Advocacy Day 2018

Washington State Capitol - Olympia, WA
Friday, Feb. 9, 10 a.m. - 3 p.m.

Together, we can make a difference.

Share on social using #advocacywa
206.363.5500 | alzwa.org
Friends and Advocates,

Welcome to our annual Alzheimer’s Association Advocacy Day.

In advocacy and public policy, we are part of a broad national effort to respond to the public health crisis that is Alzheimer’s. We have had our successes, but there is so much more to do.

The Alzheimer’s Association is proud to be playing a leadership role in the Dementia Action Collaborative (DAC), a statewide consortium of more than 60 public and private partners working to implement priority recommendations in the Washington State Plan to Address Alzheimer’s Disease and Other Dementias. So far, the DAC has developed and distributed a safety information kit, essential elements for dementia-friendly communities, and a Dementia Road Map for caregivers and families.

Your voices resonate throughout the State Plan. Your stories inform and motivate legislators. Our work is not done—neither is theirs. Together, we will provide help and hope for those facing Alzheimer’s disease and other dementias in Washington State.

Bob Le Roy
Executive Director
Alzheimer’s Association, Washington State Chapter
Serving Washington and Northern Idaho

Join us for future Advocacy Events

Advocacy Forum
June 17–19, 2018 Washington D.C.
Advocacy Forum promotes key advocacy issues in D.C. each year. Join us to meet Alzheimer’s advocates from across the country and appeal to members of Congress. Visit alz.org/forum for more information.

Public Policy Town Halls
Fall 2018
Learn about current state and federal policy issues at Town Halls events in your community. For dates and locations visit alzwa.org.
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Schedule

9:30 – 10:00 A.M.
Sign In
Columbia Room, Legislative Building, 416 Sid Snyder Ave SW, Olympia, WA 98501.
Meet your assigned team members over coffee

10:00 – 11:00 A.M.
Welcome and Introductions
Ellen Cole, Board Chair, Alzheimer’s Association Washington State Chapter
Bill Moss, Assistant Secretary for Aging & Long-Term Support Administration, DSHS

Legislative briefing: What’s going on in the Legislature and what we’re asking for
Peter Newbould, Public Policy Manager, Alzheimer’s Association Washington State Chapter
Amber Ulvenes, Legislative Consultant
Bob Le Roy, Executive Director, Alzheimer’s Association Washington State Chapter
Madeleine Foutch, Campaign Coordinator, Washingtonians for a Responsible Future

11:00 – 11:30 A.M.
Telling Your Story
Carrie McBride, Director of Communications and Marketing, Alzheimer’s Association Washington State Chapter

Role Play of a Visit
Eric Forsythe, Karen Marez, Peter Newbould, Amber Ulvenes

Explanation of logistics for team meetings in House and Senate offices
Peter Newbould

11:30 A.M. – 12:00 P.M.
Teams huddle to practice while eating box lunches

12:00 – 3:00 PM
Visits to legislators in various nearby buildings
Personal belongings may be left in the briefing room.

12:15 PM
Group photo in the Rotunda of the Legislative Building
(Except for those with early meetings)

3:15 PM
Buses Depart
% of people in hospice with a primary diagnosis of dementia

4,963

21%

For more information, view the 2017 Alzheimer’s Disease Facts and Figures report at alz.org/facts.

Over 5 million Americans are living with Alzheimer’s, and as many as 16 million will have the disease in 2050. The cost of caring for those with Alzheimer’s and other dementias is estimated to total $259 billion in 2017, increasing to $1.1 trillion (in today’s dollars) by mid-century. Nearly one in every three seniors who dies each year has Alzheimer’s or another dementia.

# Advocacy WA
Washington State Advocacy Day
Advocacy Day is a policy awareness day where your experience puts a face and heart behind needed legislation. By participating, you help shape the quality of care that you and others receive in the future.

Senators and Representatives are busy. Share your experience in 5 minutes or less.

Be Simple
Tell about your experience. If you can’t answer a question, tell them you will get back to them with information. Make notes in your reporting and the Alzheimer’s Association will follow up.

Be Connected
Ask if the person has any questions. You can help strengthen our relationship with officials by reporting what kind of information they request.

Be Flexible
Your elected official may not be able to meet with you, but ask if there is a staff member available. These relationships can be just as important.

Be Gracious
Remember to thank everyone for their time. We will provide sample follow up emails and letters to your elected official to remind them of your visit and thank them.

Make Memories
Commemorate your experience by recording your thoughts and taking pictures with your elected officials, Association staff and fellow Advocates. Share using #advocacywa.
Meet Alzheimer’s Advocate Karen Marez

I’m here today because of this amazing woman who gave me life and whose journey with Alzheimer’s disease now alters my own life’s journey. My mom was first diagnosed with dementia in 2008. As her symptoms progressed the diagnosis was fine-tuned as Alzheimer’s and she became one of the millions in our country affected by this disease. That meant I became one in the tens of millions to have a loved one with Alzheimer’s, a disease for which there is currently no cure.

