 1, 2016



**Preparing Washington for the Impacts of
Alzheimer's Disease and Other Dementias**

GUIDING PRINCIPLES

The following principles were identified by the Alzheimer's Disease Working Group as critical to success - they are assumed and emphasized throughout the Washington State Plan to Address Alzheimer's Disease.

Alzheimer's Includes Other Dementias

Reference to Alzheimer's in this Plan is considered to also include other forms of dementia.

Public-Private Framework

This is not intended as a "state government-only" Plan, but rather a framework for what public-private partners in Washington can do collectively.

Build Upon Other Work

Build upon what's being done nationally (e.g., National Alzheimer's Plan, CDC Healthy Brain Initiative), and on what's working in Washington, other states & nations.

Person & Family Centered

Develop the Plan with the needs of people with AD, their care partners, family members, and guardians at the forefront; this includes sensitivity to cultural values and beliefs.

Life Course Approach

We are in this together, from before diagnosis through end-of-life care. This Plan recognizes that we can each do something to help individuals and the State address this disease holistically.



STATE OF WASHINGTON
Office of the Governor

Dear Washingtonians:

Alzheimer's is the 3rd leading age-adjusted cause of death in Washington State. While death rates for cancer, stroke and heart disease have declined, the death rate for Alzheimer's is on the rise – currently, more than 107,000 people in Washington have Alzheimer's or other dementias, and unfortunately, that number is expected to double in the next 25 years.

Every part of our state is touched by dementia, including Alzheimer's disease. The impact is being felt by individuals and families who bear the greatest emotional and financial responsibility, by our employers and economy, by health care systems striving to meet complex needs and by local communities and state resources.

Great challenges present great opportunities, and one of these opportunities can be seen in work that has grown out of the Aging Summit I convened in 2013. During that summit, great public and private leaders from across the state identified the need to produce an Alzheimer's and other dementias state plan. In 2014, the legislature took up that call to action and passed legislation for the development of a state plan.

As a result, we have formed a cross-sector Alzheimer's Disease and Dementia Working Group – made up of consumers and public-private stakeholders – to identify major goals, strategies and recommendations as part of our state plan. This is a starting point to prepare Washington State for meeting this challenge.

While there is still no known way to prevent or cure Alzheimer's, even though local researchers in our world-class bioresearch sector may be getting close to new effective treatments, our state plan proposes common sense steps that we can take to promote brain health; address legal, financial and care planning; improve the quality of life for those living with dementia; ease the strain on family caregivers and reduce associated costs in the future.

I commend the work to date and urge my administration, including leadership from the Department of Social and Health Services, Department of Health and Health Care Authority, to convene the next generation Alzheimer's Disease and Dementia Advisory Group and continue collaborating with the Group and stakeholders to move the recommendations forward.

Now is the time to take action that improves the health of people with, or at risk of, Alzheimer's or other dementias. Join us as we work together to that end.

Very truly yours,

Jay Inslee
Governor

Frequently Used Acronyms

AD	Alzheimer's disease and other dementias
APS	Adult Protective Services
AGO	Office of the Attorney General
ALTSA	Aging and Long-Term Support Administration of the Department of Social and Health Services
ADWG	Alzheimer's Disease Working Group
AAA	Area Agencies on Aging
CMS	Centers for Medicare and Medicaid Services
CDC	Centers for Disease Control and Prevention
DOH	Washington State Department of Health
DSHS	Washington State Department of Social and Health Services
HCA	Washington State Health Care Authority
HCS	Home and Community Services (part of ALTSA/DSHS)
LTSS	Long-Term Supports and Services
OPG	Office of Public Guardianship
RCS	Residential Care Services
UW	University of Washington

"The truth is that we simply must put Alzheimer's on the front burner because if we don't, Alzheimer's will not just devour our memories, it will also break our women, cripple our families, devastate our health care system and decimate the legacy of our generation. But if we do, I'm convinced that this Woman's Nation will be able to say that, believe it or not, there once was a time when there was no cure for Alzheimer's."

*Maria Shriver, author of The Shriver Report:
A Woman's Nation Takes on Alzheimer's*

