

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

2023-2028





STATE OF WASHINGTON
OFFICE OF GOVERNOR JAY INSLEE

August 4, 2023

Dear fellow Washingtonians:

Alzheimer's is the fourth-leading age-adjusted cause of death in Washington state. In 2020, more than 125,000 Washington residents were living with Alzheimer's Disease or another type of dementia. By 2040, that number is projected to increase to more than 270,000.

Every sector and region of our state is affected by dementia. The impact is felt by individuals and families who shoulder the greatest emotional, physical, and financial responsibility; by our workplaces and economy; by health care systems and providers striving to meet complex needs; and by local communities and state agencies.

With great challenges come great opportunities. The first Washington State Plan to Address Alzheimer's Disease and Other Dementias arose from the Governor's Aging Summit, hosted in 2013. Since its publication in 2016, the Dementia Action Collaborative (DAC) has worked with public and private partners to implement the plan. Notable achievements include the creation of the Dementia Road Map: A Guide for Family and Care Partners, Project ECHO Dementia for primary care practitioners, public awareness campaigns to reach the Black/African American and Latino communities, an early legal and advance care planning program and more.

While there is no known way to prevent or cure Alzheimer's, there are actions we can take to build upon advances in knowledge and better prepare Washington state for the decades ahead. This second plan recognizes the stronger evidence base for reducing potentially modifiable risks factors for dementia, new knowledge around brain health and dementia, and emphasizes health equity for all Washingtonians.

This state plan is a call to action and proposes concrete steps for varied sectors — actions that partners throughout Washington can take to promote brain health, increase early legal, financial and advance care planning, improve quality of life for those living with dementia, ease the strain on family caregivers and reduce associated costs in the future.

I urge my administration, including leadership from the Department of Social and Health Services, Department of Health, Health Care Authority, and partners across Washington to continue their collaborative efforts to improve our response to dementia. It will take all of us to improve the health of people at risk of and living with dementia. Join us as we work together to that end.

Very truly yours,

A handwritten signature in black ink, appearing to read "Jay Inslee".

Jay Inslee
Governor

Acronyms and Terminology Used in this Report

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
AFH	Adult Family Home
ALF	Assisted Living Facility
CMS	Centers for Medicare and Medicaid Services
CDC	Centers for Disease Control and Prevention
DAC	Dementia Action Collaborative
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
SNF	Skilled Nursing Facility
UW	University of Washington

A Note about Terminology

The Dementia Action Collaborative (DAC) recognizes that different stakeholder groups using this plan may use different terms related to cognitive impairment, Alzheimer's disease and dementia and to describe the role of a person who provides the informal (unpaid) support and/or care that someone with memory loss or dementia may need.

Throughout this document, a variety of terminology may be used:

Cognitive Decline/Cognitive Impairment – Cognition is a combination of processes in the brain that includes the ability to learn, remember and make judgments. Cognitive decline can range from mild cognitive impairment to dementia, a form of decline in abilities severe enough to interfere with daily life.¹ With mild cognitive impairment (MCI), people may notice changes in memory or coming up with words, but it does not impact their ability to take care of their normal daily activities. In some cases, these mild changes in memory and thinking may be caused by conditions that are treatable and reversible.

Alzheimer's Disease and Other Dementias, Dementia

- **Dementia** is an umbrella term referring to the loss of cognitive function – memory, language, problem-solving and other thinking abilities – severe enough to interfere with a person's everyday life.
- **Alzheimer's disease** is the most common type of dementia. **Other dementias** include, but are not limited to, Frontotemporal Dementia (FTD), Lewy Body Dementia (LBD), vascular dementia, mixed dementias and more. Certain forms may present specific and different issues, but all forms of dementia create a similar set of challenges for families.

¹ <https://www.cdc.gov/aging/data/subjective-cognitive-decline-brief.html>

- Many of the actions described in this plan are designed to address these conditions collectively. This report may use “Alzheimer’s disease” and/or “other dementias” depending on the context, e.g., some research studies and/or treatments are specific to Alzheimer’s disease; interventions and approaches are often inclusive of all types of dementia.

Care partner or family caregiver – refers to the person who is mostly supporting or caring, without pay, for a family member or friend who is experiencing cognitive decline or dementia.

Memory loss or memory concerns – is a term used often in the public, mostly to refer to the early changes or stages of cognitive decline that may include subtle changes in remembering. Used in this report, it would refer to the stage when memory changes may be clear enough to be recognizable, but not severe enough to interfere with daily life.

Other friends and family – refers to people other than the primary care partner who are concerned for their friend or loved one with dementia and may provide assistance.

Family – is used in the broadest possible sense to include spouses, partners, siblings, friends, neighbors and others that the person living with memory loss or dementia considers as family.

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Executive Summary



Executive Summary

Alzheimer's disease is the 4th leading age-adjusted cause of death in Washington state. In 2020, around 125,000 people were living with Alzheimer's disease or other dementias in Washington. By 2040, that number is expected to be more than 270,000.

The progressive nature of dementia, its long duration, and its effects on memory, self-care and decision-making create challenges for individuals and families. While caring for a family member or friend living with dementia can be rewarding, it can also be difficult and some caregivers experience stress, isolation, depression, health risks and financial strain. Currently, there are more than 213,000 unpaid family care partners of people living with dementia in Washington.

Dementia, including Alzheimer's disease, is one of the costliest chronic conditions. The total value of health care, long-term care, and caregiving for a person living with probable dementia in the last five years of life is significantly higher than care for a person with heart disease or cancer.

There is no cure for Alzheimer's disease and other dementias, though research is revealing ways to reduce risks for dementia, slow the progression and improve the experience of living with dementia. Early detection and diagnosis provide opportunities to address treatable changes in memory and thinking, allow for better management of comorbidities to help avoid unnecessary hospitalizations or emergency room visits, and offer individuals and families time to make legal, financial and advance care plans. Early detection also sets the stage for more treatments as they become available.

While the greatest risk factor is advancing age, many older adults do not develop Alzheimer's disease or dementia. Another risk factor is family history and associated genetic influences, and again many family members with family history will not develop the condition. This makes it important to identify and address modifiable risk factors.

Research points to a host of contributing factors that potentially modify the risk of developing dementia. These factors offer the possibility that targeted actions by individuals and/or communities may help to reduce the risk of developing dementia over the life course. These include:

- Managing chronic conditions
- Avoiding tobacco and excessive alcohol
- Following a healthy diet
- Staying socially engaged
- Exercising the body and mind
- Preventing and treating hearing loss

An increased awareness and stronger evidence-base has also emerged around social determinants of health and how they affect health outcomes and risks, including delays in detection and treatment among racial and ethnic groups. Recent Washington state data confirm that the prevalence of dementia is higher for Blacks/African Americans and American Indian/Alaska Natives as compared to non-Hispanic whites.

What is needed now

The Dementia Action Collaborative (DAC) has been working toward the achievement of seven high level goals and is making progress. The DAC calls upon public health, health care and the long-term services and support systems to work towards early detection and diagnosis, to identify and treat chronic conditions and to work together to address physical activity, obesity, depression, smoking, hearing loss, excessive alcohol consumption and air pollution concerns to work towards the best health for all Washingtonians throughout the life course.

The projected increases in the aging population and particularly the population living with dementia, require us to amplify our efforts to improve access to and the dementia-capability of all our systems of care and support while elevating our focus on health disparities and equity.

Call to Action

The Dementia Action Collaborative invites everyone to be a part of the solution. The goals, strategies and recommendations in the plan cannot be accomplished by the DAC or state agencies alone. In the plan are suggested actions for individuals and care partners, aging network, long-term services and support organizations, health care providers and systems, public health entities and other community organizations.

GOALS

- 1** Increase public awareness, engagement and education.
 - 2** Prepare communities for significant growth in the population living with dementia.
 - 3** Promote well-being and safety of people living with dementia and their family caregivers and care partners.
 - 4** Promote equitable access to comprehensive, culturally relevant support for family caregivers and care partners.
 - 5** Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia.
 - 6** Increase equitable access to culturally relevant, dementia-capable long-term services and supports.
 - 7** Facilitate innovation and research related to risk reduction, causes of and effective interventions for cognitive decline and dementia
-

More on the specific problems, needs, strategies, recommendations and suggested actions for partners are included in the full report at www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan.

Vision and Guiding Principles

Vision

The Dementia Action Collaborative (DAC) envisions a future where all Washington health care providers are educated on risk reduction, early detection and diagnosis of dementia; all Washington communities are dementia-friendly; and all Washingtonians are supported within their own communities and cultures to reduce their risks of dementia. We envision a future that supports choice and provides equitable access to whole person care and long-term supports and services for people living with cognitive decline or dementia, and their loved ones.

Guiding Principles

1. ***Person- and family-centered***

Develop the plan with the needs and strengths of all people living with dementia, their care partners and family members at the forefront, this includes attentiveness and action to address differing cultural values.

2. ***Health equity***

Apply an equity lens throughout the plan development and implementation. Consider that equitable solutions may mean different groups need different things, not a one-size-fits-all approach.

3. ***Life course approach***

Recognize that together we can address brain health throughout the life course, incorporating strategies to reduce modifiable risks for dementia.

4. ***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 and nations.

5. ***Public-private framework***

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

The Need for a State Plan

How will this plan help?

The needs and impacts related to dementia are seen in a variety of sectors including long-term care, health care, public health, legal assistance, the business community and more. A state plan is mechanism to outline recommended actions that can be taken by various sectors and entities that align with common goals, and in doing so create a more coordinated, consistent and amplified response.

This plan recognizes that long-term services and supports are an important and costly part of dementia care. At the same time, it acknowledges that dementia is a critical public health and health care system issue as well and offers a comprehensive set of strategies to respond as future needs expand. This includes a focus on early detection and diagnosis, reducing modifiable risk factors, addressing health disparities, and closer coordination between medical care, long-term services and supports and local community-based organizations and partners.

This plan identifies opportunities and steps that individuals, state and local governments, tribal health and/or community partners can take to promote healthy aging and brain health, reduce risks for dementia, improve the quality of life for those living with the disease, ease the strain on family caregivers and reduce associated costs in the future.

This plan increases awareness about the prevalence and expanding needs of Washingtonians living with dementia and the services and resources available to them and offers forward-thinking strategies and actions to galvanize public and private stakeholders in preparing Washington state for the significant increases in the number of people living with dementia that lie ahead.

Who is this plan for?

The Washington State Plan to Address Alzheimer's Disease and Other Dementias was developed by the Dementia Action Collaborative (DAC), with input and ideas from individuals and families living with dementia and other stakeholders. The plan is intended to guide the ongoing **collaborative work of the DAC**. Plan contents will also be useful for **policy and decision-makers** beyond this group to understand dementia-related needs in Washington.

While some recommendations are intended for **state agencies**, the plan itself is not aimed solely at state government. The goals, strategies and recommendations in the plan cannot be done by the DAC or state agencies alone. It will require independent actions from **individuals, stakeholders, local governments, municipalities, and community partners** that align with the goals, strategies and recommendations of the plan.

To help partners act, this plan includes a specific component that outlines possible actions for individuals and/or different types of organizations. Each intended audience can select one or more action steps they want to take to support the plan implementation.

The Dementia Action Collaborative invites anyone to join us in taking ACTION – be a part of the solution! See Appendix C.

Background

What is Dementia?

Dementia² is a general term that refers to the loss of memory, language, problem-solving and other thinking ability severe enough to interfere with everyday life. Dementia develops when brain cells are damaged and cannot communicate with each other normally. Though dementia mostly affects older adults, it is not a part of normal aging.

² Alzheimer's Association. (2022a). 2022 Alzheimer's Disease Facts and Figures. Special Report, More Than Normal Aging: Understanding Mild Cognitive Impairment. Retrieved December 6, 2022, from <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.12638>.

Alzheimer's disease is the most common form of dementia, accounting for 60-80% of cases. Alzheimer's is a progressive disease with worsening symptoms over time.

Other types of dementia include, but are not limited to, Lewy body dementia, vascular dementia, frontotemporal dementia, and more. Different types of dementia are associated with distinct brain changes and symptoms.

The Alzheimer's Association identifies ten early signs and symptoms of dementia:

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work, or at leisure
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; and
10. Changes in mood and personality.

See Appendix G: Information About Alzheimer's Disease and Dementia for more details.

While the greatest risk factor is advancing age, many older adults who are in their nineties do not have Alzheimer's disease or dementia. Family history and associated genetic influences are important factors, but many family members of those with Alzheimer's will not develop the condition. This makes it important to find and address modifiable risk factors.

The good news is, that even while there is still no way to prevent dementia, research is revealing a host of potentially modifiable risk factors that individuals may be able to change over the life course. These include:

- Heart-brain connection - Some of the strongest evidence links brain health to heart health. This is logical because the brain is nourished by one of the body's richest networks of blood vessels, and the heart handles pumping blood through these blood vessels to the brain. This includes managing chronic conditions, such as hypertension and diabetes.
- Overall healthy aging - These include eating a healthy diet, staying socially active, avoiding tobacco and excess alcohol and exercising both the body and mind.

More on this topic is discussed later in this report.



Population Trends Related to Dementia



Population Trends Related to Dementia

Estimates of Prevalence

The precise number of people in Washington State with Alzheimer’s disease and other dementias is unknown. However, DSHS’ Research and Data Analysis Division was able to develop an estimate of dementia prevalence based upon the presence of dementia-related diagnoses in Medicare claims spanning the 2013-2018 time. Dementia was broadly defined to include Alzheimer’s and related dementia diagnoses e.g., vascular dementia, unspecified dementia, etc. Measuring the prevalence using actual health service experiences of several hundred thousand Washington state Medicare beneficiaries supports more detailed direct prevalence estimates for groups that are often under-represented in survey data. Using this approach, in 2020 the number of people living with dementia, including Alzheimer’s disease in Washington state is estimated at 125,116.

Growth of the “Oldest-Old”

Washington State now has the 2nd highest life expectancy nationwide, with an average life expectancy at birth of 79.2 years.³ In 2011, the first baby boomers started reaching 65 years of age. In Washington state, this ‘age-wave’ can be seen in the growing population of people in the 75 and older age group. In 2020, people 75 and older represented 7% of the total state population. By 2040, this age group will be 12% of the total state population.⁴ People who are age 85 or older are defined as the “oldest old”, and are the fastest growing age group in the U.S.

As Washingtonians live longer and healthier lives, we gain from their knowledge and can learn from their examples of aging well. At the same time, while Alzheimer’s disease is not a normal part of aging, age is the greatest risk factor for developing Alzheimer’s or other dementia. The risk of developing Alzheimer’s almost doubles every five years after age 65. In the Washington state data (Washington State Medicare beneficiaries) dementia prevalence can be seen increasing from 3% for people aged 65-69 years to 33% for people age 85 and older.

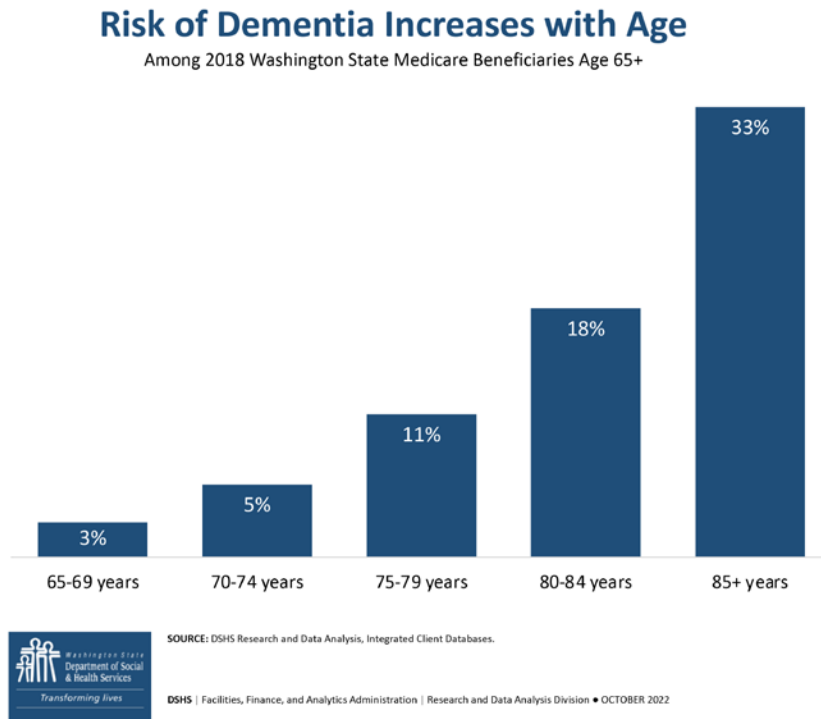


Figure 1. Risk of dementia increases with age.

³ <https://www.cdc.gov/nchs/data/nvsr/nvsr71/nvsr71-02.pdf>.

⁴ Washington State Office of Financial Management, Forecasting and Research Division. Projections of the Population Age 65 and Over for Growth Management, 2017 GMA Projections – Medium Series, January 2018; Population Estimates by Age and Sex 2020, 2021 (Preliminary) accessed August 25, 2022.

Forecasting Number of Persons with Dementia in the Future

The combination of the increasing older population and the increased likelihood of dementia with advanced age will lead to the expected growth of the dementia population.

Unless the disease can be effectively treated or prevented, the number of Washingtonians with Alzheimer’s and other dementias will increase significantly in the next 20 years. Using observed dementia prevalence rates for Washington state Medicare beneficiaries (explained above) and detailed Office of Financial Management (OFM) forecasts of the state population change through 2040, it is possible to create long-term forecasts of dementia prevalence.⁵ This forecast (Figure 2) shows we expect more than double what we had in 2020 – or 270,028 citizens age 65 and older to have a form of dementia in 2040.

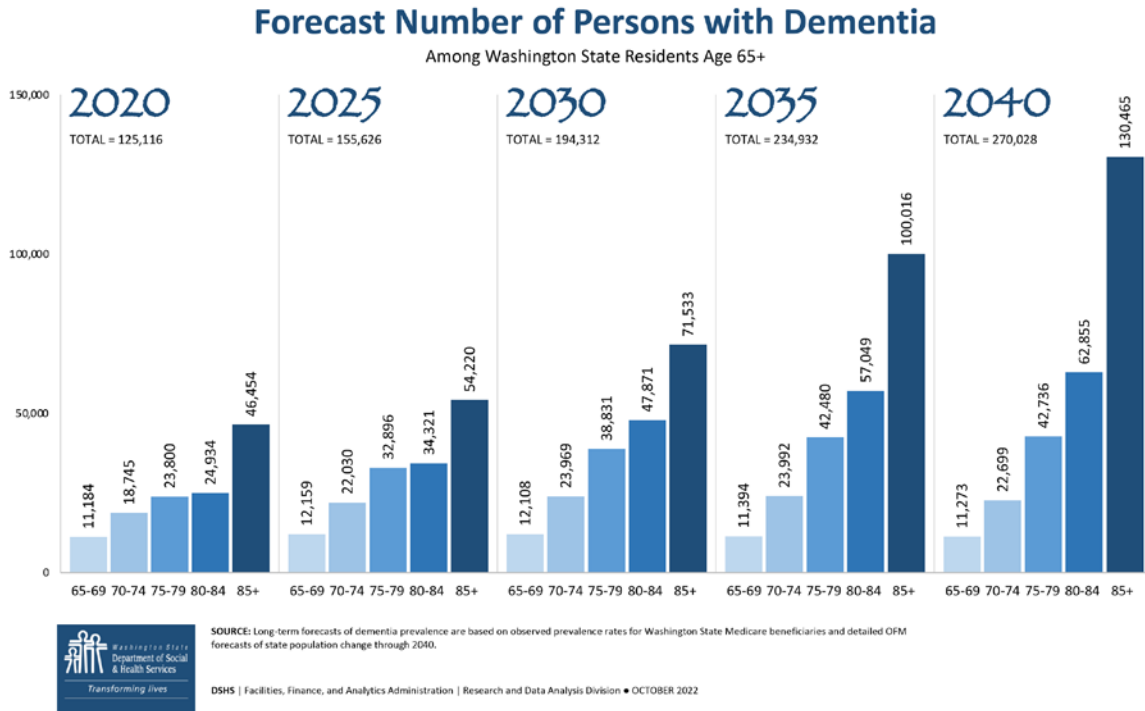


Figure 2. Forecast number of persons with dementia, 2020-2040.

⁵ Long-term forecasts of dementia prevalence are based on observed prevalence rates for Washington State Medicare beneficiaries and detailed OFM forecasts of state population change through 2040. DSHS RDA October 2022.



Current and Future Impacts of Dementias



Current and Future Impacts of Dementias

Impact on Individuals

The progressive nature of Alzheimer's disease, its long duration, and effects on decision-making, self-care and behavior create challenges for individuals. Research suggests that people 65 and over live on average four to eight years after a diagnosis of Alzheimer's disease, but some survive as long as 20 years.

In early stages, declining memory can lead to challenges in managing work, finances, or health care issues, including taking medications or driving. As the disease progresses, people living with dementia may also have trouble in initiating activities, decision-making and behavioral symptoms, such as depression and agitation.

Over time, people living with Alzheimer's or other dementia will depend more and more on others to help them with daily living to remain at home, or with a family member. More than 60% of people living with Alzheimer's disease may wander away from home at some point in the disease. And falls are more frequent for people living with dementia – and one of the most common reasons for hospitalization of people living with Alzheimer's.⁶ Eventually, people living with Alzheimer's disease will need significant or total help with bathing, dressing, eating and toileting.

Even so, a significant number of people living with dementia live alone. Estimates show that in the United States, one third of people with dementia may live alone.⁷ The number of people living alone with cognitive impairment is likely to increase, as baby boomers are more likely to live alone as they age, given they have fewer children and higher divorce rates than prior generations.⁸

The symptoms of Alzheimer's and other dementias, such as changes in memory, judgment, and the ability to plan and carry out daily activities create greater risks for self-neglect, malnutrition, injury, medication errors, financial exploitation, unmet care needs and nursing home placement – which is even greater for those who live alone.

Those living with dementia who live alone and have no one who visits, helps, or checks in regularly are the most likely to fall through the cracks. Their unmet needs become clear only when they have a medical or other care-related crisis, and emergency response from health care, law enforcement, or Adult Protective Services (APS) agencies are called.

In the later stages, a significant percentage of people living with dementia can no longer live at home. A person living with Alzheimer's disease will spend 40% of the total number of years with Alzheimer's in the most severe stage of the illness.⁹ This impact is seen in the high percentage of people living with dementia in either community residential or skilled nursing facility settings.

A recent DSHS analysis of diagnoses found in integrated Provider 1 and CARE data, reveals that 63% of Medicaid clients (age 65+) and 50% of Medicaid clients (all ages) in community residential settings, had indications of dementia, including Alzheimer's disease. In skilled nursing homes, 58% of LTSS clients (age 65+) and 52% (all ages) in skilled nursing homes services had indications of dementia.

Impact on Families

Dementia affects the whole family. Family members provide most of the care for those living with dementia. Family members caring for a person living with dementia in America, provide an average of 21.9 hours per week of care.¹⁰ The care tasks they provide can range from helping with medications or finances to being quite personal in nature. For example, dementia caregiving is more likely to involve helping with showering, bathing or managing incontinence than is caregiving for people

⁶ Stark, et al., 2013.

⁷ Lin IF, Brown SL. Unmarried boomers confront old age: A national portrait. *Gerontologist*. 2012;52:153–165. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)].

⁸ Lin IF, Brown SL. Unmarried boomers confront old age: A national portrait. *Gerontologist*. 2012;52:153–165. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)].

⁹ Alzheimer's Association, 2011.

¹⁰ Alzheimer's Association, 2015.

with other conditions. Other challenging symptoms that caregivers may meet include agitation, anxiety, hallucinations, repetitive activities, paranoia, combativeness and sleep disturbances.¹¹

In Washington state alone, we estimate there are currently around 213,145 unpaid family caregivers of persons living with dementia in Washington state.¹² These informal caregivers form the backbone of our long-term care system.

I find it difficult to find help for me, the caregiver. It feels pretty lonely and scary, especially when you don't know where to go for help.

- Family caregiver from Washington

While most family members provide such care willingly and experience benefits through this role, for some, the demands of caregiving can lead to negative outcomes – heightened stress, health risks, depression and financial strain. Washington's Behavioral Risk Factor Surveillance System (BRFSS) findings revealed that the greatest impacts on family caregivers of people living with dementia are increased stress, not enough time for self or family, and adverse impacts on family relationships.¹³ Findings also indicate that caregivers of people living with dementia are twice as likely, as compared to caregivers of people without dementia, to experience a serious mental health condition such as depression and/or anxiety.¹⁴ They are also more likely than non-caregiving peers to report their health as fair or poor.¹⁵ These emotional and physical impacts are known nationally to lead to increased health care costs for dementia caregivers.

Dementia caregiving also affects the ability to maintain an income. The National Alliance for Caregiving and AARP, based on national survey data, report that the majority (61%) of family caregivers of adults worked either full-time or part-time in 2019. Of these family caregivers, 53% of these employed family caregivers reported having to go in late, leave early and/or take time off, 15% reduced their work hours, 14% took a leave of absence and 6% gave up working. Working caregivers who left their employment, either sometime in the past year or ever while also caregiving, most commonly did so to have more time to care for their recipient (49%), with 15% reporting their job did not allow flexible work hours.¹⁶

These statistics though are based on a national sample and do not necessarily reflect the experience of Washington state caregivers. As of 2023, Washington is one of 11 states, along with Washington, D.C., that have laws requiring paid family leave. Washington's paid family and medical leave covers an individual's serious health condition and/or when time off is needed to care for a family member with a serious health condition (or a new child).¹⁷

The cost of caring for a person living with dementia is daunting - the high costs of care pose real challenges and consequences for Washington families. In the recent Dementia Action Collaborative Consumer Survey, 43% of respondents named "financial help with care costs" as one of the top two critical issues to address in the next five years.

There is a serious lack of resources (services) and supports for the middle income, across every area (in home, memory care, caregiver support, etc.). I have been caring for my mother for 3 years with essentially no help.

- A Washington family member

Researchers estimate that nationally, the total value of health, long-term care, and caregiving for a person living with probable dementia in the last 5 years of life was \$287,000 (in 2020 dollars). These costs are significantly higher than care for a person with heart disease (\$175,000) or cancer (\$173,000).¹⁸

¹¹ Alzheimer's Association. 2020 Alzheimer's Disease Facts and Figures. Alzheimer's Dement 2020;16(3):391-460.

¹² Alzheimer's Association, (2015), (DSHS RDA, 2015)

¹³ WA Department of Health, 2007.

¹⁴ Family Caregiver Alliance, 2003.

¹⁵ Alzheimer's Association, 2015.

¹⁶ Caregiving in the U.S. 2020 Research Report. AARP and National Alliance for Caregiving 2020. <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>

¹⁷ <https://paidleave.wa.gov/find-out-how-paid-leave-works/>

¹⁸ <https://aspe.hhs.gov/reports/national-plan-2022-update>

In 2023, the estimated median rate of assisted living facility care in Washington State is \$72,000 per year and nursing home care is \$96,933 per year. The costs for specialized dementia care sometimes referred to as “memory care” in either of these settings is even higher. For home care, the median rate is around \$34 per hour.

While low-income families can access Medicaid funded long-term supports and services, middle-income families must pay for these services themselves – at least until assets are exhausted. In situations of younger-onset Alzheimer’s disease, the loss of employment impacts income and health insurance as well. These families often have children still at home, compounding the impact.

In home care is very expensive for middle income people. If someone has financial resources the difficulties are a bit easier, if a family is in the middle-income level, this is devastating.

- A Washington family member

The duration of dementia, and high costs of care commonly result in families depleting their resources and eventually turning to public programs for financial assistance. The aging of the baby boomers is expected to increase the proportion of middle-class families who will “spend down” their assets to Medicaid eligibility in the future.¹⁹

Disparities in Dementia Prevalence

Available national statistics indicate that older African Americans are twice as likely as older whites to have Alzheimer’s disease and other dementias²⁰ and Hispanic/Latinos are about 1.5 times as likely to have dementia.²¹

In the recent DSHS Research and Data Analysis Division (RDA) analysis, of Washington state Medicare beneficiaries, we can see that Blacks/African Americans or American Indian/Alaska Natives in Washington state have higher rates of dementia diagnosis, after controlling for age. The prevalence of dementia (among those age 65-74) in this data is 46% higher for Blacks/African Americans and 45% higher for American Indian/Alaska Natives as compared to non-Hispanic whites. Focusing in on the age 65-74 group helps to control for differences in the age distribution across race and ethnicity groups (in part due to differences in mortality) which would otherwise mask significant variation in the impact of dementia across communities.

The DSHS-RDA data set shows a 2% higher prevalence for Hispanic/Latinos (age 65-74) as compared to non-Hispanic whites. It is important to note, though, that this data set may not reflect the overall experience of this population group as a part is ineligible for Medicare.

¹⁹ Reinhard, et al., 2014.

²⁰ SPADO, 2012.

²¹ SPADO, 2012.

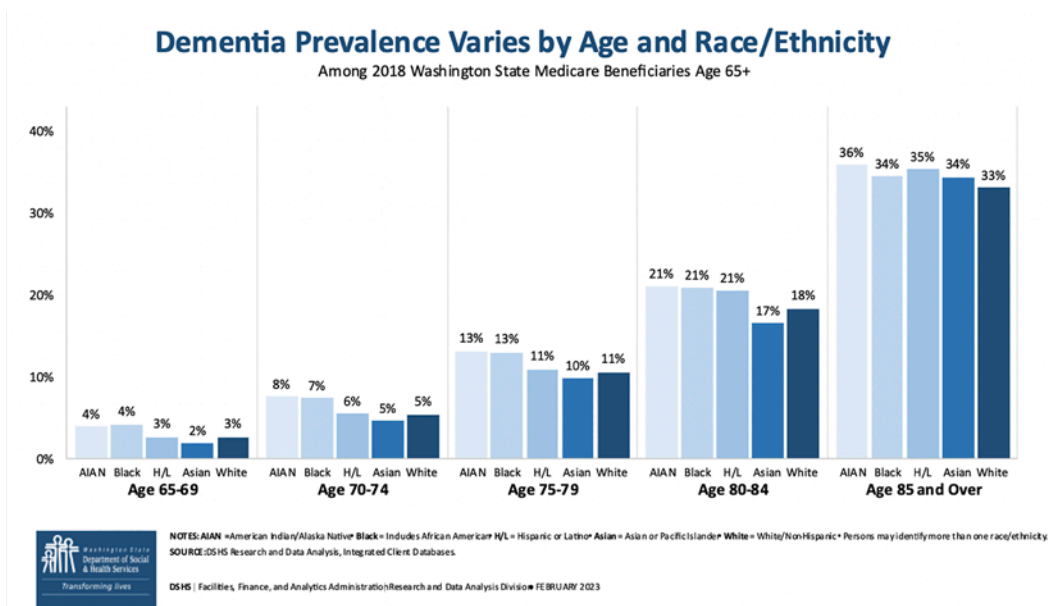


Figure 3. Dementia prevalence varies by age and race/ethnicity.

In addition to this finding of racial disparities in the prevalence of dementia, it is also important to recognize that differences in language and culture create heightened barriers to diagnosis itself, education and support resources for these populations once diagnosed. For example, while undiagnosed dementia is an issue for all groups, Medicare data indicate that African Americans are less likely than whites to be diagnosed. And when diagnosed, African Americans and Hispanics are generally diagnosed in later stages of the illness – the impact of this is a higher use of health care services and higher costs.²²

We also know from research findings that two-thirds of Americans living with Alzheimer’s disease are women. While it is true that women typically live longer than men, meaning they are more likely to reach the ages putting them at greater risk, emerging evidence suggest there may be biological reasons for the differences. This disparity was seen in the recent Washington data, showing that dementia prevalence rates are somewhat higher for women.

Dementia Prevalence Rates Are Somewhat Higher for Women

Among 2018 Washington State Medicare Beneficiaries Age 65+

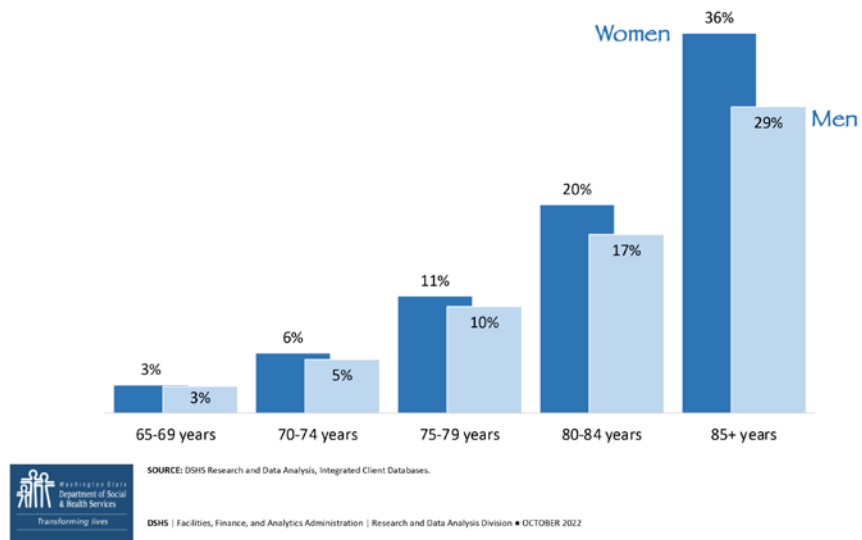


Figure 4. Dementia prevalence rates are somewhat higher for women.

²² Race, Ethnicity and Alzheimer’s Disease, 2013.

Another group with disproportionate risk are those with Down Syndrome (DS). Persons with DS are particularly vulnerable to developing Alzheimer’s disease, and with younger onset.²³ By age 55, one out of two people with DS will develop Alzheimer’s and it is not unusual to occur as young as 40. With this population, early detection, appropriate assessment tools, and tailored interventions are necessary to provide appropriate care and support for individuals with DS who develop dementia and their families.

Economic Impacts of Dementia

Costs to Individuals and Families

Services such as in-home care, respite, community residential and nursing facility care are available for citizens to purchase privately. Among these are in-home care, adult day services, adult family home, assisted living and nursing home care. Rates and availability of such services vary by community.

