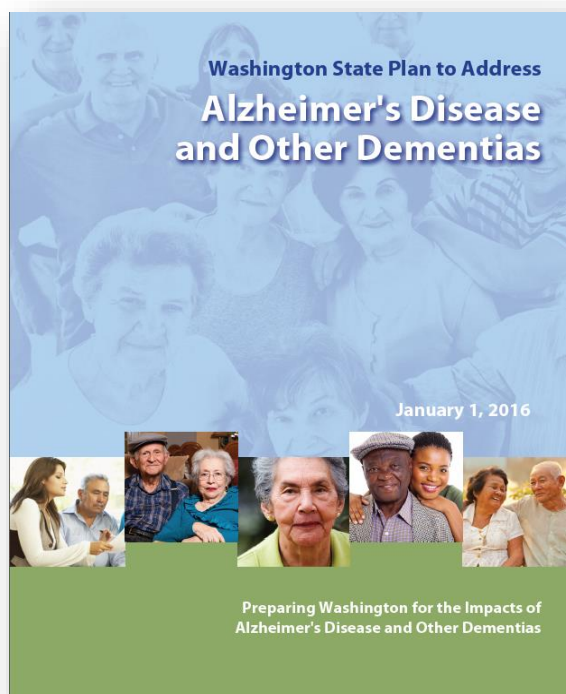


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# Dementia Action Collaborative

Progress Update: December 2016



## Introduction

In 2014, legislation established an Alzheimer’s Disease Working Group (ADWG) to create a state plan to address Alzheimer’s disease. This plan, released in January 2016 identifies goals, strategies and recommendations as a starting point to prepare for the future. The ADWG developed the first [Washington State Plan to Address Alzheimer's Disease and Other Dementias](#) as a public-private partnership. The plan’s implementation – including action planning, next steps, and policy changes – depends upon the participation and contributions of a broad group of committed partners.

## What is the Dementia Action Collaborative?

As the plan developed, members of the ADWG called for the formation of a next generation workgroup to implement it. This group is now known as the Dementia Action Collaborative (DAC) - a voluntary statewide collaboration of partners committed to preparing our state for the future. The DAC includes a range of appointed members – people with dementia, family caregivers, representatives of advocacy groups, the aging network, Alzheimer’s organizations, long-term care providers, health care professionals, legislators and governmental agencies (see roster at end of this document).

## What are the goals of the 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 at right. See [State Plan](#) for more detail on specific strategies and recommendations.

## What’s been accomplished so far?

This report shares actions and accomplishments for 2016.



## Public Awareness-Community Readiness Subcommittee

- Submitted by subcommittee Chair, Cheryl Townsend-Winter
- Implementing Recommendations from within Goals 1, 2 and 3

**Recommendation 1.A.1:** Establish a work group to develop, launch, and oversee a single web-based “point of access” portal/website linking to a comprehensive statewide array of credible and validated information, resources and supports.

### Year End Accomplishments, 12/31/2016:

- The project team evaluated existing websites to consider/decide what offers the best platform for enhancement given our goals. The team ultimately decided on the AD/Dementia page in the Community Living Connections (CLC) system. This is a website supporting the work of the CLC program; the website is managed by Aging and Long Term Support Administration (AL TSA) in partnership with a vendor (RTZ).
- The project team reviewed the 2015 ADWG survey to determine needs expressed for inclusion in a website; and compared these elements to what is currently available on the website – from this they identified 12 potential enhancements to the CLC site.
- In discussion with the CLC program manager at AL TSA, the team identified a Preliminary Website Implementation Work Group to work collaboratively in furthering the enhanced content for the website (single port of access portal).

**Status:** COMPLETED establishment of a work group. And determined a plan for enhancing an existing website with priority elements. Work on this recommendation will continue into 2017.

### 2017 Timeline:

- March 2017 - Prioritize/finalize which CLC website enhancements will be worked.
- Sept 2017 - Work with AL TSA and RTZ to get enhancements included on website.
- Dec 2017 - Develop a marketing plan for this website.

**Challenges:** The practical problem of figuring out what is missing amongst what is already out there, i.e. our Statement of Purpose/Justification was our biggest challenge. There are still big challenges related to the launch and marketing.

**Project Team:** Leads: Luisa Parada-Estrada, Joel Loiacono; Members: Debbie Hunter, Arlene Johnson, Kathy Sitker, Cheryl Townsend Winter

**Recommendation 1.F.1:** Inform and educate the public about healthy aging, including links between brain health and nutrition, exercise, stress management and oral health/periodontal disease.