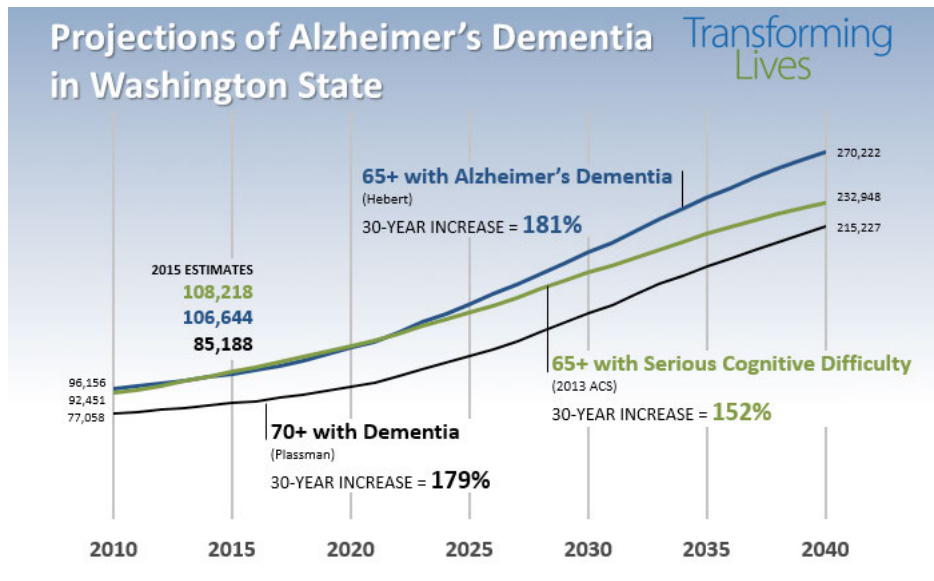
EXECUTIVE SUMMARY

THE IMPACT OF ALZHEIMER'S DISEASE IN WASHINGTON

Alzheimer's disease is the 3rd leading age-adjusted cause of death in Washington State. While death rates of cancer, stroke and heart disease have declined, the death rate for Alzheimer's is on the rise. Currently, about 107,000 people in Washington have Alzheimer's or other dementias. By 2040, that number is expected to grow to over 270,000.

Dementia, including Alzheimer's disease is one of the most costly chronic conditions to society. It poses a financial burden, similar to that of heart disease and cancer.

The progressive nature of dementia, its long duration, and its effects on memory, self-care, decision-making, and behavior create particular challenges for individuals and families.



Family members provide the majority of care. It's estimated that there are up to 324,000 unpaid family caregivers of persons living with dementia in Washington State. For many, the demands of caregiving lead to negative outcomes – stress, health risks, isolation, depression, and financial strain. Dementia also impacts Washington's employment and economy as more family caregivers need to miss work days, reduce work hours or leave their jobs.

Washington State's long-term services and supports system (LTSS) has demonstrated the ability to provide the majority of LTSS in the community. However, the system is already struggling to keep pace with the demand. The growing dementia population across the state will require us to intensify efforts to improve access to, and dementia-capability of, long-term services and supports.

Lack of early diagnosis leads to missed opportunities for: treatment; support and education for individuals and families; making legal and financial plans; and identifying choices for end-of-life care. It also contributes to otherwise preventable emergency room visits and hospitalizations. As health care system improvements such as Healthier Washington evolve in Washington State, it is essential that best practices around the early detection, diagnosis, treatment and management of dementia and co-occurring chronic illnesses are integrated into practice.

HOW WILL THIS PLAN HELP?

There is still no known way to prevent or cure Alzheimer's, but there are steps that individuals, the state and community partners can take to promote healthy aging and brain health, to improve the quality of life for those living with the disease, to ease the strain on family caregivers, and to reduce associated costs in the future.

During the Aging Summit, convened by Governor Jay Inslee in 2013, leaders from both public and private sectors identified the need to produce a state plan to address Alzheimer's disease. In 2014, the legislature took up that call and passed legislation to do so.

The Alzheimer's Disease Working Group (ADWG), appointed through Substitute Senate Bill (SSB) 6124, was charged with examining the needs of individuals with Alzheimer's, the services available to meet these needs, and the capacity of the state and current providers to meet these and future needs.

"I had to sell everything including jewelry, clothes and shoes. I wanted to keep us all together for as long as possible. Our high school son even handed over his college fund account. [My husband] forgot his children, he forgot his own home, and then he forgot me."

Debbie H., caregiver

While LTSS are an important (and the most costly) component of dementia care, the ADWG finds that dementia is a critical public health issue and recommends that the state adopt a

more comprehensive set of strategies to respond as future needs expand. This includes a change in thinking and practice in terms of medical care for individuals with dementia and closer coordination between medical care, LTSS and community services.



This plan shares findings of the ADWG on needs around the state, and offers forward-thinking strategies and actions to galvanize public and private stakeholders in preparing Washington State for the significant increases in Alzheimer's and other dementias that lie ahead.

A CALL TO ACTION

This plan is a starting point. It builds on opportunities to make positive changes, offering hope for living better with dementia by promoting early detection and better management of the condition, protecting persons with dementia from abuse and exploitation, expanding cost-effective services for people with dementia and their family caregivers, preparing communities for dementia, and improving the dementia-capability of long-term services and supports.