Estimated statewide median rates for the following services follow in the table below:

Table 1. Estimated private pay rates for long-term care settings. Genworth Cost of Care Survey, 2021.

Homemaker Services	\$34.34 per hour
Home Health Aide	\$34.50 per hour
Adult day health care	\$120 per day
Assisted living facility care (ALF)	Private room - \$6,000 per month \$72,000 per year
Memory care (in ALF)	\$7,500 per month \$90,000 per year
Adult family home care	\$163 - \$204 per day* \$59,495 - \$74,460 per year
Nursing home care	Semi-Private room - \$9,429 per month \$96,933 per year
	Private room - \$10,466 per month \$125,597 per year

Rates above (with exception of AFH) are from Median Cost Estimates for private pay from [Genworth’s 2021 Cost of Care Survey](#).²⁴ Memory Care is estimated at 25% higher than ALF. Costs may vary by geographic area and client needs. *DSHS Management Services estimates an average \$163/day for Adult Family Home care under Medicaid; some AFHs offer additional Meaningful Day Services that increase rate by \$40/day (No private pay estimate available).

Because dementia may span the course of many years and care needs increase over that time, a significant percentage of individuals and families eventually turn to long-term services and supports (LTSS) provided through state and federal public funding, such as Medicaid and the Older Americans Act.

Costs to State and Federal Governments

Individuals living with dementia use more health and long-term care resources. For example, they are hospitalized 2-3 times as often as people of the same age who do not have dementia.²⁵ Similarly, estimates from national data show that nearly seven out of ten residents in assisted living residences have some form of cognitive impairment.²⁶ In Washington state, 63% of DSHS Medicaid clients (age 65+) and 50% (all ages) in community residential service settings had indications of dementia.²⁷

²³ Bittles AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ, Montgomery PD. The influence of intellectual disability on life expectancy. *J Gerontol A Biol Sci Med Sci*. 2002 Jul;57(7):M470-2. doi: 10.1093/gerona/57.7.m470. PMID: 12084811. <https://pubmed.ncbi.nlm.nih.gov/12084811/>.

²⁴ Genworth, 2015.

²⁵ <https://aspe.hhs.gov/reports/national-plan-2022-update#15>

²⁶ <https://aspe.hhs.gov/reports/national-plan-2022-update#16>

²⁷ Unpublished DSHS-RDA data. Mancuso, 6.10.23 Unduplicated persons receiving ALTA in-home services in any month in CY 2020.

As the number of people living with dementia grows over the next few decades, dementia will place a major strain on our care systems as well as Medicare and Medicaid, the major funders of clinical care, institutional and home and community-based services (HCBS). Most Americans underestimate the risk of disability and the need for long-term care and are unprepared financially.²⁸

Dementia diagnoses are associated with higher Medicare costs and Medicaid LTSS expenditures.

In Washington state, we can already see these impacts on health care costs. Figure 5 describes per-member per-month (PMPM) Medicare expenditures for Medicare beneficiaries ages 65 and above with and without a dementia diagnosis, stratified by age. Data are presented for fee-for-service (FFS) Medicare beneficiaries in CY 2018, and Medicare expenditures reflected in the figure include all Part A and Part B services (e.g., hospital care, skilled nursing facility, lab tests, surgery, home health care, doctor and health care providers' services and outpatient care). Costs associated with Medicare Part D pharmacy data are excluded.

The figure shows that Medicare beneficiaries living with dementia are significantly more expensive than beneficiaries without dementia (\$2,229 PMPM versus \$803 PMPM). The disparity is greater among persons 65-69 age group, with average Medicare costs of \$2,963 PMPM for persons aged 65 to 69 living with dementia, relative to \$608 PMPM among persons aged 65 to 69 without dementia.

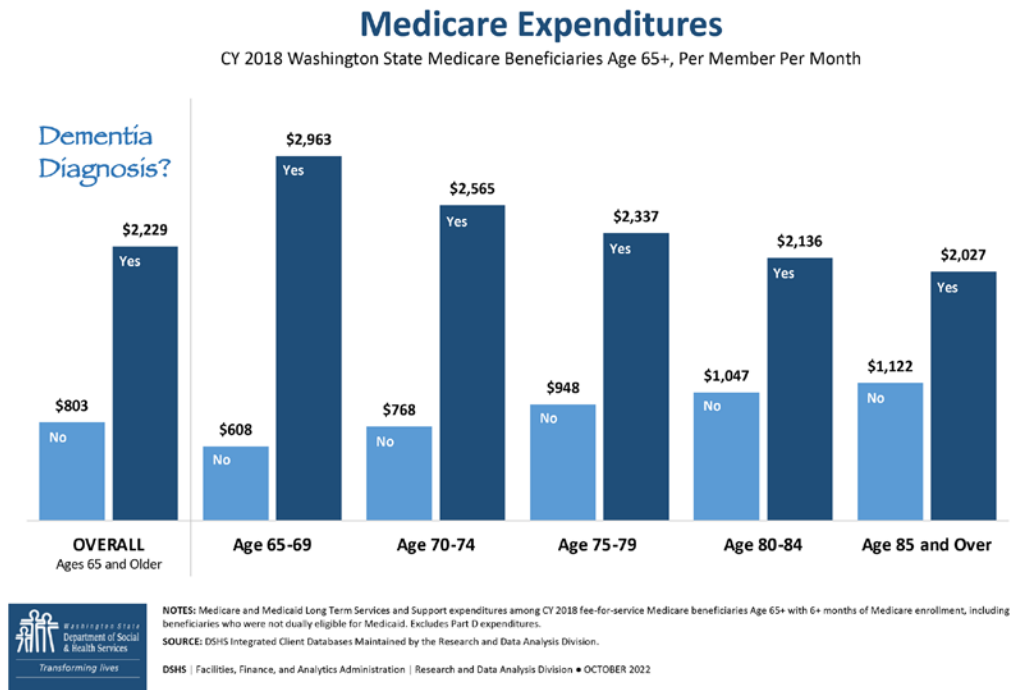


Figure 5. Per-member per-month (PMPM) Medicare expenditures for beneficiaries age 65+.

Higher expenditures for people with dementia, as compared to those without dementia, are also clear in long-term care services. Figure 6 describes per-member per-month (PMPM) Medicaid LTSS expenditures for Medicare beneficiaries ages 65 and above living with and without a dementia diagnosis, stratified by age. Note that these costs are averaged over both persons who received Medicaid LTSS services and persons in the FFS Medicare population who did not use Medicaid LTSS services over the course of the CY 2018 measurement year. The figure shows that Medicare beneficiaries ages 65 and above living with dementia use significantly more Medicaid LTSS services than

²⁸ <https://aspe.hhs.gov/reports/national-plan-2022-update#17>

Medicare beneficiaries age 65 and above without dementia (\$557 PMPM versus \$43 PMPM). The disparity is greatest among persons in the 65-69 age group, with average Medicaid LTSS costs of \$926 PMPM for persons aged 65 to 69 living with dementia, compared to only \$37 PMPM among persons aged 65 to 69 without dementia.

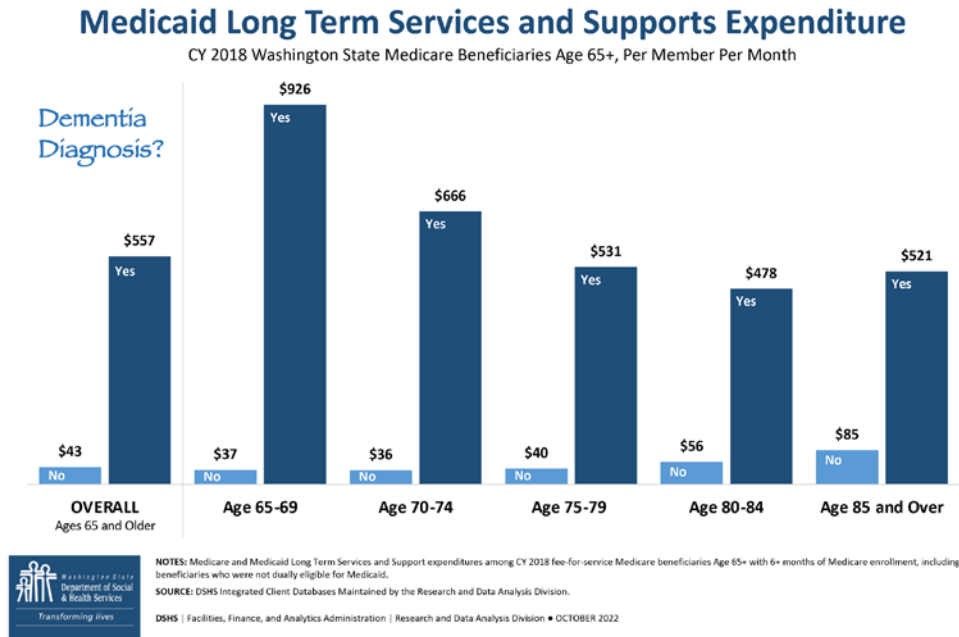


Figure 6. Per-member per-month (PMPM) Medicaid LTSS expenditures for Medicare beneficiaries age 65 and above living with and without a dementia diagnosis.

The impact of both health and long-term care expenditures together is shown in Figure 7. Figure 7 combines the cost data in Figure 5 and Figure 6 into an overall perspective on PMPM Medicare and Medicaid LTSS costs for FFS Medicare beneficiaries living with and without dementia in CY 2018. In summary, dementia is an important cost driver for both Medicare and Medicaid, with a greater proportional impact on Medicaid LTSS expenditures.

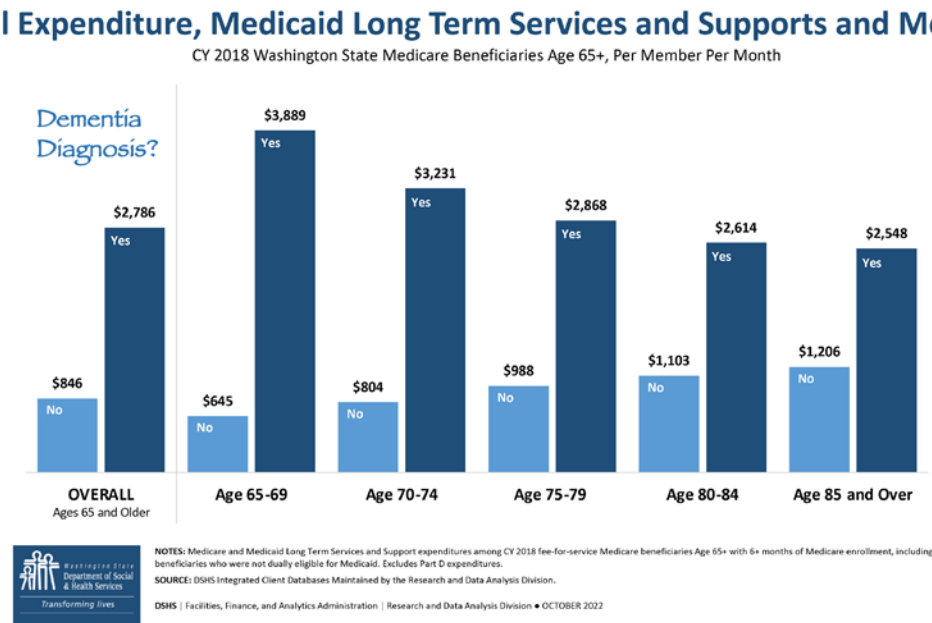


Figure 7. Total expenditures on PMPM Medicare and Medicaid LTSS costs for FFS Medicare beneficiaries living with and without dementia in CY 2018.



Advances in Knowledge



Advances in Knowledge

Brain Health and Risk Reduction

While the greatest risk factor for dementia is age, dementia is not a normal or inevitable part of typical brain aging. As we get older, it is common to experience some cognitive decline with typical brain aging, such as subtle changes in memory or losing things from time to time. Even with mild cognitive decline, that may include more memory or thinking changes, many people can still manage the necessary aspects of their daily lives. It is when changes in memory, thinking and judgment begin to change daily life, that such changes could be signs of a possible dementia.

Since the first *Washington State Plan to Address Alzheimer's Disease and Other Dementias* was published in 2016, new information has been published around the evidence-base for brain health and potentially modifiable risk factors for dementia.

Modifiable risk factors are the lifestyle and behaviors that can reduce a person's chances of developing a disease. Most modifiable risk factors for dementia are related to cardiovascular disease and other chronic health conditions. They include hypertension, lack of physical activity, obesity, diabetes, depression, excessive alcohol consumption, smoking, hearing loss, poor sleep, use of harmful substances and excessive air pollution. Maintaining a healthy lifestyle including engaging in lifelong learning and socialization along with managing related chronic conditions is good for your overall physical health, helps and improves brain health and may help decrease the risk of dementia or slow its progression.

This encouraging news published in *The Lancet*,²⁹ shows that through the lens of a life course model, nearly 40% of all dementias might be prevented or delayed.³⁰ Since dementia takes years to develop, there are opportunities throughout one's life to develop and maintain healthy lifestyle habits that could reduce your risk of dementia or slow its progression. It is never too late to break old habits and start new ones.

²⁹ The Lancet Commission Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, Gill Livingston, Jonathan Huntley, Andrew Sommerlad, David Ames, Clive Ballard, Sube Banerjee, Carol Brayne, Alistair Burns, Jiska Cohen-Mansfield, Claudia Cooper, Sergi G Costafreda, Amit Dias, Nick Fox, Laura N Gitlin, Robert Howard, Helen C Kales, Mika Kivimäki, Eric B Larson, Adesola Ogunniyi, Vasiliki Orgeta, Karen Ritchie, Kenneth Rockwood, Elizabeth L Sampson, Quincy Samus, Lon S Schneider, Geir Selbæk, Linda Teri, Naaheed Mukadam.

³⁰ Effect of Intensive vs Standard Blood Pressure Control on Probable Dementia: A Randomized Clinical Trial. *JAMA*. 2019;321(6):553–561. doi:10.1001/jama.2018.21442.

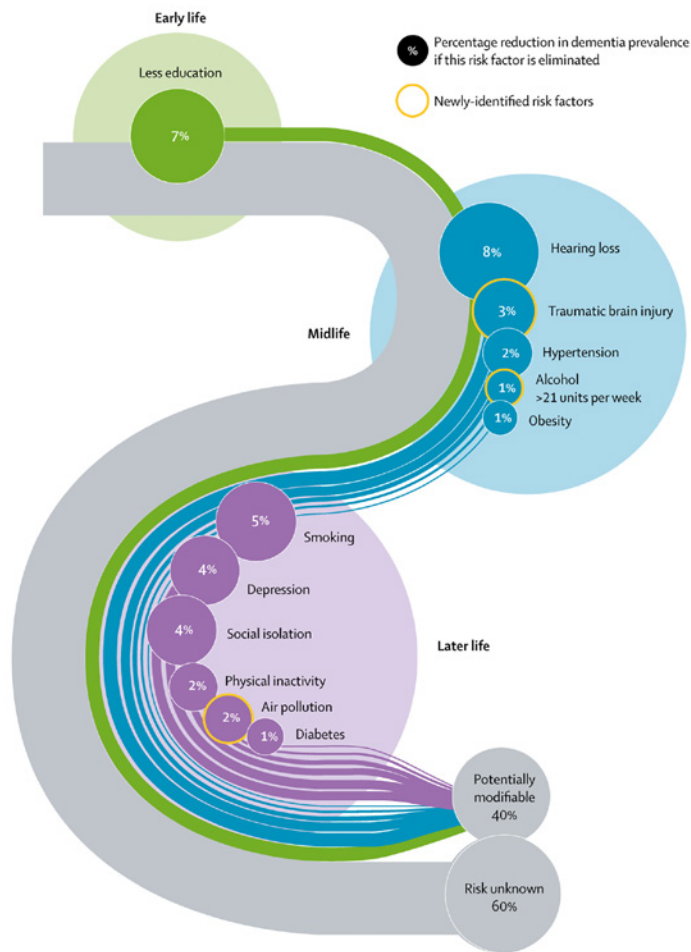


Figure 8. Twelve potentially modifiable risk factors for dementia (Lancet Commission, 2020).

A graphic from the Lancet Commission identifies the 12 potentially modifiable risk factors that account for the 40% of worldwide dementias, and where in the life course intervention might occur. It shows how these risk factors occur at different times through the life course and are related to social determinants of health.³¹

The evidence about these potentially modifiable risk factors offers a starting point for both individuals and organizations to make an impact. Preventing or mitigating chronic diseases, such as diabetes and mid-life hypertension, can potentially change a person’s risk factors for dementia. The national Centers for Disease Control and Prevention (CDC) recommends:

Things You Can Do:

- **Get Active and Maintain a Healthy Weight** – Regular physical activity is important for good health and combined with a healthy diet may lead to a healthy weight.
- **Manage Blood Sugar** – Learn how to manage your blood sugar if you have diabetes.
- **Prevent and Manage High Blood Pressure** – Tens of millions of adults in the United States have high blood pressure, and many do not have it under control. Learn the facts.
- **Prevent and Correct Hearing Loss** – Make sure to talk to a hearing care professional to treat and manage hearing loss.
- **Find Support** – Depression is not just having “the blues” or the emotions we feel when grieving the loss of a loved one. It is a medical condition that can be treatable.

³¹ [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext).

Things You Should Try to Limit or Avoid:

- **Excessive Alcohol** – If you drink, do so in moderation. Learn about alcohol use and your health.
- **Smoking** – Quitting smoking improves your health and reduces your risk of heart disease, cancer, lung disease, and other smoking-related illnesses.

Washington state data shared earlier show that Alzheimer’s disease and other dementias are no exception when it comes to health disparities. Since the prior plan was published, an increased awareness and evidence-base has appeared around social determinants of health, structural factors and redlining. This includes a focus on how they affect health outcomes and risks including delays in detection and treatment, among racial and ethnic groups as well as in different geographies and among people with different physical abilities.

Above, we learned that hypertension and diabetes, if prevented or mitigated, may reduce the risk for dementia. In Washington, health disparities currently exist in both the prevalence of both diabetes and high blood pressure. Data from Washington’s Behavioral Risk Factor Surveillance Survey (BRFSS) from 2019-2021 show that:

- The prevalence of diagnosed diabetes in adults varies among race and ethnicity groups in Washington state:
 - American Indian or Alaska Native (non-Hispanic) - 15.9%
 - Native Hawaiian or Pacific Islander (non-Hispanic) - 13.4%
 - Black adults (non-Hispanic) - 13.4%
 - Hispanic - 9.0%
 - Asian adults (non-Hispanic) - 7.3%
 - White adults (non-Hispanic) - 8.8%
- The prevalence of high blood pressure also varies among race and ethnicity groups in Washington State:
 - Black adults (non-Hispanic) - 37.3%
 - American Indian or Alaska Native (non-Hispanic) - 37.4%
 - White adults (non-Hispanic) - 32.2%

We also see in the Lancet article that factors such as less education, obesity, physical inactivity, social isolation, depression and air pollution increase the risk for dementia. Such conditions are often seen in areas of more socioeconomic disadvantage. In fact, a recent study using a precision public health approach, showed that living in the most disadvantaged neighborhoods was associated with increased risk of dementia when adjusting for age, sex and year of death.³²

So, while the Lancet Commission article and other advances in research provide hope for reducing risks for dementia, to advance equity at the same time, it is imperative that states and communities also work to address social determinants of health over the life course, including the following:

- Education access and quality
- Health care access and quality
- Neighborhood, built environment, and access to quality food
- Social and community context
- Economic stability

Source: *Healthy People 2030*

³² Association of Neighborhood-Level Disadvantage with Alzheimer Disease Neuropathology - PMC (nih.gov) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7290421/>

Dementia

Since publication of the 2016 Washington State Plan to Address Alzheimer's and Other Dementias, there are now advances in Alzheimer's disease biomarker tests, new drug treatments and increased evidence of connections between dementia and COVID-19.

The FDA approved biomarker confirmation of Alzheimer's disease continues to be cerebrospinal fluid and the non-reimbursed Positron Emission Tomography (PET) scan. The biomarker tests are needed to start treatments, such as Lecanemab or other medications that emerge over time.

In 2021, Aducanumab received accelerated approval from the FDA as the first drug to attack the disease process and is intended to treat mild cognitive impairment and mild dementia. Coverage by Medicare is only allowed for people in approved drug trials due to the accelerated approval from FDA. While Aducanumab is FDA approved with a limited scope of use, the silver lining is that this drug is the first of its kind and a breakthrough, even if it is not the cure.

In July 2023, Lecanemab received traditional approval from the FDA, it is an anti-amyloid monoclonal antibody treatment for Alzheimer's disease. Clinical trials result in slowed rate of cognitive decline and reduced amyloid plaques. The traditional approval from FDA means that Medicare will cover the treatment for patients with mild cognitive impairment or mild dementia. However, Centers for Medicare and Medicaid Services (CMS) will require prescribing providers to participate in a data collection effort by participating in a registry. This registry hosted by CMS will inform how the drug is working including benefits and harms to patients and if it improves health outcomes.

Both drugs listed above have associated risks; for additional information visit the National Institute on Aging.³³

There are many Alzheimer's drugs in the development pipeline with a wide variety of how the drug therapy works, what it focuses on, and trial participants. Soon, we can expect to see additional pharmacological treatments for symptom control and to slow disease progression.

Other increases in knowledge around dementia arose in recent years from the COVID-19 pandemic. A meta-analysis showed that there is a link between dementia and COVID-19; persons living with dementia have an increased mortality when they contract COVID-19. The association is influenced by age and comorbidities.³⁴ The long-term effects of COVID-19 on persons living with dementia is still an unknown, more research is needed.

The DAC's next steps are to work collaboratively with partners to increase public and provider awareness of the potentially modifiable risk factors and encourage researchers to collaborate towards further advancements in care and treatment.

³³ <https://www.nia.nih.gov/health/how-alzheimers-disease-treated>.

³⁴ Prevalence of dementia and its impact on mortality in patients with coronavirus disease 2019: A systematic review and meta-analysis - July - 2021 - Geriatrics & Gerontology International - Wiley Online Library. <https://onlinelibrary.wiley.com/doi/abs/10.1111/ggi.14107>.



Trends in Dementia Landscape



Trends in Dementia Landscape

Changes At the National Level

On the national landscape, there have also been advances that may impact or bolster efforts around dementia here in Washington state.

In December 2022, President Joseph Biden signed into law, a \$226 million increase for Alzheimer's research funding at the National Institutes of Health (NIH), bringing the total federal funding for Alzheimer's research to more than \$3.7 billion. The bill also included \$33 million to fund and implement the BOLD Infrastructure for Alzheimer's Act at CDC which is a \$10 million increase over the FY2021 level. In the annual bypass budget, NIH estimates an additional \$321 million is needed for Alzheimer's research in FY2024 to meet key milestones.

Over the last decade these increases have been advocated for by the Alzheimer's Association and the Alzheimer's Impact Movement (AIM) and reflect an eight-fold increase. Billions of dollars are also being spent through other United States funding streams and biotech companies. These funds will allow the NIH to accelerate investment in collaborations that speed discovery, groundbreaking prevention trials and the testing of new therapeutics.

The federal government has become more invested in dementia research and the best treatment and care of both ADRD patients and their caregivers with the passage of the National Alzheimer's Project Act of 2011 (NAPA). The first National Plan to Address Alzheimer's Disease was published in May 2012. The goals of the plan have been to prevent and to effectively treat ADRD by 2025, to enhance care quality and efficiency, to expand support for people with the disease and their families, to enhance public awareness and engagement, to track progress and to drive improvement. The national plan had been updated in 2013 to include new federally supported programs available to States and organizations to foster research and to improve the care of patients and caregivers.

NAPA is set to expire in 2025 but legislation is currently being worked on in Congress (The NAPA Reauthorization Act) to extend the project. When passed, this bill will continue the work of the national plan through 2035. Additionally, the December 2021 update to the plan added a new national goal for the first time. This goal focuses on healthy aging and reducing risk factors for cognitive decline and dementia. In addition to the creation of the National Plan to Address Alzheimer's Disease, NAPA also directed the U.S. Department of Health and Human Services (HHS) to create and convene the Advisory Council on Alzheimer's Research, Care, and Services, which includes a combination of federal agency representatives and non-federal members, to oversee implementation of the national plan. The advisory council released the most recent update in December 2022.

In 2018, the bi-partisan BOLD Infrastructure for Alzheimer's Act (P.L. 115-406) was unanimously passed with the intention of providing a public health infrastructure across the country to implement effective Alzheimer's interventions focused on public health issues, such as increasing early detection and diagnosis, reducing risk and preventing avoidable hospitalizations. The act set up the Related Dementias Public Health Centers of Excellence; provided funding to state, local and tribal public health departments; and increased data analysis and timely reporting. The Bold Act authorized \$100 million over five years to carry out various public health activities addressing Alzheimer's and other dementias.

Over the years, there have been more achievements that have been supported by the national plan and advisory council. These include the HOPE for Alzheimer's Act, the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406), the Younger Onset Alzheimer's Disease Act, the Promoting Alzheimer's Awareness to Prevent Elder Abuse Act (P.L. 116-252) and the Improving HOPE for Alzheimer's Act.

Addressing Disparities in Dementia and Health Equity

As mentioned in the preceding section, disparities exist for both dementia and in many factors that increase the risk for dementia. The Dementia Action Collaborative (DAC) is committed to applying an equity lens in the implementation of this plan and acknowledges that equitable solutions may mean different groups need different things, not a one-size-fits-all approach.

With funding from the legislature requested by the DAC, the Washington state Department of Health (DOH) has begun this work to develop awareness campaign strategies and messages to reach populations at disproportionate risk of dementia, starting with people in Black and African American communities. Over the last several years, DOH contracted with media consulting groups to decide the best ways to convey messages around the value of early detection, diagnosis and planning. This effort included insight interviews with community leaders and subject matter experts and focus groups with individuals and organizations in Black and African American communities. The outcome was a set of recommendations for culturally proper outreach strategies and culturally tailored campaign messages and materials, including a dedicated web page with resources for individuals experiencing memory loss and their care partners, and resources for organizations to share the important materials created from this campaign.

The DAC recognizes that health disparities are driven by systemic racism and will require a strong, continuous and coordinated effort to look critically at the policies, systems, practices and personal biases that continue to give advantage to some communities over others. Promoting equity requires attention to the root causes of health issues and a focus on the communities that are most affected.

Governor Inslee established a Washington state Pro-Equity Anti-Racism (PEAR) plan and framework for all state agencies. The PEAR framework finds priority investment in 15 determinants of equity to achieve outcomes that benefit all tribes, communities and employees of Washington's ecosystem, and calls for investing more of our state's resources "upstream" to address root causes where the needs are greatest to ensure that individuals in underserved communities have their basic needs met long term in Washington's ecosystem. The newly formed Washington State Office of Equity (wa.gov) and the PEAR Plan & Playbook (2022-2027) will guide and monitor the work.

Each state agency involved in DAC is working within their respective purviews to address social determinants of health and equity and will incorporate strategies for both in their work, including implementation of this plan where possible.

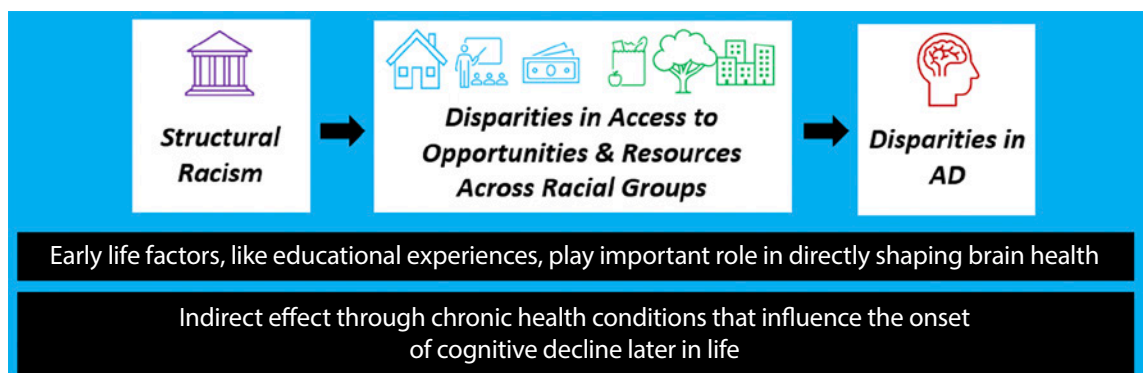


Figure 9. Avila-Rieger, PhD, Columbia University Irving Medical Center, Public presentation 2022.

In developing this plan, DAC members accept that narrowing disparities in dementia will require risk reduction and prevention policies throughout the life course, including efforts that target the root causes of structural racism. While this plan alone cannot address all the root causes of dementia or the entirety of social determinants of health, it does recognize the need for a multi-sector and life course approach. Changes will take time, resources, and ongoing attention of multiple actors.

The state agencies involved, and the DAC are committed, but not limited to, the following strategies:

- Pursue and/or partner in efforts to address structural racism and social determinants of health at all ages
- Pursue and sustain multi-sector initiatives that address health disparities for older adults
- Identify and address potentially modifiable risk factors for dementia and the populations in which these risks are disproportionate
- Increase representation of diverse communities in our work
- Build on government-to-government relationship with tribal partners to understand distinct needs
- Develop partnering opportunities with diverse and tribal communities
- Continually evaluate existing policy to consider what is working and not

Increasing Intersect of Dementia with Public Safety and Law Enforcement

The presence of dementia can raise safety concerns over time. What comes immediately to mind for most people are concerns around driving and wandering. Others concerns include access to items that may be harmful if a person does not understand or remember precautions related to them – items such as medications, toxic substances and firearms. In addition, people living with dementia are known to have more falls, more chronic conditions to be managed and are more vulnerable to harm from others (e.g., exploitation, abuse, and neglect) than people without dementia. Some of these concerns are more easily managed than others and may result in challenges for both family members and first responders. The Dementia Action Collaborative created a Dementia Safety Info-Kit to inform families of resources and information about such concerns.

The changes in memory, thinking and behavior that go with dementia increase the chances of interacting with first responders, such as law enforcement. Regarding wandering, for example, a person living with dementia may become disoriented and lost, even in their own neighborhood or community – either on foot or in a car. The Alzheimer’s Association says that 60% of people living with dementia may wander at some point. Wandering can be dangerous – inclement weather, busy roadways and unfamiliar terrain pose a greater risk to the person who is confused. If not found within 24 hours, up to half of those who wander risk serious injury or death. If a family does not quickly find a person who has left home themselves, they may call law enforcement to help. On the other hand, an officer may encounter a person out walking or driving who appears confused, not knowing the cause of the confusion.

An officer may also come across a person living with dementia who is driving erratically, not obeying street signs or speed limits. Or they may be called to a scene in a business where a person living with dementia has “shoplifted”, when they may have simply forgotten to pay. In these situations, the individual may not even be aware of the problem or infraction that has occurred. When confronted they could become more confused and/or agitated.

It is also not uncommon for paramedic and ambulance services to be called to help people living with dementia. This may be due to health crises such as a heart attack, seizure or a fall or due to a behavior that is putting the individual or family at risk.

During 2022-2023 plan development, the DAC invited the Washington state Department of Health (DOH) Emergency Medical Services (EMS) office, local EMS, State Patrol and local law enforcement to share insights, background, challenges and needs at large and specific to working with persons living with dementia and their care partners.

The EMS system in Washington State is set up to reduce morbidity rate of people throughout the state by getting people to the right facility promptly. There are 482 licensed aid and ambulance services including air and ground in Washington, of those 302 can conduct patient transport, the

others provide first response only. The Washington State DOH EMS program keeps a Geographic Information System (GIS) map that provides the locations of licensed ambulance services and other emergency care system components. The map below shows the EMS service providers, note the blank spaces which in turn increase response time. Many rural communities are dependent upon volunteers and lack adequate funding to support paid staff, and advanced life support level personnel and services. Washington state has 16,993 certified EMS providers; 25% are volunteers.

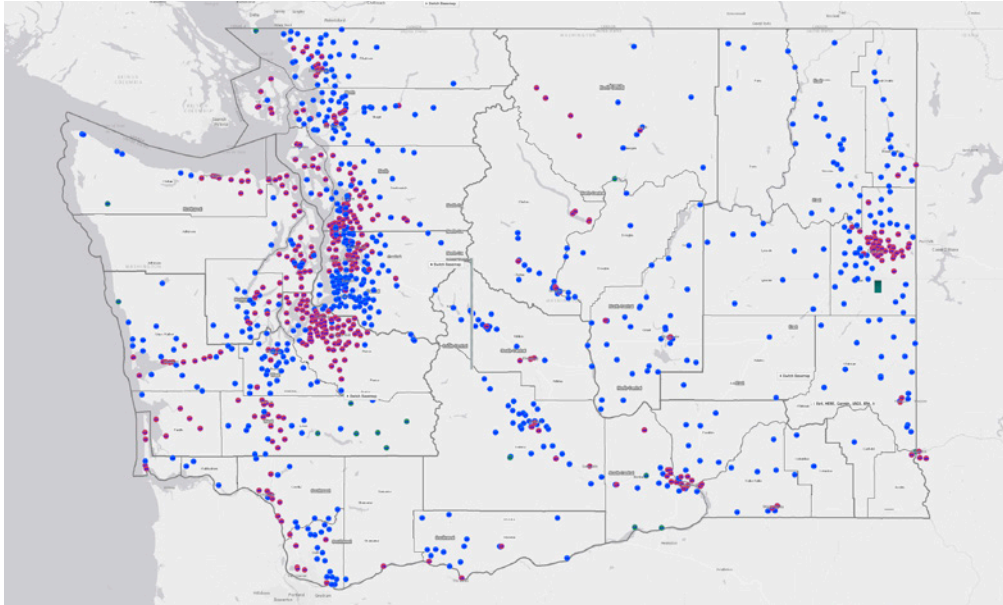


Figure 10. Map of EMS service providers: Blue is basic life support with EMTs; Green is intermediate life support with advanced EMTs; Pink is advance life support with paramedics.

Each dot above is an individual EMS service provider who receives medical oversight and direction from the medical director for their county; the medical director oversees protocols, trainings and policy activities. All the EMS service providers can receive state level support from the DOH EMS office that conducts rulemaking, develops standards for training, equipment and patient care and oversight of the medical directors.