My mom was an avid green thumb, a patient expert at completing 3,000 piece puzzles and a frequent volunteer with her church quilting group; but as the disease progressed, she forgot the names of most flowers in her garden, she began to cut puzzle pieces to wrongly fit where she was sure they belonged. She was sure the quilting group had started creating five-sided quilts because of how long it now took her to hem them. These were skill areas she had honed over 70+ years, yet little by little they disappeared.

I’m now in the “after-journey” of this disease. Mom has been gone now for over three years, but I remain resolute in my part as an Alzheimer’s advocate. I find when I share my mom’s journey, people let go of their preconceived notions that it’s either just a part of growing old and that it is something that won’t ever affect them. Unfortunately, the odds are good that it will indeed affect a number of them at some point as it’s the third leading cause of death in our state.

I think it’s also important to acknowledge that the costs of Alzheimer’s. We were fortunate my mom had long term care insurance which helped us for the portion of time she was in memory care, but I know so many people who don’t have this in place. Passing the Long Term Care Trust Act will help to provide an avenue to those who don’t yet have it. Enduring the emotional and physical effects of this disease is hard enough; if we can help with the financial burden in some way, we should do it.

The Dementia Action Collaborative also needs funding to continue carrying out the goals of the Washington State Plan to Address Alzheimer’s Disease and Other Dementias., including providing resources to the public, something my family would have benefited from when we were caring for my mom.

All of us have a part to play. My part is sharing my story so people learn more about the disease. The Alzheimer’s Association’s part is providing educational and emotional support to those affected and raising funds for research. And the Washington Legislature’s part is ensuring the implementation of our state’s plan.
Personal stories are an effective way to help legislators and policymakers understand how their work affects people. That’s where you come in as an Alzheimer’s advocate!

Sharing statistics about the disease isn’t enough. People are hard wired to learn through stories. It’s YOUR story legislators will remember long after Advocacy Day is over.

Here are some tips to help you tell your story in a way that will inspire action and have a lasting impact!

1. **Tell the Story of SELF**
   - **Why are you an advocate?**
     - Paint a picture of life before Alzheimer’s. Why should they identify with you? Share a photo of a loved one.
     - Put them in the moment of diagnosis/realization. Give details. What happened? How did you feel? It’s okay to get emotional!
     - Share moments of struggle. What inspired you to become an advocate? What have you learned?

2. **Find the Story of US**
   - **Why is your cause theirs too?**
     - “Do you know somebody with Alzheimer's?” Give space for them to tell their story or say how lucky they are if they don’t.
     - Share local impact. Provide stats or impacts relevant to their constituents.
     - Say Thank You! Let them know how much their support means to YOU.

3. **Tell the Story of NOW**
   - **Why is inaction no longer an option?**
     - Deliver the ask. Be clear and concise about what we want from them.
     - Offer to follow up. If they have questions, it’s okay to say, "I don’t know, but we will get back to you." It’s a good excuse for our team to follow up.
     - Finish on the personal. Tie back to the story of self. How would their support impact people like you and your family?
1. **Story of SELF: Why are you an advocate?**
Example: “My mom was an avid green thumb, a patient expert at completing 3,000 piece puzzles and a frequent volunteer with her church quilting group. She became one of the millions in our country affected by this disease.”

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

2. **Story of US: Why is your cause theirs too?**
Example: “Alzheimer’s disease is the third leading cause of death in our state. Projections for Washington are at 270,000 residents living with Alzheimer’s by the year 2040.”

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

3. **Story of NOW: Why is inaction no longer an option?**
Example: “Because of my experience, I’m asking you to pass the Long Term Care Trust Act and fund implementation of the Washington State Plan to Address Alzheimer’s Disease and Other Dementias.”

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

**Stuck?**
Try framing your story with some of these prompts:
1. Once upon a time...
2. And every day...
3. Until one day...
4. And because of this (repeat as needed)
5. Until finally...
6. And ever since that day...
Alzheimer’s is a Public Health Crisis 
Devastating Washington State

In 2016

335,000
family caregivers provided

382 million hours
of unpaid care valued at

$4.8 Billion

110,000
Washingtonians
are living with Alzheimer’s.

By 2025 the number
is expected to increase by

27.3%

Medicaid costs of
caring for people with
Alzheimer’s in 2017

$461 Million

Medicaid costs are
expected to increase
45% by 2025.

Alzheimer’s disease is the
MOST EXPENSIVE
disease in the U.S. costing
$259 BILLION in 2017.

Peter Newbould
Public Policy Manager
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pnewbould@alz.org
alz.org | 800.272.3900
What Washington Officials Can Do To Address the Crisis

Implement the *Washington State Plan to Address Alzheimer’s Disease and Other Dementias* by funding dedicated agency staff to support the work of the Dementia Action Collaborative (budget proviso by Sen. Keiser and Rep. Tharinger).

