



Western and Central Washington and Inland Northwest Chapters

2014 Public Policy Town Halls

Throughout August 2014, the Alzheimer's Association hosted 15 Public Policy Town Halls across Washington State and Northern Idaho. The events included a panel of community members reflecting the breadth and depth of the Alzheimer's experience. The objectives were to educate the public, solicit input, and provide an opportunity to interact with elected leaders. Topics included the National Alzheimer's Plan and current federal legislative priorities, an Alzheimer's Disease Plan for Washington State, and *Voices for Better Health in Washington State*, a project to improve care and promote advocacy for Washington's dual eligibles.

The National Alzheimer's Plan

The National Alzheimer's Project Act, unanimously passed by both Houses of Congress and signed by President Obama in January 2011, called for the creation and implementation of a National Alzheimer's Plan. The first draft of the Plan was released in May 2012, updates in June 2013 and April 2014. Implementation of the Plan is governed by the Advisory Council on Alzheimer's Research, Care, and Services under the auspices of the Department of Health & Human Services.

The Plan has five overarching goals:

1. Prevent and effectively treat Alzheimer's disease by 2025
2. Enhance public awareness and engagement
3. Enhance care quality and efficiency
4. Expand supports for people with Alzheimer's Disease and their families
5. Improve data to track progress

Accomplishments in 2013:

1. Identified 11 risk genes providing new insights about disease pathways and possible drug targets
2. Provided training on dementia and support to more than 23,000 health care providers
3. Focused and coordinated public/private efforts that reduced the inappropriate use of antipsychotics among nursing home residents with dementia by nearly 14%
4. Provided funding to states for the development of long-term services and supports systems

Action Steps for 2014:

1. Accelerate efforts to identify the earliest stages of Alzheimer's and develop and test targets for interventions
2. Increase collaboration in science, data sharing, and prioritization among disease experts, providers, and caregivers
3. Expand current work to strengthen dementia care guidelines and quality measures

4. Assist health care providers to better address ethical considerations related to dementia care
5. Enhance support for global collaboration on dementia, including the February 2015 G8 Summit on Dementia

Federal Legislative Priorities

The Alzheimer's Accountability Act

- Would ensure that Congress knows what scientists need to find an effective Alzheimer's treatment
- Would require scientists at the National Institutes of Health to submit an annual Alzheimer's budget to Congress

The HOPE for Alzheimer's Act

- Would provide Medicare coverage for a package of services including clinical diagnosis and care planning with medical and non-medical options for treatment and support
- Would require documentation of diagnosis, treatment, and care planning in each individual's medical record

An Alzheimer's Disease Plan for Washington State

In March 2014, Governor Jay Inslee signed Substitute Senate Bill 6124 providing legislative authorization to develop an Alzheimer's Disease Plan for Washington State. SB 6124 passed both chambers with bipartisan majorities. The goals of the State Plan will be to:

1. Leverage our state's rich history of commitment and innovation in health and senior care to address the full range of Alzheimer's issues
2. Explore the current and anticipated impact of Alzheimer's disease in Washington State
3. Outline the steps the state must take to sustain and improve its services and supports for people living with Alzheimer's and their families and mitigate the catastrophic emotional and economic impact of what has become nothing less than a public health epidemic
4. Prepare the state to address critical needs including improving the quality of the health care system, increasing awareness among the public, and equipping unpaid caregivers, health care professionals and others to deal with individuals with Alzheimer's at all stages of the disease
5. Ensure availability and access to services and supports for diagnosis, detection, treatment, and affordable options for long-term care
6. Create the infrastructure and accountability to manage and measure the state's response to the Alzheimer's epidemic

Under the auspices of the Department of Social and Health Services (DSHS), a diverse group of stakeholders—including persons with dementia, family caregivers, health policy advocates, the State Long-Term Care Ombudsman, professional caregivers, the Alzheimer's Association, the Alzheimer's Society of Washington, members of the Legislature, Executive Staff (Governor's Office), and state agencies (DSHS, AL TSA, HCA, DOH), representatives of the elder law,

medical, and research communities, and the Veterans Administration—has been selected for a working group to develop the plan.

The first of a series of the working group’s public meetings is scheduled for September 4, 2014 at the Aging and Long-Term Support Administration Offices in Lacey, Washington.

Voices for Better Health in Washington State

The purpose of this project is to advance care and establish a strong voice for over 115,000 Washingtonians who are dual eligibles (“duals”)—individuals who qualify for both Medicare and Medicaid. Duals—many of whom are living with Alzheimer’s disease or other dementias—tend to be poorer, sicker, and heavily dependent on supportive services. In today’s fragmented health care system, they are forced to navigate through a complicated and confusing maze of multiple doctors, medications, and programs.