Law enforcement in Washington State is delivered at a variety of levels including state patrol, county sheriff and local police. The Washington State Patrol oversees the Silver Alert program which is an endangered missing person advisory for persons 60 years and older and may apply to persons living with cognitive impairment or dementia. Change to the program in the recent years is beneficial in that now they can alert community members of an endangered missing person, often living with dementia, who left on foot; previously the program was limited to alerts of persons who left by vehicle.

During a DAC meeting, a panel of local law enforcement leadership in three areas of the state shed light on their typical encounters related to dementia, and gaps they felt are needing to be filled. The calls they receive for people living with dementia may involve falls, accusations of mistreatment, wandering and/or behaviors that may 'appear' to be disorderly. Typically, law enforcement officers rely on a historian or family member to fill in the gaps of the situation involving a person living with dementia, but this can become a challenge particularly if the person lives alone and/or they don't know the person is living with dementia. Each call presents its own unique set of uncertainties and challenges.

Other challenges and gaps named by the DAC panel impact both law enforcement and EMS. One of these gaps is the lack of support outside of typical business hours i.e., quick response to help with behavior-related concerns. A hospital emergency department is not intended for or equipped

to help a person living with dementia when they are not having a medical emergency, but often the resources EMS would call for such support with behavioral symptoms are not open beyond regular business hours.

Another challenge is that there is not a quick or reliable way to know – in the moment – if the person who needs to be transported may be living with dementia themselves and/or if they may be a caregiver for a person living with dementia. This event could result in the responders leaving a person living with dementia home alone without needed supervision or supports. An overarching gap is a lack of dementia-specific training and knowledge of local resources available to help this population.

This expert panel shared suggestions and examples for potential programmatic improvements to meet some of these challenges. For example, one of the new Building Dementia Capable Communities pilot sites (in Spokane), has been working in partnership with local emergency response and with the state Department of Health (DOH) Emergency Medical Services (EMS) office to develop a training module to meet identified needs, including: education about dementia, how to communicate effectively with people living with dementia, best practice approaches, patient rights, cultural competency and working with families of persons with dementia. These partners are currently working together to create a curriculum that could be available statewide, with a flexible part to make it adaptable to community-specific needs and resources.

Educate MDs and all medical professionals and first responders to signs and symptoms of dementia and how to appropriately deal with the problems arising.

- Family care partner in Washington

Other examples of responses include models developed in local areas with a variety of partners. For example, in Spokane, Integrated Medical Services developed community assistance response (CARES) teams that include masters social work students who - upon referral from EMS - go out in teams of two to visit people who have had recent or frequent emergency calls. The CARES team assesses the situation and provides information and linkage to community resources/wrap-around services. In addition, their local behavioral response unit has a licensed mental health care worker and paramedic who often meet persons living with dementia and then make referral to a CARES team. While this program does not prevent or fix the root problem, it offers resources and support to individuals and their families to reduce or prevent further problems.

Given the feedback and assessment of what is available, and needed, the DAC will work to find opportunities to develop short term stabilization services that are available all hours of the day; increase dementia specific training to EMS and law enforcement; and work to increase training and educational opportunities for health care providers and family care partners on home and firearm safety.

In the 2023 legislative session, passage of SSB 5440 highlighted the emerging issue that dementia is not only challenging our first responders but also the criminal justice system. This bill acknowledges that there are circumstances where people living with dementia, a developmental or intellectual disability diagnosis, or traumatic brain injury are better served outside of the criminal justice system. Additional services and supports and community capacity will be developed that may intersect with current recommendations in this plan.

Workforce Shortages and Challenges

The increasing prevalence of dementia will increase the need for more members of the workforce who are involved in the diagnosing, treating, and caring for persons living with memory loss or dementia over time – both in the home and in other settings. During the update of the plan, the issue of workforce capacity was raised in many discussions, across multiple sectors. The limited available workforce is present for families when they reach out for home care or respite care, and either can-

not receive such services, or have a delay in receiving them. It is present for residential care facilities who struggle to find and keep long-term care workers. The topic of workforce comes up regarding available health care providers skilled in care for older adults in general, and with dementia care in specific. There is also a clear need to provide more and ongoing training around dementia for both health care and long-term care providers.

For medical care, the tasks of diagnosing and treating dementia typically falls to primary care practitioners. Yet many primary care practitioners report they are not comfortable making a diagnosis of Alzheimer’s or other dementia. As many as half, in a national study, reported they do not feel adequately prepared to care for individuals with dementia. Only a small percentage of primary care providers (less than 10%) specialize in serving older adults, only 1% of nurse practitioners specialize in gerontological care, less than 1% of registered nurses, physician assistants and pharmacists identify themselves as specializing in geriatrics. In Washington state, there are 126 known geriatricians.

The long-term care sector is struggling already in its ability to meet the current needs. The annual turnover rate for all direct care workers is approximately 40%. And the demand for direct care workers such as home health and personal care aids is projected to grow by 27.6% between 2025 and 2030.

To complicate this further, we also know that the availability of an informal caregiving network in Washington state – the family members that often provide the bulk of care for people living with dementia – will decline over time. Figure 11 shows the increasing size of the older adult population (including those living with dementia), alongside the declining number of people who might be available to care for them.

Given the workforce shortage and declining number of people to care for older adults in the future, the DAC will be working alongside statewide efforts and partners collectively to increase the availability of the workforce and to increase their dementia capability.

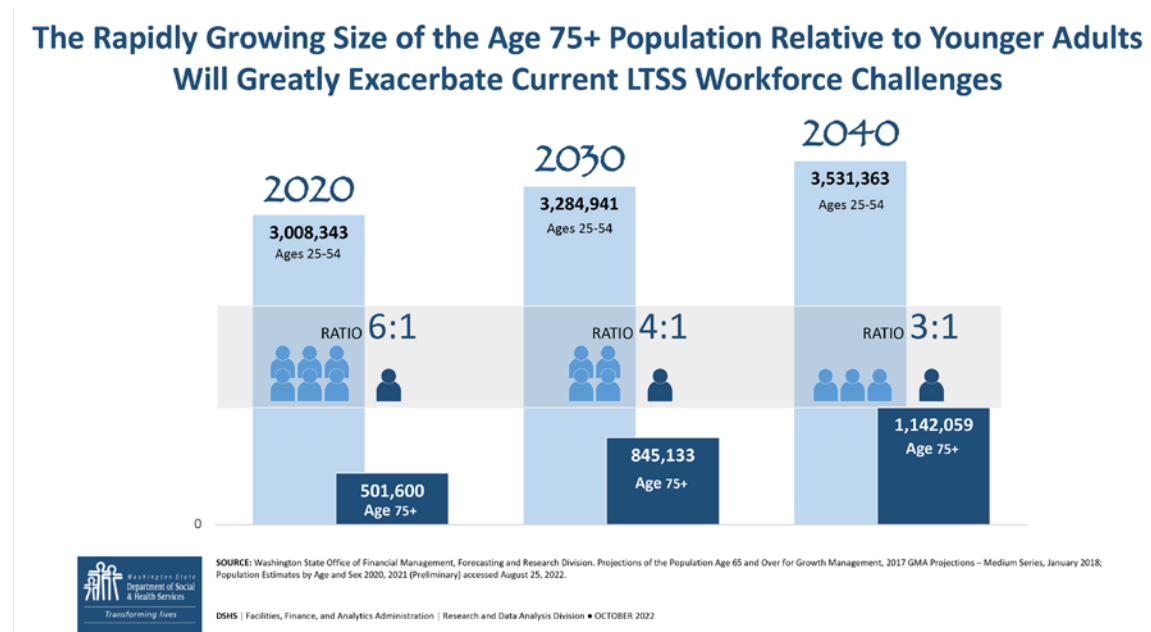


Figure 11. The rapidly growing size of the age 75+ population relative to younger adults will greatly exacerbate current LTSS workforce challenges.



Advances in State Programs to Expand Long-Term Services and Supports for People Living with Dementia



Advances in State Programs to Expand Long-Term Services and Supports (LTSS) for People Living with Dementia

Washington Medicaid Transformation Project

Washington State's Family Caregiver Support Program (FCSP) has proven through its expansion project, the ability to delay an individual's transition to Medicaid long-term care services. When access to FCSP services increased, use of Medicaid long-term care service decreased. This occurred even though more expansion study caregivers were already enrolled in Medicaid medical coverage.³⁵

This finding from the expansion study, allowed Washington to increase funding for family caregivers through a Center for Medicare and Medicaid Services (CMS) Medicaid Transformation Waiver (1115 Waiver) that includes components related to long term services and supports.

This program, called Medicaid Alternative Care/Tailored Services for Older Adults (MAC/TSOA) which began in 2017, has proven successful and has been renewed for continuance as of late June 2023. The MAC/TSOA program offers an added benefit package for individuals who are eligible for Medicaid but are not currently accessing Medicaid-funded LTSS. This benefit package supports unpaid caregivers, avoiding or delaying the need for more intensive Medicaid-funded services; and set up a new eligibility category and benefit package for individuals "at risk" of future Medicaid LTSS use who currently do not meet Medicaid financial eligibility criteria.

WA Cares/Long Term Care Trust Act

In 2019, after five years of in-depth study and analysis, Washington became the first state to pass legislation creating a public long-term care insurance program to address the nationwide crisis: an aging population in which the vast majority lack the financial resources to pay for the care they need as they age.¹

Based on the belief that no one should be forced into poverty before they can get care, this new program will help people living with dementia and their family caregivers. The program will offer a wide array of services that a person might need and is designed to help people age in place - at home, in their own communities, with their loved ones. The benefit is designed to help people age in place - at home, in their own communities, with their loved ones. It can be used to buy things like home modifications, adaptive equipment and technology, home-delivered meals, in-home personal care, training, respite care and support for unpaid family caregivers. If an individual needs greater care and can no longer stay at home, the benefit also may be used to pay for assisted living, adult family home care, and nursing home services.

The program will offer a lifetime benefit of \$36,500 (adjusted annually up to inflation) to people who qualify (are vested). This could provide up to 5 years of respite care, 1 year of part-time in-home care, 8 to 12 months of assisted living care, 6 to 8 months of adult family home care, and 4 to 6 months of care in a skilled nursing facility.

How will this work? Starting July 1, 2023, workers contribute a small amount (0.58%) from wages to the WA Cares Fund while working. And earn a long-term care benefit (up to \$36,500) to use when needed. Everyone working contributes at the same low rate regardless of salary, for as long as they work in the state. Upon retirement or when unemployed, contributions cease. Benefits become available for people who qualify July 1, 2026. Learn more at: [WA Cares Fund](#)

COVID-19 Pandemic Impacts and Responses

The COVID-19 pandemic of recent years created major challenges for all Washingtonians. Older adults, particularly those from historically marginalized communities, had disproportionate impacts from this global pandemic.³⁶ People living with dementia were also found to be at greater risk of

³⁵ Lavelle, Mancuso, Huber, & Felver, 2014

³⁶ <https://doh.wa.gov/sites/default/files/2022-02/COVID-19MorbidityMortalityRaceEthnicityLanguageWAState.pdf>.

COVID-19. The pandemic directly affected individuals living with dementia and their family caregivers both of which experienced not only the health impacts, fear and uncertainty of heightened risk, but also an increased level of social isolation. Family care partners had fewer people to engage with and/or help in the home, and experienced restrictions for visiting loved ones living with dementia in care facilities.

The pandemic worsened workforce shortages for both the health and long-term care workforces. The long-term care workforce, already challenged to meet the increasing demand of a growing population, required state level actions to expand flexibility for training deadlines, certification, and fingerprint-based background checks for providers. This involved an increase in the availability of online training, regular communications with the legislature and stakeholders, providing regular updates to policy guidance, and addressing collective bargaining agreement memorandums of understanding.

Throughout the pandemic, Washington state used existing relationships among state agencies, federal administrations, and aging network partners to respond to the needs of the state's most vulnerable individuals.

The COVID-19 pandemic exposed many challenges in our health, long-term care, and community care systems, but also revealed opportunities and innovations in the use of technology, virtual social engagement and care practices, and the creativity and commitment of care providers and support organizations in their abilities to change and adapt existing care services. It also serves to remind us that planning for emergencies, as related to people living with dementia, is critical for individuals, families, and organizations alike.

Movement Towards Age-Friendly and Dementia-Friendly Efforts

During listening sessions hosted by the Dementia Action Collaborative (DAC), it was clear that many of the challenges for people living with dementia and their families arose out of the need for more "age-friendly" systems and communities in general. Washington state's AL TSA has shown a commitment to supporting older adults to age in their communities and settings of choice.

In collaboration with the Washington State Department of Health (DOH) and the Health Care Authority (HCA), AL TSA has engaged in cross-sector work to explore joining the AARP Network of Age-Friendly states and communities. This designation is approved by the American Association of Retired Persons (AARP), and its framework helps prepare states and communities for the needs related to a growing population of older adults. Currently, four local communities in Washington are participating with this network. Washington, like Massachusetts, if moving forward with a state designation would strive to create both an Age- and Dementia-Friendly state. This exploration aligns with the potential creation of a state Multisector Plan on Aging (MPA). AL TSA, in collaboration with DOH, HCA, the Governor's Office, and AARP is currently taking part in a learning collaborative cohort, convened by the Center for Health Care Strategies (CHCS), of states interested in developing MPAs.

Work of other partners is also moving towards dementia-friendly concepts and communities. Dementia Friendly America (DFA), administered by USAging, is a national network of communities, organizations and individuals seeking to ensure that communities across the U.S are equipped to support people living with dementia and their caregivers. Dementia friendly communities foster the ability of people living with dementia to remain in community and engage and thrive in day to day living. Currently, two local communities in Washington are active in this network.

The University of Washington Memory and Brain Wellness Center, on behalf of the Dementia Action Collaborative, has offered virtual Dementia Friendly Washington conferences in 2020 and 2021 to equip people across the state to take actions to make their communities more dementia friendly. This movement, hindered by the pandemic, is hoping to re-energize this effort with another conference in fall 2023.

Other avenues to promote age- and dementia-friendly communities are available in the broader community in the areas of technology and the built environment. In the DAC Consumer survey, 70% of respondents felt that assistive technology can help people living with dementia and/or their family members. The most useful assistive technologies identified are those that track location if a person were to wander away from home, detect falls or medical emergencies in the home, provide connectivity to family and friends, and remind individuals to take their medications.

Similarly, the built environment is important when considering aging in place. The built environment includes spaces that people interact with during everyday life including the bedroom, kitchen, bathroom, living room, front and back yard, and the community. The literature shows that the built environment contributes to well-being of people, including people living with dementia; it impacts how people socialize, feel, and respond. As an example, visual changes and falls are common in people living with dementia, so ensuring the toilet and grab bars in the bathroom are a different color than the surroundings is an example of a relatively simple environmental change. For new builds or locations considering remodeling, a layout that considers wayfinding assistance through visual cues is another example of built environment changes.³⁷

DAC related efforts related to this movement are outlined in the next section.

³⁷ Features of the social and built environment that contribute to the well-being of people with dementia who live at home: A scoping review - ScienceDirect. Dementia-Friendly Design: A Set of Design Criteria and Design Typologies Supporting Wayfinding - PMC (nih.gov).



Progress from the WA State Plan to Address Alzheimer's Disease and Other Dementias 2016-2022



Progress from the WA State Plan to Address Alzheimer’s Disease and Other Dementias (2016 – 2022)

When the first Washington State Plan to Address Alzheimer’s Disease and other Dementias was published, its enacting legislation expired. Members of the original Alzheimer’s Disease Working Group (ADWG) called for the formation of a next generation workgroup to implement the plan. They committed to moving the work forward and established the Dementia Action Collaborative (DAC). AL TSA agreed to spearhead, convene and support the DAC which included the original appointed members of the ADWG and other participants who shared their time on an in-kind basis to address identified priorities. In addition, the DAC received help from the participation of people living with dementia and family caregivers along with representatives of advocacy groups, the aging network, Alzheimer’s organizations, long-term care providers, health care professionals, legislators and governmental agencies.

With no dedicated funding at the time the plan was published, the DAC Steering Team decided to focus on identifying high-value recommendations that could be accomplished through existing resources and heightened collaboration. The DAC operationalized and prioritized its work into four subcommittees: Public Awareness/Community Readiness, Health and Medical, Long Term Supports and Services and Advocacy. Over the years, even throughout the pandemic, this dedicated group contributed between 1,800 and 1,900 hours of volunteer or in-kind service each year to accomplish recommendations in the plan.

Since 2016, the DAC made significant progress, including the following highlights, which gained funding support from the state legislature:

Dementia Road Map: A Guide for Family and Care Partners – Evolving out of input during the development of the original state plan, this collaboratively developed guide for family and friend care partners is a pivotal tool to increase awareness about “what to expect” over the course of dementia, what resources may be helpful, how to access services and resources. Written in a clear, positive voice, the guide helps readers understand what they CAN do to help and includes Action Steps to take along the dementia journey. While available online, more than 100,000 copies of the booklet have been distributed in Washington state. It has proved useful to families, but also to health care providers, case managers and others to use in educating themselves or others. The Dementia Road Map has been translated (and printed) into Spanish and is currently being translated into Russian. Multiple states have requested permission to adapt it for their own areas. Find the Dementia Road Map and more at: [Dementia Action Collaborative](#).

DAC staff in four state agencies – Designated staff at Aging and Long Term Support Administration (AL TSA), Department of Health (DOH), Developmental Disabilities Administration (DDA), and Health Care Authority (HCA) each heighten awareness of and bring attention to dementia in their respective agencies. The DAC staff work to (1) Integrate goals and objectives related to dementia into their respective agency strategic plans (2) Identify recommendations in the plan which could be implemented in their respective areas through heightened collaboration and existing resources (3) Identify high-value recommendations and related funding requirements for upcoming biennial budgets (4) Coordinate and/or support the work of the DAC in implementing the selected recommendations. Learn more at: [Dementia Action Collaborative](#)

- \$160,000 per year partially supports the DAC staff team positions at four state agencies to support the plan and DAC efforts

When I first came across the Dementia Roadmap I was thrilled! It is so helpful for me to understand what my mom is experiencing and how I can help support her during this time. It’s a great resource and should be advertised on TV and online, social media, etc.

- Family care partner in Washington

Project ECHO Dementia – A learning and telementoring model in which front-line primary health care providers throughout Washington state meet in a virtual conference room with an interdisciplinary panel of experts in memory loss and dementia. Hosted by the University of Washington Memory and Brain Wellness Center, Project ECHO Dementia is offered two times a month and includes a brief 15-minute didactic followed by an hour of case-based learning where everyone is both a teacher and a learner. Learn more at: [Project ECHO Dementia](#).

The UW-MBWC, building off the Project ECHO Dementia platform, also launched the Dementia Friendly Washington Learning Collaborative to inspire, equip and support expansion of dementia-friendly community efforts by sharing with and learning from other individuals and organizations across the state. Learn more at: [Dementia-Friendly Washington Learning Collaborative](#).

- \$226,000 per year supports UW Neurology/Memory and Brain Wellness Center for Project ECHO Dementia

Public Awareness Campaign Messages for Communities – The Department of Health is providing funds to develop digital awareness campaign materials and strategies to support and advance state plan messaging around the importance and value of early detection of cognitive impairment, diagnosis and early planning, including tailored messaging for racial and ethnic groups at increased risk of dementia. Contracted media companies conducted insight interviews and focus groups in Black, African American and Latino communities to determine culturally appropriate outreach strategies, messages and materials. See this work at: doh.wa.gov/memory

- \$150,000 per year supports WA state DOH in public awareness campaign efforts.

Dementia Friends – This global public awareness movement is changing the way people think, act and talk about dementia. Developed by the Alzheimer’s Society in the United Kingdom, Dementia Friends helps communities across the world understand what dementia is and how it affects people. Everyone can make a difference for people touched by dementia. The University of Washington Memory and Brain Wellness Center is the designated lead in Washington state, on behalf of the Dementia Action Collaborative. Dementia Friends Washington partners with organizations that take the lead in their county or tribe. Currently operating in more than 15 counties, Dementia Friends is focused on expanding across Washington state www.dementiafriendswa.uw.edu.

- \$100,000 per year supports UW Neurology/Memory and Brain Wellness Center for Dementia Friends expansion.

Dementia Legal Planning Project - This program promotes early legal and advance care planning by offering free assistance to complete powers of attorney for finances and health care, health care directives, dementia directive forms. Serves people 60 and over and people living with dementia of any age. Provided by the Washington Pro Bono Council, staff will match eligible clients with attorneys who are trained and volunteer to provide this assistance. This project utilizes the DAC developed

[Dementia Legal Planning Toolkit](#) designed to educate, inform and provide the forms to complete legal and advance care planning documents. Learn more at: [Dementia Legal Planning Project](#).

- \$113,000 per year to AL TSA which contracts out to run the program that promotes early legal and advance care planning for dementia.

The cost for care, help, and availability is lacking. I am heartsick at how unprepared we are as our parents’ champions. And when both parents are alive, you have to be wealthy to find an acceptable memory care or assisted living accommodations!

- Family member in Washington

Building Dementia Capable Communities – The Building Dementia Capable Communities program, also known as the Dementia Resource Catalyst program, is designed to: support people living with dementia, including those in early stages, to stay active, socially engaged and in their own homes; support family caregivers so they can stay healthy and continue to help their loved ones with dementia; increase the dementia-capability of Area Agencies on Aging (AAAs), Family Caregiver Support Programs (FCSPs) and aging network partners; and promote efforts to build Dementia Friendly Communities. Currently three AAAs are receiving funds to demonstrate this program.

- \$750,000 per year supports two AAAs to operate Building Dementia Capable Communities programs on an ongoing basis. Another \$375,000 per year will support one more AAA project (currently funded for two years, on one-time basis).

Many more accomplishments have been made over the past six years. To see a more substantial list of progress, go to Appendix D: Highlights of Progress Summary 2022.



Updating the State Plan, 2022-23: The Process



Updating the State Plan, 2022-23: The Process

In 2022, HB 1646 codified the Dementia Action Collaborative (DAC), identified members to be appointed by the Governor, required an update of the plan by October 1, 2023, and annual recommendations each year thereafter through 2028.

DSHS-ALTSA is the convener of the DAC, provides administrative and program management support to the process and continues as co-leader, alongside a member of an Alzheimer's organization. A Steering Team provides oversight and direction to the DAC staff, DAC and the plan update process.

Meetings of the Dementia Action Collaborative

To update the plan, the DAC devoted most of its time together in 2022-23 to this effort – adding additional meetings to its calendar. The DAC alternated meetings of the full DAC membership (meeting 7 times) and its three topic-focused subcommittees (each meeting 4-5 times) to inform and support the activities needed to update the plan. Each full DAC meeting included an educational and/or information sharing component to share around updates and needs in the dementia landscape. For example, over this year alone, topics included but were not limited to:

- Demographic Trends Impacting Need for Long-Term Services and Supports (David Mancuso, PhD; WA-DSHS Research and Data Analysis Division)
- Washington State BRFSS Cognitive Decline Module - Self-Reported Cognitive Decline (Mark Serafin, MA, MS; WA-DOH Department of Health)
- Addressing Disparities in Dementia (Justina Avila-Rieger, PhD; Columbia University)
- Advances in knowledge of dementia (Nancy Isenberg, MD, MPH; Center for Healthy Aging/Neurology Swedish Neuroscience Institute)
- Advances in knowledge of brain health and risk reduction (Lisa McGuire, PhD; National Center for Chronic Disease Prevention and Health Promotion), Centers for Disease Control and Prevention (CDC)
- Life course perspective and risk reduction (Kris Rhoads, PhD; UW Memory and Brain Wellness Center)
- Safety Issues in Dementia: Wandering, Driving, Home Safety (Maggie Christofferson, Alzheimer's Association)

In addition, each full-DAC meeting also included opportunities to refresh the plan's vision, guiding principles and goals, for cross-subcommittee/sector discussion and coordination, to hear input from DAC surveys and listening sessions, to discuss new information and its relevance and for public input.

Steps in the Process

DAC topic-focused subcommittees first performed a detailed review of progress made on the 2016 plan recommendations and considered the recommendations that had not yet been started or completed. Each subcommittee also identified challenges that led to incompleteness and lessons for going forward. The subcommittees also determined which of the not yet initiated recommendations were still relevant and if/how they might be adjusted to make them more possible. A next step was to identify advances that have been made in the areas of brain health, dementia, and dementia care as well as new opportunities in the dementia landscape to build upon since the original plan was published.

Subcommittees also found critical areas in their respective areas of focus that have been emerging as priorities, looked into and discussed specific issues or potential approaches of interest, and formulated, refined and prioritized recommendations.

Public Input

The process invited public participation and comment in several ways to inform the plan update. These activities included:

- An online survey to attain input from people living with dementia and their family care partners (1600+ consumer respondents).
- Six virtual listening sessions with ASL interpretation, including one focusing on tribal communities, and two with Spanish language interpretation (400 registrants, 251 attendees).
- Public comment segments available at each full DAC meeting.
- The draft plan was posted for public comment the month of July 2023.

Need lots more education for communities, churches, etc. - how to respect and help those with Dementia to have dignity, respect, and be patient.

- Family member in Washington

My doctor never believed me when I tried to get diagnosed because I was young. Doctors here need more training in compassion for Younger-onset Alzheimer's and how to treat them. I lost years of my life because their lack of training and no funding to get a better doctor.

- Washingtonian living with dementia

Unfortunately, when a loved one is diagnosed there is no direction of where to go next. You stumble around trying to find all the resources you can to help them and hope it doesn't get significantly worse before you can get them they help they need. Most family and friends trying to help are completely lost and leave the doctor with no real direction of what to do next.

- Family caregiver in Washington

Increase rates for facilities caring for Medicaid residents. Many are declining Medicaid [clients] due to reimbursement not covering actual cost of care. In-home 24-hour care is not usually affordable and providing 24-hour care for someone with dementia is overwhelming.

- Family care partner in Washington state



Washington State's Seven Goals



Washington State's Seven Goals

The Dementia Action Collaborative refreshed the seven goals identified in the first Plan. Each goal has several strategies that support work toward that goal. Each strategy has multiple recommendations or action steps.

1. Increase public awareness, engagement and education
2. Prepare communities for significant growth in the population living with dementia
3. Promote well-being and safety of people living with dementia and their family caregivers and care partners
4. Promote equitable access to comprehensive, culturally relevant support for family caregivers and care partners
5. Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia
6. Increase equitable access to culturally relevant, dementia-capable long-term services and supports
7. Facilitate innovation and research related to risk reduction, causes of and effective interventions for cognitive decline and dementia

The DAC uses a three-level approach to defining the recommendations. The goals are broad visionary statements. Underneath the goals, there are multiple strategies, or high-level tactics to achieve the goals. Each strategy has one or more recommendations (action steps).

The broad and complex nature of this plan and the need to collaborate among many partners, will require a phased approach to implementation. The DAC has identified suggested timeframes to initiate work for each recommendation. Short-term would be within 1-2 years, mid-term within 3-4 years, and long-term in 5 years or beyond. The identified time limits are estimates. It is possible that there may be instances where some work may need to be deferred depending upon the availability of staff and budget resources. Conversely, work might start earlier on some recommendations if opportunities present.

The Goals, Strategies and Recommendations are shown below. The columns on the right show suggested time limits to begin work on each recommendation.

Goal 1: Increase public awareness, engagement and education.

Almost everyone is affected in some way by Alzheimer's and other dementias, but many are unaware of where to go or what to do to get a diagnosis, obtain services and support or what help is available to a person with dementia and their family. Information about dementia, including Alzheimer's is sometimes difficult to find, and no comprehensive single source of information exists for Washington residents. The Dementia Action Collaborative (DAC) has been creating resources and a centralized website www.Memorylossinfo.org to help with these challenges. The goal as we move forward is to increase awareness about this site and continue to improve upon it. During the DAC consumer survey, respondents reported the top three best places or ways to raise public awareness are through health care providers, aging services or senior centers and social media. This feedback will be woven into the ongoing outreach and public awareness campaigns.

There continues to be a stigma with a diagnosis of dementia. This, along with a belief that nothing can be done to cure it, may lead people to delay obtaining a diagnosis. In fact, data from the 2020 Washington State Behavioral Risk Factor Surveillance System (BRFSS) Cognitive Decline Module, show that only 49% of respondents, who said they experienced worsening memory loss, had discussed this with a physician.

Delaying a diagnosis, though, means missing opportunities to improve how the condition is treated and experienced. There are steps that individuals, professionals and organizations can take at any

point to help people living with memory loss or dementia. It is important to offer hope and resources early on to help people plan for their future and live their best lives with dementia. This may include the opportunities to have a medical evaluation around the reasons for memory and thinking changes and how they are best addressed, to consider and document legal, financial and care plans and preferences and to learn about community and educational activities for those living with dementia and support services for their care partners. Since 2016, the DAC has engaged in several initiatives to increase public awareness around the value of an early and correct diagnosis, especially in communities that experience health inequities including a higher prevalence of dementia.

People hear the “D” word and expect me to be incoherent. Raise awareness about early memory loss and the fact that people with dementia can have a different, but still enjoyable and productive life.

- Washingtonian living with dementia

Initiatives to build dementia friendly communities are underway, through Dementia Friends, the Dementia-Friendly Washington Learning Collaborative, Memory Hub at the University of Washington, conferences focusing on Creating a Dementia-Friendly Washington and other community-based events such as Memory or Alzheimer’s Cafés. These efforts can change the experience of those living with dementia. While this work is underway, there is much more to do to confront stigma and create a sense of hope and empowerment for people living with dementia.

Building on exciting developments on brain health and risk reduction for dementia throughout the life course, the DAC will continue to focus on creating public awareness about brain health, including promoting education curricula to be embedded into K-12 health, university and residency programs. This will provide an opportunity for younger people to learn about the potential to protect their own brain health, while also providing knowledge to the future health workforce.

The work of informing and educating the public about dementia is ongoing as there will always be individuals and families that are newly diagnosed, as well as the development of new and improved resources and information, based on the newest research, policies and funding. It also cannot be done by any one organization – it will take all of us working together to continually confront stigma and increase awareness around dementia and our many resources and services that are available to help.

Goal 1: Increase public awareness, engagement, and education

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Increase awareness of existing services and resources.	1. Develop a communication plan and strategy to sustain an up-to-date compilation of Dementia Action Collaborative (DAC) resources and information.	☒		
	2. Sustain, improve and promote www.Memory-lossinfowa.org as source of information for the public by connecting with organizations and requesting they share the link.	☒		
	3. Develop mechanisms to make outreach presentations to community organizations and the public about DAC strategies and resources, including use of alternative methods, such as brief videos.		☒	
	4. Develop and share alternative methods to inform the public about DAC resources, such as brief videos.		☒	

Goal 1: Increase public awareness, engagement, and education

Strategy	Recommendations (needed policies or responses)	Short	Mid	Long
A: Increase awareness of existing services and resources.	5. Collaborate with existing providers of information, resources and crisis phone lines (e.g., 211, 988) within the state of WA to increase knowledge of DAC and other dementia-related resources and services.		☒	
	B: Confront stigma against, and create a sense of hope and empowerment for, people living with dementia.	1. Identify, compile and share recommended resources that offer ways to communicate with and about people living with dementia in a culturally competent, respectful, hopeful and positive manner.		☒
C: Increase awareness about the early warning signs of dementia and the value of timely diagnosis of dementia.	2. Increase awareness of models of stigma-free, dementia-friendly communities, places and events (e.g., Alzheimer’s Cafes) to combat stigma and increase societal acceptance and integration.	☒		
	3. Increase awareness of dementia and available resources by engaging public and private ‘champions’ including faith, business community leaders, educators and health professionals to deliver the Dementia Friends public awareness program. Expand the reach of campaigns by identifying and engaging partners that reach and serve diverse communities and partners that are not a part of the traditional service system.	☒		
	1. Increase and broaden the current DAC public awareness campaign work to increase information and education around the value of timely diagnosis, particularly in communities at elevated risk of dementia.	☒		
	2. Identify and advocate for funding to Community and Faith-Based Organizations to act as trusted messengers in their communities to build partnerships and promote and share the DAC public awareness campaign highlighting the importance of early detection, diagnosis and planning.			☒
	3. Educate the public and provide information and resources about issues specific to persons with younger-onset dementia and their families.			☒
4. Invite and engage with tribes to learn insights and input, along with gaps and needs, related to cognitive health and dementia education.	☒			
5. Utilize learning and insights from tribal engagement to develop relevant plans to address cognitive health and dementia needs.			☒	

Goal 1: Increase public awareness, engagement, and education

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
D: Promote legal, financial and advance care planning before the onset, or in the early stages, of dementia to avoid costly or unnecessary court proceedings and/or guardianships.	1. Review and update legal planning tools and resources as needed to respond to evolving needs and changes in the legal environment.	☒		
	2. Increase awareness about the Dementia Legal Planning Toolkit and the Dementia Legal Planning Program to educate the public and health care providers about the need for legal and advance care planning, with particular efforts to target underserved communities and those at elevated risk of dementia.	☒		
	3. Identify priority populations, process and funding for translation and dissemination of the Dementia Legal Planning Toolkit. This will involve partnering with representatives from priority populations to understand the needs and gaps pertaining to dementia legal and financial planning and updating and translating the legal planning toolkit.	☒		
	4. Increase awareness within the legal profession about dementia, the Dementia Legal Planning Toolkit and resources for clients living with dementia.	☒		

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
E: Increase public awareness about brain health and risk reduction for dementia throughout the life course.	1. Identify credible educational materials designed to increase awareness of the importance of brain health, modifiable risk factors and the connection between heart health and brain health, including materials for diverse cultures.	☒		
	2. Integrate the best available evidence about brain health and modifiable risk factors for dementia into existing state, local and tribal public health communications that promote health and chronic disease management for people across the life course.		☒	
	3. Identify culturally sensitive materials designed to increase awareness of the importance of brain health, modifiable risk factors and the connection between heart health and brain health, for tribal communities.	☒		
	4. Partner with state agency programs and statewide health associations that focus on chronic diseases contributing to dementia risk to share and coordinate on brain health communications (e.g., American Heart Association-Washington, Washington State Diabetes Network).	☒		

Goal 1: Increase public awareness, engagement, and education

Strategy	Recommendations (needed policies or responses)	Short	Mid	Long
E: Increase public awareness about brain health and risk reduction for dementia throughout the life course.	5. Explore strategies with community partners to support increased access for at-risk populations to participate in actions that reduce modifiable risk factors.		☒	
	6. Explore, find and encourage adoption of risk reduction education curricula to be embedded into K-12 health, university level curricula and residency programs.			☒

Goal 2: Prepare communities for significant growth in the population living with dementia.