- In 2014, the Legislature passed a bill to develop a “state plan” for how best to deliver services to Washingtonians who have or will be diagnosed with Alzheimer’s and other dementias and those who care for them. The State Plan, presented to the Legislature in early 2016, is being implemented by the Dementia Action Collaborative. The “DAC” and its Subcommittees and Project Teams is a voluntary, statewide, public-private partnership of 65 stakeholders, including individuals living with Alzheimer’s, family caregivers, advocates, and agency personnel.
- Legislators should help implement the State Plan by funding these new DAC resources:
  + An online, interactive “Dementia Road Map” with timely and relevant information for caregivers on a broad spectrum of issues, decisions, services, and supports.
  + A web portal to provide information to the public.
  + The Bree Collaborative’s evidence-based standards for diagnosis, treatment, supportive care, and advanced planning to be disseminated to primary care physicians.
- The Joint Legislative Executive Committee on Aging and Disability Issues has recommended this funding. Project funding and DAC volunteers are to be coordinated by one half-time equivalent staff at each of four integral agencies: The Department of Health, the Health Care Authority, the Developmental Disabilities Administration, and the Aging and Long-Term Support Administration.
- Full implementation of the State Plan is a complex and continuing process likely to span at least five years. To ensure sustainability, progress, and the constant engagement of DAC members, State investment to support the Plan is critical.

Pass the Long-Term Care Trust Act to help people save for their own long-term care expenses

- Most people lack the personal savings to cover the high cost of long-term supports and services necessary when one declines following a diagnosis of Alzheimer’s or other dementia. The coalition Washingtonians for a Responsible Future points out that 25% of baby boomers in Washington have less than $25,000 in personal savings.
- This bipartisan legislation, HB 2533 by Reps. Jinkins and Johnson, and SB 6238 by Sen. Palumbo, offers an opportunity for people to save toward their own needs. It proposes a 0.49% payroll premium to pay a modest care benefit while protecting family savings and assets. A small percentage would be deducted from Washington workers’ pay to fund the Trust. People would pay while they’re working and be eligible to draw on the benefits of the Trust after they’ve worked three of the previous six years, or ten years total.

1-20-18

alz.org | 800.272.3900

#advocacywa
The Road Ahead: Preparing for Increases in Dementia

Dementia impacts thousands of people across Washington

- While there is currently no cure for Alzheimer’s or other dementias, increased awareness of diagnosis, proactive medical care and use of support services can help reduce the impacts.
- Dementia is one of the costliest chronic diseases to society. Straightforward costs include medical and long term care bills, but hidden costs such as family members missing work are also critical.
- In a national study, Medicaid payments for people with dementia on Medicare were 19x as great as those for older adults without dementia.

The Dementia Action Collaborative, a group of public-private partners, convened in 2016 to implement the Washington State Plan to Address Alzheimer’s Disease and Other Dementias. This Collaborative includes people with dementia, caregivers, advocacy groups, long-term care providers, health care professionals, legislators and government agencies.

The Collaborative has started to address our state’s needs and goals related to being dementia-prepared and dementia-friendly. But it is clear that a long-term, sustainable approach and reliable funding is necessary to prepare Washington for the growing numbers of people dementia.

Plan to Address Alzheimer’s Disease and Other Dementias Goals:

- Increase public awareness, engagement, and education
- Prepare communities for significant growth in the dementia population
- Ensure well-being and safety of people living with dementia and their family caregivers
- Ensure access to comprehensive supports for family caregivers
- Identify dementia early and provide dementia-capable evidence-based health care
- Ensure dementia-capable long term services and supports are available in the setting of choice
- Promote innovation and research related to causes of and effective interventions of dementia

Dementia is drastically under-diagnosed. Without the proper diagnosis, it is hard to provide proper care and support. This leads to increased hospitalizations, more expensive care, and other negative outcomes. The Collaborative is working to improve diagnosis.
The Collaborative needs support to expand its reach and address the under-diagnosis of dementia through the dissemination of evidence-based guidance around diagnosis, treatment and supportive care.

The Bree Collaborative, with support from the Dementia Action Collaborative, has developed evidence-based recommendations for health systems to improve quality of care for people with dementia. By distributing this guidance to health care providers, and developing ways to provide training to implement these practices, the Collaborative could directly effect the lives of people with dementia and their family members.

A **dementia-friendly community** is one in which people with memory loss fully belong. Community members are informed about dementia, equipped to be helpful as needed and committed to inclusion.

**With sufficient support, the Dementia Action Collaborative plans to:**
- Expand and promote early stage memory loss groups across the state.
- Develop guidance for models of social engagement such as Alzheimer’s Cafes, Zoo Walks, Museum and Art programs and other community-focused activities for people with dementia and their families.

Successful community programs need sustainable funding sources, beyond what the Collaborative can support.