The Chapters are working to shape Washington’s duals integration demonstration by leading a coalition of health advocacy organizations and state agencies to bring together patients, advocates, delivery systems, and providers to improve the health of the growing number of duals in our state.

The duals integration demonstration consists of two strategies, or models for delivering care:

1. Health Homes—a fee for service model emphasizing care coordination
2. *HealthPathWashington*—a fully-capitated managed care model

Key Issues Identified During the 2014 Public Policy Town Halls

Eleven key issues emerged in the public input offered at the Town Halls:

1. Lack of awareness
2. Difficulties with diagnosis
3. Poor dementia care
4. Specific challenges facing those with younger-onset Alzheimer’s
5. Unprepared and overwhelmed caregivers and families
6. Cost
7. Need for care coordination
8. Personal and public safety challenges and the need for secure respite care
9. Inaccuracy of Alzheimer’s-related statistics
10. Better reflecting the diversity of the Alzheimer’s community
11. Need for more information about non-medical therapies and interventions

Lack of awareness This includes a lack of knowledge and widespread misunderstanding about Alzheimer’s and other dementias.

“At times, I will tell friends that my husband has vascular dementia. Their first response will be about putting him in a nursing home. People don’t understand that there are phases of dementia. And fortunately, we are going through one of the easier phases.” – Lacey/Olympia

“So much is influenced by people’s understanding of what dementia is and what they don’t understand. It makes you feel lonely and you are just so thankful for those who remain in your life, but they also don’t understand.” – Lacey/Olympia

“My family was involved in a situation that very few of my close friends knew of or understood. I didn’t know how to open up with and share what was going on.” – Tacoma

Difficulties with diagnosis Challenges lead to delayed diagnosis, poor experiences in the diagnostic process, missed opportunities to immediately connect families with available support, and a lack of documentation in a patient’s primary medical record.

“Many physicians are so focused on their specialty that they fail to see the overall picture.” – Kelso

“We need to require physicians to take [continuing education] on how to diagnose in order to recognize cognitive impairment and how to refer them to next steps and services. Doctor’s office visits are too short, too brief. They need more training!” – Bremerton

“I went through a whole year where no one believed what I was saying, that I had Alzheimer’s. But I’m an attorney. I’m an advocate. But not everyone is like me. People are looking for reassurance when they start realizing they [are changing]. It’s a scary, scary thing.” – Everett

“We are kind of the ‘new kids on the block’ in terms of diseases. We are like cancer was in the 50’s. Doctors today still lack knowledge on treatment, diagnosis, etc.” – Issaquah

“The hardest part for me was trying to access info. I’m a caregiver for my mom and my great aunt – both have dementia. Finding information was the hardest piece. I wasn’t expecting this. Trying to get information, I thought, why don’t we treat this as a public health issue? Once we figured out what was going on, it was easier. But getting from behaviors to diagnosis was so difficult. It was really hard and not integrated at all. That needs to be different.” – Lacey/Olympia

“My wife was diagnosed and had found out that she had excess fluid on brain. [It’s] difficult to provide correct medication when we don’t have an easy method to diagnose. We need research to diagnose more effectively.” – Sequim

“My wife was first diagnosed with depression, not dementia. Doctors did not want to diagnose her with dementia. [We were] frustrated with the medical system in the [Wenatchee] Valley—it feels like they don’t know a lot about dementia. Earlier diagnosis means that me and my wife could have had better care.” – East Wenatchee

“Physicians are missing from the room. In the area, mental health and Alzheimer’s and dementia... doctors are behind the eight ball. Doctors need to make connections with the resources but they don’t know it. They can’t cure it, so they don’t learn more about it.” – East Wenatchee

Poor dementia care A lack of knowledgeable personnel equipped to meet the unique needs posed by Alzheimer’s and other dementias results in poor quality of care in facilities.

“My aunt didn’t have the resources of my family. She was put into a facility pretty early. It was tough to go see my aunt.... strapped down and angry.... [I]t’s not how you want to see your loved ones go.” – Tacoma

“I worked in nursing homes for close to 25 years. The person was expected to ask for pain meds. A person with dementia, even when they are verbal, they don’t tell you that. Training people to recognize the signs and symptoms of pain is a huge challenge.” – Tacoma

Specific challenges facing those with younger-onset Alzheimer’s Preconceived notions of Alzheimer’s and age can delay diagnosis and make it difficult to find support and services.