Given the estimated increase in people living with dementia, more than doubling between 2020 and 2040, existing services and facilities are not prepared to keep up with the projected growth, and consequently, more responsibility will be placed on individuals, families and local communities.

The state's public health system can play a key role in helping ensure communities are ready for the projected growth in the number of people affected by dementia. For example, a core element of public health is surveillance, or data collection. Good data drives resource development, asset allocation and provides the information required to target population needs in a way that anecdotal stories or individual advocacy efforts do not.

Other significant opportunities for public health, on the state, local and tribal levels, to address the needs of individuals at risk of or diagnosed with dementia, their families and care partners exist in the potential to reduce risks related to dementia. The Centers for Disease Control and Prevention (CDC) developed the Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: *The 2023-2027 Road Map*, the *Road Map for Indian County*, and the U.S. Department of Health and Human Services', *Healthy People 2030*, identify multiple strategies and activities for public health to be engaged in.

Public health strives to achieve lasting change in the health of populations, beyond the treatment of individuals. While there is no cure for dementia, several of the potentially modifiable risk factors mentioned earlier in this report, are also connected to overall health, including heart health and may be affected by individual lifestyle and community actions that promote overall healthy aging. This may include efforts over the life-course to reduce falls and brain injuries, promote physical activity, heart- and brain-healthy nutrition, social engagement and by finding and managing chronic conditions. Many of these risk factors are addressed by public health, such as hypertension, a lack of physical activity, obesity, diabetes, depression, smoking, hearing loss, excessive binge drinking and air pollution.

Dementia-friendly communities are critical to helping people stay home and out of facilities. Dementia Friendly America is a wonderful initiative that I'd like to see further implemented throughout the state.

- Family care partner in Washington

The multiple and diverse actions needed, though, to promote healthy aging, cannot be implemented by any one organization or the public health sector alone – they demand that individuals and organizations across multiple sectors work together to create communities that embrace and support individuals as they age.

To address stigma and provide opportunities for meaningful and positive community involvement, the DAC seeks to involve public and private partners in planning efforts and to infuse Age-Friendly and Dementia-Friendly concepts into local communities so that existing resources can reach farther and people living with dementia and their families have the information and support they need.

Goal 2: Prepare communities for significant growth in the population living with dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Attain, analyze, and use available data to inform dementia-related efforts.	1. Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline and the BRFSS optional module for Care-giving, every three years to monitor change and measure impacts over time.	☒	☒	
	2. Leverage existing data sources including: BRFSS, Medicare, Medicaid, All Payers Claims Database, Health Systems (Electronic Health Records) and Washington Health Alliance to understand the human and economic impact of dementia on individuals and family caregivers and to inform public health policies, interventions and development of other chronic disease plans.	☒		
B: Include Alzheimer’s, dementia and healthy aging in state and local government plans.	1. Develop and use communication tools to share dementia-related statistics (e.g., dementia prevalence and projections, dementia caregiving, care costs) with state agencies, health and aging network partners.	☒		
	2. Integrate goals and objectives related to cognitive impairment, memory loss and dementia, including the impact on unpaid care partners, into local and state governmental agencies’ strategic plans. Such plans include state and area plans on aging, fall prevention and the Washington State Health Improvement Plan (SHIP).		☒	
	3. Support ongoing activities at DOH, such as injury/falls prevention, emergency preparedness and chronic disease prevention to incorporate needs specific to persons living with dementia.	☒		
	4. Work with state agency and aging partners and stakeholders to pursue a Multisector Plan for Aging.	☒		
C: Infuse Age-Friendly and Dementia-Friendly concepts into local communities.	1. Disseminate existing tools and resources that share dementia-friendly approaches and programs, including the national Dementia Friendly America initiative.	☒		

Goal 2: Prepare communities for significant growth in the population living with dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
C: Infuse Age-Friendly and Dementia-Friendly concepts into local communities.	2. Collaborate with aging partners and stakeholders to engage with the AARP Network of Age-Friendly States and Communities initiative while integrating dementia-friendly community principles and strategies into the process.	☒		
	3. Encourage and support state agencies, aging partners and community-based organizations to become familiar with and work towards incorporating the Reframing Aging and other age friendly communication practices.		☒	

Goal 3: Promote well-being and safety of people living with dementia and their family caregivers and care partners.

While the extent of elder abuse is unknown, the National Center on Elder Abuse cited an article from 2016 that said “Older people with dementia are particularly susceptible to abuse. Nearly one in two older adults with cognitive impairment experiences abuse. In addition to being dependent upon others for help, elders with dementia are more likely to experience deficits in memory, communication, and judgment that make it harder for them to identify, prevent, and report mistreatment.”³⁸ People living with dementia are also more susceptible to financial exploitation by family members and friends, paid providers, legal guardians and other fiduciaries. Additionally, strangers may seek out vulnerable adults through elaborate mail, telephone and internet scams.

People living with dementia and their families, though, may at times be rather isolated. This makes it essential to educate people who work in the community and may come in contact with people living with memory loss or dementia (e.g., mail carriers, utility workers, librarians, bank personnel, clergy, staff at programs such as meals on wheels and others) to recognize signs of abuse, neglect, self-neglect or exploitation and make referrals to appropriate sources of assistance.

There are many well-being and safety challenges for individuals diagnosed with dementia, their families and care partners, as well as community providers, such as law enforcement, Emergency Medical Services and others. In the DAC consumer survey, a number of family care partners shared specific concerns about driving and the lack of assessment resources available to assist individuals and families with this decision.

Developing age-friendly and dementia-friendly communities is one of the most important issues to be addressed. This includes personal safety.

- Washington state survey respondent

It is important to address safety concerns of individuals living with dementia. At the same time, it is also critical to honor and respect each person’s strengths and independence. As dementia impacts each person differently and changes over time, the DAC is hoping to help individuals and family care partners, as they strive to balance safety and independence, by increasing access to information, resources and support with these challenges.

³⁸ NCEA - Research Statistics and Data (acl.gov).

Goal 3: Promote well-being and safety of people living with dementia and their family caregivers/care partners

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Increase awareness about how to prevent, recognize and respond to neglect, abuse and exploitation of people with memory loss and dementia.	1. Decide with partners how to communicate and share information around the potential for abuse, neglect and exploitation of people with dementia, how to recognize signs of abuse, ways to support both family and professional caregivers and communities to prevent and report such abuses.		☒	
	2. Explore and evaluate feasibility for implementation and dissemination of existing models or potential programs that educate people who work in the community and may come in contact with people living with memory loss or dementia (e.g., mail carriers, utility workers, librarians, bank personnel, clergy, staff at programs such as meals on wheels) to recognize signs of abuse, neglect, self-neglect or exploitation and make referrals to appropriate sources of assistance.		☒	
	3. Promote and disseminate training for first responders about dementia, to include information on red flags of neglect, abuse and exploitation and appropriate sources of assistance.			☒
B: Promote safety and the quick return of people living with dementia who may wander.	1. Update and disseminate the Dementia Safety Info on-line toolkit and create a hard copy version that includes awareness of programs to protect people who may wander e.g., Silver Alert, Project Lifesaver and assistive technology that helps promote safety.		☒	
	2. Increase awareness of programs designed to identify and locate people with dementia who may wander, such as MedicAlert (Safe Return), Silver Alert and Project Lifesaver.		☒	
	3. Promote and disseminate training for first responders about dementia. Information may address recognizing signs and symptoms, communication skills, understanding behaviors including wandering and community resources available. (Connects with 3A3).			☒

Goal 3: Promote well-being and safety of people living with dementia and their family caregivers/care partners

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
B: Promote safety and the quick return of people living with dementia who may wander.	4. Identify, pilot and/or replicate models of community partnerships between first responders and aging services to help individuals living with dementia and/or their family caregivers to get the care and support they need.		☒	
C: Provide informational materials to help navigate questions and precautions around driving for people living with dementia.	1. Update the Dementia Safety Info Kit to enhance possible driving precautions and disseminate.	☒		
	2. Conduct an environmental scan of safe driver assessment programs in Washington state.		☒	
	3. Promote awareness of existing safe driver assessment programs and professionals that complete safe driver assessments.			☒

Goal 4: Promote equitable access to comprehensive and culturally relevant support for family caregivers and care partners.

Family caregivers are the backbone of long-term care services. They provide the most care for people living with dementia. In this plan, family caregivers are defined broadly as unpaid caregivers who have a close familial or personal relationship to the person living with dementia. They include spouses, domestic partners, friends and neighbors, children, extended family – anyone with a caring connection to the person and uncompensated responsibility for providing care.

Given the expected increases in the state’s dementia population, the workforce challenges we face and the population shifts coming that will decrease the number of family available to care for their older relatives, we must provide comprehensive supports for family caregivers.

While each caregiving situation is different, there are some commonalities. First and foremost, caregivers want to know what to expect in their journey of caring for a person living with dementia. They need to know what is “out there” to help them and how to find such help. Most caregivers need a periodic break to do their grocery shopping, attend to their own health and well-being or even to get a full night of sleep. They also want to have someone to turn to when they need information, advice, or emotional support.

Provide better in home service or allow more hours, for those that are still in their own home. Family who work cannot always be available to care for their loved ones adequately and keep their jobs, nor can they usually afford the extra cost for the extra care.

- Family caregiver in Washington

The [Dementia Road Map: A Guide for Family and Care Partners](#), developed as an outcome of the original state plan offers basic information and has been widely distributed throughout Washington state. It is currently available in English, Spanish and (soon) in Russian. The DAC plans to continue its dissemination and pursue translated versions to reach diverse communities.

In the DAC survey, consumer respondents felt that providing education and support for family care partners is currently one of the top four critical needs in our state (40% of respondents considered it one of the top three most critical issues). Family care partner comments reveal their concerns about

the costs of care, that long-term care is too expensive and/or that Medicaid and Medicare do not cover enough of the costs. They convey the desire for more practical and emotional support and an increase of in-home or residential services, particularly in rural areas.

A majority of respondents also felt that assistive technologies could be a useful resource for helping people living with dementia, or family caregivers, with top three areas of interest in technologies being: to detect falls or medical emergencies in the home, and to track location for individuals who may wander (62% of respondents for each), and to stay connected with family and friends (48% of respondents).

The cost for care, help, and availability is lacking. I am heartsick at how unprepared we are as our parents' champions. And when both parents are alive, you have to be wealthy to find an acceptable memory care or assisted living accommodations!

- Family member in Washington

Washington State's Family Caregiver Support Program (FCSP) has demonstrated the ability to delay an individual's transition to Medicaid long-term care services during an expansion of family caregiver services. When access to FCSP services increased, use of more costly Medicaid decreased. This occurred even though more expansion study caregivers were already enrolled in Medicaid medical coverage.³⁹

This evaluative finding allowed Washington to expand funding for family caregivers through a Center for Medicare and Medicaid Services (CMS) Medicaid Transformation Waiver, which includes the Medicaid Alternative/Tailored Services for Older Adults (MAC/TSOA) programs mentioned earlier in this report.

A consistent message heard about Washington's many programs and services, including the Family Caregiver Support Program, is that they are not widely known. Many family caregivers or care partners do not identify themselves in the caregiver role or are not aware that services and supports are available for them. Many of the strategies and recommendations included here are aimed to inform, educate and reach out in a variety of ways to do just that.

Goal 4: Promote equitable access to comprehensive, culturally relevant support for family caregivers and care partners

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Promote the awareness of, and guidance and education around, existing supports, services, and resources for family and other informal care partners.	1. Sustain, update and disseminate the <i>Dementia Road Map: A Guide for Family and Care Partners</i> that helps family members know what to expect over time and plan for the future, as well as possible action steps along the way.	☒		
	2. Identify and pursue needed language and cultural translations of the <i>Dementia Road Map: A Guide for Family and Care Partners</i> .	☒		

³⁹ Lavelle, Mancuso, Huber, & Felver, 2014.

Goal 4: Promote equitable access to comprehensive, culturally relevant support for family caregivers and care partners

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Promote the awareness of, and guidance and education around, existing supports, services, and resources for family and other informal care partners.	3. Create and determine best ways to disseminate, a user-friendly document that outlines the continuum of community-based and residential long-term care services in Washington state including respite care and other family caregiver supports, how to access them, financial assistance available and eligibility requirements.	☒		
	4. Collaborate to inform and sustain up-to-date content on the Memorylossinfo.org webpage to include supports for dementia family caregivers and care partners e.g., links to find Alzheimer’s/ Memory Cafes, early-stage and Dementia Friendly activities and links to Adult Family Home (AFH)/ Assisted Living Facility (ALF) locators.			☒
B: Increase availability of and access to education, support groups and support services.	1. Increase awareness, availability and use of evidence-based programs for people with dementia and their family caregivers, such as STAR-C, Dealing with Dementia, REACH, Savvy Caregiver, Staying Connected (early stage), Powerful Tools for Caregivers and supportive services such as behavior consultation.	☒		
	2. Increase awareness, availability, and use of online and web-based education on understanding and responding to behavioral symptoms of dementia, with focused outreach efforts for rural or hard-to-reach areas.	☒		
	3. Increase availability and awareness of in-person and online support groups for family caregivers, to increase accessibility in rural or hard to reach areas and for those with currently limited options such as the deaf/hard-of-hearing or limited-English speaking communities.			☒
C: Increase access to respite care options for family caregivers.	1. Create an informational tool that explains the concept of respite and resources for building natural support networks and care teams to support the person with dementia and the family caregiver.			☒
	2. Advocate for increased state funding for respite care to allow more average Family Caregiver Support Program (FCSP) benefit hours per month.		☒	
	3. Explore use of Volunteer Services for non-personal care respite/socialization.		☒	

Goal 4: Promote equitable access to comprehensive, culturally relevant support for family caregivers and care partners

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
D: Reach family members early in the disease process through early support and dementia-friendly social engagement options.	1. Advocate to increase the availability of education, support and social engagement opportunities that include family care partners of people living with early-stage dementia by expanding the Building Dementia Capable Communities (aka Dementia Resource Catalyst pilot) statewide.	☒		
	2. Seek funding (private, federal, or state) and partnerships to support innovations in demonstrating local, collaborative models of early-stage and dementia-friendly recreational programming.		☒	
E: Increase the number of culturally and linguistically diverse family caregivers who participate in education and support programs.	1. Identify leaders and trusted messengers in communities at elevated risk of dementia (e.g., indigenous populations, Black/African American, LGBTQ+) to discuss dementia caregiving along with community-specific strengths, needs and approaches for education and support.	☒		
	2. Develop partnerships with leaders and trusted messengers and/or organizations to collaborate on the identification, development and/or delivery of culturally sensitive support opportunities for dementia family caregivers.	☒		
	3. Collaborate with community partners to identify champions from diverse community aging networks (and health partners) to assist in sharing materials and messages to increase awareness about dementia and family caregiver support services.			☒
F: Build on government-to-government relationship with Washington tribal partners to understand the distinctive needs of American Indian/ Alaska Native family caregivers of persons living with dementia.	1. Collaborate with AL TSA Tribal Affairs, Tribal Liaisons, Office of Indian Policy, and other trusted leaders and organizations that work with tribal partners to identify existing resources or new approaches for education and support of dementia family caregivers that responds to community-specific strengths and needs.	☒		
	2. Develop partnerships with trusted leaders and/or organizations to collaboratively develop or disseminate culturally appropriate education and support opportunities for dementia family caregivers.		☒	
G: Develop supports for family caregivers who are employed.	1. Adapt the Caregivers in the Workplace toolkit that includes information to raise awareness about family caregiving, caregivers in the workforce, policies to support and other resources to inform employers and support working caregivers in WA state.		☒	

Goal 4: Promote equitable access to comprehensive, culturally relevant support for family caregivers and care partners

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
G: Develop supports for family caregivers who are employed.	2. Identify contacts and initiate discussions, using the toolkit (developed above), with businesses and/or related associations, around approaches and policies to better support employed family caregivers.			☒
	3. Enhance information and education for Employee Assistance Programs (EAPs) to make them aware of needs around dementia and dementia caregiving, and ways EAPs may be able to better support their employees who are also family caregivers.			☒
H: Develop supports for family care partners of people living with dementia who are younger than 65 years old, which may include persons with developmental disabilities and young-onset Alzheimer’s or other dementias.	1. Educate professionals, i.e., case managers, health care providers, first responders, about working with families of people with Intellectual or developmental disability (IDD) and dementia including the special challenges, issues and resources available for support.	☒		
	2. Provide education for family care partners who provide primary care for their adult children or siblings with developmental disabilities and dementia, to include information about healthy lifestyle choices, resources and supports.		☒	
	3. Assess, and compile for sharing, what education and support opportunities are currently available for family care partners of people living with younger-onset Alzheimer’s and other dementias e.g., frontotemporal dementias, dementia related to traumatic brain injury.			☒

Goal 5: Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia.

In late 2021, the National Plan to Address Alzheimer’s Disease added a sixth goal: *Accelerate Action to Promote Healthy Aging and Reduce Risk Factors for Alzheimer’s Disease and Related Dementias*. This new national goal not only includes a new research priority, but also a call to action for the health care workforce to learn about and apply risk reduction efforts to their practices. The 2020 Lancet Commission identifies 12 potentially modifiable risk factors that might prevent or delay up to 40% of dementias. Most of the 12 risk factors can be addressed in a variety of ways, including during visits with primary care providers. While goal 1 of this plan will address the public awareness of the risk factors that are modifiable, goal 5 is now expanding to include risk reduction as a strategy and set of recommendations. This will align the Washington state plan with the National Plan to Address Alzheimer’s Disease, but

Primary and other health care providers need to be more attuned to looking for dementia and listen to family members concerns as often the patient puts up a “good front” with the provider and therefore if family members are not listened to, don’t diagnose or mis-diagnose dementia.

- Family caregiver in Washington

also fulfills the public opinion from the Dementia Action Collaborative Survey to Understand the Needs of People Living with Dementia and Their Caregivers/Care Partners. Question four in the survey asked: *In your opinion which of the following would be the BEST places or ways to raise public awareness about dementia in your community?* The top response given by 65% of respondents was health care professionals followed by aging services and senior centers.

There are many benefits to early detection and diagnosis of dementia. Of primary importance is that it allows for some forms of cognitive impairment to be found and reversed. While there's still no way to cure dementia or Alzheimer's disease, an early formal diagnosis offers opportunities for better outcomes.

Early detection and diagnosis offer individuals and their families a "reason" or way to understand the changes that have been occurring, which is often a relief. It also allows families time to adapt to changes, to get legal and financial affairs in order, to take part in research and gives an opportunity to engage in advance care planning. Early detection offers health care providers key information to reduce poor health outcomes and prevent emergencies for both the individual and their family caregivers.

Although there are many benefits to early detection, estimates show that fewer than half of the people who meet diagnostic criteria for dementia have received that diagnosis from a physician.^{1,1}

One issue found from the DAC survey and the public listening sessions was how difficult it was to obtain a diagnosis for many people facing possible dementia. In the written survey, 50% of participants said they had a somewhat difficult or very difficult time getting a medical assessment/diagnosis for themselves or family member from a local health provider. Compared to 40% of participants who said they had a very easy or somewhat easy time getting a medical assessment/diagnosis. A similar story was heard during the listening sessions; for most, it took multiple visits with physicians and specialists over many months to arrive at a possible diagnosis. Both diagnosis and care quality varied widely depending upon the person's provider and location. Rural residents found it especially difficult to access specialists. Furthermore, there was wide variability in referrals to local services and support after diagnosis.

Compared to individuals without dementia, people living with dementia have as many or more serious co-occurring conditions, take more medication and are more likely to be hospitalized than individuals of the same age without dementia. Individuals living with dementia may also be less able to manage their medical and/or behavioral conditions – which contributes to a decline in the individuals' abilities to carry out daily activities. In addition, the high prevalence of hearing loss in older adults may complicate identification and or treatment as cognitive testing and follow up often relies heavily on a person's ability to hear and respond to questions and instructions.

"Dementia-capable" health care systems are those "that provide individualized, coordinated, and integrated medical and psychosocial care for patients and their care partners, delivered by cohesive teams of clinicians, staff, and health care administrators."¹

To improve care quality and prepare for the future growth of this population in our systems, it is critical to integrate evidenced based dementia care models to detect cognitive impairment, make and disclose timely diagnosis, coordinate care for wellness and to manage co-occurring conditions, provide early and ongoing education and support of family caregivers, and address the need for advance planning while cognitive capacity exists. Potential for improvement might be found in expanding the reach of Project ECHO dementia and Cognition in Primary Care educational opportunities for providers and health systems.

Goal 5: Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Promote risk reduction and prevention of dementia.	1. Identify and promote strategies to maintain and improve brain health for all ages, genders and across diverse populations by educating and promoting brain health and dementia risk reduction across health disciplines including dental, audiology, optometry, primary care, cardiology, behavioral health disciplines, etc.	☒		
	2. Identify, adapt or develop tools and resources for primary care providers and allied health professionals to promote healthy brains for patients of all ages before and after symptoms of cognitive impairment present.	☒		
	3. Increase community health worker capacity to promote brain health messages and to support brain health interventions.		☒	
	4. Explore opportunities to promote wellness for Medicaid-eligible adults, such as, but not limited to, annual wellness visits and/or an adult wellness checklist.		☒	
B: Promote early detection, diagnosis and treatment.	1. Establish baseline assessment recommendations across primary care.	☒		
	2. Partner with allied health fields such as optometry, dental, audiology, etc. to establish baseline assessment recommendations and referral pathways.		☒	
	3. Identify and disseminate culturally appropriate education tools on how to conduct cognitive assessment during Medicare Annual Wellness Visit, billing options and conversation prompts.		☒	
	4. Identify and disseminate culturally appropriate assessment tools, including diagnosis pathway tools and guidance and a checklist of reversible causes.	☒		
C: Identify and disseminate evidence-based dementia care models and practices that are available throughout the state.	1. Identify and select a comprehensive dementia-care model that includes dementia as the organizing principle while also containing a minimum set of core elements for comprehensive care along the care continuum and that follows a population-health approach that tiers services to level of need.		☒	

Goal 5: Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
C: Identify and disseminate evidence-based dementia care models and practices that are available throughout the state.	2. Sustain and expand local partnerships to foster relationships between health care and community organizations that provide ongoing support for persons living with dementia. Such partnerships will facilitate increased knowledge around and referrals to community services and resources, electronic health record improvements specific to dementia and a dementia-capable provider network.	☒		
	3. Expand the reach of the Cognition in Primary Care program to facilitate the detection of cognitive impairment and improve care for people living with dementia.	☒		
	4. Partner with Northwest Geriatric Workforce Enhancement Center to align dementia education opportunities for providers throughout Washington state.	☒		
	5. Create and offer annual training for care coordinators with FQHCs and insurance companies to provide up to date information on community supports and evidence-based practice modifications.	☒		
	6. Increase awareness of the benefits of palliative and hospice care options throughout the care continuum with people living with dementia and their families and care partners through primary care providers.			☒
	D: Build a dementia-capable workforce across the care continuum.	1. Establish a dementia champions recognition program within primary care and allied health settings.	☒	
2. Promote culturally relevant educational resources for primary care staff in tribal communities caring for individuals with cognitive decline, dementia and their families and care partners.		☒		
3. Partner with tribal entities to strengthen primary care teams in Indian Country to meet the needs of people with cognitive decline, dementia, and their families and care partners.		☒		
4. Increase cultural competency of the existing dementia workforce to ensure culturally sensitive care, services and research opportunities are provided to high-risk populations.				☒

Goal 5: Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
D: Build a dementia-capable workforce across the care continuum.	5. Conduct environmental scan exploring the use, implementation and funding sources of incentives for loan forgiveness specific to geriatrics.			☒
	6. Explore opportunities to pilot peer network navigator program embedded into primary care.			☒
	7. Partner with health training institutions and residency programs in Washington state to understand core curriculum and explore opportunities to expand geriatric and dementia care education.		☒	
	8. Establish dementia care nurse competencies and define nursing role and responsibilities as leaders in interdisciplinary teams.	☒		
E: Explore and support policies that promote the capacity of primary care providers and staff to adequately assess, diagnosis, counsel and treat persons living with cognitive decline and/or dementia.	1. Review and update the 2017 Dr. Robert Bree Collaborative Alzheimer’s Disease and Other Dementias Report and Recommendations to reflect changes and new priorities.		☒	
	2. Conduct provider survey to understand gaps, challenges and successes on the front lines. Invite allied health professionals and primary care providers to participate in provider survey. Utilize survey results to improve policies that promote detection, diagnosis and care management of dementia.	☒		
	3. Test implementation of payment models for comprehensive dementia care, especially in underserved communities.			☒
F: Increase awareness of challenges associated with dementia and co-occurring conditions.	1. Provide learning opportunities and guidelines to health professionals containing information on how fragility and sensory loss such as hearing, vision and balance impacts the diagnosis and/or treatment of the person living with cognitive decline.	☒		
	2. Conduct an environmental scan to explore barriers and possible solutions to accessing palliative care and hospice for persons living with dementia.		☒	
	3. Increase awareness of the benefits of palliative and hospice care options throughout the care continuum with persons living with dementia and their families and care partners through primary care providers.		☒	
	4. Inform and promote a transition to digital documentation and transmission of advance directives in partnership with WA state agencies.	☒		

Goal 5: Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long	
G: Reduce preventable emergency department visits, hospitalizations and readmissions.	1. Conduct a needs assessment focusing on age friendly health clinics, hospitals and emergency departments.	☒			
	2. Support and promote Age-Friendly Health Systems and Geriatric Emergency Department training opportunities.		☒		
	3. Adapt existing data sets to include dementia to assess level of preventable hospital readmissions and engage with health systems in tracking readmissions for persons living with dementia.			☒	
	4. Partner with Washington State Hospital Association and health systems to provide support implementation strategies related to the CARE Act.			☒	
	5. Conduct an environmental scan exploring the routine use of delirium risk assessment in hospital settings.			☒	
	6. Utilize the existing DAC tools to improve awareness among primary care clinicians and care partners of potentially avoidable causes of ED visits, hospital admissions and readmissions for people with cognitive decline and dementia. Emphasize the importance of partnership and communication between clinicians and care partners.			☒	
	7. Identify models and pilot opportunities for short term stabilization of persons living with dementia displaying challenging behaviors to avoid unnecessary emergency hospitalizations that are available 24 hours a day, 7 days a week.			☒	
H: Improve understanding of and response to challenging and/or complex behaviors.	1. Conduct an environmental scan to identify supports and training available to primary care providers and care partners for addressing challenging behaviors for persons living with dementia.	☒			
	2. Provide culturally appropriate continuing education opportunities for primary care provider teams about understanding and responding to behaviors associated with dementia, including the use of non-pharmacological approaches, and reducing the use of antipsychotics.		☒		
	3. Explore a central hotline for providers to help primary care providers in effectively responding to individuals with challenging behaviors.		☒		

Goal 5: Promote risk reduction and evidence-based health care for people at risk of or living with cognitive impairment and dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
I: Increase primary care workforce awareness of the critical role of care partners and caregivers.	1. In the provider survey, include knowledge-based questions about unpaid caregiver supports, services, trainings, decision making aids and DAC tools and resources. Utilize survey results to respond to the issues found.	☒		
	2. Partner with GWEC, WA Hospital Association, Health Professionals associations, etc. to share and disseminate tools and resources related to care partner stress, ability and knowledge.		☒	
J: Promote the expansion of Project ECHO Dementia.	1. Using the existing Project ECHO Dementia platform, expand dementia-specific training to increase interprofessional coordination, provide continuous monitoring and assessment and expand access to high quality dementia care services.	☒		
	2. Expand upon Project ECHO Dementia outreach to include health professional association conferences, rural health convenings tribal health convenings, and provider groups caring for underserved communities.	☒		
	3. Reach providers, including Federally Qualified Health Centers, in all 39 counties with Project ECHO dementia core curriculum.	☒		
	4. Using the provider survey as a baseline, increase awareness and uptake of Project ECHO dementia, DAC tools and resources for providers.	☒		

Goal 6: Increase equitable access to culturally relevant, dementia capable long-term services and supports.

As most people living with dementia prefer to remain in their homes and communities for as long as possible, community-based services play a vital role in providing necessary assistance for the individual, and respite care and support for their caregivers. The DAC supports efforts that develop and enhance programs that offer in-home care, adult day services, respite care options and expand dementia-friendly community initiatives. We also recognize the importance of extending these services to traditionally underserved populations, including low-income individuals, racial and ethnic minorities and residents of rural areas. Collaboration with community organizations and tailoring services to meet the unique needs of these populations can help bridge the gaps in access to care.

Respondents to the DAC survey and listening sessions reported the top three critical needs as: increased home care supports, financial help with care costs and the need to promote quality in long-

Much more could be done locally. In particular, a setting where social support opportunities could be provided for caregivers and patients in the same setting with others who are dealing with the same challenges. Currently, there are only support groups for the caregivers.

- Family caregiver in Washington

term services such as residential care, community-based services and home care. Workforce shortages and a diminished and undertrained workforce act as barriers to quality care and stable living options. Housing specifically designed for, or attuned to the needs of, people living with dementia, such as memory care facilities or age-friendly housing, will need to expand to accommodate the growing demand. Recommendations put forth acknowledge the need to partner with and support initiatives that maximize workforce recruitment opportunities, and provide dementia specific training for professionals, while supporting family caregivers and making better use of natural community supports.

Many individuals and caregivers are unaware of the wide range of services and technological innovations designed to support individuals with dementia. Raising public awareness about available resources, existing information and assistance helplines, developing informational resources and collaborating with healthcare professionals can help individuals navigate the complex landscape of dementia care. Promoting the use of assistive technologies, such as reminder systems and fall detection devices, can empower individuals living with dementia and their caregivers to keep independence and safety.

It is important to promote equitable access to long-term services and supports (LTSS) for people living with dementia. By focusing on risk reduction, expanding community-based supports, educating about available services and assistive technology and addressing housing and workforce shortages, we aim to enhance the lives of individuals living with dementia and their caregivers. Achieving equity in dementia care ensures that everyone, regardless of their background or circumstances, can access the necessary resources to live with dignity and receive the support they need.

Goal 6: Increase equitable access to culturally relevant, dementia capable long-term services and supports

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Reduce risks for cognitive decline and dementia by educating about risk factors.	1. Raise awareness among adults involved in community programs (e.g., nutrition sites, senior centers) of ways to reduce modifiable risks for dementia and cognitive decline including the links between heart health and brain health, and the value of early diagnosis, with particular attention to racial and ethnic groups at increased risk of dementia.	☒		
	2. Enhance Home and Community Services (HCS)/ Area Agency on Aging (AAA) Case Management Core training to include more information around the importance and number of ways to reduce risks for dementia and cognitive decline, the value of early detection and diagnosis, responding to behaviors and assessing and addressing hearing loss and other sensory limitations.		☒	
B: Expand access to affordable community-based supports for persons living with dementia and their families.	1. Support and expand access to a robust array of community-based services such as adult day services, Program of All-inclusive Care for the Elderly (PACE), Memory Care & Wellness services and Exercise for Mobility, including promotion of virtual offerings as needed.	☒		

Goal 6: Increase equitable access to culturally relevant, dementia capable long-term services and supports

<i>Strategy</i>	<i>Recommendations (needed policies or responses)</i>	<i>Short</i>	<i>Mid</i>	<i>Long</i>
B: <i>Expand access to affordable community-based supports for Persons Living with Dementia and their families.</i>	2. Expand the Building Dementia Capable Communities program (aka Dementia Resource Catalyst pilot) statewide to enhance the dementia-capability of the Community Living Connections (AAA) Information & Assistance system for people living with dementia in the community, and their family care partners.	☒		
	3. Provide information and education on utilizing WA Cares benefits to improve access to respite, paid family caregivers, assistive equipment and technologies.			☒
	4. Advocate to sustain 1115 Medicaid Transformation Project Demonstration waiver programs, Medicaid Alternative Care and Tailored Supports for Older Adults (MAC/TSOA), and optimize service options for people living with dementia and their family care partner.		☒	
	5. Explore specific needs of people living with dementia without family/friends to support them and identify potential responses, services, and outreach mechanisms to inform of what is available.			☒
	6. Identify opportunities to provide services and programming to those living with young onset dementia.		☒	
	7. Review and advocate for the necessary adjustments to Medicaid daily rates that promote and expand access to Specialized Dementia Care in Assisted Living Facilities.	☒		
	C: <i>Improve quality of, and consumer information about, residential Long-Term Care Options.</i>	1. Propose strategies and mechanisms to define and promote dementia care quality standards for Washington assisted living settings advertising themselves as “Memory Care” and/or “Specialized Dementia Care.”		☒
2. Develop a Memory Care specific disclosure form (or addendum to a larger disclosure form) that includes both a definition of Memory Care that serves to find the adult family homes and assisted living facilities that need to use the form and best practice elements to be include in Memory Care programming.			☒	
3. Develop educational materials to inform consumers about long-term care (including Memory Care) in assisted living facilities e.g., what to expect, questions to ask, how to find, etc.		☒		

Goal 6: Increase equitable access to culturally relevant, dementia capable long-term services and supports

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
C: Improve quality of, and consumer information about, residential Long-Term Care Options.	4. Advocate for the development of an online platform that is easily updateable by providers, to make disclosure forms, including the Memory Care specific forms, available to individuals and families so that they can more easily be informed of and compare services and offerings when choosing a facility residence.			☒
	5. Explore with stakeholders opportunities to pilot value-based payment model with Long-Term Care facilities to provide innovative and/or evidence-based interventions and services.			☒
D: Strengthen numbers and effectiveness of Long-Term Services and Supports workforce.	1. Engage with and help with efforts of Department of Social and Health Services (DSHS) and other partners to recruit paid caregivers for Long Term Services and Supports (home, residential and other long-term care settings).	☒		
	2. Update Dementia-Capable Caregiver training and develop advanced training modules for Adult Family Home and Assisted Living Facility staff.		☒	
	3. Collaborate with Adult Protective Services (APS) to raise awareness and knowledge about dementia and dementia resources and services among APS staff, to help community partners recognize and know how to report potential signs of abuse, neglect or exploitation in people living with dementia.		☒	
	4. Collaborate with Adult Protective Services (APS) to promote awareness about, and increase dementia awareness within, local multi-disciplinary teams in order to improve knowledge of dementia and dementia resources among community organizations, law enforcement, local attorneys and advocacy groups.		☒	
E: Increase awareness of assistive technologies that promote independence for people with dementia and support for family caregivers.	1. Identify priority assistive technologies that promote independence, safety and aging in place. This might include low-tech or high-tech devices such as assistive listening devices or hearing aids, alert systems, medication aids or reminders, identification jewelry, locating devices, etc. and integrate into Dementia Safety Info Kit and/or through other mechanisms as they evolve.	☒		

Goal 6: Increase equitable access to culturally relevant, dementia capable Long-Term Services and Supports

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
E: Increase awareness of assistive technologies that promote independence for people with dementia and support for family caregivers.	2. Develop training module(s) for individuals and family caregivers around the availability and use of assistive technology options, appropriateness and potential cautions.		☒	
	3. Educate LTSS staff on the availability and use of assistive technology options, appropriateness and potential cautions.		☒	
	4. Develop mechanisms within existing information systems (i.e., CARE/TCARE, care coordination systems) to prompt sharing of assistive technologies helpful to family caregivers of people with dementia.			
F: Engage with and support or partner with promising housing models to strengthen dementia-capability.	1. Identify housing-plus service models, such as those in senior housing or the existing Housing and Urban Development (HUD) pilot, with potential to serve people living with dementia and explore opportunities for advocacy.	☒		
	2. Explore educational opportunities currently provided for residents in congregate housing settings and their interest in offering opportunities for education around brain health/dementia risk reduction, chronic disease management and/or dementia supports and services. Identify, where possible, mutual interest in dementia-related education and potential partners to address these needs.		☒	
	3. Develop, with building managers of congregate senior housing, a pilot training module around dementia, dementia-capability and supportive resources.			☒
	4. Identify existing HomeShare program models and examine their experiences to evaluate practices for people living with dementia for feasibility to expand and replicate more broadly across Washington.			