**Dementia Action Collaborative Tools**

- **Dementia Road Map** - a guide for family and care partners to help them navigate the future.
- **Dementia Safety Info-Kit** - straight-forward information around safety concerns for people with dementia, including a collection of resources to help.
- **Dementia-Friendly Communities fact sheet** - an introduction to the concept of dementia-friendly communities, including examples of success in Washington and beyond.

If you would like to help us create more Dementia-Friendly Communities in Washington, visit [www.dshs.wa.gov/altsa/dementia-action-collaborative](http://www.dshs.wa.gov/altsa/dementia-action-collaborative).

With support, the Collaborative can effect change in Washington: in local communities, in hospitals and doctor’s offices, in government, and in legislation.

300,000 family members are in need of support and relief as they care for their loved one with dementia.
The Dementia Action Collaborative (DAC) is a volunteer, state-wide, public-private partnership committed to implementing recommendations in the Washington State Plan to Address Alzheimer's Disease and Other Dementias. To-date, it has been our strategy to first do what we could through heightened collaboration among our partners and work within the limits of existing resources to the greatest extent possible.

We have created some impactful tools for information and assistance, such as the evidence-based recommendations for dementia care developed with the Bree Collaborative and the Dementia Road Map, as well as informational materials regarding brain health, home safety, and elements of dementia friendly communities. We envision an incremental approach to developing, enhancing, and disseminating these and future resources, but we believe we have gone as far as we can without additional support in dedicated staff and funding.

Dedicated staff at the lead agencies—Department of Health (DOH), Health Care Authority (HCA), Department of Social and Health Services (DSHS) Aging and Long-Term Support Administration and Developmental Disabilities Administration (DDA)—will significantly enhance and effectively coordinate agency involvement in the ongoing work of DAC volunteers to successfully implement more recommendations and realize the shared vision and full potential of the State Plan.

We recommend, and seek funding via budget proviso in the supplemental budget, that the above agencies each are allotted .5 FTE to work together with one another and the DAC Chair and Subcommittee Chairs to:

1) Integrate goals and objectives related to dementia into agency strategic plans

2) Identify recommendations in their respective areas which could be implemented through heightened collaboration and existing resources

3) Identify high-value recommendations and related funding requirements for upcoming biennial budgets

4) Coordinate the work of implementing the selected recommendations.
Proposed Proviso Language

Department of Social & Health Services (at Aging and Long-Term Support Administration and Developmental Disabilities Administration): 2 one-half FTEs
(____) $40,000 of the general fund-state appropriation for fiscal year 2019 and $40,000 of the general fund-federal appropriation are provided solely to assist the Dementia Action Collaborative, a public-private entity charged with implementation of recommendations in the Washington State Plan to Address Alzheimer's Disease and Other Dementias.

Health Care Authority: one-half FTE
(____) $20,000 of the general fund-state appropriation for fiscal year 2019 and $20,000 of the general fund-federal appropriation are provided solely to assist the Dementia Action Collaborative, a public-private entity charged with implementation of recommendations in the Washington State Plan to Address Alzheimer's Disease and Other Dementias.

Department of Health: one-half FTE
(____) $40,000 of the general fund-state appropriation for fiscal year 2019 is provided solely to assist the Dementia Action Collaborative, a public-private entity charged with implementation of recommendations in the Washington State Plan to Address Alzheimer's Disease and Other Dementias.

Cost of Proposed Proviso

2018-19 = 2 FTE = $160,000 in total funds ($100,000 General Fund-State and $60,000 General Fund-Federal)

Ways & Means Staff: James Kettel

Contact: Amber Ulvenes, Alzheimer’s Association Contract Lobbyist, amber@ulvenesconsulting.com, 360.280.0384
We face a crisis in long-term care: Most people will not be able to pay for what they need.

- Most Washingtonians over 65 will eventually need long-term care services, including help with bathing, dressing, toileting, and eating. ¹
- Long-term care is prohibitively expensive. The average lifetime cost is $260,000.²
- Most people have not saved enough to pay for their own care. Median retirement savings for people over 65 is just $148,000.³
- Medicare does not cover long-term care services.
- Nationally, family caregivers spend an average of 20 percent of their income on out-of-pocket costs related to caregiving.⁴

Long-Term Care Trust Act would provide long-term care insurance for people employed in Washington.

- The program provides 365 days worth of coverage.
- Vested Washingtonians receive benefit of $100 per day.
- The benefit would cover the complete cost of one year of long-term care for the average Washingtonian who needs in-home long-term care.⁵
- The benefit coverage is financed by a 0.49% (half of one percent) payroll deduction on all workers (an average of $23.30/ month)⁶.
- Vesting period is three of the last six years, or ten years total.

Long-Term Care Trust Act would help protect the state budget from increased spending on Medicaid-funded long-term care.