The ADWG believes the recommendations will have a positive impact for all stakeholders from individuals with dementia, to families, providers and governments; and issues a call to action:

- To establish a next generation Alzheimer's/Dementia Action Advisory Group to provide guidance and oversight to state plan implementation;
- To collectively pursue the goals, strategies and recommendations;
- To engage and sustain commitment from a network of public and private partners;
- To integrate activities into broader initiatives that are addressing improved health and quality of life such as Healthier Washington, the Medicaid Transformation Waiver, and the Bree Collaborative End of Life Care Recommendations;
- To identify opportunities to improve our state's response to dementia.

GOALS AND STRATEGIES

1 INCREASE PUBLIC AWARENESS, ENGAGEMENT AND EDUCATION

STRATEGIES

- A. Ensure statewide coordination of information and referral
- B. Create a sense of hope and empowerment for people with dementia and reduce stigma
- C. Promote early detection and diagnosis
- D. Promote advance care planning and legal and financial planning in the early stages of dementia in order to avoid costly or unnecessary court proceedings and/or guardianships
- E. Increase public awareness via educational and promotional campaigns developed and implemented collaboratively with the public and private sectors
- F. Increase public awareness about the connections between health and wellness, brain health, and dementia

2 PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION

STRATEGIES

- A. Attain, analyze, and use available data
- B. Include Alzheimer's, dementia and healthy aging in state and local government plans
- C. Infuse age-friendly and dementia-friendly concepts into local communities
- D. Promote healthy aging and brain health

3

ENSURE WELL-BEING AND SAFETY OF PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

STRATEGIES

- A. Increase awareness to reduce the risk for neglect, abuse, and exploitation of people with memory loss
- B. Promote in-home and community safety and the quick return of people with dementia who may wander
- C. Enhance legal protections for people living with dementia
- D. Promote practices to ensure driving safety of individuals with memory loss and/or dementia

4

ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS

STRATEGIES

- A. Provide guidance and support for dementia caregivers in navigating service systems
- B. Increase availability of, and access to, education and support services
- C. Increase availability of, and referral to, support groups for caregivers
- D. Increase access to respite
- E. Reach individuals and family members early in the disease process through collaborative models of social engagement
- F. Increase the number of culturally and linguistically-diverse caregivers who participate in education and support programs
- G. Collaborate with Tribes to meet unique needs of Native American family caregivers living with dementia
- H. Develop supports for family caregivers who are employed, caring for people with developmental disabilities and dementia, and those living with younger onset dementia
- I. Expand tele-health and web-based resources for family caregivers

5

IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE

STRATEGIES

- A. Endorse a set of evidence-based standards of care for dementia to promote high-quality health care
- B. Promote early detection, diagnosis and treatment
- C. Develop a dementia-capable, culturally competent primary care workforce throughout the state
- D. Support development and implementation of dementia-related, outcome-based performance measures
- E. Support policies that promote the capacity of primary care to adequately screen, diagnose, counsel, and treat patients with cognitive impairment/dementia

- F. Increase awareness of the challenges associated with dementia and co-occurring conditions
- G. Reduce preventable emergency department visits, hospitalizations and readmissions by improving communication and transitions of care
- H. Improve understanding of, and response to, challenging and/or complex behaviors
- I. Increase primary care workforce awareness of the critical role of care partners/caregivers

6 ENSURE DEMENTIA-CAPABLE LONG-TERM SERVICES AND SUPPORTS ARE AVAILABLE IN THE SETTING OF CHOICE

STRATEGIES

- A. Enhance coordination of care
- B. Expand access to affordable care to delay nursing home placement and spend-down to Medicaid
- C. Strengthen numbers and effectiveness of LTSS workers
- D. Reduce the burden of long-term care costs on families and the state
- E. Improve the quality of long-term services and supports for people with dementia
- F. Increase awareness of assistive technologies that promote independence for people with dementia and support for family caregivers

7 PROMOTE INNOVATION AND RESEARCH RELATED TO CAUSES OF AND EFFECTIVE INTERVENTIONS FOR DEMENTIA

STRATEGIES


- A. Increase support for basic, clinical and translational research around cognitive health, dementia and effective dementia care
- B. Develop relationships with key community stakeholders to assess and pilot culturally-specific/relevant services
- C. Increase the number of research participants

Specific problems, needs, recommended actions steps and timeframes for each strategy are included in the full report www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan.

NEXT STEPS

The broad and complex nature of this Plan requires collaboration among many partners, and a phased approach to implementation with short-, mid- or long-term timeframes for each recommendation. The timeframes suggested are based on current resources and may be adjusted as staff and funding resources allow.

In early 2016, the Governor and partners have agreed to convene the next generation Alzheimer's Disease/Dementia Action Advisory Group to develop a work plan for implementation, determining when, and by whom, each short-term recommendation will be acted upon.



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For more information, please visit:
<https://www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan>