Goal 7: Facilitate innovation and research related to risk reduction, causes of and effective interventions for cognitive decline and dementia.

All the strategies and recommendations above focus on alleviating or managing the impacts of dementia on people and their families. The National Alzheimer’s Plan prioritizes funding for research, both basic and translational research. While there is no cure for dementia currently, there are emerging drug therapies. New research, with promising results, is occurring regularly.

A huge challenge to Alzheimer’s research is finding enough volunteers to translate basic research into clinical studies and clinical trials.

Moving from basic research to clinical settings requires: participation in clinical trials, communication and dissemination of the results throughout the medical community, and long-term data collection and analysis. One way the DAC can aid in this challenge is by bringing researchers together to collaborate, share findings and discuss emerging effective cognitive health best practices.

The State has a role to play in making sure that people with early-stage dementia are made aware of opportunities to participate in research, in leveraging resources, and in providing data and communicating results. Other disease-model plans have shown success in reducing disease burden among Washington residents. The State also acknowledges that there is much work to do in ensuring the research participants are representative of the population. To achieve this, relationship building, listening and learning from diverse populations and tribal communities are “must do” actions.

Goal 7: Facilitate innovation and research related to risk reduction, causes of and effective interventions for cognitive decline and dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A: Promote and optimize the integration of existing and emerging research to inform effective cognitive health practices.	1. Expand the reach of the bi-monthly Washington State Alzheimer’s and Dementia Research Network to showcase new, emerging and recently published cognitive decline, dementia, and dementia care service research.	☒		
	2. Host a collaborative Alzheimer’s and Dementia research summit, highlighting the latest research, current and emerging state of effective cognitive health best practices, provider survey results and next steps.	☒		
	3. Explore validated healthy aging and resiliency measures, implementation and benefits.			☒
	4. Leverage a broad array of existing data sources including, but not limited to: Medicare, Medicaid, All Payers Claims Database, Health Systems (Electronic Health Records) and Washington Health Alliance, to elevate healthy aging, identify cognitive status, dementia diagnosis and resiliency measures supporting people over the life course.			☒
B: Develop relationships with key community stakeholders to assess and pilot culturally specific and relevant research programs and projects.	1. Invite and engage with diverse communities to learn insights and input on cognitive health, dementia and dementia care research priorities.	☒		
	2. Promote strategic partnerships among associations, government agencies, insurers, other payers, private industry, public organizations and elected officials to support and advance research and policy related to cognitive health.		☒	

Goal 7: Facilitate innovation and research related to risk reduction, causes of and effective interventions for cognitive decline and dementia

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
C: Increase the number of people interested and able to enroll in research opportunities.	1. Establish talking points and decision-making guides for community clinicians to guide conversations that lead to referral and participation in clinical trials and dementia related research.		☒	
	2. Establish conversation guide for participant and care partners to guide through the process of getting engaged with research.	☒		



Implementing this Plan



Implementing this Plan

Mobilizing a State Response

The Washington State Plan to Address Alzheimer's Disease and Other Dementias is envisioned as a partnership opportunity for public and private agencies. Its implementation – including action planning, next steps and policy changes – will depend on the participation, funding and contributions of a broad group of diverse, multi-sector and committed partners.

A Call to Action

The DAC assumes that changes can be made within or built upon existing systems of care and services, yet also acknowledges the need for new actions and accountability. The strategies and recommendations in this plan cannot be accomplished by state government or any single organization alone.

Some of the recommendations can be accomplished within existing resources, and some through heightened collaboration of partners, but others will take increased staff resources and funding to be fully realized.

ALL will take sustained commitment, focus and coordination – the DAC will seek and support engagement and collaboration from the public and private sector to work towards the goals, strategies and recommendations herein.

This plan is a call to action:

- For the Dementia Action Collaborative (DAC) to provide ongoing guidance and oversight for state plan implementation
- For state agencies to collaborate on dementia-related concerns that benefit from a coordinated approach e.g., reducing potentially modifiable risk factors, reducing preventable hospitalizations, a multi-sector state plan on aging, disparities/equity
- To collectively pursue and monitor progress in implementing the proposed goals, strategies and recommendations
- To integrate dementia-related awareness and actions into broader initiatives that address improved health and quality of life such as the Healthy Brain Initiative, Medicaid Transformation Waiver, WA Cares
- To public and private community partners across the state to take actions that align with the goals and strategies outlined in the plan
- To identify emerging opportunities to improve our state's response to dementia

Suggested Actions for Community Partners

- Be part of the solution - take action

The Dementia Action Collaborative invites anyone to join us in taking ACTION – to be a part of the solution for Washington state!

The goals, strategies and recommendations in the plan cannot be accomplished by the DAC or state agencies alone. It will require independent actions from individuals, stakeholders and community partners that align with and amplify our collective work towards the goals, strategies and recommendations.

In Appendix C: Suggested Actions for Partners you will see multiple suggested actions that individuals, community partners and organizations can take now. Included with the suggested actions, where possible, is a link to the materials and/ or a resource that may help you to take action.



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Thousands of people in Washington completed a survey, attended a public listening session, shared their thoughts at a DAC meeting and/or talked to a DAC member about their needs, challenges, hopes and fears surrounding dementia. Their experiences and ideas helped shape our state plan. We are thankful for the people of Washington state who took the time to contribute their thoughts.

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Appendices



Appendices

A: Existing Services, Resources and Health Care System Capacity

Type, Cost and Availability of Dementia Services

People living with dementia and/or their family care partners may benefit from a variety of services over time. This includes health care, community support services, family caregiver supports, in-home or residential long-term services and supports, and/or nursing facility care. These may not necessarily be known specifically as “dementia services” but may serve people living with dementia.

This section first covers the two large categories of health care services and systems and long-term services and supports that are either directed at or serve people living with dementia, including information on their current availability and Medicaid reimbursement rates in Washington state, where applicable.

Additional sections, required through HB 1646, are included as well, covering dementia-specific training requirements for long-term services and supports staff, and state funding and Alzheimer’s Disease research through Washington state universities.

Health Care System and Services

- Primary care and specialty providers, including geriatricians.
- Health Care Systems
- Geriatric psychiatric units

Primary care providers are pivotal actors in the diagnosis and care of persons living with cognitive decline and/or dementia. Most dementia diagnoses are provided by the primary care provider.⁴⁰ However, access to a primary care provider varies depending on geographic location, socioeconomic status, and health care coverage. Access to a primary care provider is important not only to provide dementia care, but also upstream to offer risk reduction opportunities and screenings.

AVAILABILITY: According to the Community Checkup report by the Washington Health Alliance, access to primary care for adults of all ages, both commercially insured and those covered by Medicaid fall below the national benchmarks; see the table below for details.⁴¹ It is important to recognize that limited access is due to a few compounding issues such as transportation, education levels, limited financial resources, lack of local providers and lack of local providers accepting specific insurance or Medicaid coverage.

	WA State Average Commercially insured	National 90th Percentile Commercially insured	WA State Average Medicaid - insured	Nat’l 90 th Percentile Medicaid - insured
Ages 20-44	88%	96%	67%	82%
Ages 45-64	93%	97%	72%	88%
Ages 65+	97%	98%	31%	93%

Table 2. Access to primary care by age group.⁴²

Geriatricians are medical doctors specially trained to focus on the needs of older adults. They are part of the primary care workforce and are uniquely qualified to care for older adults living with multiple chronic diseases, including dementia.

AVAILABILITY: As of 2021, Washington state had 126 geriatricians, the Alzheimer’s Disease Facts and Figures report estimated the number of geriatricians Washington will need to serve 10% and 30% of the population 65 years and older in 2050 to be 399 geriatricians and 1,198 geriatricians respectively.¹ The workforce shortage extends into all areas of health care, especially those caring for older adults.

⁴⁰ Alzheimer’s Association, 2023.

⁴¹ 2023 Community Checkup Report; Catalyzing Change in Washington Health Care [2023-community-checkup-report.pdf \(wacommunitycheckup.org\)](https://www.wacommunitycheckup.org).

⁴² The above table shows Washington state primary care access compared to a national statistic from the National Committee for Quality Assurance (NCQA) Healthcare Effectiveness Data and Information Set (HEDIS). The numbers represented in the columns labeled National 90th percentile showcase the averages of those in the top 10% nationally.

Health Care Systems also provide dementia services; when a person is living with dementia, it impacts every aspect of their life. When a person living with dementia experiences an emergency department or is admitted to the hospital, even when dementia is not the primary reason for the visit, the presence of dementia will impact their treatment and outcomes. Responses to facilitate more dementia-capable responses for such visits may be to increase the quality of care for older adults in an emergency department, such as the “Geriatric Emergency Department Accreditation” process established by American College of Emergency Physicians (ACEP).

Currently, Washington state has three accredited geriatric emergency departments⁴³ that focus on staff development and interdisciplinary staffing. The [Geriatric Emergency Department Accreditation program](#) promotes geriatric focused improvements to care transitions, physical environments, and supplies.

Another possible response emerging is the movement towards Age- and/or Dementia-Friendly health care systems. An example of this is the “Age Friendly Health Systems” initiative, headed by the John A. Hartford Foundation and the Institute for Health care Improvement, in partnership with the American Hospital Association (AHA) and the Catholic Health Association of the United States (CHA), designed to meet this challenge head on.

Currently, Washington state has over 50 Age Friendly Health Systems⁴⁴ which align a set of evidence-based elements known as the “4Ms.” The 4Ms are: What Matters (the person’s goal and care preferences), Medication (ensure any medication that is necessary does not interfere with the person’s goals), Mentation (prevent, identify, treat, and manage dementia, depression, and delirium), and Mobility (ensure the person can move safely every day). Health systems that train and implement the 4Ms report return on investments both on inpatient and outpatient services.

Geriatric Psychiatric Units

For individuals living with dementia who show severe, disruptive or unsafe behaviors, hospital units skilled in evaluation, treatment and care coordination may become necessary at some point. There is no coordinating or regulatory body that sets expectations for services that should be available in these settings for the quality of these services. Ideally, individuals can be admitted to geriatric psychiatric (geropsych) units in community-based hospitals for short-term evaluation and treatment, but these are few, and beds are limited.

AVAILABILITY: The following hospitals accept and specialize in caring for patients presenting with geriatric psychiatric behavioral challenges. Geriatric psychiatric beds and services are not specifically licensed for in Washington State. These services are provided under a psychiatric or acute hospital license.

- Northwest Hospital Geropsychiatric Center, North Seattle (27 beds, accepts both voluntary and involuntary admissions)
- MultiCare Auburn Regional Medical Center, South Seattle (38 beds, accepts both voluntary and involuntary admissions)

The Department of Health’s Office of Community Health Systems reports there are no geropsych inpatient beds in Washington’s Critical Access Hospitals (CAHs) and there is no other entity that can report services in other rural hospitals in the state, so this information is difficult to obtain.

If beds are not available, individuals may be transferred to emergency departments and end up waiting for geropsych or regular psychiatric hospital beds, or even admitted to medical floors with continuous supervision, long after medical conditions have resolved. Geropsych units also report that limited long-term care options can increase lengths of stay in hospitals, further complicating the issues.

⁴³ [Geriatric Emergency Department Accreditation // Home \(acep.org\)](#).

⁴⁴ [What Is an Age-Friendly Health System? | IHI - Institute for Healthcare Improvement](#).

If an individual's behavior has reached a certain threshold so that they meet the criteria for involuntary treatment under the state's civil commitment law (RCW 71.05), he or she may be involuntarily detained. They may be transferred to a geropsych bed, a regular psychiatric hospital bed, or remain in the emergency room or medical unit of a community hospital on a single bed certification (SBC) until a psychiatric bed becomes available. Patients are treated primarily for psychiatric symptoms, even though most individuals living with dementia have co-occurring medical and behavior issues. The units in which they are treated are not designed for dementia care and may sometimes worsen unwanted behaviors, such as aggression, making placement even more challenging. Medical conditions can either progress or are difficult to resolve promptly. This in turn can delay, or in some instances, even prevent discharge to proper community-based housing and treatment.

Individuals who are not hospitalized under the state's civil commitment law (i.e., voluntary admitted) are often hospitalized because they are unsafe to discharge to their originating setting, which may incur lengthy hospital stays for the coordination of services. These types of circumstances often encounter decision-making concerns which require the assignment of guardianship which also delays the discharge planning process.

Available specialized geropsychiatric units are limited to the Seattle area. Added units and alternatives to inpatient geropsychiatry care needed throughout the state for assessment of individuals exhibiting severe behaviors, which will require further investigation, investment and development.

In addition, there is a great need for community-based services that can be provided by individuals knowledgeable about older adults and dementia to help understand and support the person living with dementia and their caregiver when dementia-related behaviors are putting either the individual or family at risk of harm or compromising the person's ability to stay in their home. These types of services are extremely limited. One such program exists in King County – the Geriatric Regional Assessment Team (GRAT).

- GRAT provides a home visiting team of behavioral health and aging experts who can assess an individual's situation and intervene before a situation escalates to a crisis, integrating behavioral health response services with non-crisis supports and connections to broader aging network services.
- GRAT is currently funded through a braiding of local tax dollars, MIDD (King County Behavioral Health Sales Tax) and VSHSL (Veterans, Seniors and Human Services Levy) funds.
- Health Care Authority and GRAT are partnering to develop a toolkit for other areas that may want to build a similar program in their area.

When individuals with dementia and behavior challenges are admitted to the psychiatric or acute care hospitals, they need to be transitioned back into the community. ALISA manages a 1915c Residential Support Waiver (RSW) that offers enhanced services in residential care settings that may serve eligible clients living with dementia with behavioral symptoms. Below are two RSW programs, offered through the Waiver, under Medicaid contract with specific facilities, for eligible clients:

- Expanded Community Services (ECS) are designed for Medicaid clients living with exceptional care needs due to behavioral or mental health issues, and for whom successful placement is not possible because of significant behavioral challenges. DSHS contracts with and offers an enhanced rate to residential providers and skilled nursing facilities for this service. In June 2023, ECS services are offered in 1,506 Adult Family Homes, 59 Assisted Living Facilities, and 29 Skilled Nursing Facilities offer Expanded Behavior Services.
- An Enhanced Service Facility designation was developed to offer behavioral supports and other care in specialized residential facilities that are designed for individuals living with mental health and/or chemical dependency disorders; organic or traumatic brain injuries; and/or cognitive/developmental impairments who are relocating from a psychiatric hospital when acute inpatient treatment is no longer medically necessary, or the individual cannot benefit from active

treatment. To be eligible, clients must meet Nursing Facility Level of Care and Enhanced Service Facility criteria. This program is currently budgeted for nine statewide facilities with a total capacity for 131 beds.

- See more about these programs in the section below, under Long-Term Dementia Care Beds Availability.

Long-Term Services and Supports (LTSS)

Washington's Department of Social and Health Services' AL TSA works in partnership with thirteen AAAs who are responsible for planning, coordinating, and advocating for the development of a comprehensive service delivery system for long-term services and supports (LTSS) at local levels to meet the needs of older adults in their planning and service areas – including, but not limited to, people living with dementia.

Washington state ranks second in the nation for its long-term services and supports system performance.⁴⁵ Even so, the need for and capacity to deliver such services is of growing concern. In the DAC consumer survey, fielded in 2022-2023 by the Dementia Action Collaborative to inform this plan update, the top five 'critical issues that our state should address' were related to the provision of long-term supports and services. These are:

1. Increase home care supports
2. Financial help with care costs
3. Promoting quality in long-term care, such as residential care, community-based and home care
4. Family caregiver education and support
5. Increase residential care availability

LTSS subsections below include:

- Home and Community-Based Resources
- Publicly funded Home and Community Based Resources
- Long-term dementia care beds (residential settings)
- Skilled nursing facilities and dementia beds/units
- Dementia specific training requirements for long-term services and supports staff

Home and Community-Based Resources

The section offers a summary of key services for people living with Alzheimer's disease and other dementias available in the private pay market and through publicly funded systems.

Alzheimer's and Dementia Specific Information and Support

Persons with dementia and their caregivers in Washington State can access information and supportive services through private organizations such as the Alzheimer's Association or the Alzheimer Society of Washington. Dementia Support Northwest (formerly the Alzheimer Society of Washington) is a non-profit grassroots organization, providing advocacy, care and support to those living with dementia and their families in Whatcom County, including programs for people with early stage memory loss, caregiver and care partner support groups, caregiver support groups, Project Lifesaver (an electronic technology program (bracelet) to locate those who wander or who may become lost in partnership with the Whatcom County Sheriff's office) and memory awareness screenings.

⁴⁵ Reinhard, et al., 2014.

The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s care, support, and research. The Association’s Washington State Chapter serves all of Washington as well as Northern Idaho from offices in Seattle and Spokane. Specific services provided include:

- Toll-free Helpline (1-800-272-3900) – information, assistance, referrals, and answers to questions about Alzheimer’s disease and related disorders 24 hours a day, 7 days a week
- Web-based Resources (www.alzwa.org) – information about dementia, links to local services and supports, and peer-to-peer connections
- Support Groups – available in community settings or via telephone at a variety of times of the day and week for spouses, adult children, family caregivers, and people with dementia
- Early-Stage Programming – information, support groups, and social engagement for individuals in the early stage of the disease and their caregivers
- Care Consultation – individualized assistance, problem solving, care planning and coordination for persons living with memory loss and their families
- Education – evidence-based, dementia-specific education and training for family and professional caregivers
- MedicAlert + Safe Return – nationwide program that provides assistance when someone living with Alzheimer’s or a related dementia wanders and becomes lost.
- Advocacy – grass roots efforts to engage elected officials at all levels of government to improve and increase dementia care and services, access to community-based care, quality care in residential settings, and funding for research.

In-Home and Residential Services Available for Private Pay Consumers

Services such as in-home care, respite, community residential and nursing facility care are available for citizens to purchase privately. Among these are in-home care, adult day services, adult family home, assisted living and nursing home care. Rates and availability of such services vary by community.

Estimated statewide median rates for the following services follow in the table below:

Homemaker Services	\$34.34 per hour
Home Health Aide	\$34.50 per hour
Adult day health care	\$120 per day
Assisted living facility care (ALF)	Private room - \$6,000 per month \$72,000 per year
Memory care (in ALF)	\$7,500 per month \$90,000 per year
Adult family home care	\$163 - \$204 per day* \$59,495 - \$74,460 per year
Nursing home care	Semi-Private room - \$9,429 per month \$96,933 per year Private room - \$10,466 per month \$125,597 per year

*Rates above (with exception of AFH) are from Median Cost Estimates for private pay from [Genworth’s 2021 Cost of Care Survey](#).^[1] Memory Care is estimated at 25% higher than ALF. Costs may vary by geographic area and client needs. *DSHS Management Services estimates an average \$163/day for Adult Family Home care under Medicaid; some AFHs offer additional Meaningful Day Services that increase rate by \$40/day (No private pay estimate available).*

Table 3. Estimated private pay rates for long-term care settings. Genworth Cost of Care Survey, 2021.

^[1] Genworth, 2015.

Because Alzheimer's disease and other dementias may span the course of many years and care needs increase over that time, a significant percentage of individuals and families eventually turn to long-term services and supports (LTSS) provided through state and federal public funding, such as Medicaid and the Older Americans Act. These services are covered in following section.

Publicly funded Home and Community-Based Resources

Washington State's Department of Social and Health Services, AL TSA has developed a statewide network of home and community-based services that are available to help people stay healthy and age-in-place in their homes and communities. Resources support adults living at home who need information and services to assist with chronic care needs or disabilities and adults who are no longer able to live at home but want to live in a residential setting.

Adults living with memory issues and/or diagnosed dementia are served in numerous programs and different settings of the long-term services and supports (LTSS) system. This has prompted, over time, the development of policies that are inclusive of people living with dementia (e.g., Medicaid Waiver eligibility incorporates cognitive impairment) and some dementia-specific services targeted to the particular needs of the population (e.g., STAR-C and the Specialized Dementia Care Program in Assisted Living Facilities). Other services, while not dementia-specific, assist a substantial percentage of people living with memory loss/dementia (e.g., Information & Assistance/Aging & Disability Resource Centers, case management, personal care providers).

Included below is a sample of the publicly funded long-term services and supports of particular relevance to people living with Alzheimer's or related dementias and/or their family caregivers.

Adult Protective Services (APS)

Individuals living with dementia or other cognitive impairments are thought to be at greater risk of abuse and neglect than those of the general older adult population. APS receives and investigates allegations of abuse (physical, mental, sexual, and exploitation), abandonment, neglect, self-neglect, and financial exploitation of vulnerable adults living in their own homes and in facilities where there is an allegation of mistreatment by someone outside of the facility. The target population are adults 60+ who cannot care for themselves; or adults 18+ that have a legal guardian; have a documented developmental disability; receive services from a DSHS-contracted individual provider; receive in-home services through a licensed health, hospice or home care agency; or have a personal care aide who performs care under his/her direction for compensation, per 74.39.050 RCW.

AVAILABILITY: Adult Protective Services are available statewide to individuals of all income levels. Reports can be made online or by phone: Call 1-866 ENDHARM (1-866-363-4276).

Community Living Connections (CLC)

Community Living Connections (CLC) is the name that encompasses the Information & Assistance (I & A) programs available to older adults, caregivers, families and professionals assisting or advocating on behalf of older adults in Washington state. CLC is operationalized through 13 AAAs and is known nationally as Aging and Disability Resource Centers (ADRCs) which are designed to broaden services to individuals of all ages with long-term service and support needs. These services are integrated points of entry into the long-term and home or community-based service and support system and are intended to address the frustration many consumers and their families experience when they need to obtain information and access to services.

AVAILABILITY: I & A is operationalized through Area Agencies on Aging/Community Living Connections and are available statewide. There is no cost for services. Any consumer or professional can contact one phone number 855-567-0252 to be connected with their local area's I & A program, or can find it here: www.waclc.org/connect.

Family Caregiver Support Programs, including Respite

The Family Caregiver Support Program (FCSP) serves unpaid family caregivers of adults (18+) living with functional disabilities. The FCSP serves a significant population of families living with dementia. Statistics from FCSP data reveal that more than 70% of care receivers have either a probable or firm diagnosis of Alzheimer’s disease/dementia or are suspected to have memory or cognitive problems (2022).

The Family Caregiver Support Program (FCSP) offers an evidence-based caregiver assessment/consultation and care planning process (TCARE®) in addition to support and services that includes: help in finding and accessing local resources and services; caregiver support groups and counseling; training on specific caregiving topics (including Alzheimer’s disease/dementia); education on caregiving skills and self-care (e.g., Powerful Tools for Caregivers); access to supplies/equipment; and support/practical information and caregiving suggestions. In addition, respite care is available based upon a sliding fee scale.

AVAILABILITY: Family Caregiver Support Program services are operationalized through Area Agencies on Aging/Community Living Connections and are available statewide, funded through both state and federal funds (OAA). There is no cost for services except for Respite Care for which there is a sliding fee scale based on income.

MAC/TSOA: Since 2017, family caregiver support services similar to those above are also funded through a CMS/1115 Waiver: Medicaid Alternative Care (MAC) and Tailored Services for Older Adults (TSOA). Eligible clients may access a budget to be spent on a variety of services – the budget is around \$758 per month. This can provide approximately 20 hours of respite services to the family caregiver and/or can be used in conjunction with other services if respite is not needed or available. These other services might include home delivered meals, Personal Emergency Response system (PERS) for fall prevention and medication management, home modifications, assistive technology, incontinence supplies, support groups and counseling, and more. The monthly budget may be used flexibly over a 6-month period, meaning they might use the current monthly of \$830 per month each month, or spend \$1,000 one month and less in another, as long as spending does not go over \$4,980 for a 6-month period.

Adult Day Service Programs

“Adult day care” is a supervised daytime program providing core services for adults with conditions that do not require the intervention or services of a registered nurse or licensed rehabilitative therapist. “Adult day health” provides supervision along with skilled nursing and/or rehabilitative therapy services. Both these programs may serve people with dementia where they are available.

AVAILABILITY: The availability of adult day service programs was impacted significantly by the pandemic. In 2016, there were around 40 adult day sites. Currently, based on DSHS data and information from Leading Age, there are around 15 adult day centers contracted for publicly supported service provision. More adult day service providers are available on a private basis, these may be found through local area I & A programs, or here: www.waclc.org/connect

MEDICAID REIMBURSEMENT RATES (January 2023):

- Adult Day Health, King County - \$98.22 per day
- Adult Day Health, Metropolitan Counties - \$91.79 per day
- Adult Day Health, Non-Metropolitan counties - \$88.33 per day
- Adult Day Care, King County - \$65.16 per day
- Adult Day Care, Metropolitan Counties - \$59.30 per day
- Adult Day Care, Non-Metropolitan Counties - \$56.83 per day

“Memory Care & Wellness Services” (MCWS) is a dementia-specific, evidence-informed, adult day program for individuals and family caregivers. The program offers a blend of health, social and

family caregiver supports and integrates a structured, specialized exercise program called Exercise for Mobility. A University of Washington study of MCWS showed that for participants in the program with dementia, quality of life improved and the frequency of behavior problems decreased. For family caregivers, distress over behavior problems decreased for caregivers in the program, while distress increased in the comparison group of caregivers. Depressive symptoms, stress and burden also decreased for caregivers participating in the Memory Care & Wellness Services program.⁴⁶

AVAILABILITY: This program too, has been impacted by limited adult day services infrastructure. In 2016, it was available in two AAA areas. The MCWS program is now available only in King County, supported through limited funding from the Family Caregiver Support Program.

REIMBURSEMENT RATE: Family Caregiver Support Program (January 2023):

– Family Caregiver Support Program Rate: King County - \$122.78 per 5-hour day

STAR-C Dementia Consultation (focus on tailored coaching/behavioral problem-solving)
STAR-C is an evidence-based dementia consultation program for caregivers. Trained, certified consultants provide in-home education and consultation during four home visits and offer additional phone support over a six-week period. Developed at the University of Washington, this in-home education/consultation program has shown to improve care receiver quality of life, reduce the frequency of problem behaviors, and lower caregiving depression, burden, and distress over care receiver behavior changes.⁴⁷ The service is targeted to unpaid family caregivers who care for a person with Alzheimer’s disease or other dementia, and is funded through the Family Caregiver Support Program (FCSP).

AVAILABILITY: STAR-C Dementia Consultation is available through six of our 13 Area Agencies on Aging (AAAs). Training and certification of consultants has been supported through Older Americans Act and federal grant funding as available, and services are offered through FCSP or MAC/TSOA funds.

In-Home Services Agencies

In-home service agencies are designed for individuals who, because of their health concerns, need care supports to remain in the home. Some families pay privately for such care with an individual or home care agency. Medicaid clients can utilize CDWA (Individual Providers) and licensed and contracted home care agencies. In-home service agencies are licensed via the Washington State Department of Health to administer or provide home health, home care, hospice or hospice care center services.

“Home health services” may include nursing services, home health aide services, physical-occupational-speech therapy services, nutritional services, medical social services, home medical supplies or equipment services, and professional medical equipment assessment services. “In-home hospice” services may include symptom and pain management provided to a terminally ill patient, and emotional, spiritual and bereavement support for the patient and family.

As part of Washington’s Medicaid State Plan and Medicaid Waivers, home care agencies are contracted to provide non-medical services that may include personal care such as assistance with dressing, feeding and personal hygiene to facilitate self-care; assistance with household tasks, such as housekeeping, shopping, meal planning and preparation, and transportation; respite care assistance and support provided to the family; or other nonmedical tasks, or delegate tasks of nursing.

Financial assistance for personal care in the home may be available for individuals who meet the financial and functional eligibility for the Community First Choice Program. Cognitive impairment is a consideration in eligibility and in the algorithm that generates the level of service authorization/rates for long-term services and supports.

⁴⁶ Logsdon, Pike, Korte, & Goehring, 2014.

⁴⁷ See: <https://academic.oup.com/gerontologist/article/45/6/802/553053>.

AVAILABILITY: In 2023, there are 530 in-home service agencies licensed across the state – licenses would include home care, home health, and hospice agencies. Forty-seven (47) home care agencies were contracted to provide personal care services to Medicaid eligible clients.

DSHS data from CY 2020, reveal that 26.9% of ALTSA-LTSS in-home services clients (age 65+) and 18.1% (all ages) had indications of dementia, including Alzheimer’s disease.⁴⁸

MEDICAID REIMBURSEMENT RATE (July 2023):

– Home Care agency = \$40.48 per hour

Long-term dementia care beds availability

The term “dementia care beds” has no standard/official definition in our service system and might be interpreted differently by different people/stakeholders. As this was the request from the legislation, however, this report acknowledges that people living with dementia may be served in a variety of generalized residential settings on a long-term basis, some of which have staff with training in dementia-capability, and some of which have specific expectations around dementia.

The mean age of LTSS recipients living with dementia is 80.8 years of age.

DSHS data from CY 2020, reveal that 63.2% of LTSS clients (age 65+) and 50% (all ages) in community residential service settings (Adult Family Homes, Assisted Living Facilities, including Enhanced Service Facilities) had indications of dementia, including Alzheimer’s disease.⁴⁹

Medicaid rates for LTSS services may change each year. Up to date information may be found on the DSHS/ALTSA website. [Office of Rates Management | DSHS \(wa.gov\)](#). Please note that Medicaid rates found at this site will typically be less than private pay rates.

DSHS-ALTSA strives to maintain a viable network of in-home, community-based residential and skilled nursing services that allows an individual to receive care under Medicaid in a setting of choice that can meet their needs in a less expensive and less restrictive setting than a nursing home or hospital. Reimbursement rates alone do not determine provider willingness to participate as a Medicaid contractor, but higher rates are certainly an important incentive. ALTSA has worked with stakeholders, providers, and the legislature over the years to request rate increases to encourage more providers to participate with Medicaid, increasing availability for consumers. For example, in the 2024 legislative session, the Specialized Dementia Care Program received a \$22 million funding increase for the coming biennium.

Adult Family Homes

Adult Family Homes (AFHs) are a community residential care option in Washington. An AFH is a residential home in which a person or persons provide personal care, special care and room and board for two to six residents who are not related by blood or marriage to the persons providing the services. An adult family home may be licensed to provide care to up to eight adults if the home receives approval under WAC 388-76-10031 or 388-76-10032. The homes are private businesses and provide the residents with a room, meals, laundry, supervision, assistance with activities of daily living, and personal care. Some provide nursing services. Residents can pay privately or be funded through DSHS.

Adult Family Homes may be designated as a specialty home (on their license) for dementia if they meet all certification and training requirements (Training Requirements below). See Chapter 388-76 WAC for more on adult family home licensing requirements. The current training curriculum for dementia in AFH setting, is entitled “Dementia, Level 1: Dementia Capable Caregiving.”

AVAILABILITY: In August 2022, there were 4,232 licensed AFHs (4,117 of which have met the requirements to be designated as dementia specialty homes).

⁴⁸ Unpublished DSHS-RDA data. Mancuso, 6.10.23 Unduplicated persons receiving ALTSA in-home services in any month in CY 2020.

⁴⁹ Unpublished DSHS-RDA data. Mancuso, 6.10.23 Unduplicated persons receiving ALTSA in-home services in any month in CY 2020.

MEDICAID REIMBURSEMENT RATES: Medicaid rates for LTSS services may change each year. Up to date information may be found on the DSHS/ALISA website. [Office of Rates Management | DSHS \(wa.gov\)](#)

Rates vary depending on CARE Classification (i.e., Level/type of care needed)

Currently, rates are set at:

- King, Pierce and Snohomish Counties: \$121.13 - \$230.18 per day
- Other Counties: \$110.73 - \$205.27 per day

An Expanded Community Services (ECS) Add-on rate is available and can be seen at the site above for Medicaid Reimbursement rates.

Assisted Living Facilities

Assisted Living Facilities (ALFs), formerly called “boarding homes”, are community-based residential settings licensed to provide care for seven or more residents, with the express purpose of providing housing, basic services (assistance with personal care, activities of daily living and room and board) and the general responsibility for safety and well-being of the resident. See Chapter 388-78A WAC. ALFs are available to individuals requiring support and supervision. Some ALFs provide intermittent nursing services or may serve residents living with mental health problems or dementia. The majority are privately owned businesses. Most residents pay for their care privately.

If an ALF serves one or more clients with special needs, such as dementia, all long-term care workers must receive training regarding the specialty needs of individual clients in the home. (Training Requirements below). The current training curriculum for dementia in ALF settings, is entitled “Dementia, Level 1: Dementia Capable Caregiving.”