- Washington now spends $2.1 billion annually on Medicaid-funded long-term service and supports. This spending is projected to increase by 91% in 2040 to $8.02 billion per biennium.⁷
- In its first year, the program would save Washington $19 million in Medicaid spending.⁸
- By the 10th year, it would save the state $70 million every two years (biennium).⁹
- By 2040, this legislation could save Washington State $1.4 billion per biennium.¹⁰

Contacts: Kate White Tudor of W4A (360) 402-1272; Joanna Grist of AARP (206) 795-6837; Lauri St. Ours of WHCA (360) 402-1327; Madeleine Foutch with SEIU 775 (206) 250-2311

Updated: 1/10/18
Long-Term Care insurance coverage would strengthen Washington’s economy.

- Coverage reduces the burden on family caregivers, enabling them to continue working and save for their own retirement.
- Family members who leave the workforce to care for loved ones typically lose $300,000 in income and benefits. Women lose the most, an average of $324,044.11
- The program would increase workforce and business productivity by reducing the number of family caregivers who must take time off work or quit paid employment.

People would choose how to use their benefits.

- Under the Trust Act, families would get to choose the care setting that meets their loved ones’ needs. Coverage can be used on in-home care aides, adult family homes, assisted living, or skilled-nursing facilities.
- Beneficiaries can choose to use their 365 days of coverage consecutively or in smaller chunks, as they need help.

We did the math.

- The legislature directed Milliman to study and analyze two policy options to help make long-term care more accessible and affordable: a public benefit trust similar to Social Security, paid into by all workers, and a public/private solution to help stabilize the existing private-insurance market.
- Milliman found the public benefit would have significant and broad impact on both family and state budgets.
- They also found that reviving the private market would require large state subsidies and risk-sharing to increase the number seniors who could afford meaningful coverage.

Citations

2 Ibid
9 Ibid

Updated: 1/10/18
State needs long-term care plan for our elders


Are you prepared for the day when you can no longer live in your home without assistance? Most of us will need long-term care as we age, but as a society we are largely unprepared for the significant costs of this care. Many assume Medicare will cover these costs, but that’s not the case. Medicare pays for hospital stays in a medical crisis and short-term rehabilitation stays but after that, those benefits stop and you’re on the hook for long-term care costs.

A year of full-time long-term care could be $50,000 to $100,000. This is an expense families find hard to absorb, because it’s more than their household income. Multiply this huge shortfall by the 10,000 people per day who are turning 65, and it’s clear we’re facing an enormous crisis in care. That’s why Washington needs to pass legislation this year to address this problem.

House Bill 2533/Senate Bill 6238, known as the “Long-Term Care Trust Act” (LTCTA), would establish a public trust, similar to unemployment insurance, which would fund a long-term care benefit open to all who pay into the program. If enacted, Washington workers would have a small percentage deducted from each paycheck to fund the trust.

People would pay while they’re working and be eligible to draw on the benefits of the trust after they’ve worked three of the past six years, or 10 years total. This program would provide up to 365 days of coverage, with benefits of $100 a day. People could use those days consecutively or in smaller chunks, depending on what they need.

Currently, more than 90 percent of adults are uninsured for long-term care and count on family members for help. To qualify for state-supported Medicaid care, people must first spend away their life savings, leaving them no safety net and nothing to pass on to their children and grandchildren.

As a growing number of people face this need, Medicaid long-term care will likely consume more than 10 percent of the state budget by 2030, with spending more than doubling from $1.7 billion in 2015 to $4.1 billion. The Long-Term Care Trust Act could save the state millions by helping seniors avoid or delay Medicaid enrollment. It also creates peace of mind for families who are trying to care for an aging loved one while maintaining paid employment. Frequently, when someone needs in-home care, an adult child must quit full-time employment to provide that care.

That not only costs caregivers what they would have earned in salary and health benefits at an outside job, but also sacrifices credit toward their own retirement. Adult children who quit their jobs to take care of elderly parents are often at an age where re-entering the workforce after an absence of months or years could dramatically reduce their income earning potential. Taking this financial hit in midlife puts their own retirement at risk and may increase the likelihood that the cycle of being unable to pay for care would repeat generation after generation.

This legislation has broad support from senior advocacy organizations, including AARP, the Alzheimer’s Association, the Washington Health Care Association, SEIU 775, the Adult Family Home Council, the Long-term Care Ombudsman Program, and many others. We’re facing a very large and expensive problem, but working together, we can ensure our elders are taken care of and that, when it’s our turn to receive care, our children don’t face these burdens alone.
In Washington, 11.1 percent – one in nine – of those aged 45 and over report they are experiencing confusion or memory loss that is happening more often or is getting worse (“subjective cognitive decline”).

More than half of them have not talked to a health care professional about it.

For those with worsening memory problems, 43.2 percent say it has created “functional difficulties” – that is, caused them to give up day-to-day activities and/or interfered with work or social activities.