“With early onset, you realize this is not an old timer’s disease. We need to be more on fire about getting funding for this and finding a cure.” – Tacoma

“I think as part of the national plan, [we need] a cure by 2025. So by then I will be 47 and my sister will be 45, the age my mother was diagnosed. My brother will be 43, the age my grandfather passed away.” – Tacoma

Unprepared, overwhelmed caregivers and families Caregivers need critical support to provide in-home care but have trouble finding affordable services and education to care for a loved one, and to alleviate the emotional and physical burden of caregiving.

“There is a tremendous need in communities for caregiver support. Caregivers are often much sicker than people for whom they care.” – Bremerton

“It’s not just the patient, but the entire family is impacted by a chronic or fatal disease. Education and support for families is essential.” – Kelso

“Sometimes other family members don’t want to know about the dementia because they don’t want the responsibility.... [I] have no family support and [am] fearful of the future. [I am] now the primary decision-maker and [am] overwhelmed.” – Kelso

“We need state and federal legislatures to provide more opportunities for caregiver financial support when family caregivers are often the best suited for the job.” – Bremerton

“There was one woman who my mom’s friend found who was just a caring woman that would help us and care for my dad so that our family could do things and not stay with him all the time. Being able to find people that really care is really big.” – Tacoma

“My dad and brothers and sisters are primary caregivers. I help when I can, but it’s full time work. Two of them need to be at the house to assist. It’s been tough.... I think for us one of the most frustrating things is that we don’t have an opportunity to fight. It’s just to survive and that is very frustrating to us.” – Tacoma

“I am terrified of the future because I know that eventually I will have to institutionalize him. I am blessed. My kids and grandkids live here in the valley. I’ve started attending a caregiver support group. It’s hard. I don’t want to give him up for someone else to take care of him.” – Mount Vernon

“There is a stigma seen in families where one is the primary caregiver and the others don’t want to deal with the sadness and don’t want to be embarrassed in public. [This leads] to isolation.” – Yakima

“[I] did not realize the big job [I] was taking on. Help others who are caregivers. Men are unique caregivers and fantastic advocates. Caregiving: once you place your loved one, caregiving is not over. There is no single right or wrong answer. Everyone’s needs and resources are different.” – East Wenatchee

Cost The costs to treat and care for Alzheimer’s and related dementias can be tremendously high and unaffordable over time.

“I work in the case management program that serves caregivers in Snohomish. There is a major issue I’m seeing – middle income, dual eligible, those folks that have income from \$3,000 to \$3,500, they can’t afford care.” – Everett

“I don’t think my dad will say this but I think there needs to be a [financial] support system for [caregivers]. What comes to mind is employment: my dad is in a good place with his job [but] others are not. Is there a way we can assist with that?” – Tacoma

“I turn 65 in 2020. The issue that I know is happening is that very few people in my generation are prepared for retirement. We don’t have the savings for long term care.” – Lacey/Olympia

“Just like the senior services offices offer [discounted or free] legal advice, I feel strongly that we should also be offering through senior services some form of financial road mapping so that families can protect and preserve some of their assets through this financially draining drama we call caregiving. No money would exchange hands, [but advice would be given] on timing of events that might help prevent a family from losing its life savings.” – Sequim

“Medicare, Medicaid...I don’t know which covers what. Too many things my husband needed weren’t covered at all.” – East Wenatchee

Need for care coordination Patients and families experience challenges and frustrations as a result of a fragmented health care system.

“[There can be many] transitions from one care setting to another and [there are many] challenges involved. A care coordinator will be the person who ties all the parts together for the patient and family – [she/he] makes it less complicated when there are multiple doctors, care settings, transitions, etc.” – Kelso

“The current system set up as silos of care that cater to people who utilize multiple services and resource between silos.... We do not have the resources in order to move forward with this epidemic.” – Bremerton

“The lack of information and coordination across a broad spectrum of providers and families cannot be understated.” – Bremerton

“My wife and I went to four different doctors to treat her various problems. No one ever asked us what the other doctors said. I felt like we were staring all over each time we went to a different one.” – Yakima

Personal and public safety challenges and the need for secure respite care Families, community members, and law enforcement are finding it difficult to address and respond to behaviors that often put patients and community members in harm’s way.