AVAILABILITY: In August 2022, there were 554 licensed Assisted Living Facilities in Washington State.

MEDICAID REIMBURSEMENT RATES: Medicaid rates for LTSS services may change each year. Up to date information may be found on the DSHS/ALISA website. [Office of Rates Management | DSHS \(wa.gov\)](#)

Rates vary depending on CARE Classification (i.e., Level/type of care needed)

Currently, rates are set at:

- King, Pierce and Snohomish Counties: \$99.81 - \$208.62 per day
- Other Counties: \$92.29 - \$195.47 per day

An Expanded Community Services (ECS) Add-on rate is available, as is a Capital Add-on rate, and can be seen at the site above for Medicaid Reimbursement rates.

Specialized Dementia Care Settings within ALFs

There are currently no standards or definition in the private pay market of what “memory care” or “specialized dementia care” units are or must provide. With no standard terminology, the number of such specialized memory care or dementia units in ALFs across the state is not officially tracked. The Dementia Action Collaborative, as part of their work, though, reviewed websites, marketing materials and contract information, and contacted facilities directly to create an estimate. As of 2023, there are around 252 ALFs advertising themselves as offering dedicated memory care services either in an entire building/facility or a specific dedicated portion of a building/facility.

For publicly funded residents, Washington state has a Specialized Dementia Care Program (SDCP) contract, with standards, to guide practices for those on Medicaid.

The SDCP serves individuals living with Alzheimer’s disease or other dementia who are eligible for both the Medicaid/COPES waiver and the SDCP. SDCP services are provided within facilities that are either dedicated solely to the care of persons living with dementia or providing such care in a separate unit dedicated solely to the care of persons living with dementia within larger facilities. Pilot project findings demonstrated that participation in the SDCP resulted in significant delay in nursing home placement. Standards of Care were adopted and placed into WAC 388-110-220(3) in 2003. SDCP eligibility can be found in WAC 388-106-0033.

AL TSA has also been piloting, and determining feasibility of, a SDCP Plus model which builds upon the SDCP contract by adding an increased staffing requirement along with behavioral supports. To be eligible for this program clients must meet SDCP eligibility criteria, and either be discharging or diverting from a state hospital or in long-term civil commitment.

AVAILABILITY: In 2023, the Specialized Dementia Care Program contract (to serve eligible Medicaid clients) was available in all DSHS regions through contracts with 83 facilities. The SDCP served 1,018 individuals during 2022.

MEDICAID REIMBURSEMENT RATES: Medicaid rates for LTSS services may change each year. Up to date information may be found on the DSHS/AL TSA website. [Office of Rates Management | DSHS \(wa.gov\)](#)

Rates vary depending on CARE Classification (i.e., Level/type of care needed)

Currently, rates are set at:

- King, Pierce and Snohomish Counties: \$147.06 - \$252.10 per day
- Other Counties: \$140.12 - \$233.53 per day

Expanded Community Services (ECS)

Expanded Community Services (ECS) are designed for clients with exceptional care needs due to behavioral or mental health issues when current services are not adequate due to significant behavioral challenges. ECS offers an enhanced rate to specifically contracted COPES residential providers (AFHs, ALFs) or Expanded Community Services-contracted skilled nursing facility providers (for assisted living facilities this enhanced rate is created through an “Add-On” to the rates determined by CARE Classification for setting type); and includes behavioral support services that are provided through contracts with COPES Expanded Community Services Behavior Support Specialist providers or through the Skilled Nursing Facility enhanced rates.

The contracted behavior support services include:

- Person-centered, on-site client training for the client and caregiving staff;
- An individualized crisis response and behavior support plan that is reviewed and modified as the client’s needs change; and
- An individualized crisis response and behavior support plan that is reviewed and modified as the client’s needs change; and
- Monthly psychopharmacological medication reviews.

AVAILABILITY: In 2023, there are 1,506 AFHs and 59 ALFs with ECS contracts and 26 SNFs with an EBS contract across the state.

MEDICAID REIMBURSEMENT RATES: Medicaid rates for LTSS services may change each year. Up to date information may be found on the DSHS/AL TSA website. [Office of Rates Management | DSHS \(wa.gov\)](#)

Currently, rates are set at:

- Adult Family Homes + ECS
 - King, Pierce and Snohomish Counties: \$221.91 - \$230.18 per day
 - Other Counties: \$221.91 - \$221.91 per day
- Assisted Living ADD-ON (for AL contracts)
 - King, Pierce and Snohomish Counties: \$0.18 - \$46.29 per day
 - Other Counties: \$1.35 - \$53.87 per day
- Assisted Living ADD-ON (for EARC contracts)
 - King, Pierce and Snohomish Counties: \$.60 - \$68.68 per day
 - Other Counties: \$1.35 - \$68.68 per day

Enhanced Services Facility (ESF)

Enhanced Services Facility (ESF) is a residential option, of 8 to 16 beds, reserved for individuals with the highest level of mental health and/or chemical dependency disorders; organic or traumatic brain injuries; and/or cognitive/developmental impairments, who have not been successful in other residential settings. Clients in an ESF will receive personal care services, medication oversight, and specialized staffing, with 24-hour on-site nursing with 8 hours per day of behavior support provided by on-site behavioral health professionals to implement client-specific behavior support plans. Behavioral and mental health services are provided by a Managed Care Organization through the client’s private insurance or Medicaid coverage.

ESF contract requires the provider to include: (1) behavior support section in each client’s Person-Centered Service Plan (PCSP); (2) A crisis prevention and response protocol (3) A plan to ensure coordination with local community crisis responders.

AVAILABILITY: In 2023, there are 9 Enhanced Services Facilities across Washington located in Everett, Lakewood, Olympia, Spokane, Spokane Valley and Vancouver.

MEDICAID REIMBURSEMENT RATES Medicaid rates for LTSS services may change each year. Up to date information may be found on the DSHS/ALISA website. [Office of Rates Management | DSHS \(wa.gov\)](#)

Currently, rates are set at:

- Enhanced Services Facility
 - \$596.10 per day
- Unified Residential Care ESF (Provides additional support services)
 - \$596.10 per day

Skilled Nursing Facilities (SNF)

Skilled Nursing Facilities (SNFs) provide care for individuals whose conditions are complex and/or medically unstable and who require frequent medical or nursing interventions. These facilities have nursing services 24-hours a day. They provide at least daily nursing supervision to residents needing health services and restorative or maintenance assistance with medications, eating, dressing, walking and other personal care needs.

AVAILABILITY: In 2022, there were 202 Skilled Nursing Facilities across Washington State. DSHS data from CY 2020, reveal that 58% of LTSS clients (age 65+) and 51.8% (all ages) in skilled nursing home services had indications of dementia, including Alzheimer’s disease.⁵⁰

⁵⁰ Unpublished DSHS-RDA data. Mancuso, 6.10.23 Unduplicated persons receiving ALISA in-home services in any month in CY 2020.

MEDICAID REIMBURSEMENT RATES:

- The Weighted Average Daily Rate, effective 8/1/23, is \$359.97, representing a wide range of daily rates. SNF rate website: <https://www.dshs.wa.gov/altsa/management-services-division/nursing-facility-rates-and-reports>.
- An ADD-ON rate for eligible Medicaid clients is available for Expanded Behavior Services (EBS).

Dementia-Specific Training Requirements

The State of Washington has been working towards strong training requirements related to dementia care in varied settings and provider types.

Licensed Certified Nursing Staff

Licensed certified nursing staff, including Registered Nurses (RNs), Licensed Practical Nursing (LPNs), and Nursing Assistants-Certified (NACs), have standards of practice and competencies expectations to include maintaining, updating and demonstrating sufficient knowledge, skills, and judgement to practice safely and ethically in their designated role. Post-licensure, RNs and LPNs participate in on-going continuing education to augment professional knowledge, skill set and judgement. The ongoing trainings may be obtained through mentorship programs, clinical presentations, certification classes, and specialty certification classes. It is expected each discipline must have the optimal knowledge base to work within the specialty needs of their resident population – including understanding and meeting the needs and behaviors of individuals with cognitive impairment including Alzheimer’s disease, dementia, delirium, developmental disabilities, mental illnesses, and other conditions.

To be certified to practice in Washington as a Nursing Assistant-Certified (NAC), regulations mandate that in addition to general competencies, nursing assistants must be able to identify the psychosocial characteristics of patients living with dementia and Alzheimer’s disease. In addition, the regulations specify the areas of competency that are considered standards of practice for nursing assistants. A nursing assistant must demonstrate competency in the care of residents living with Alzheimer’s disease and dementia in the following areas: (a) uses techniques for addressing the unique needs and behaviors of individuals with cognitive impairment including Alzheimer’s disease, dementia, delirium, developmental disabilities, mental illnesses, and other conditions; (b) communicates with cognitively impaired clients or residents in a manner appropriate to their needs; (c) demonstrates sensitivity to the behavior of cognitively impaired clients or residents; and (d) appropriately responds to the behavior of cognitively impaired clients or residents.

Nursing Homes

Each nursing home must provide residents who are living with dementia, an environment designed to attain or maintain the highest level of functioning and wellbeing possible. All staff who have direct resident contact, must be trained in special needs and care approaches applicable to residents living with dementia. The training must be ongoing and consistent with the requirements of the nursing home staff development program. Staff development programs, under the direction of RN or LPN, must include in-service education to maintain a knowledge base specific to the resident population, including dementia care as applicable. Facility must have staff with the appropriate competencies and skills sets to provide nursing and related services to assure resident safety and attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident, as determined by resident assessments and individual plans of care. Training requirements include dementia management training and resident abuse prevention training.

Long-Term Care Workers

Long-term care workers include all persons who provide paid, hands-on personal care services for older adults or persons with disabilities, including Individual Providers of home care services, direct care workers employed by home care agencies or a consumer directed employer, providers

of home care services to persons with developmental disabilities under Title [71A RCW](#), all direct care workers in state-licensed assisted living facilities, enhanced services facilities, and adult family homes, respite care providers, direct care workers employed by community residential service businesses, and any other direct care worker providing home or community-based services to the elderly or persons with functional disabilities or developmental disabilities.

Washington state, per [RCW 74.39A.074](#), has training requirements for long-term care workers who provide personal care services to older adults or those living with disabilities. Long-term care services are provided by employees of licensed home care agencies, Adult Family Homes, Assisted Living Facilities and Individual Providers. Home care agency workers provide care for clients in their own homes.

Long-term care workers who are not an RN, LPN, Advanced Registered Nurse Practitioner or Nursing Assistant-Certified are required to complete 5 hours of orientation and safety training before providing paid personal care – and 70 hours of basic training on topics, including dementia, within the first 120 days. They must apply to the Department of Health (DOH) for a Home Care Aide credential, and they have up to 200 days (or 260 days if they are non-English speakers) from their date of hire for DOH to issue them this credential which includes passing a written and skills demonstration certification exam.

The Department of Social and Health Services, within one of its functions, licenses and monitors the state’s residential care options, including Assisted Living Facilities (ALF) and Adult Family Homes (AFH). Within that network, three care specialties currently exist which require long-term caregivers to receive specialty training, one of which is related to dementia. These three specialties have established training curricula and requirements that are detailed in the Washington Administrative Code (WAC), Chapter 388-112 – Residential Long-Term Care Services.

The current training curriculum for dementia in AFH and ALF settings, is entitled “Dementia, Level 1: Dementia Capable Caregiving.” It is an eight-hour DSHS required specialty training that was updated in 2020 to cover competencies established for separate 30-hour geriatric behavioral health curriculum. Approved instructors have completed required coursework in dementia and adult education and meet RCW requirements for education and experience.

Training provides the learner with the following:

- Introduction to dementia
- Hallucinations and delusions
- Enhancing quality of life
- Working with families
- Sexuality and intimacy
- Medications treatments and therapies
- Activities of daily living
- Communication
- Trauma-informed care
- Challenging behavior support

As of this report writing, DSHS/ALTSAs Training Unit is working to create eLearning courses from the lessons within this curriculum, although the full course will not be available for some time. An original recommendation from a 2014 stakeholder group (SSB 5630) related to improving and expanding specialty training for ALF and AFH called for a level 2 and level 3 training, although at this time, it is not in the queue for development.

Individual Providers (IPs) provide care to Medicaid-eligible older adults in their own homes. Consumer Direct Care Network Washington (CDWA) is the legal employer of all IPs in the state of Washington. CDWA is responsible for payroll, background checks, collecting employment documents, monitoring credentialing, tax reporting, and employment-related instruction. Per a Collective Bargaining Agreement, all IPs are trained by the SEIU 775 Benefits Group (BG)/Training Partnership. The BG does include dementia and mental health topics in their Home Care Aide certification training, however, not all IPs are Home Care Aides. IPs do have requirements for population-specific training, which may include dementia. As part of their basic training (population-specific courses) or Continuing Education, learners have options to take population-specific courses that should reflect the needs of their clients.

State funding and Alzheimer’s disease research through Washington universities

The University of Washington is home to the NIH-designated Alzheimer’s Disease Research Center (UW ADRC). In existence since 1985, the UW ADRC is an active collaborator in multiple national initiatives that harness the combined power of the thirty-seven national Alzheimer’s Disease Research Centers. The UW ADRC’s current scientific focus is investigating the biological heterogeneity of Alzheimer’s disease— the different biological mechanisms of Alzheimer’s disease and other degenerative dementias (ADRD), as well as the factors that counter them. New technologies have emerged to analyze the biology of ADRD and require well characterized human subjects and well-curated biospecimens which the UW ADRC provides to hundreds of other research projects and studies. The UW ADRC advances research in numerous areas, including genetic risk, developing neuroimaging and body fluid biomarkers for pre-clinical detection, and discovering novel treatments tailored to the specifics of an individual’s disease. Additionally, UW ADRC has a particular focus on increasing the inclusion of LatinX and American Indian/Alaska Natives in our research activities.

To date, the UW ADRC has had the following accomplishments in three core areas of focus:

Research

1. Discovered new genes for early onset Alzheimer’s disease and frontotemporal dementia
2. Pioneered the investigation of other genetic contributions to the risk for AD
3. Made major contributions to determining mechanisms of disease, and for risk and protective factors for Alzheimer’s disease
4. Published over 1000 peer-reviewed scientific papers
5. Developed novel biomarkers of Alzheimer’s disease, such as blood-based biomarkers, and imaging biomarkers
6. Collaborated with and provided participants, samples, tissues, and/or data to hundreds of research teams to accelerate discovery in all areas of ADRD research

Clinical

1. Currently enrolls and follows over 400 volunteers living with Alzheimer’s disease, related dementias, and cognitively normal people in clinical research
2. Conducts clinical trials for treatment of Alzheimer’s disease, both for slowing its progression, and for prevention

Training and Outreach

1. Uses the Community-based participatory research (CPBR) model to engage with underserved groups in the Pacific Northwest, in particular the LatinX communities and Native Americans, to foster greater inclusion in research
2. Trained hundreds of students, postdoctoral fellows, clinical fellows, and junior faculty to become the field's future leaders and workforce
3. Presented over 2000 community education and outreach events across the Pacific Northwest
4. Works to effectively inform the community, patients, families, and health care providers of progress in Alzheimer's disease research, treatment, and prevention

The UW ADRC Satellite Core is located at Washington State University's (WSU) Partnership for Native Health (P4NH). The P4NH is housed within the Institute for Research and Education to Advance Community Health (IREACH) at Washington State University. In existence since 2009, conducting community-centered research to improve health, health care, and quality of life of American Indians and Alaska Natives through an interdisciplinary approach. More information can be found on their [website](#).

Starting in 2020, the UW ADRC developed the Research Education Component (REC) which provides training and mentoring opportunities to new researchers entering the Alzheimer's disease and related dementia research space. Activities include lectures, training on ADRC resources, annual ADRC symposium, and the development of an annual Open Neuroscience Workshop. The REC opportunities are available via zoom.

Currently, the UW ADRC supports (in part) over thirty faculty and over sixty staff or other non-faculty roles. The annual budget for the UW ADRC is approximately \$3 million, which includes both direct and indirect funds. The research resources provided by the ADRC support affiliated studies at the UW and surrounding institutions, including teams at Washington State University and the Allen Institute for Brain Science, that collectively amount to at least 10 times this amount of funding. The National Institute of Health provides the bulk of the research funding, totaling nearly \$70 million since 1985. The State of Washington provides funding in the form of tenure line partial salary for some faculty who are members of UW ADRC. In addition to grant funds, the UW ADRC has received approximately \$10 million in donations, including a major gift from the Ellison Foundation to advance precision medicine for Alzheimer's disease.

B: Inventory of Long-Term Services and Supports

Background

Individuals living with dementias and their care partners can access information and supportive services through organizations in the private sector such as the Alzheimer’s Association Washington State Chapter, Dementia Support Northwest, or through home care agencies and adult day services centers. Because of the duration of illness and changing care needs over time, many individuals with dementia may eventually turn to long-term services and supports (LTSS) provided by state and federal public funding such as the Older Americans Act and Medicaid.

Washington State has developed a statewide network of home and community-based services – these range from information and assistance, meals or education around disease management to assistance with tasks such as bathing, dressing, ambulation, transfers, toileting, medication administration/reminders, personal hygiene, meal preparation, transportation and other personal, household or health-related tasks. These services and supports allow individuals to choose the setting and services that will best meet their needs and preferences for quality, independence and self-determination.

Adults with dementia of every stage are served in programs and settings throughout the LTSS system. This has prompted, over time, the development of some dementia-specific services targeted to the particular needs of the population. Other services, while not dementia-specific, assist a substantial number of people living with memory loss or dementia.

Included below is an inventory of publicly funded long-term services and supports available for people with dementias and/or their family care partners.

Services Available through Aging & Disability Network

Area Agencies on Aging (AAAs) provide a network of community-based services funded by local, state and the federal Older Americans Act funding. The table below provides a summary of these services and programs. A number of programs offered through the Older Americans Act and State funds are required by all AAAs and others are discretionary and decisions about priorities and funding levels are made through the local Area Planning process.

Service/Program	Target Population	Description/Limitations
Building Dementia Capable Communities	People living with dementia of any age, and/or people not yet diagnosed that are concerned they may have dementia. Unpaid family caregiver of individual with dementia.	Building Dementia Capable Communities (also referred to as the Dementia Resource Catalyst) program, is designed to: support people living with dementia to stay active, socially engaged, and in their own homes; support family caregivers so they can stay healthy and continue to help their family member; increase the dementia-capability of Area Agencies on Aging (AAAs), Family Caregiver Support Programs (FCSPs) and aging network partners; and promote efforts to build Dementia Friendly Communities. As of June 2023, two AAAs are receiving funds to demonstrate this program. A third was funded for FY 2024.

Service/Program	Target Population	Description/Limitations
Memory Care & Wellness Services	<p>Unpaid family caregivers who care for a person with a diagnosis of Alzheimer’s disease or other dementia (care receiver).</p> <p>Funded through the Family Caregiver Support Program when the following criteria are met, including: The care receiver must live at home (not in a licensed care setting), and either live with the primary family caregiver or be receiving 40+ hours per week of care/supervision from the family caregiver. Caregiver eligibility is based on TCARE® assessed levels of burden, depression, etc. (See more on TCARE® in the Appendix, under the FCSP).</p>	<p>Availability: Two current AAAs with this program funding are the Northwest Regional Council (Island, San Juan, Skagit, Whatcom counties) and Aging and Long-Term Care of Eastern Washington (Ferry, Pend Oreille, Spokane, Stevens, Whitman counties).</p> <p>Memory Care and Wellness Services is an evidence-informed, dementia-specific day program for individuals and family caregivers. The program offers a blend of health, social and family caregiver supports and integrates a structured, specialized exercise program called Exercise for Mobility</p> <p>A University of Washington study of Memory Care and Wellness Services showed that for participants in the program with dementia, quality of life improved and the frequency of behavior problems decreased. For family caregivers, distress over behavior problems decreased for caregivers in the program, while distress increased in the comparison group of caregivers. Depressive symptoms, stress and burden also decreased for caregivers participating in the Memory Care and Wellness program.</p> <p>Availability: The Memory Care & Wellness Services program is offered by Full Life Care of King County in Partnership with Aging and Disability Services of Seattle and King County.</p>
Reducing Disability in Alzheimer’s Disease	<p>Individuals with Alzheimer’s Disease or other dementia with assistance from a family care partner.</p>	<p>Reducing Disability in Alzheimer’s Disease (RDAD) is an evidence-based dementia caregiving program offering nine home visits by a trained, certified “coach” over the course of six-weeks. It’s focuses on safe and gentle exercises for the person with dementia and training care partners to manage behavioral symptoms by identifying pleasant events.</p> <p>Availability: RDAD is currently offered by Aging & Disability Resources of Pierce County.</p>

Service/Program	Target Population	Description/Limitations
STAR-C Dementia Consultation (focus on Behavioral Problem-Solving)	<p>Unpaid family caregivers who care for a person with Alzheimer’s disease or other dementia.</p> <p>Funded by the Dementia Catalyst Program when the following criteria are met: The care receiver must live at home (not in a licensed care setting), and must meet certain FCSP eligibility based on TCARE® assessed levels of burden, depression, etc. (See more on TCARE® in the Appendix under the FCSP).</p>	<p>STAR-C is an evidence-based dementia consultation program for caregivers. Trained, certified consultants provide in-home education and consultation during four home visits and offer additional phone support over a six-week period.</p> <p>Developed at the University of Washington, this in-home education/consultation program has shown to improve care receiver quality of life, reduce the frequency of problem behaviors, and lower caregiving depression, burden, and distress over care receiver behavior changes.^{11,12}</p> <p>Availability: STAR-C Dementia Consultation is available through limited funding in six Area Agencies on Aging. Further expansion would require additional infrastructure funding.</p>
Community Living Connections (Also known as Aging and Disability Resource Centers or No Wrong Door System)	<p>Older adults (60+) or individuals with disabilities and/or their family/caregivers, regardless of economic circumstances.</p> <p>While not dementia-specific, Community Living Connections serves individuals and families living with memory loss/dementia.</p>	<p>The Community Living Connections (CLC) network provides individuals and families living with dementia a local access point to call for information, person-centered options counseling, care transition coaching, and assistance to access services.</p> <p>Services include, but are not limited to: Information-giving, options counseling, and access assistance.</p> <p>Availability: Programs and services are available statewide through Area Agencies on Aging for older adults and individuals who are helping older adults. Also available is a statewide website and resource directory at www.waclc.org or by calling 855-567-0252.</p>
Aging & Disability Network Services (In-Home Services)	<p>Individuals age 60+, though delivery is targeted to the most vulnerable adults, including individuals with memory loss/dementia.</p> <p>National statistics indicate around 6% - 17% of clients served in these programs have a memory-related illness.</p>	<p>The Aging & Disability Network consists of Area Agencies on Aging statewide that provide an array of home and community services including nutrition, transportation, adult day services, ombudsmen services, legal assistance, and support services and assistance.</p> <p>Services enhance the quality of life, social interaction, and reduce the effects of chronic illness or disability for homebound as well as more active seniors.</p>

Service/Program	Target Population	Description/Limitations
Care Transitions	<p>Funded by Older Americans Act Title III.</p> <p>Individuals of all economic backgrounds and ages however, different geographical areas have garnered different funding sources that target specific populations.</p> <p>No statistics specific to dementia/cognitive impairment are available. The model is well suited to serve individuals with dementia or depression, provided they have willing and able informal caregivers.</p>	<p>Availability: Available statewide through the 13 Area Agencies on Aging.</p> <p>Care Transition services are provided to support acute care hospital discharge. This may include: assessment of needs, arrangement, coordination and monitoring of services and resources to support these transitional needs.</p> <p>Services are provided through Area Agencies on Aging who develop and utilize existing partnerships and protocols with local hospitals to accept acute care discharge and long-term care referrals and assist with care transition from hospital to home or facility to home.</p> <p>Length of support will vary based on local program guidelines.</p> <p>Availability: As of SFY23 all 13 AAA's have been allocated state specific Care Transitions funding. Note: Some programs still in development.</p>
Chronic Disease Self-Management Program (CDSMP)	<p>Individuals who are age 18+ with one or more chronic conditions. Family, friends, and caregivers of people with chronic conditions are welcome to attend CDSME workshops. Workshops are appropriate for people living with early-stage memory loss and their caregivers.</p>	<p>The AL TSA (AL TSA) continues work on the 3-year ACL Chronic Disease Self-Management Programs (CDSMP) sustainability grant project through April 2023. Together with DOH, and Accountable Communities of Health (ACH's), AL TSA is building infrastructure to sustain, regionalize and scale CDSMP programming. Our goal is to create a regionalized hub-and-spoke or "dandelion" network model for providing CDSMP.</p> <p>This work has been done with Comagine Health as the core organization and various community partners and host organizations as spokes. Additionally, this project focuses on promoting health equity by increasing access to CDSMP for underserved, primarily rural populations.</p> <p>The specific types of CDSME program that Washington State have implemented included:</p> <ol style="list-style-type: none"> 1) Chronic Disease Self-Management Program

Service/Program	Target Population	Description/Limitations
		<p>2) Tomando Control de su Salud 3) Diabetes Self-Management Program 4) Chronic Pain Self-Management 5) Better Choices, Better Health (Online CDSMP)</p> <p>Availability: CDSMP is available statewide through at least 16 organizations partnering with Comagine.</p>
<p>Family Caregiver Support Program (FCSP)</p>	<p>Unpaid family caregivers of adults (18+) with functional disabilities.</p> <p>During an initial screening, unpaid family caregivers are asked if the person they are caring for has problems with memory or cognition.</p> <p>In 2022, statistics reveal around 70% of care receivers have either a firm diagnosis of Alzheimer’s disease/dementia or suspected memory/cognition problems.</p>	<p>The Family Caregiver Support Program (FCSP) offers an evidence-based caregiver assessment & consultation and care planning process (TCARE®) in addition to support and services that includes: help in finding and accessing local resources and services; caregiver support groups and counseling; training on specific caregiving topics (including Alzheimer’s disease/dementia); education (e.g., Powerful Tools for Caregivers); respite care; access to supplies/equipment; and support/practical information and caregiving suggestions.</p> <p>Several evidence-based services, mentioned above, are supported through Family Caregiver Support Program funding. (See Appendix for more information).</p> <p>Availability: Family Caregiver Support Program is available statewide.</p>
<p>Legal Services</p>	<p>Individuals 60 years of age or older with a focus is on socially and economically needy older individuals who are experiencing legal problems.</p>	<p>Legal Services Programs foster a cost-effective, high-quality service that is integrated into the aging services network. The Legal Services Program provides access to the justice system by offering representation by a legal advocate (attorney, paralegal, or law student). Services provided include legal advice; brief legal services such as phone calls, letter writing, document review and drafting, or negotiation; representation at administrative hearings; representation in court; referral to other legal resources.</p> <p>Availability/Access Limitations: Targeting of services to the most vulnerable adults is necessary due to funding limitations. This results in waiting times for services such as the CLEAR Senior legal hotline.</p>

Service/Program**Dementia Legal Planning Project****Target Population**

Individuals with dementia of any age, individuals 60+

Description/Limitations

Made available through state funding on behalf of the Dementia Action Collaborative to promote early legal and advance care planning, this project is operated by the Washington State Pro Bono Council. It offers assistance to eligible individuals who need help navigating the completion of the following legal documents: Powers of attorney for finances and health care, health care directives, dementia directive form.

The program trains and matches volunteer lawyers with eligible clients for assistance. For more information <https://www.probonocouncil.org/dementia-legal-planning>

Availability/Access Limitations: While not managed or coordinated by the AAAs, the service is available statewide, through either in-person or virtual means as needed for eligible individuals. This free service does not provide legal assistance beyond form completion and is subject to capacity.

Washington Caregivers Learning Portal
wacaregivingjourney.com

Unpaid family caregivers

The Washington Caregivers Learning Portal is an online education and training platform, for family caregivers of older adults. The learning portal provides on-demand, personalized skills-based training to help caregivers provide care confidently and keep their loved ones at home for longer, in order to improve outcomes and reduce costs of care. It offers education and instruction about Alzheimer's, safety and injury prevention, brain health, diabetes, stroke, caregiver wellbeing, and many other health related topics.

The Washington Caregivers Learning Portal is powered by Trualta Care Network's proprietary learning management system.

Availability: Free to all residents of Washington at wacaregivingjourney.com

Medicaid State Plan and Medicaid Waiver Services

The table below provides a summary of state plan and waiver services and programs that support individuals with care needs related to functional limitations. Programs provide services that meet the care needs of individuals with dementia, cognitive impairments, and physical limitations in community-based settings.

Service/Program	Target Population	Description/Limitations
Dementia Specialty Training (Dementia, Level 1: Dementia Capable Caregiving)	The Department of Social and Health Service’s Dementia Specialty Training is required for administrators and long-term care workers in Adult Family Homes and Assisted Living Facilities, serving both Medicaid and non-Medicaid clients	<p>Dementia, Level 1: Dementia Capable Caregiving is an eight-hour DSHS required specialty training.</p> <p>Approved instructors have completed required coursework in dementia and adult education and meet RCW requirements for education and experience.</p> <p>Training provides the learner with an</p> <ul style="list-style-type: none"> • Introduction to dementia • Hallucinations and delusions • Enhancing quality of life • Working with families • Sexuality and intimacy • Medications treatments and therapies • Activities of daily living • Communication • Trauma-informed care • Challenging behavior support <p>The course is instructor led and offered in-person and virtually by approved instructors. This course is accompanied by a textbook, interactive activities, and final exam.</p>
Specialized Dementia Care Program in Assisted Living Facilities (SDCP)	<p>Individuals who are both COPES and Specialized Dementia Care Program-eligible with Alzheimer’s disease or other dementia and receiving care in a facility contracted to provide Specialized Dementia Care Program services.</p> <p>Specialized Dementia Care Program eligibility is defined in WAC 388-106-0033.</p> <p>In 2022, the Specialized Dementia Care Program served 1,018 clients. (See Appendix for more information.)</p>	<p>Specialized Dementia Care Program (SDCP) services are provided within SDCP-contracted Assisted Living Facilities, which must be either dedicated solely to the care of persons with dementia or providing such care to persons with dementia in a separate unit dedicated solely to the care of persons with dementia within larger facilities.</p> <p>The Assisted Living Facility must be contracted with DSHS to provide Specialized Dementia Care Services, which include: care, supervision, and activities tailored to the specific needs, interests, abilities, and preferences of the person; coordination with the person’s family to ensure the person’s routines and preferences are</p>

Service/Program	Target Population	Description/Limitations
		<p>honored; dementia specific training for staff; awake staff twenty-four hours a day; a safe outdoor environment with walking paths and access to a secure outdoor area; and intermittent nursing services, help with medications, personal care, and other support services.</p> <p>The Specialized Dementia Care Program is available statewide, based upon availability of qualified providers. Currently, there are 85 contractors.</p>
<p>Community Options Program Entry Services (COPES)</p>	<p>To be eligible for Community Options Program Entry Services (COPES), individuals must be age 18 or older and blind, aged, or disabled per Social Security criteria; meet Nursing Facility Level of Care (NFLOC) criteria and income requirements, and live in their own home, Assisted Living Facility, or Adult Family Home. See Appendix for more on NFLOC.</p> <p>Cognitive impairment is a consideration in eligibility and in the algorithm that generates the level of service authorization/rates for long-term services and supports.</p>	<p>COPES Waiver services offer additional services beyond Community First Choice Services (CFC) to provide client training, skilled nursing, home delivered meals, home modifications, specialized medical equipment and supplies, transportation, adult day care, adult day health, and home health aides to those who qualify functionally and financially.</p> <p>Individuals can choose to receive COPES waiver services in home or community residential facility settings.</p>
<p>Community First Choice (CFC)</p>	<p>To be eligible for Community First Choice, individuals may be of any age, and have functional limitations due to age, physical, cognitive, intellectual, or mental health conditions and unmet needs for personal care; meet institutional level of care and income requirements; and live in their own home, Assisted Living Facility, or Adult Family Home. See Appendix for more on Nursing Facility Level of Care (NFLOC).</p>	<p>CFC services include personal care assistance, skills acquisition training, Personal Emergency Response Systems (PERS), training on how to manage a paid personal care provider, community transition services, nurse delegation, and assistive technology that increases an individual's independence or substitutes for human assistance with an activity of daily living or health-related task.</p>

Service/Program

Medicaid Alternative Care (MAC) and Tailored Services for Older Adults (TSOA)

Target Population

MAC eligibility:

Care Receiver (client) must meet all of the following criteria:

- Be age 55+;
- Currently receiving categorically needy (CN) or alternative benefit plan (ABP) Medicaid coverage group (Apple Health);
- Meets nursing facility level of care (NFLOC) but has chosen not to receive Medicaid LTSS other state programs;
- Resides in their own home or a family member's home; and
- Has an unpaid family caregiver who is age 18 or older.

TSOA eligibility:

Care Receiver (client) must meet all of the following criteria:

- Be age 55+;
- Be a U.S. citizen or have eligible immigrant status;
- Not currently eligible for categorically needy (CN) or alternative benefit plan (ABP) Medicaid coverage group (Apple Health);
- Meets nursing facility level of care (NFLOC);
- Meets financial requirements i.e., Income up to 300% of the Supplemental Security Income (SSI) Federal Benefit Rate; and has resources below \$53,100 for a single or \$112,990 for a married couple; and
- Has an unpaid family caregiver who is age 18 or older; or
- Does not have an unpaid family caregiver available.

Description/Limitations

The MAC-TSOA program, which began in 2017, offers an additional benefit package for individuals who are eligible for Medicaid but are not currently accessing Medicaid-funded LTSS.

Eligible clients may access a budget to be spent on a variety of services (budget around \$758 per month/2022).

The benefit package offers services similar to the Family Caregiver Support Program such as home delivered meals, Personal Emergency Response system (PERS) for fall prevention and medication management, home modifications, assistive technology, incontinence supplies, support groups and counseling, and more.