### Percent of Those Aged 45+ with Subjective Cognitive Decline

<table>
<thead>
<tr>
<th>All</th>
<th>Gender</th>
<th>Age</th>
<th>Educational Attainment</th>
<th>Percent with memory problems who have not talked to a health care provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.1%</td>
<td>Men</td>
<td>Women</td>
<td>45-59</td>
<td>60-64</td>
</tr>
<tr>
<td>11.7%</td>
<td>10.5%</td>
<td>10.5%</td>
<td>10.9%</td>
<td>10.4%</td>
</tr>
</tbody>
</table>

### Percent with memory problems who say it created difficulties and burden

- Interfered with Work/Social Activities: 32.7%
- Gave Up Day-to-Day Activities: 31.0%
- Needed Assistance with Day-to-Day Activities: 24.6%

### Percent with memory problems who live alone

- 28.3%

### Percent with memory problems who have at least one other chronic condition*

- 79.5%

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*Defined as arthritis, asthma, COPD, cancer, cardiovascular disease, and diabetes

This Fact Sheet is supported by Cooperative Agreement #NU58DP006115 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the Alzheimer’s Association and do not necessarily represent the official views of the CDC.
**Washington State Alzheimer’s Ambassadors**

Ambassadors are grassroots volunteers recruited to help achieve the Alzheimer’s Association’s federal public policy goals. Ambassadors are the main point of in-district contact for targeted members of Congress and serve on the Association’s Public Policy Committee.

Elizabeth Bonnett  
Ambassador to Congresswoman Jaime Herrera Beutler (R-3rd)

Ellen Cole  
Ambassador to Senator Maria Cantwell (D)

Katie Denmark  
Ambassador to Congressman Dave Reichert (R-8th)

Madeleine Fraley  
Ambassador to Congressman Derek Kilmer (D-6th)

Ann Hedreen  
Ambassador to Congressman Adam Smith (D-9th)

Chris Henderson  
Ambassador to Congresswoman Pramila Jayapal (D-7th)

Debbie Hunter  
Ambassador to Congressman Dan Newhouse (R-4th)

Patricia Le Roy  
Ambassador to Congressman Denny Heck (D-10th)

Myriam Marquez  
Ambassador to Senator Patty Murray (D)

Pete Minden  
Ambassador to Congresswoman Suzan DelBene (D-1st)

Mark Newbold  
Ambassador to Congresswoman Cathy McMorris Rodgers (R-5th)

David Schmelke  
Ambassador to Congressman Rick Larsen (D-2nd)

**Consider volunteering to be an Alzheimer’s Congressional Team member as an ACTor**

ACTors work with an Ambassador to participate in meetings with their assigned member of Congress, write letters to the editor of local papers and escort members and Congressional staff at Chapter events such as the Walk to End Alzheimer’s and Town Halls. Time commitment needed is one hour per month.  
Contact Peter Newbould at pnewbould@alz.org or 206.529.3867.
ALZHEIMER’S IS THE MOST EXPENSIVE DISEASE IN AMERICA.

-Cost to America, 2017

$259 BILLION

Medicare and Medicaid pay two-thirds of costs

Medicare $131B
Medicaid $44B

Over the LAST 34 years, increase in the U.S. National Debt
$18.8 Trillion

Over the NEXT 34 years, cost of Alzheimer’s to America
$20.4 Trillion

In 2017, for every $100 spent on research...
Medicare and Medicaid spent $12,500 on care

@alz_wa
“Alzheimer’s is the most under-recognized threat to public health in the 21st century.”
Dr. David Satcher, former U.S. Surgeon General and former CDC Director

While Alzheimer’s has traditionally been seen as an aging issue, **ALZHEIMER’S is a PUBLIC HEALTH ISSUE** because:

- **The BURDEN is LARGE and growing larger**
  - 5 million people are living with Alzheimer’s, two-thirds of whom are women; the number of people with the disease is projected to triple to as many as 16 million in 2050
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- **$259 billion**
  - Annual costs exceed quarter of a trillion dollars ($259 billion in 2017) and costs are expected to rise to $1.1 trillion in 2050
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- **The IMPACT is MAJOR**
  - Governments – Medicare and Medicaid bear two-thirds of the health and long term care costs of those with Alzheimer’s
  - Among people with dementia, one in every four hospitalizations is preventable

- **$10 BILLION**
  - More than 15 million caregivers have over $10 billion in additional health care costs each year due to caregiver burden

- **2/3**
  - Impacts governments – Medicare and Medicaid bear two-thirds of the health and long term care costs of those with Alzheimer’s

The **BOLD INFRASTRUCTURE FOR ALZHEIMER’S ACT (S. 2076 / H.R. 4256)** will enable public health officials to:

- Promote prevention – regular physical activity, attention to heart health can reduce the risk of cognitive decline and may reduce risk of Alzheimer’s
- Promote early detection and diagnosis – as many as half of people with Alzheimer’s are not diagnosed, and less than half of the diagnosed are not aware of the diagnosis
- Collect data – Collecting data on subjective cognitive decline and Alzheimer’s caregivers can help identify the burden and impact in each state

#advocacywa
Fiscal Year 2019 Alzheimer’s Research Funding

The escalating Alzheimer’s epidemic has profound implications for government budgets.