“My husband gets lost. I am afraid that he will wander off from the yard, a restaurant, etc.” – Kelso

“[I am] concerned about [my] spouse cooking, [as he is] forgetful and causing fires. [We] need to access adaptive technology. For instance, shut off valves for electricity/gas range.” – Kelso

“[It’s] important to offer information and education on driving (more resources, more education, more physicians and advocates in community to inform caregivers about safety).” – Bremerton

“There is a need for respite. There is a need for a safe and secure environment.” – Bremerton

“Folks are following the procedures given to them by their docs and/or the [Department] of Licensing, but when they go in and try work with the system to ‘encourage’ their loved one to surrender their [driver’s license], they often meet up with an agent [who] tells the person with dementia that if they can pass the eye test, they can still have their [license]. This is insane since many times the doc has told the family the person cannot drive any more.... There are so many driving with dementia accidents.... in our county, it is frightening.” – Sequim

“We are making headway with law enforcement. We are training law enforcement, [addressing] police interventions, [and] offering resources on how to work with PWDs.” – Bremerton

“There is a huge need for adult day health for the social interaction and increasing engagement at home and the ability to maintain functioning a little bit longer, make friends and have an opportunity to shine. The caregivers get a few hours when they know their loved one is safe and have a built in support though the staff.” – Issaquah

“Six in ten people with dementia will wander. [We need to] make sure to include first responders in the training so they know what to look for and are sensitive to the needs. Memory cafes are also beneficial for the caregivers and are very effective in helping reduce isolation and depression. Adds another element of care and support.” – Issaquah

Inaccuracy of Alzheimer’s-related statistics Alzheimer’s-related deaths are underreported or mischaracterized, thereby impeding access to accurate and comprehensive data and statistics.

“When my wife passed away, she was docile at home and she knew me and my kids. But she forgot how to breathe, she was breathing like a dying bird, and she passed away in the night. But the doctors refused to say on the death certificate that she passed away of Alzheimer’s. All that does is make the statistics crazy.” – Everett

“My mom has Alzheimer’s and my dad recently passed of Parkinson’s related issues.... As advocates.... is there a way we can influence that data gathering?” – Everett

“The primary cause of death may be related to Alzheimer’s but not listed on the death certificate. The body forgetting to breathe may occur, so it may not be listed as Alzheimer’s.” – Issaquah

Better reflecting the diversity of the Alzheimer’s community Although Alzheimer’s affects a wide range of communities, resources for and outreach to all of these diverse communities are limited.

“One of the biggest concerns I have in our community right now is trying to help the outliers. Persons with dementia come in all different versions, shapes, and sizes.”
– Lacey/Olympia

“The Alzheimer’s Association needs to offer resources to communities of faith and offer involvement.” – Sequim

“Other people who need training and education, people in grassroots, youth, artists, etc., [who] fall through the cracks, [who have] different education systems....” –

“We need to better represent communities of color as the impact in those communities is high; we need to do this from the ‘inside’ of those communities.” – Tukwila

“There is the challenge of engaging diverse communities that are less willing to come forward for help because of socioeconomic and cultural reasons.” – Tukwila

Need for more information about non-medical therapies and interventions As patients and their families become increasingly wary of pharmaceutical-centric approaches to care, they are seeking more information about alternative or supplemental therapies and interventions.

“Non-pharmaceutical interventions are very important.... art, music, massage, aromatherapy, and other environmental treatments.” – Tukwila

“While medical models [that address] Alzheimer’s are critical (research on cures, medication, interventions to be determined), any [state] plan should include strong recommendations for evidence-based activities we know are helpful, even for those with genetic markers for high risk. This includes walking. This includes proper nutrition. The plan should support these activities and should consider co-branding with other groups that endorse activities that benefit those who will be at risk.” – Seattle

“[A] lot of people want more of an approach and answers about care models that [are] not based on medicine alone. There is great concern about possible side effects of some drugs.” – Seattle

“Symptom management is usually about pain management that solves an immediate need, but not the underlying concern. [It’s about] following intuition, being kind... [patients] need physical presence.” – Tacoma

Additional thoughts offered by participants

“First, the [state] plan should consider a public health lens to frame approaches to address the issue across the life cycle of an individual, years before problems emerge. We know from many interventions of all stripes that actions done upstream, at the population level, and well before ‘care’ is administered are the most cost-effective and efficient in terms of overall outcomes and most particularly for scarce resources.” – Seattle

“[T]he [state] plan appears to be prefaced on an assumption the world’s most inefficient and most expensive health care system (the current one in the USA) is a model to plan around. To the extent possible, a plan should also be looking to other national models (Japan, Germany, England), where costs are managed better and people have better health outcomes. Can the plan learn from other national systems and say it encourages reforms to health delivery shown to be less costly and more efficient [?]” – Seattle

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- Mayor Patty Lent
- Sen. Linda Evans Parlette
- Rep. Steve Tharinger

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We’re here to help you 24 hours a day, 7 days a week.

Alzheimer’s Association Mission Statement

To eliminate Alzheimer’s disease through the advancement of research, provide and enhance care and support for all affected, and reduce the risk of dementia through the promotion of brain health.