Service/Program	Target Population	Description/Limitations
Residential Support Waiver (RSW) Services	<p>The RSW serves clients who are returning to the community from state hospitals or community hospital psychiatric units, or have a history of failed/denied community residential settings, or are at risk of losing their current community residential setting due to behavioral challenges.</p> <p>Many RSW clients have been unsuccessful in other community residential settings. RSW clients require additional or specialized staffing to assist with complex behavioral or clinical needs and would require nursing facility services or a psychiatric setting as the alternative to a RSW community residential setting.</p> <p>Statewide reporting indicates there are currently 1801 Clients receiving RSW Services (ECS, SBS, ESF) as of September 2022.</p>	<p>The RSW is a home and community-based waiver designed to provide personal care, community options, and specialized services for eligible clients with personal care and behavioral support needs. The RSW provides a cohesive and comprehensive continuum of specialized services targeted to adults with extremely challenging behavior. All clients who receive RSW services should also receive behavior support services.</p> <p>Clients can receive RSW services in a variety of settings. The waiver offers three levels of residential services with progressively intensive supports designed to facilitate successful community living, while providing options based on client need.</p> <p>The RSW was authorized by the Centers for Medicaid and Medicare Services in August 2014.</p> <p>Guidelines for program services are in WAC 388-106-0336 through 0348. Licensing regulations are found in Chapter 388-107 WAC.</p>
Enhanced Service Facility (ESF)	<p>ESFs are designed for individuals with mental health and/or chemical dependency disorders; organic or traumatic brain injuries; and/or cognitive/developmental impairments who are relocating from a psychiatric hospital when acute inpatient treatment is no longer medically necessary, or the individual cannot benefit from active treatment. Additionally, ESFs are designed to accommodate Clients who require behavioral supports not available in other traditional settings (AFHs, ALFs, SNFs).</p>	<p>Enhanced Service Facilities range in 8 to 16 bed maximum capacity in a homelike environment that offers specialized 24 hour, on-site nursing supports and 8 hours a day of mental health professional engagement for behavioral supports.</p> <p>To be eligible, clients must meet Nursing Facility Level of Care (NFLOC), COPES waiver eligibility, and Enhanced Service Facility criteria. This new Medicaid program will be funded through a 1915(c) waiver. Additionally, access to community mental health, substance use services are provided to the client by the local Managed Care Organization through the client's private insurance or Medicaid coverage.</p>

Service/Program	Target Population	Description/Limitations
	<p>Statewide reporting indicates there are currently 87 Clients receiving ESF Services as of September 2022.</p> <p>ESFs are a component of expansion services that will create an additional 144 beds for the 2022 – 2023 biennium.</p>	<p>Additionally, ESFs provide:</p> <ul style="list-style-type: none"> • Person-centered Care Planning and Crisis Plans that address a client’s unique behavioral and personal care, medical or habilitative, dietary needs. • Access to meaningful personal interests/ activities. • Access to community mental and substance use or medical services. • Monthly psychopharmacological medication reviews. <p>ESFs are also designed to reduce rates of client re-hospitalization, homelessness, or incarceration because of their acute, complex behavioral needs.</p>
Expanded Community Services (ECS)	<p>Expanded Community Services are designed for clients with exceptional care needs due to behavioral or mental health issues when current services are not adequate for successful placement due to significant behavioral challenges.</p> <p>To be eligible, clients must meet COPES and Expanded Community Services program criteria.</p> <p>Statewide reporting indicates there are currently 834 Clients receiving ECS Services as of September 2022.</p>	<p>Expanded Community Services offers an enhanced rate to specifically contracted COPES residential providers (AFHs, ALFs) or Expanded Community Services-contracted skilled nursing facility providers; and behavioral support services that are provided through contracts with COPES Expanded Community Services Behavior Support Specialist providers or through the Skilled Nursing Facility enhanced rate.</p> <p>The contracted behavior support services include:</p> <ul style="list-style-type: none"> • Person-centered, on-site client training for the client and caregiving staff; • An individualized crisis response and behavior support plan that is reviewed and modified as the client’s needs change; and • An individualized crisis response and behavior support plan that is reviewed and modified as the client’s needs change; and monthly psychopharmacological medication reviews.
Specialized Behavior Supports (SBS)	<p>Clients receiving SBS in an AFH with an SBS contract will receive the same services as in an ECS setting in addition to receiving assistance from additional one-to-one staffing. The SBS contract requires an</p>	<p>Specialized Behavior Supports offers an enhanced rate to specifically contracted COPES residential providers (AFHs) and behavioral support services that are provided through contracts with COPES Expanded Community Services Behavior Support Specialist providers.</p>

Service/Program**Target Population****Description/Limitations**

additional 6-8 hours of daily staffing to provide closer supervision and behavioral support for each SBS client.

Note: an AFH with an SBS contract may only serve up to three SBS residents at any given time.

The contracted behavior support services include:

- Person-centered, on-site client training for the client and caregiving staff
- An individualized crisis response and behavior support plan that is reviewed and modified as the client's needs change; and
- An individualized crisis response and behavior support plan that is reviewed and modified as the client's needs change; and
- Monthly psychopharmacological medication reviews.

Additionally, the specialty contracted AFH for SBS will provide 6-8 hours of daily staffing to provide closer supervision and behavioral support for each SBS client.

Development of Activities Calendar that is client-centered to promote personal interests/activities & meaningful community engagement.

Health Home Services

Individuals with chronic illnesses who are eligible for Medicaid or both Medicare and Medicaid.

Individuals must have at least one chronic condition and be at risk for a second chronic condition. This significant risk for health problems can lead to unnecessary use of hospitals, emergency rooms, and other expensive institutional settings. (See Appendix for more information.)

Health Home Services provide integration and coordination of primary, long-term services and supports, and behavioral health/substance use services for high-risk, high-cost clients who could benefit from intensive care coordination. Health Home Care Coordinators deliver face-to-face services to actively engage the client to take care of their own health care, bridge the systems of care between providers, and identify potential gaps in care.

A Health Home provides six specific services beyond the clinical services offered by a typical primary care provider: comprehensive care management, care coordination, health promotion, comprehensive transitional care and follow-up, individual and family support, and referral to community and social support services.

Service/Program	Target Population	Description/Limitations
Medicaid Personal Care (MPC)	Individuals who meet the functional criteria based on the social service assessment and financial eligibility based on eligibility for a non-institutional categorically needy or Alternative Benefit Plan Medicaid Program. Functional eligibility for this program is based on Chapter 388-106 WAC .	<p>Medicaid Personal Care is a program allowed under Washington State’s Medicaid State Plan that provides assistance with activities of daily living to eligible individuals.</p> <p>Activities of daily living include tasks such as bathing, dressing, eating, toileting, transferring, ambulating, etc.</p> <p>Medicaid Personal Care services are available in the client’s own home, an Adult Family Home, or an Adult Residential Center.</p>
New Freedom Consumer Directed Services Program	<p>Individuals who are 18+ and blind, aged, or disabled per Social Security criteria; have functional disabilities based on medical issues or chronic illness; live in their own homes; and meet Nursing Facility Level of Care and income requirements (see Appendix for more information).</p> <p>New Freedom is currently operating in King and Pierce Counties.</p>	New Freedom is a voluntary budget-based program that provides participants, who are eligible for home and community-based services through the Medicaid waiver, the opportunity for increased choice and control over their services and supports. Funded through 1915(c) Medicaid waiver.
Program of All-Inclusive Care for the Elderly (PACE)	Individuals must be age 55 or older, meet Nursing Facility Level of Care (NFLOC), and live in the PACE service area. PACE is currently offered in King, Spokane, Snohomish and Pierce Counties.	The PACE program is a fully integrated managed care program that includes an Adult Day Health center component. PACE clients receive transportation to and from the PACE center to receive physical, occupational, speech therapy; medications; nursing services; clinic visits; meals and activities. The center includes quiet space, activities, and a “wandering walk” tailored specifically to clients with dementia.

Long-Term Services, Supports Settings, and Provider Types

Long-Term Services and Supports are provided in a number of settings and by many different types of providers. The table below provides a summary of the types of long-term care settings, providers, and non-Medicaid services.

Service/Program	Target Population	Description/Limitations
Assisted Living Facilities (ALF)	<p>ALFs are available to individuals who are age 18 and older requiring support and supervision. Services vary depending on the type of contract the ALF obtains from ALTSA.</p> <p>554 facilities across WA as of June 2023</p>	<p>An assisted living facility (ALF), formerly called a boarding home, is a community setting licensed to care for seven or more residents. The majority are privately owned businesses. The facility provides housing, basic services and assumes general responsibility for the safety and well-being of the resident. Most residents pay for their care privately. ALFs allow residents to live an independent lifestyle in a community setting while receiving necessary services from staff. ALFs can vary in size and ownership from a family operated 7-bed facility to a 150-bed facility operated by a large national corporation. Some ALFs provide intermittent nursing services or may serve residents with mental health problems, developmental disabilities, or dementia.</p> <p>ALFs that contract with ALTSA provide one or more of the following service packages:</p> <p><i>Assisted Living</i></p> <ul style="list-style-type: none">• Private apartments, with an emphasis on privacy, independence, and personal choice• Intermittent nursing services• Medication administration and personal care services <p><i>Adult Residential Care (ARC)</i></p> <ul style="list-style-type: none">• Medication assistance and personal care services• Residents may need/receive limited supervision <p><i>Enhanced Adult Residential Care (EARC)</i></p> <ul style="list-style-type: none">• Medication administration and personal care services• No more than two people will share a room• Intermittent nursing services

Service/Program	Target Population	Description/Limitations
		<p><i>Specialized Dementia Care Program (EARC-SDC)</i></p> <ul style="list-style-type: none"> • In a SDCP-contracted ALF which is dedicated solely to the care of persons with dementia or providing such care within a unit dedicated solely to the care of person with dementia. • Includes service package of EARC plus services outlined SDCP paragraph above.
<p>Adult Family Homes (AFH)</p>	<p>AFHs are available to anyone over age 18 requiring support and supervision.</p> <p>4,232 in WA as of June 2023</p> <p>4,117 with Dementia Specialty Training designation</p>	<p>Adult Family Homes (AFHs) are regular residential homes licensed to care for two to six residents. An AFH may be licensed to provide care to up to eight adults if the home receives approval under WAC Chapter 388-76 or 388-76-10032. The homes are private businesses and provide the residents with a room, meals, laundry, supervision, assistance with activities of daily living, and personal care. Some provide nursing or other special care and services. Primary authority for adult family homes can be found in Chapter 388-76 WAC and Chapter 70.128 RCW.</p> <p>Residents can pay privately or be funded through DSHS. AFH residents have the right to exercise reasonable control over life decisions. See www.aasa.dshs.wa.gov/Professional/afh/AFHinfo.htm for more information on Resident Rights and more.</p>
<p>Meaningful Day</p>	<p>Residents of Adult Family Homes Community First Choice (CFC) services.</p>	<p>Meaningful Day is available from an eligible Adult Family Home provider. It offers individualized activities to eligible clients. The Adult Family Home provider uses person centered planning to develop proactive individualized, strategies to engage individuals in activities designed to refocus behavior, improve health, and reduce challenging behaviors.</p>
<p>In-Home Care Service Agencies</p>	<p>Individuals who may be ill, disabled, or vulnerable, and wish to remain in a community-based setting.</p>	<p>Home care agencies recruit, train, pay, supervise, and handle the care provided by the aide they send to your home. These agencies are licensed by Washington State. Use The National Association of Home Care and Hospice locator to find a home care agency in your area or contact your local Senior Information and Assistance office.</p>

Service/Program	Target Population	Description/Limitations
Skilled Nursing Facility Care (SNF)	<p>Individuals whose conditions are complex and/or medically unstable and who require 24-hour medical or nursing intervention or oversight.</p> <p>202 Nursing Facilities across WA.</p>	<p>Skilled nursing facilities have nursing services available 24-hours a day. They provide daily nursing supervision to residents needing health services and restorative or maintenance help with medications, eating, dressing, walking, and other personal care needs.</p>
CDWA Consumer Directed Employers (Formerly Individual Providers)	<p>Individuals who need assistance with personal care or respite services.</p>	<p>CDWA is the consumer directed employer for Individual Providers working with individuals through in-home long-term care services. It is responsible for the hiring of qualified providers and monitoring for completion of initial and ongoing trainings.</p> <p>CDWA is also responsible for assisting individuals to find qualified providers.</p>
Adult Day Services	<p>Individuals who have an unmet need for personal care services, routine health monitoring with consultation from a registered nurse, general therapeutic activities, or supervision and/or protection.</p> <p>19 contracted providers in WA as of October 2022.</p>	<p>Adult Day Care (ADC) is a supervised daytime program providing core services for adults with medical or disabling conditions that do not require the intervention or services of a registered nurse or licensed rehabilitative therapist acting under the supervision of the client’s authorizing practitioner. Services may include personal care, routine health monitoring, health education, nutritious meals, or supervision/protection.</p> <p>Adult Day Health (ADH) is a supervised daytime program providing skilled nursing and/or rehabilitative therapy services in addition to the core services of adult day care. Adult day health services may also include physical therapy, Speech-language pathology, audiology, or counseling services.</p> <p>Memory Care & Wellness Services (MCWS) is an evidence-informed, dementia-specific day program for individuals and family caregivers. The program offers a blend of health, social and family caregiver supports and integrates a structured, specialized exercise program called <i>Exercise for Mobility</i>. Available in King County.</p>

Service/Program	Target Population	Description/Limitations
Continuing Care Retirement Communities (CCRCs)	Individuals who wish to live in an independent living setting but expect to need personal care or skilled nursing assistance at some point in the future.	<p>CCRCs give older adults the choice of living in one location for the duration of their life while guaranteeing that added care will be provided when needed. Individuals can move into a CCRC when they are fully independent, and access assisted living, personal care, and skilled nursing as their needs change.</p> <p>CCRCs have various levels of contract types. Individuals may enter CCRCs with different levels of financial commitment and service level agreements. Entry fees and monthly fees are typically included in the service agreement.</p>
State-Funded Volunteer Services	Adults age 18+ living at home and unable to perform certain personal care tasks due to a functional or cognitive impairment and not receiving services under Medicaid long-term services and supports.	Volunteer services provide assist with general household tasks. Tasks may include housekeeping, laundry, shopping, cooking, moving, minor home repair, yard care, transportation, supervision, communications, pet care, auto maintenance, socialization, electronic device/computer use, budgeting, emergency preparedness, access to benefits/employment opportunities, and health & nutrition enhancement.
Transportation <i>Public Transportation</i> <i>Dial-a-Ride</i> <i>Paratransit</i>	Individuals who need transportation to medical and health services, social services, meal programs or for shopping aid and cannot provide or arrange their own transport because they do not have a car, are unable to drive, cannot afford to drive, or require assistance to access public transportation.	<p>Transportation services help eligible clients with getting to and from social services, medical and health care services, meal programs, senior centers, essential shopping, and some recreational activities.</p> <p>Transportation services may include personal aid for those with limited physical mobility, door-to-door service, individually scheduled rides to appointments, and reduced fares.</p>
Personal Emergency Response Systems (PERS)	Individuals living alone who are unable to secure help in a medical emergency, or who are at risk of falling which if they fell would make it difficult to call for help	Although there are a wide variety of PERS products (also called Medical Alert Systems), typically a PERS basic/standard unit consists of a small button-sized transmitter that is worn by the individual, most individuals choose a pendant or wrist bracelet “help” button; and a console that is programed to signal a response monitoring center once a “help” button is

Service/Program	Target Population	Description/Limitations
		<p>activated. The response monitoring center is staffed by trained professionals and may be nationally or locally based.</p> <p>A few companies offer this service with differences in contract terms, technology, level of service, and cost that the user should be aware of. Companies provide this service by selling devices, renting devices, or providing paid monthly services. In some cases, the cost of the device may be subsidized by another program.</p> <p>Depending on the type of system used, service provided may include storing relevant medical information with a monitoring center, GPS location, medication reminders, 24/7 monitoring, direct communication with a monitoring center dispatcher, fall detection, an auto call to the identified the emergency contact, or an auto call to 911.</p>
Senior Centers	Individuals who would benefit from supplemental meals, a service point connection, or the social support of a communal setting.	Adult Activity, or Senior Centers, are spaces in a community where older people can meet, share a meal, get services, and take part in health, wellness, and recreational activities. Senior centers also serve as a referral hub, providing information about and referrals to services that may benefit older individuals.
Senior Nutrition	Individuals not able to prepare nutritious meals due to limited mobility, cognitive impairment, lack of knowledge or skills, or lack of incentive to prepare and eat meals alone.	<p>Nutritious meals are provided in community (congregate) settings or through home-delivery for individuals who have difficulty leaving their homes.</p> <p>Meals provided in a congregate setting meet at least one-third of the current Recommended Dietary Allowance and allow for special dietary needs. Home-delivered meals are provided at least once a day, five or more days a week. Meals may be hot, cold, frozen, dried, canned or supplemental foods with a satisfactory storage life.</p> <p>Additional senior nutrition services include outreach, case management, and referral to other types of services individuals may benefit from.</p>

Service/Program	Target Population	Description/Limitations
Office of Deaf and Hard of Hearing (ODHH)	Individuals who are deaf, hard of hearing, deaf-blind, or speech disabled.	<p>The Office of the Deaf and Hard of Hearing (ODHH) offers programs and services for Deaf, Deaf Blind, Deaf disabled, Hard of Hearing, Late Deafened, and Speech Disabled individuals, their families, and service providers to ensure that services and resources are accessible and inclusive to in Washington State.</p> <p>ODHH collaborates with Regional Service Centers and with the Deaf Blind Service Center to advocate for equitable social and human services.</p>
Department of Social and Health Services (DSHS)	Individuals in need of multiple types of social services to meet their basic needs and attain life stability.	<p>DSHS act as a resource network with individuals often accessing services and supports across administrations and divisions.</p> <p><i>Economic Services Administration (ESA)</i> ESA's core services include helping low-income people meet their basic needs and achieve economic independence through cash grants, food, and medical assistance. Also, Child Support Enforcement & Financial Recovery, and Disability Determination.</p> <p><i>Behavioral Health Administration (BHA)</i> Provides funding and supports effective prevention and intervention services for youth and families, and treatment and recovery support for youth and adults with addiction and mental health conditions. Includes Western and Eastern State Hospitals, Office of Forensic Mental Health Services, Office of the Patient Rights Ombuds, Services for American Indians and Alaska Natives, Community-Based Treatment, and the Special Commitment Center.</p> <p><i>Developmental Disabilities Administration (DDA)</i> Service areas include residential supports, personal care, employment supports, respite care, and case management.</p> <p><i>Division of Vocational Services (DVR)</i> Service areas include residential supports, personal care, employment supports,</p>

Service/Program	Target Population	Description/Limitations
		<p>respite care, and case management for those with an Intellectual Disability, Cerebral Palsy, Epilepsy, Autism or another neurological or other condition like Intellectual Disability.</p> <p>ALSA</p> <p>For Seniors and people with disabilities, and Kinship caregivers, provides support for community living and residential care, personal care, dementia care, family caregiver support and case management. Includes the unit of ALSA Tribal Affairs.</p>

Protective Services

Protective services safeguard the right of vulnerable adults to live a life free from mistreatment and abuse, financial exploitation, self-neglect, neglect by others, and abandonment. The table below provides a summary of these services and programs.

Service/Program	Target Population	Description/Limitations
<p>Adult Protective Services (APS)</p>	<p>Any adult 60+ who cannot care for him or herself; or adults 18+ that have a legal guardian; have a developmental disability, etc. (see full definition of target population/eligibility in Appendix).</p>	<p>APS receives and investigates allegations of abuse (physical, mental, sexual, and exploitation of person), abandonment, neglect, self-neglect, and financial exploitation of vulnerable adults living in their own homes and in facilities where there is an allegation of mistreatment by someone outside of the facility.</p> <p>APS is available statewide to individuals of all income levels.</p> <p>To make a report: Call 1-866-ENDHARM (1-866-363-4276) to report suspected abuse or neglect of a child or a vulnerable adult.</p>

<p>Long-Term Care Ombudsman</p>	<p>Residents living in a care facility and his/her relatives or friends.</p>	<p>The Long-Term Care Ombudsman Program is a federally mandated program which works to protect and promote rights of individuals living in licensed, long-term adult care facilities (e.g., adult family home, assisted living facility, nursing home). This is accomplished by providing information to consumers about their long-term care options, working to resolve problems on behalf of residents, and advocating for improvement in the long-term care system.</p>
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Service/Program**Office of Public Guardianship****Target Population**

Low-income individuals age 18+ that are receiving long-term care services; have been determined to the superior court to be incapacitated to make personal, medical, or financial decisions; and do not have a qualified or willing guardian.

Description/Limitations

The Office of Public Guardianship (OPG) acts as a conduit to provide qualified surrogate decision-makers for low-income adults in need of guardianship and/or conservatorship. The OPG contracts with Certified Professional Guardians and Conservators (CPGCs) to provide guardianship and/or conservatorship services when no one else is willing or able to serve. Established in 2007 as a pilot program, the program was expanded to serve King County in 2009, Snohomish in 2010, and Clark, Kitsap, and Thurston County in 2011. The program was permanently funded in 2019 and is now available statewide.

Priority is given to individuals who are: Indigent/homeless; At significant risk of harm from abuse, exploitation, abandonment, neglect or self-neglect; In imminent danger of loss or significant reduction in public services necessary to live successfully in the most integrated and least restrictive environment.

Inventory Appendix: Additional Information

Adult Family Home – A residential home in which a person or persons provide personal care, special care and room and board to more than one but not more than six adults who are not related by blood or marriage to the person or persons providing the services.

An adult family home may be licensed to provide care to up to eight adults if the home receives approval under [WAC Chapter 388-76](#) or [388-76-10032](#).

Adult family homes may also be designated as a specialty home (on their license) in one or more of the following three categories: Developmental Disability, Mental Illness, and Dementia if they meet all certification and training requirements. See Chapter [388-76 WAC](#) for more on adult family home licensing requirements.

Adult Protective Services target population – A Vulnerable Adult is: any adult 60+ who cannot care for him or herself; or adults 18+ that have a legal guardian; have a developmental disability; live in a facility licensed by DSHS; receive services from a DSHS-contracted individual provider; receive in-home services through a licensed health, hospice or home care agency; or have a personal care aide who performs care under his/her direction for compensation, per [74.39.050 RCW](#). More on Adult Protect Services can be found at: www.adsa.dshs.wa.gov/APS/

Aging and Disability Network Services – The National Aging Network (the Aging Network) was established in 1965 with the passage of the Older Americans Act and is one of the Nation’s largest provider networks of home and community-based care for older persons, adults with disabilities and their caregivers. The Administration on Aging, an agency in the U.S. Department of Health and Human Services, is a lead partner of the Aging Network which consists of 56 State Units on Aging, 629 Area Agencies on Aging, 246 tribal organizations, 20,000 service providers, and thousands of volunteers.

Area Agencies on Aging (AAAs) – local organizations that develop and promote services and options to maximize independence for elders, adults with disabilities, and family caregivers. Washington has thirteen Area Agencies on Aging that are comprised of county governments, regional councils, and tribes. A citizen advisory council guides the work. The Washington Association of Area Agencies on Aging is a membership organization made up of the 13 Area Agencies on Aging in Washington State that seeks to enhance the effectiveness of each AAA through a strong agenda of information, debate, advocacy and education.

Assisted Living Facility – a facility, for seven or more residents, with the express purpose of providing housing, basic services (assistance with personal care, activities of daily living and room and board) and the general responsibility for safety and well-being of the resident. See [Chapter 388-78A WAC](#) for more on assisted living licensing requirements.

Community First Choice (CFC) – Established by the Affordable Care Act (ACA) under 1915(k) of the Social Security Act, CFC is a Medicaid program intended to promote choice, flexibility, and community care over institutional care. CFC services are funded with a combination of state dollars and with Title XIX (Medicaid) federal dollars and is administered by the Washington State Department of Social and Health Services (DSHS).

Services are provided to eligible children and adults in their own home, an adult family home, or an assisted living facility. Services include Personal Care, Relief Care, Assistive Technology, Personal Emergency Response System (PERS), Caregiver Management Training, Community Transition Services and Skills Acquisition Training.

CFC services are an effective alternative to nursing home placement and are an integral component of Washington State’s successful rebalancing of services from institutional to community-based settings.

Community Living Connections (CLC) – known nationally as *Aging and Disability Resource Centers* or *No-Wrong-Door*, serve as integrated and unbiased focal points to make it easier for consumers to learn about and access long-term services and supports (LTSS). Serving persons of all ages and economic circumstances, CLCs provide: objective information about the full range of available public and private LTSS options; person-centered options and benefits counseling, person-centered plan development support; and help as needed and desired for plan implementation, including accessing services.

As part of their role, CLCs also provide evidence-based **care transition coaching**; where consumers (or their caregivers) learn self-management skills to ensure their needs are met during the transition from one setting or care-level to another. Patients who participate in care transition coaching are significantly less likely to be readmitted and more likely to achieve self-identified personal goals around symptom management and functional recovery, for as long as six to nine months. Community Living Connections relies on strong partnerships with other social services organizations; health care providers; and aging and disability advocates to create integrated cross-referring networks. A statewide website with resource directory and a toll-free number are available to further support consumers in learning about their options and how to access services.

Community Options Program Entry System (COPES) Waiver – COPES is a 1915c waiver, first implemented in 1982 and is one of the oldest waivers in the nation, offered by Home and Community Services. COPES provides for “wrap-around” services to those of CFC, as an alternative to nursing home care for aged, blind, or disabled adults who live in their own homes or residential settings. Services include environmental modifications, specialized medical equipment and supplies, non-medical transportation, home delivered meals, client training and wellness education, adult day health, adult day care, community choice guiding, community support goods and services, and skilled nursing.

Family Caregiver Support Program – The Family Caregiver Support Program (FCSP) services unpaid family caregivers. It integrates an evidence-based caregiver assessment/consultation and care planning process known as TCARE® - Tailored Caregiver Assessment & Referral®.

The *Tailored Caregiver Assessment and Referral (TCARE®)* system was created by Rhonda Montgomery, PhD and colleagues at the University of Wisconsin-Milwaukee. The TCARE® protocol is designed to tailor services to the unique needs of each caregiver thereby reducing stress, depression and burdens associated with caregiving. TCARE® provides a consistent, objective and reliable screening and assessment process that identifies at-risk caregivers, targets resources to those most in need and determines whether support and services make a measurable difference to caregivers. TCARE® also helps inform policy through the collection of statewide data. The effectiveness of TCARE® is documented in published research articles based upon a national randomized control study, in which Washington State participated. For more information, visit the national TCARE® website at www.tcare.ai.

Health Home Services – Health Home services are available to individuals with chronic illnesses and who are eligible for Medicaid or both Medicare and Medicaid. Individuals must also be at significant risk for health problems that can lead to unnecessary use of hospitals, emergency rooms, and other expensive institutional settings such as psychiatric hospitals and nursing homes. Washington uses a predictive risk modeling system called PRISM to find individuals who are at significant risk.

Individuals receiving Health Home services are assigned a Health Home coordinator who partners with beneficiaries, their families, doctors, and other agencies providing services to ensure coordination across these systems of care. The health home coordinator visits in-person and is also available by telephone to help the individual, their families, and service providers. For more information, go to: www.hca.wa.gov/Pages/health_homes.aspx

Memory Care & Wellness Services – A supervised daytime program for individuals with dementia and their family caregivers. Memory Care & Wellness Services (MCWS) offers a program that is a blend of health, social and family caregiver supports – it is defined, and requirements are specified in the “Memory Care & Wellness Services Standards of Care, December 2010” (currently under refinement).

Memory Care & Wellness Services build upon the core services listed under Adult Day Care and add the following: A program day of five hours, offered two days per week; staffing that accommodates increasing functional and behavioral support needs of participants as they progress in their dementia, including: 1:4 (vs.1:6) staff to client ratio; and skilled nursing and/or therapy and social services available during program hours for the participant with targeted education and support of the family caregiver, as needed. A structured, specialized exercise program, Exercise for Mobility is integrated into the program.

Started through federal Alzheimer’s demonstration grants, this program has shown that for individuals with dementia, quality of life improved and the frequency of behavior problems decreased. For family caregivers, distress over behavior problems decreased in participating caregivers while increasing in comparison group caregivers. Depressive symptoms, stress and burden also decreased. (Logsdon et al, 2014)

Nursing Facility Level of Care (NFLOC) criteria – The individual must: require care provided by or under the supervision of a registered nurse or a licensed practical nurse on a daily basis; have an unmet or partially met need with at least three ADLs as defined in [WAC 388-106-0355](#); or have cognitive impairment and require supervision due to one or more of the following: disorientation, memory impairment, impaired decision-making, or wandering and have an unmet or partially met need with an ADL as defined in [WAC 388-106-0355](#).

Reducing Disability in Alzheimer’s disease (RDAD) – RDAD is an evidence-based, in-home exercise program consisting of nine home visits by a specially-trained/certified RDAD “coach” over a six-week period.

RDAD research at the University of Washington demonstrated significant short and long-term benefits for people in the treatment group. Physical functioning improved and fewer participants ended up in nursing homes due to behavioral disturbances. (Teri et al, 2003; Logsdon et al, 2005)

During the one-hour in-home sessions, the coach teaches easy-to-follow exercises to both the caregiver and care receiver (i.e., the person with dementia). The coach teaches the caregiver how to encourage and safely supervise the care receiver while doing the exercises. The coach also teaches caregivers how to handle some of the problems that occur with older adults who have memory problems or dementia.

RDAD is currently being translated through a National Institute on Aging grant (2012-17), with Washington (and Oregon) AAAs in the following Washington areas: Olympic, King County, Pierce, Snohomish, Southwest WA, and Southeast WA. The federal grant is in operation from 2012-2017.

Specialized Dementia Care Program (SDCP) – Initiated as a partnership with providers, stakeholders, and the University of Washington (1999), the SDCP demonstrated the ability to accept and retain individuals with greater cognitive impairment and behavioral disturbances than traditional assisted living programs. For more information, see the University of Washington’s final outcome report on the [Dementia Care Pilot Project](#), 2003.

Participation in SDCP has shown to significantly delay nursing home placement. Based on the positive pilot project findings, Standards of Care were adopted and placed into [WAC 388-110-220\(3\)](#) in 2003. SDCP eligibility can be found in [WAC 388-106-0033](#).

STAR-C – STAR-C is an evidence-based dementia consultation program designed to help caregivers reduce or eliminate behaviors that are difficult to manage, such as anxiousness, resistance to care, wandering, or verbal or physical aggression.

This in-home education/consultation program, developed at the University of Washington, has shown to improve care receiver quality of life, reduce the frequency of problem behaviors, and lower caregiving depression, burden, and distress over care receiver behavior changes. (Teri et al, 2005; Logsdon et al, 2005) STAR-C is implemented in the caregivers' homes by skilled consultants who are certified by the University of Washington to deliver STAR-C. It is now delivered over a six-week period, with 4 home visits and more phone support.

STAR-C was first translated in Oregon through a federal demonstration grant and then modified into a condensed version in Oregon and Washington (2012-2014). It is now being continued in two service areas in Oregon and implemented in the following Washington areas: Central WA, King County, Lewis/Mason/Thurston AAA, Northwest WA, Southwest WA and Southeast WA.

Funding to pilot a translation of STAR-C into Washington's Family Caregiver Support Program occurred through Older Americans Act (OAA) Title III administrative funding in partnership with the University of Washington, ALTA and participating AAAs (using local FCSP funds to support service delivery). While the pilot has resulted in positive feedback from participating caregivers and AAAs along with the development of basic processes for certification of community consultants and integration into the FCSP, further expansion would require more infrastructure for ongoing sustainability and fidelity to this evidence-based practice.

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C: Suggested Actions for Partners

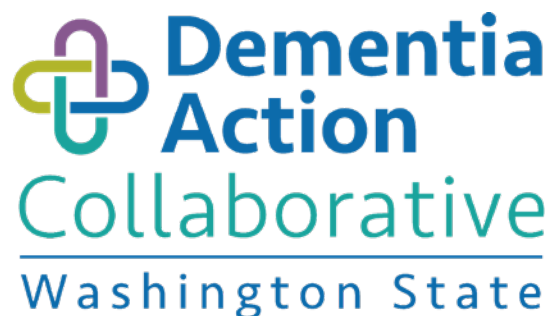
Suggested Actions for Individuals and Care Partners, Aging Network and Long-Term Supports & Services, Public Health Entities, Health Care Providers

Introduction

The goals, strategies and recommendations in the Washington State Plan to Address Alzheimer’s Disease and Other Dementias cannot be accomplished by the Dementia Action Collaborative (DAC) or state agencies alone. It will require individuals, stakeholders and community partners to take action that align with the goals, strategies and recommendations within the plan.

This section includes suggested action steps for a variety of targeted audiences. The document, intended for use electronically, also provides links to more information or resources related to suggested actions, when possible. Individuals, stakeholders, and community partners are invited to choose one or more action steps to implement that will support the plan implementation. Browse the ideas to learn more.

Working together on common goals and strategies, will allow a more coordinated and amplified response. The Dementia Action Collaborative invites everyone to join us in taking ACTION – be a part of the solution!



Possible Actions for Individuals and Care Partners

We can't cure dementia yet, but there are actions we can take to help individuals be aware of ways to reduce their risks for dementia, and to provide assistance and support for individuals living with dementia and their family caregivers. Below are suggested actions you can take!

<i>Suggested Action Steps</i>	<i>Learn More</i>
Learn about, and take actions, to keep your brain healthy.	ACL Talking About Brain Health
Learn about the warning signs of dementia – and the value of a timely diagnosis.	Dementia Washington State Department of Health 10 Early Signs and Symptoms of Alzheimer's
If you have warning signs of dementia, talk to your health care provider about them. If you notice warning signs in a family member, have a discussion with them around the importance of getting a medical evaluation.	Dementia Washington State Department of Health Washington State Chapter; Serving Washington and Northern Idaho
Learn tips and suggestions in working with your health care provider about diagnosis and ongoing care.	Partnering with Your Healthcare Provider Dementia & Palliative Education Network
If you are living with dementia, it is important to stay active and engaged. Learn about Memory Café social programs, support groups and more in your community.	Find Memory Cafes (National directory) Memory Loss Info Washington Washington State Chapter; Serving Washington and Northern Idaho
Learn ways you can help people you may know that are living with dementia by becoming a <i>Dementia Friend!</i>	Dementia Friends in Washington State - Memory and Brain Wellness Center Dementia Friends USA
Check out Memorylossinfo.org – a website with information about dementia and links users to local service organizations.	Memory Loss Info Washington
If you are a family care partner or friend of a person living with dementia, find help and resources available with the Dementia Road Map: A Guide for Family and Care Partners.	Memory Loss Info Washington Dementia Road Map: A Guide for Family and Care Partners
If you are a family care partner, learn more about dementia, self-care, and other caregiving topics for free through the Washington Caregivers Learning Portal.	Washington Caregivers Learning Portal
If you are a family care partner, contact your local Family Caregiver Support Program for guidance, support and services (or services for the person living with dementia).	Family Caregiver Support Programs OR call 855-567-0252

Suggested Action Steps

Learn More

If you, or someone you know, needs financial assistance with long-term services and supports, contact or refer them to a local Community Living Connections or Home and Community Services (HCS) office.