- Alzheimer’s is the most expensive disease in America, costing more than heart disease and cancer.
- In 2017, caring for people with Alzheimer’s and other dementias cost the United States an estimated $259 billion. Cumulatively between now and 2050, it will cost $20.4 trillion – two-thirds of which will be borne by Medicare and Medicaid.
- Nearly one in every five dollars of Medicare spending is spent on people with Alzheimer’s and other dementias.

Despite the recent increased investment in Alzheimer’s research, funding still falls short of the need.

- For fiscal year 2017, Congress approved a $400 million increase in Alzheimer’s research funding at the National Institutes of Health (NIH), bringing the total Alzheimer’s research budget at the NIH to $1.4 billion.
- Currently, an additional $400 million increase for fiscal year 2018 is pending in Congress.
- However, even with the recent funding increases, in 2017, the NIH spent only $100 on Alzheimer’s research for every $12,500 Medicare and Medicaid spent caring for people with the disease.

Congressional action is needed to stay on the path to discovering scientific breakthroughs.

- The National Alzheimer’s Plan has established a goal of developing preventions and effective treatments for Alzheimer’s by 2025.
- To achieve the breakthroughs needed to reach this goal, Congress needs to approve an additional $425 million in Alzheimer’s research funding as part of the fiscal year 2019 appropriations process.
BOLD Infrastructure for Alzheimer’s Act

How is Alzheimer’s a public health issue?

- While Alzheimer’s has been viewed as an aging issue, it also has an effect on a community level.
- Specifically, Alzheimer’s meets the three-point criteria for identifying a public health issue: (1) the burden is large; (2) the impact is major; and (3) there are ways to intervene.

How large is the burden?

- More than 5 million Americans have Alzheimer’s.
- It is the most expensive disease in America; costs now exceed a quarter of a trillion dollars per year.
- And the burden is growing larger. The number of people living with Alzheimer’s is projected to triple to as many as 16 million in 2050, and the costs are expected to rise to $1.1 trillion.

What Is Public Health?

Health care primarily involves medical treatment and care for particular individuals – that is, the prevention, treatment, and management of illness among individuals by medical professionals. Public health, on the other hand, works on a community level to protect and improve the health and safety of an entire community or group of people. Public health promotes healthy lifestyles, prevents illnesses and injuries, and detects and controls diseases. By working with diverse communities, public health expands the reach and impact of health care efforts.

2017 Costs of Alzheimer’s = $259 Billion

How major is the impact?

- Due to the toll of caring for someone with Alzheimer’s, caregivers have more than $10 billion in additional health care costs each year.
- Among people with dementia, 1 in every 4 hospitalizations is preventable.
- Alzheimer’s imposes a significant cost on federal and state budgets:
  - More than two-thirds of the health and long-term care costs of caring for those with Alzheimer’s are borne by Medicare and Medicaid.
  - Nearly one in every five dollars spent by Medicare is spent on people with Alzheimer’s and other dementias.
- And the impact is growing larger. By 2050, one in every three Medicare dollars will be spent on someone with Alzheimer’s and other dementias.
How can the public health community intervene?

- Public health officials can use the traditional tools and techniques of public health to improve the quality of life for those living with Alzheimer’s and to reduce the costs associated with it.

- Public health interventions include primary prevention, early detection and diagnosis, data collection, and access to quality care and services.

How specifically can these interventions be applied to Alzheimer’s?

- Primary Prevention: A growing scientific consensus has concluded that healthy living – regular physical activity, attention to heart health, and preventing head injuries – can reduce the risk of cognitive decline and may reduce the risk of Alzheimer’s. Public health can integrate brain health messages into existing, relevant public health campaigns.

- Early Detection and Diagnosis: As many as half of people living with Alzheimer’s have not been diagnosed. Public health can undertake public awareness campaigns to promote early detection and diagnosis and can educate medical professionals about assessment tools.

- Data Collection: Working with the Centers for Disease Control and Prevention (CDC), states can collect data on cognitive decline and Alzheimer’s caregiving using tools such as the world’s largest continuous public health survey, the Behavioral Risk Factor Surveillance System (BRFSS).

- Access to Care and Services: For people with Alzheimer’s, public health can encourage health professionals to follow evidence-based clinical care guidelines, create tools to aid in the delivery of care, and report on quality care dementia practices.

An Under-Recognized Crisis

“Alzheimer’s is the most under-recognized threat to public health in the 21st century.”

– Dr. David Satcher, former U.S. Surgeon General and Director of the Centers for Disease Control and Prevention

What is the federal government’s role?

- CDC leads the nation’s public health efforts and funds most public health activities at the state level.