[Community Living Connections](#)
OR call 1-855-587-0252.
[Home and Community Services](#)

It's a good idea for all adults to make legal and financial plans in the event you can no longer make such decisions for yourself – see the *Dementia Legal Planning Toolkit* for guidance.

[Washington Law Help](#)
[Dementia Action Collaborative | DSHS](#)

If a family member or friend is recently diagnosed, encourage early conversations and planning about their wishes for care over time and near the end of life – see the *Dementia Legal Planning Toolkit*.

[Washington Law Help](#)

If you (or someone you care about) need help to complete Powers of Attorney and health care directives, contact the *Dementia Legal Planning Project*.

[Dementia Legal Planning Project](#)

Be an advocate for dementia supports, contact the Alzheimer's Association to participate in their annual Alzheimer's Advocacy Day.

[Washington State Chapter; Serving Washington and Northern Idaho](#)

Start, or participate in, creating a more dementia-friendly community.

[Dementia Friends in Washington State - Memory and Brain Wellness Center](#)

If you or someone you know is living with dementia, learn more about getting involved with research studies.

[Find Clinical Trials](#)
[Trial Match \(Alzheimer's Association\)](#)

More information and resources for individuals and families

- Area Agencies on Aging (AAAs)/Community Living Connections (CLCs) are sources of specialized information, supports and service options in local areas. They also offer Family Caregiver Support Programs that assist family and friend care partners. The statewide network for AAAs is referred to as Community Living Connections. Visit www.waclc.org/connect or call 855-567-0252.
- Alzheimer's Association has free literature on all-things dementia available in English and Spanish, 24/7 phone support (in a caller's preferred language through a translation service), the latest information on brain health, available medications for people with dementia, support groups, trainings, and care consultation to help with decision-making. Visit www.alzwa.org or call 800-272-3900.

Possible Actions for Aging Network and Long Term Supports & Services Partners

We can't cure dementia yet, but there are actions we can take to help individuals be aware of ways to reduce their risks for dementia, and to provide assistance and support for individuals living with dementia and their family caregivers. Below are suggested actions you can take!

Suggested Action Steps	Learn More
Promote healthy aging and brain health in communities you serve – provide information that helps people take care of their brain.	ACL Talking About Brain Health
Share information about the warning signs of dementia, and the value of a timely diagnosis.	Dementia Washington State Department of Health 10 Early Signs and Symptoms of Alzheimer's
Help reduce stigma around dementia by becoming a Dementia Friend!	Dementia Friends in Washington State - Memory and Brain Wellness Center Dementia Friends USA
Spread the word about the Memorylossinfo.org web page that links people to dementia supports and services and DAC resources – add a link to it on your webpage.	Memory Loss Info Washington
Help families plan - make the Dementia Road Map: A Guide for Family and Care Partners available through your organization – add a link to it on your webpage or get paper copies to share.	Memory Loss Info Washington
Help individuals and families living with a serious illness or health condition to understand their options - make the Palliative Care Road Map available through your organization – add a link to it on your webpage or get paper copies to share.	Palliative Care Road Map: A Guide for living with serious illness and conditions for patients and those who care for them
Refer or link family care partners to their local Family Caregiver Support Program to get guidance, support and services (or services for the person living with dementia) for themselves.	Family Caregiver Support Programs OR call 855-567-0252
Help answer frequently asked questions about Intellectual/Developmental Disabilities and Dementia.	National Task Group on Intellectual Disabilities and Dementia Practices
Encourage family caregivers to take free trainings and learn more about dementia, self-care, and providing care through the Washington Caregivers Learning Portal.	Washington Caregivers Learning Portal
Make the <i>Dementia Legal Planning Toolkit</i> available through your organization – add a link to it on your webpage or get paper copies to share.	Memory Loss Info Washington Dementia Legal Planning Toolkit

Suggested Action Steps

Learn More

Share information about the *Dementia Legal Planning Project* – free legal help in completing Powers of Attorney and health care directives – add a link to it on your webpage or share outreach materials.

[Dementia Legal Planning Project](#)

Help family care partners with challenging aspects of care, such as behavioral symptoms, bathing, sun-downing, and more - share link to *Tips for Family and Care Partners*.

[Tip Sheets for Family and Care Partners](#)

Help family care partners of people living with Down's Syndrome and dementia with guidance in the *Alzheimer's Disease and Down's Syndrome: A Practical Guidebook for Caregivers*.

[Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers](#)

Be an advocate for dementia supports, contact the Alzheimer's Association to participate in annual Alzheimer's Advocacy Day during the legislative session.

[Alzheimer's Association Advocacy](#)

Learn about resources and efforts to help reduce disparities in dementia.

[DAC African American Action Brief for Organizations](#)

[Barriers to Equity in Alzheimer's and Dementia Care](#)

Refer residents and families with concerns about their nursing home, adult family home, or assisted living facility to the Long-Term Care Ombudsman.

[WA State Long-Term Care Ombudsman Program](#)

If you suspect a vulnerable adult is experiencing abuse, neglect, or exploitation, report your concerns to Adult Protective Services.

[Report Online](#) or Call 1-877-734-6277

If you have concerns about the treatment of a resident in a long-term care setting such as a Nursing Home, Assisted Living, or Adult Family Home contact Residential Care Services.

[Report Online](#) or Call 1-800-562-6078

Inform people with intellectual and developmental disabilities and their families with concerns about their services about the Developmental Disabilities Ombuds office.

[Developmental Disabilities Ombuds](#)

Start, or participate in, creating a more dementia-friendly community in your area.

[Dementia Friends in Washington State - Memory and Brain Wellness Center](#)

Counter ageism by changing how we communicate/talk about aging.

[Reframing Aging](#)

More information and resources for individuals and families

- Area Agencies on Aging (AAAs)/Community Living Connections (CLCs) are sources of specialized information, supports and service options in local areas. They also offer Family Caregiver Support Programs that assist family and friend care partners. The statewide network for AAAs is referred to as Community Living Connections. Visit www.waclc.org/connect or call 855-567-0252.

- Alzheimer’s Association has free literature on all-things dementia available in English and Spanish, 24/7 phone support (in a caller’s preferred language through a translation service), the latest information on brain health, available medications for people with dementia, support groups, trainings, and care consultation to help with decision-making. Visit www.alzwa.org or call 800-272-3900.

Possible Actions for Public Health Entities and Partners

We can’t cure dementia yet, but there are actions we can take to help individuals be aware of ways to reduce their risks for dementia, and to provide assistance and support for individuals living with dementia and their family caregivers. Below are suggested actions you can take!

<i>Suggested Action Steps</i>	<i>Learn More</i>
Promote healthy living habits across the life course to reduce risk of dementia – provide information that helps people take care of their brain.	Talking About Brain Health and Aging: The Basics Lancet Commission Infographic: Life-course Model-12 Potentially Modifiable Risk Factors 10 Ways to Love Your Brain Dementia prevention, intervention, and care: 2020 report of the Lancet Commission
Share information about the warning signs of dementia, and the value of a timely diagnosis.	Dementia Washington State Department of Health
Be aware of and participate in efforts to reduce/eliminate disparities in dementia.	DAC African American Action Brief for Organizations Dementia Washington State Department of Health
Spread the word about the Memorylossinfowa.org web page-links people to dementia supports and services and DAC resources – add a link to it on your organization’s website.	Memory Loss Info Washington
Help families plan ahead – make the Dementia Road Map: A Guide for Family and Caregivers available through your organization – add a link to it on your webpage or get paper copies to share if participating in community events. Available in English and Spanish.	Dementia Road Map: A Guide For Family and Care Partners
Make the Dementia Legal Planning Toolkit available through your organization – add a link to it on your webpage or get paper copies to share.	Dementia Legal Planning Toolkit
Share information about the Dementia Legal Planning Project – free legal help in completing Powers of Attorney and health care directives – add a link to it on your webpage or share outreach materials if participating in community events.	Dementia Legal Planning Project Washington Law Help

Suggested Action Steps

Learn More

Promote the connection between brain health and chronic disease management through National Health Observances:

- American Heart Health (February)
- World Hearing Day (March)
- National Stroke Awareness Month (May)
- Better Hearing and Speech Month (May)
- Older American's Month (May)
- Alzheimer's & Brain Awareness Month (June)
- Healthy Aging Month (September)
- World Alzheimer's Month (September)
- Falls Prevention Awareness Day (9/23)
- National Alzheimer's Disease Awareness Month (November)
- National Family Caregiver Month (November)
- American Diabetes Month (November)

[2023 Health Observances Calendar | Healthgrades Partner Solutions](#)
[Talking About Brain Health & Aging: The Basics](#)
[10 Ways to Love Your Brain](#)
[Healthy Heart, Healthy Brain | ASTHO](#)

Help family of people living with Down's Syndrome and dementia with guidance in the Alzheimer's Disease and Down's Syndrome: A Practical Guidebook for Caregivers.

[Disease and Down's Syndrome: A Practical Guidebook for Caregivers](#)

When engaged in strategic or project planning, consider the connection between healthy aging, brain health, and the needs of people living with dementia and their caregivers.

[Lancet Commission Infographic: Life-course Model-12 Potentially Modifiable Risk Factors](#)
[Dementia prevention, intervention, and care: 2020 report of the Lancet Commission](#)
[CDC Alzheimer's Disease and Healthy Aging Data Portal](#)
[National Healthy Brain Initiative Road Map Series](#)

Counter ageism by changing how we communicate/talk about aging.

[Reframing Aging](#)

Utilize hearing loops, pocket talkers, or other communication tools when meeting with groups of older adults, or with individuals with hearing loss.

[Get in the Hearing Loop - Hearing Loss Association of America](#)

Through worksite wellness programs, offer information and resources for employees who are also family caregivers.

[Worksite Wellness: How to Create an Environment that Supports Health](#)
[AARP: Supporting Caregivers in the Workplace: A Practical Guide for Employers](#)

When planning programs, initiatives and activities to support the health of Washingtonians, include the needs of people living with dementia and their caregivers.

[Dementia Action Collaborative | DSHS](#)

Possible Actions for Health Care Providers and Health Systems

We can't cure dementia yet, but there are actions we can take to help individuals be aware of ways to reduce their risks for dementia, and to provide assistance and support for individuals living with dementia and their family caregivers. Below are suggested actions you can take!

<i>Suggested Action Steps</i>	<i>Learn More</i>
Promote healthy living habits across the lifespan to reduce risk of dementia.	Optimizing brain health across the life course: WHO position paper
Counter ageism by changing how we communicate/talk about aging.	Reframing Aging
Incorporate age friendly smart phrases into Electronic Health Records systems.	IHI Age Friendly Health Systems EPIC Implementation Guide
Utilize hearing loops, pocket talkers, or other communication tools when meeting with groups of older adults or with individuals who have hearing loss.	Get in the Hearing Loop - Hearing Loss Association of America
Ask and record the patient's preferred care partner's name and contact information at each visit.	Identify Family Caregivers guide
Take the Cognition in Primary Care training when it is offered. A training program to facilitate detection of cognitive impairment and improve care for people with dementia, intended for primary care teams.	Cognition in Primary Care
Participate in Project ECHO Dementia, a web-based learning model for primary and allied care providers.	Project ECHO Dementia
Bookmark and use the Dementia Care Plan and Clinical Tool Beyond Diagnosis & Clinical Provider Practice Tool – These include guidance for identifying and diagnosing dementia and ongoing care. Ongoing care topics include: managing co-occurring chronic conditions, difficult behaviors, medication therapy, safety, advance care planning, and more.	Dementia Care Plan and Clinical Tool Beyond Diagnosis Clinical Provider Practice Tool
Make the Dementia Legal Planning Toolkit available through your organization – add link to your webpage or get paper copies to share.	Dementia Action Collaborative DSHS
Tell patients and their care partners about the Dementia Legal Planning Project – free legal help in completing Powers of Attorney and health care directives – add link to your webpage or share outreach materials.	Dementia Legal Planning Toolkit
Help families plan – make the Dementia Road Map: A Guide for Family and Care Partner available through your organization – add link to your webpage or get paper copies to share.	Dementia Action Collaborative DSHS

Suggested Action Steps

Learn More

Make an objective assessment of the caregiver by asking the caregiver about how they are doing, encourage them to take care of their own health, and refer to social worker and/or behavioral health as needed. Include a team approach when assessing the caregiver and providing supports.

[Caregiver Self-Assessment Questionnaire](#)

Get familiar with local dementia resources and caregiver supports by connect with the local Area Agency on Aging then include them in the resources of the Electronic Health Records.

[Agencies That Help | DSHS](#)
[Washington Community Living Connections](#)

Refer unpaid family care partners to their local Family Caregiver Support Program so they can get guidance, support and services themselves (or services for the person living with dementia).

[Family Caregiver Support Programs](#)
Refer a patient at this link -
www.waclc.org/connect
OR Call 855.567.0252

Utilize the National Task Group on Intellectual Disabilities and Dementia Practices screening tool for persons with intellectual disabilities.

[NTG-EDSD Screening Tool | Dementia and ID or DD](#)

Help families plan – make the Palliative Care Road Map available through your organization – add a link to it on your webpage or get paper copies to share.

[Palliative Care Road Map: A Guide for living with serious illness and conditions for patients and those who care for them](#)

Through worksite wellness programs, offer information and resources for employees who are also family caregivers.

[Worksite Wellness: How to Create an Environment that Supports Health](#)

D: Highlights of Progress Summary 2022

Goals of the 2016 plan

The purpose of the plan is to promote strategic actions that will prepare Washington State for the future. The high-level goals are shown here. See the State Plan for more detail.

What's been accomplished?

The DAC focused first on actions that could be accomplished through heightened collaboration and existing resources, and over the last several years has put forth several moderate requests to the state legislature to fund high value priorities. This report shares activities and accomplishments from 2016 through 2022.



A Quick Glance - Select Highlights of DAC Accomplishments, by Year

2014

- SSB 6124 directs DSHS to appoint members to and convene an Alzheimer's Disease Working Group (ADWG) to develop a state Alzheimer's plan
- ADWG is convened and process initiated

2016

- WA State Plan to Address Alzheimer's Disease and Other Dementias is published
- DSHS-AL TSA supports establishment of Dementia Action Collaborative (DAC) with voluntary support of ADWG partners
- Association of State and Territorial Health Organizations/Alzheimer's Association grant awarded to DOH, with UW and National Asian Pacific Center on Aging
- Dementia Friendly Communities Fact Sheet developed
- Behavioral Risk Factor Surveillance Survey (BRFSS) Cognitive Decline Module 2016

2017

- Dementia Safety Info Kit produced
- Brief Cognitive Screening Tools for Primary Care Practice position paper produced
- Dementia Road Map: A Guide for Family and Care Partners published
- Alzheimer's Disease and Other Dementias Report and Recommendations for primary care practitioners published by BREE Collaborative published
- Clinical Provider Practice Tool for Washington produced
- Starting an Alzheimer's Café "how to" guide produced
- Outreach to tribal leaders and representatives to determine needs of tribal families in caring for people with dementia
- Memory Sundays share brain health messaging through African American churches

2018

- Dementia portal/webpage enhancements and new URL created – MemoryLossInfoWa.org
- Community Health Worker training on Memory Loss/Dementia completed (AL TSA-ACL grant)
- New DOH webpage on dementia launched
- Dementia Friendly Walking Group “how-to” guide created & Dementia Friendly webinars held
- Four part-time positions to support DAC/AD Plan efforts at AL TSA, DDA, DOH, HCA funded to support work of the plan, beginning FY 2018 (\$160K per year)

2019

- Funding approved for digital public awareness campaign strategies, including racial/ethnic groups at increased risk, to DOH beginning FY 2019 (\$150K per year)
- Funding approved to promote early legal and advance care planning; educational materials, attorney training, and pro bono services to support these activities, to AL TSA FY 2019 (\$113K per year)
- Funding approved for Project ECHO Dementia to offer training via telemedicine for primary care practitioners, to UW Memory and Brain Wellness Center FY 2019 (\$226K per year)
- Dementia Friends Pilot Evaluation shows positive outcomes
- Healthy Aging Workgroup at DOH identifies opportunities for activities related to Healthy Brain Initiative Road Map
- Spanish translation of Dementia Road Map: A Guide for Family and Care Partners published
- Dementia Capable Systems grant at AL TSA completed
- Savvy Caregiver in Indian Country trainings for tribes offered through AL TSA

2020

- Dementia Legal Planning Toolkit published & educational webinars, attorney CLEs offered
- First Dementia Friendly Washington: Inspiring Change conference held
- Trust for America’s Health (TFAH) grant to foster an Age-Friendly Public Health Systems awarded to DOH
- Project ECHO Dementia launches at UW Memory and Brain Wellness Center (UW-MBWC)
- Dementia Module integrated into Case Manager Program Training at AL TSA
- Alzheimer’s Research Network virtual learning community launches through HCA

2021

- Media companies contracted by DOH to develop culturally appropriate strategies, messages and materials on the value of dementia diagnosis, tailored to the African American community
- First virtual, free legal and advance care planning clinic held by Northwest Justice Project
- Collaborating for a Dementia-Friendly Washington: Expanding Possibilities conference held
- Dementia Friendly Washington Learning Collaborative launched through UW-MBWC
- Five local health jurisdictions selected as part of the Trust for America’s Health (TFAH) Age Friendly Public Health Systems Learning and Action Network through DOH
- Funding for two pilots to Build Dementia Capable Communities (BDCC), began 7/1/2021 (\$750K per year) – two AAAs selected, began planning and implementation (AL TSA)
- African Americans and Alzheimer’s Disease: A Call to Action for Community Organizations, an action brief to promote actions to reduce dementia disparities produced

- Intellectual/Developmental Disabilities and Dementia training for direct support professionals completed
- Savvy Caregiver in Indian Country offered

2022

- Two BDCC programs build infrastructure and began reaching out to community partners to enhance linkages and referral networks, created mechanisms for tracking activities and services, and began trainings for AAA and network staff and consumers around dementia.
- DOH launched webpage to host tailored materials for Black and African American community doh.wa.gov/memory
- Media companies contracted by DOH to develop culturally appropriate strategies, messages and materials on the value of dementia diagnosis, tailored to the Hispanic/Latino/x community
- Launched Dementia Legal Planning Project to offer free legal assistance to complete powers of attorney and health care directive documents
- State partners offered brain health and dementia awareness activities for state employees through SmartHealth wellness program
- Funding to expand Dementia Friends global awareness program statewide began 7/1/2022 (\$100,000 per year)
- Caregiver Module included in statewide BRFSS
- TFAH Age Friendly Public Health Systems Learning and Action Network began
- Intellectual/Developmental Disabilities and Dementia training for direct support professionals offered five times to train trainers
- A Dementia Care Plan and Clinical Tool – Beyond Diagnosis was produced
- Developed Partnering with Your Healthcare Provider: A Resources for People with Memory Problems and their Care Partners
- A Care Transitions toolkit for hospitals and health systems was produced
- Hosted Alzheimer’s Research Network quarterly meetings

More details on the accomplishments listed above (including tools and resources developed), accomplishments not included here, and DAC work underway are outlined in the full Dementia Action Collaborative Progress Report 2022 which can be found at [Dementia Action Collaborative](#) (DAC Documents).

E: DAC Communications Tools and Resources

<i>Resources for individuals and families living with cognitive impairment or dementia</i>	<i>Where to find it online</i>	<i>How to request physical copies:</i>
<p><i>Dementia Road Map: A Guide for Family and Care Partners</i></p> <p>Available in English and Spanish</p>	<p><i>Find online at:</i> https://www.dshs.wa.gov/altsa/dementia-action-collaborative OR memorylossinfowa.org</p>	<p><i>English:</i></p> <p>1-5 print copies: email requested number with name and street mailing address to: Dementiaroadmap@dshs.wa.gov</p> <p>6+ print copies – Visit http://myprint.wa.gov</p> <p><i>Spanish:</i></p> <p>Request any number of copies through: InquiryWA@alz.org</p>
<p><i>Dementia Safety Info Kit</i></p>	<p><i>Find online at:</i> https://www.dshs.wa.gov/altsa/dementia-action-collaborative OR memorylossinfowa.org</p>	<p>Download only (direct link below)</p> <p>Improving Safety for People with Dementia: Info Kit (wa.gov)</p>
<p><i>Dementia Legal Planning Toolkit</i></p>	<p><i>Find online at:</i> Washingtonlawhelp.org OR memorylossinfowa.org</p>	<p>Dementia Legal Planning Toolkit Order Form</p>
<p><i>Partnering with your Healthcare Provider: A resource for People Living with Memory Problems and their Care Partners</i></p>	<p><i>Find online at:</i> https://www.dshs.wa.gov/altsa/dementia-action-collaborative</p>	<p>Video and print resources online only:</p> <p>Partnering with Your Healthcare Provider Dementia & Palliative Education Network (uw.edu)</p>
<p><i>Your Medical Evaluation - What to Expect - Bob and Juanita share their experience</i></p>	<p><i>Find online at:</i> memorylossinfowa.org (Medical/dental tab)</p>	<p>Download only (direct link below)</p> <p>Your medical appointment: what to expect</p>
<p><i>Let's Talk Dementia Videos</i></p>	<p><i>Find online at:</i> https://www.dshs.wa.gov/altsa/dementia-action-collaborative</p>	<p>Videos only – no written materials</p>
<p><i>Department of Health – Dementia Website</i></p> <p>Available in English and Spanish</p>	<p>Dementia Washington State Department of Health Demencia Washington State Department of Health</p>	<p>Website only</p>

<i>Resources for community organizations, Area Agencies on Aging, Libraries, Faith Based organizations, etc.</i>	<i>Where to find it online</i>	<i>Hard copies? If so, where to get it</i>
<i>African Americans and Alzheimer's Disease: A Call to Action for Organizations</i>	Find online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) DAC African American Action Brief for Organizations.pdf (wa.gov)
<i>The Alzheimer's Café Model: A Guide to Getting Started in Your Community</i>	Find online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) PowerPoint Presentation (wa.gov)
<i>Dementia Friendly Walking Groups: A Start-Up Guide for Community Based Organizations</i>	Find online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) Dementia-Friendly Walking Groups Guide.pdf
<i>DAC Dementia Friends Evaluation Summary</i>	Find online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) Dementia Friends Research Brief.pdf (wa.gov)
<i>Promotional Toolkit - memorylossinfo.org webpage, including a Rack Card</i>	Access toolkit here: https://drive.google.com/drive/folders/1IWUTYi1vixHdyw-4kO-QTP_niOsXiUZ47?usp=sharing	To request the Promotional Toolkit as PDFs via email, visit the Rack Card Order Form
<i>Rack card to promote the Memorylossinfo.org webpage</i>	To order print copies, please use the Rack Card Order Form . The rack card is also available in PDF as part of the Promotional Toolkit .	Link to the Rack Card Order Form
<i>Rack card to promote the Value of Early Diagnosis</i>	Link to the Rack Card Order Form	Link to the Rack Card Order Form
<i>Let's Talk Dementia Videos</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Videos only – no written materials
<i>Children's Book List – Busting Dementia Stigma – One Children's Book at a Time</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below)
<i>Department of Health – Community Dementia Education Resources Website</i> Available in English and Spanish	Community Dementia Education Resources Washington State Department of Health Recursos educativos comunitarios sobre la demencia Washington State Department of Health	Website only

<i>Resources for health care providers, care teams, and hospital care teams</i>	<i>Where to find it online</i>	<i>Hard copies? If so, where to get it</i>
<i>Brief Cognitive Screening Tools for Primary Care Practice</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) DAC Screening Position Paper.pdf (wa.gov)
<i>Clinical Provider Practice Tool</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) DAC-CP-PracticeTool_2017_DRAFT-3 (wa.gov)
<i>Dementia Care Plan and Clinical Tool Beyond Diagnosis</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) Dementia Care Plan and Clinical Tool Beyond Diagnosis.pdf (wa.gov)
<i>Care Transitions: Hospital to Home for People Living with Dementia</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) DAC care transitions - January 2023.pdf (wa.gov)
<i>Bree Dementia Care Guidelines</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative Or at: http://www.breecollaborative.org	Download only (direct link below) Alzheimer's Disease and Other Dementias Bree Collaborative (qualityhealth.org)

<i>Resources for everyone</i>	<i>Where to find it online</i>	<i>Hard copies? If so, where to get it</i>
<i>Dementia Action Collaborative Introduction Sheet</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) DAC One-pager.pdf (wa.gov)
<i>Dementia Friendly Communities Fact Sheet</i>	View online at: https://www.dshs.wa.gov/altsa/dementia-action-collaborative	Download only (direct link below) DFC-WA Fact Sheet - Short Version.pdf

F: WA State and National Resource Links

Washington state

Alzheimer's Association Washington Chapter

Serving 47 counties in Washington and North Idaho, the Alzheimer's Association Washington State Chapter is the premier resource in the Pacific Northwest for people impacted by dementia. Through five local offices and a network of dedicated volunteers, our Chapter offers a broad range of care and support services, education, and advocacy, as well as funding for Alzheimer's and dementia research.

www.alz.org/alzwa

Dementia Support Northwest

Dementia Support Northwest provides professional education and training to those likely to engage with those living with dementia through our partnership with our local Area Agency on Aging, the Northwest Regional Council in Bellingham. Trainings for community groups and professionals alike promote our vision for a more understanding, accepting, and supportive community for those affected by cognitive decline.

www.dementiasupportnw.org

DSHS AL TSA

Home and Community Services (HCS) provides and administers long-term care services to eligible individuals and collaborates with Area Agencies on Aging (AAA) offices statewide to share community service options, including supports for family caregivers. To find information in your area, call your local HCS or AAA office.

Residential Care Services provides licensing, certification, and regulatory oversight to long-term care facilities including: Nursing Home, Assisted Living Facilities, Adult Family Homes, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), Supported Living; and Enhanced Services Facilities.

Office of the Deaf and Hard of Hearing provides service to individuals who are deaf, hard of hearing, deaf-blind and speech-disabled facing communication barriers. Services includes telecommunications, reasonable accommodations and client services.

General Information: (360) 725-2300 or 1-800-422-3263

<http://www.dshs.wa.gov/altsa>

National Organizations and Resources

AARP Global Council on Brain Health

www.aarp.org/health/brain-health/global-council-on-brain-health/

Alzheimers.gov

<http://www.alzheimers.gov>

Alzheimers.gov in Spanish

www.alzheimers.gov/es

Alzheimer's Association, National

<http://www.alz.org>

Alzheimer's Association Research Center Trial Match

http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp

Alzheimer's Association 2023 Facts & Figures
www.alz.org/alzheimers-dementia/facts-figures

Alzheimer's Disease Education and Referral Center, National Institute on Aging
<http://www.nia.nih.gov/alzheimers>

Alzheimer's Foundation of America
www.alzfdn.org

Alzheimer's Prevention Initiative
www.alzheimerspreventioninitiative.com

BOLD Public Health Center of Excellence Early Detection of Dementia
www.bolddementiadetection.org

Caregiver Action Network
www.caregiveraction.org

Centers for Disease Control: The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health
www.cdc.gov/aging/healthybrain/roadmap.htm

Center for Disease Control: Dementia
www.cdc.gov/aging/healthybrain/roadmap.htm

Eldercare Locator
<https://eldercare.acl.gov/Public/Index.aspx>

Hand in Hand, a Training Series for Nursing Homes
qsep.cms.gov/pubs/HandinHand.aspx

Healthy People 2030: Dementias
health.gov/healthypeople/objectives-and-data/browse-objectives/dementias

International Association for Indigenous Aging: Brain Health
www.iasquared.org/brain-health

Latino Alzheimer's and Memory Disorders Alliance
www.latinoalzheimersalliance.org

Leaders Engaged on Alzheimer's Disease
www.leadcoalition.org

Mayo Clinic Alzheimer's Disease Center
www.mayoclinic.com/health/alzheimers-disease/DS00161

Milken Institute: The Alliance to Improve Dementia Care
www.milkeninstitute.org/centers/center-for-the-future-of-aging/alliance-to-improve-dementia-care

Minnesota ACT on Alzheimer's website
www.actonalz.org

Namaste Care for People with Dementia
www.namastecare.com

National Alliance for Caregiving

www.caregiving.org

National Alzheimer's Project Act (NAPA) home page, and link to the National Plan to Address Alzheimer's Disease

www.aspe.hhs.gov/collaborations-committees-advisory-groups/napa

National Indian Council on Aging, Inc. - Alzheimer's and Dementia

www.nicoa.org

National Institute on Aging: Caring for a Person with Alzheimer's Disease

www.nih.gov

National Institute on Aging: Dementia

www.nia.nih.gov/health/topics/dementia

National Task Group on Intellectual Disabilities and Dementia Practices

www.the-ntg.org

Public Health Strategies on Caregiving Across the Full Community

www.cdc.gov/aging/caregiving/promoting-caregiving

Public Health Center of Excellence on Dementia Caregiving

www.bolddementiacaregiving.org

Public Health Center of Excellence Dementia Risk Reduction

www.alz.org

SAGE USA – Issue Brief: LGBTQ+ and Dementia

www.sageusa.org

US Aging – Dementia Friendly America

www.usaging.org/dfa

Us Against Alzheimer's

www.usagainstalzheimer.org

International Resources

Alzheimer's Disease International (World Reports)

www.alz.co.uk

International Alzheimer's Disease Research Portfolio (IADRP)

iadrp.nia.nih.gov

Prime Minister's Challenge on Dementia 2020 (United Kingdom)

www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020

Dementia Friendly Communities (Scotland)

www.connectingcommunities.co.uk

Dementia Friends (United Kingdom)

www.dementiafriends.org.uk

G: Information About Alzheimer’s Disease and Dementia

10 Warning Signs of Alzheimer’s Disease

1. Memory loss that disrupts daily life

One of the most common signs of Alzheimer’s disease, especially in the early stage, is forgetting recently learned information. Others include forgetting important dates or events, asking the same questions over and over, and increasingly needing to rely on memory aids (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.

2. Challenges in planning or solving problems

Some people living with dementia may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

3. Difficulty completing familiar tasks

People with Alzheimer’s often find it hard to complete daily tasks. Sometimes they may have trouble driving to a familiar location, organizing a grocery list or remembering the rules of a favorite game.

4. Confusion with time or place

People living with Alzheimer’s can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

5. Trouble understanding visual images and spatial relationships

For some people, having vision problems is a sign of Alzheimer’s. This may lead to difficulty with balance or trouble reading. They may also have problems judging distance and determining color or contrast, causing issues with driving.

6. New problems with words in speaking or writing

People living with Alzheimer’s may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have trouble naming a familiar object or use the wrong name (e.g., calling a “watch” a “hand-clock”).

7. Misplacing things and losing the ability to retrace steps

A person living with Alzheimer’s disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. He or she may accuse others of stealing, especially as the disease progresses.

8. Decreased or poor judgment

Individuals may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money or pay less attention to grooming or keeping themselves clean.

9. Withdrawal from work or social activities

A person living with Alzheimer’s disease may experience changes in the ability to hold or follow a conversation. As a result, he or she may withdraw from hobbies, social activities or other engagements. They may have trouble keeping up with a favorite team or activity.

10. Changes in mood and personality

Individuals living with Alzheimer's may experience mood and personality changes. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, with friends or when out of their comfort zone.

From the Alzheimer's Association

Different Types of Dementia

Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain.

Alzheimer's disease

Alzheimer's is the most common form of dementia and accounts for 60 to 80 percent of dementia cases. Early symptoms include difficulty remembering recent conversations, names or events; apathy and depression. Later symptoms include impaired communication, poor judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.

Alzheimer's is not a normal part of aging, although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age. Up to 5 percent of people with the disease have early onset (also known as younger-onset) Alzheimer's disease, which often appears when someone is in their 40s or 50s.

Vascular dementia

Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than Alzheimer's, accounting for about 10 percent of dementia cases. Symptoms include impaired judgment or ability to make decisions, plan or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's.

Dementia with Lewy bodies

People with dementia with Lewy bodies often have memory loss and thinking problems common in Alzheimer's, but are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features. Symptoms include memory loss and thinking problems common in Alzheimer's, but are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features.

Mixed dementia

In mixed dementia abnormalities linked to more than one type of dementia occur simultaneously in the brain. Recent studies suggest that mixed dementia is more common than previously thought.

Parkinson's disease

As Parkinson's disease progresses, it often results in a progressive dementia similar to dementia with Lewy bodies or Alzheimer's. Symptoms of the disease include problems with movement. If dementia develops, symptoms are often similar to dementia with Lewy bodies.

Frontotemporal dementia

Includes dementias such as behavioral variant FTD (bvFTD), primary progressive aphasia, Pick's disease and progressive supranuclear palsy. Typical symptoms include changes in personality and behavior and difficulty with language.

Creutzfeldt-Jakob disease

CJD is the most common human form of a group of rare, fatal brain disorders affecting people and certain other mammals. Variant CJD (“mad cow disease”) occurs in cattle, and has been transmitted to people under certain circumstances. Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.

Normal pressure hydrocephalus

Symptoms include difficulty walking, memory loss and inability to control urination. Caused by the buildup of fluid in the brain. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

Huntington’s disease

Huntington’s disease is a progressive brain disorder caused by a single defective gene on chromosome 4. Symptoms include abnormal involuntary movements, a severe decline in thinking and reasoning skills, and irritability, depression and other mood changes.

Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). The most common cause is alcohol misuse. Symptoms include strikingly severe memory problems while other thinking and social skills seem relatively unaffected.

From the Alzheimer’s Association

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I: Legislative Charge – HB 1646

See <https://app.leg.wa.gov/billsummary?BillNumber=1646&Initiative=false&Year=2021>.