- CDC’s Healthy Brain Initiative, launched in 2005, created the Public Health Road Map, which includes action items for public health departments to promote cognitive functioning, address cognitive impairment, and help meet the needs of caregivers.

- Congress can strengthen CDC’s efforts to combat Alzheimer’s disease by passing the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act.

What does the BOLD Infrastructure for Alzheimer’s Act (S. 2076 / H.R. 4256) do?

- Establishes Alzheimer’s Centers of Excellence around the country to expand and promote innovative and effective Alzheimer’s interventions.

- Provides funding to state, local, and tribal public health departments to implement those interventions and to carry out the Public Health Road Map, including promoting early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.

- Increases the collection, analysis, and timely reporting of data on cognitive decline and caregiving to inform future public health actions.
2017 ALZHEIMER’S DISEASE FACTS AND FIGURES

ALZHEIMER’S DISEASE IS THE 6TH LEADING CAUSE OF DEATH IN THE UNITED STATES

MORE THAN 5 MILLION AMERICANS ARE LIVING WITH ALZHEIMER’S BY 2050, THIS NUMBER COULD RISE AS HIGH AS 16 MILLION

EVERY 66 SECONDS someone in the United States develops the disease

1 IN 3 seniors dies with Alzheimer’s or another dementia

IT KILLS MORE THAN breast cancer and prostate cancer COMBINED

THE BRAINS BEHIND SAVING YOURS:

MORE THAN 15 MILLION AMERICANS provide unpaid care for people with Alzheimer’s or other dementias

IN 2016 these caregivers provided an estimated 18.2 BILLION HOURS of care valued at over $230 BILLION

In 2017, Alzheimer’s and other dementias will cost the nation $259 billion

By 2050, these costs could rise as high as $1.1 TRILLION

35% of caregivers for people with Alzheimer’s or another dementia report that their health has gotten worse due to care responsibilities, compared to 19% of caregivers for older people without dementia

Since 2000, deaths from heart disease have decreased by 14% while deaths from Alzheimer’s disease have increased by 89%
MAKE ALZHEIMER’S A PRIORITY ON CAPITOL HILL

More than five million Americans have Alzheimer’s today. On its current path with the aging of America, three times as many will have Alzheimer’s by 2050. And though already the nation’s costliest disease, Alzheimer’s cost will more than quadruple over this same period.

Help the Alzheimer’s Impact Movement stand with our congressional champions who recognize Alzheimer’s is a national crisis and are fighting for urgent, decisive action to address the disease.

AIM is a nonpartisan, nonprofit advocacy organization working with the Alzheimer’s Association, its sister organization, to end Alzheimer’s disease. Together, AIM and the Association have placed Alzheimer’s on Capitol Hill’s agenda. Over just the past several years, Congress has doubled Alzheimer’s research funding at the National Institutes of Health (NIH) to just under one billion dollars annually.

But Congress still has much more to do, and those of us committed to ending Alzheimer’s must support our champions on the Hill fighting to make it happen. Today, Alzheimer’s stands as the very last of the leading causes of death in the United States with still no way to prevent, cure or even slow its progression. All too often, those with Alzheimer’s fall through the cracks of our health care system.

Please, support the work of AIM. AIM needs your help to continue to push Congress to end Alzheimer’s. We have momentum. We have solutions. We have champions. **It’s time to act!**

AIM’S MOST IMPORTANT TOOL IS ITS POLITICAL ACTION COMMITTEE, AIMPAC.

AIMPAC supports members of the United States Congress from both political parties with a priority on those who are proven Alzheimer’s champions and who have the most influence over the outcome of our legislative priorities.

Only members of AIM can contribute to AIMPAC. Individuals can join and maintain their AIM membership with a contribution of at least $20 per year.

For more information about the Alzheimer’s Impact Movement email: info@alzimpact.org

JOIN THE MOVEMENT TO END ALZHEIMER’S AT ALZIMPACT.ORG

CREATE A WORLD WITHOUT ALZHEIMER’S. SUPPORT AIM.

- AIM works to advance the legislative priorities of its sister organization, the Alzheimer’s Association.

- AIM complements the advocacy efforts of the Alzheimer’s Association. AIM ensures that our movement can engage Congress with our agenda throughout their lives as members – both in the congressional office and on the campaign trail.

- AIM is strictly bipartisan. Our supporters come from across the political spectrum, united by the conviction that Alzheimer’s must be confronted now. Our supporters are both determined and pragmatic. They know that for our cause to succeed on Capitol Hill, we need champions from both parties.

- AIM members have access to information and opportunities available nowhere else. This is one way that AIM conveys its appreciation to some of the most remarkable supporters of the Alzheimer’s movement – men and women who support AIM as part of their commitment to do all they can to end Alzheimer’s.

- Your support for AIM ensures we can bring the Alzheimer’s agenda before Congress whether these members be on the Hill or on the campaign trail. **Become an AIM member.** Join us as we press the fight to end this devastating disease.