**Year End Accomplishments, 12/31/2016:**

- \$25,000 Grant was received by a collaboration of the University of Washington (UW), the Department of Health (DOH) and the National Asian Pacific Center on Aging.
- Six focus groups were run by UW, with outreach to Chinese and Japanese adult children of older adults to investigate/discuss potential messaging around dementia.
- Preliminary findings from the focus groups were shared at the 2016 UW Elders Futures Friendly Conference and the 2016 Gerontological Society of America international conference.
- The Washington Dental Service Foundation hosted a new educational module for caregivers and home health staff on providing oral care for people with dementia.

**Status:** Partial completion. The grant received created a specific timeline for DOH staff – they are working now to identify evidence-based messages around brain health.

**2017 Timeline:**

- June 2017 - Complete data analysis and “action brief” from focus groups mentioned above.
- August 2017 – Finalize and begin to disseminate evidence-based messages about brain health; to include adding links to the DOH website that include local, state and other national dementia resources.
- Throughout 2017 - Washington Dental Service Foundation will disseminate and promote a course titled *Oral Health for Clients with Dementia*, in partnership with the Adult Family Home Council of Washington.

**Challenge:** High level of community interest yet limited funding so had to limit the number of focus groups.

**Project Team:** Leads: Marci Getz and Basia Belza; Members: Myriam Marquez, Karen Lewis, Cynthia Karlsson, Lesley Steinman, Kathy Lofy

**Recommendation 2.C.1:** Review emerging models/movements of livable, age-friendly and dementia-friendly communities, and determine elements most critical to developing dementia-friendly communities in Washington state.

**Year End Accomplishments, 12/31/2016:**

- Reviewed work of other states and countries around “dementia-friendly” practices and initiatives. Discussed/decided upon elements to include for Washington state initiative.
- Developed fact sheets of 8 – 10 “Critical Elements” for Washington state Dementia-Friendly (DF) Communities initiative (both a short and expanded version).
- Developed recommendation for how to integrate DF initiative/principles into WA State Age-Friendly (AF) Initiatives.
- Developed an inventory of DF activities/programs offered in Washington state.
- Created a plan to begin working with the libraries in 2017 to promote DF practices. This will help the team in initiating such outreach with other regional or statewide systems (museums, parks, senior centers, etc.).

**Status:** COMPLETED determination of elements.

**2017 Timeline:**

- January 2017 - Initiate inquiry regarding interest in statewide networking to people doing dementia-friendly programs.

**Ongoing Work:**

- Maintain google chart of Washington DF and AF initiatives: goals, timeline, potential synergies.
- AARP state office will be a conduit to help integrate the DF principles into the Livable Communities Initiatives.
- LTSS Project Team will integrate the DF inventory into their ongoing work.
- Move forward with dissemination/promotion using fact sheets and asking for help distributing.
- The Washington State Library Association has offered opportunities to do some education/exploration including regional learning days and/or a statewide conference in 2017. A running log regarding the process of engaging with a statewide library system will be kept to help model reaching out to other systems.
- For future reference/consideration: Unveil “products” of DAC at Governor Conference on Dementia in a couple of years. Develop awards for efforts towards dementia-friendly.

**Challenge:** A very large volume of material to research as the concept is very abstract and tough to pin down. Secondly, the project team chose to work on 5 products which provides great diversity but fewer team members to work on each one.

**Project Team:** Lead: Marigrace Becker; Members: Hilarie Hauptman, Cathy McCaul, Carla Calogaro, Marty Richards, Lynne Korte

**Recommendation 3.B.1:** Compile and make accessible educational materials about ways to improve safety for people with dementia. Information may address fall prevention, wandering, disaster preparedness, and home safety assessments.

**Year End Accomplishments, 12/31/2016:**

- Investigated what is currently available re: safety for dementia that is targeted to families living with dementia, prioritized most relevant, and determined criteria for inclusion in an “info kit”.
- Determined best way to compile information for usability i.e., (PDF document).
- Finalized online Dementia Safety Info Kit (compilation of best, credible documents available via PDF and websites).
- Created plan to disseminate through DAC partners, re: awareness of these materials.

**Status:** COMPLETED

**2017 Timeline:**

- January 2017 - Post Dementia Safety Info Kit to DAC Webpage
- January 2017 - Discuss/plan for further dissemination (by January 30, 2017).
- March 2017 - DAC members to post/link to Dementia Safety Info Kit on DAC webpage.

**Challenge:** Small project team; and took significant time to investigate, narrow in and format information for public. (This effort was supported through work aligned with a current Dementia Capable Systems grant).

**Project Team:** Lynne Korte, Bob Wellington, Dave Budd

**Dementia Action Collaborative Washington State**

**Info Kit**

### Safety Concerns for People with Dementia

Not all memory loss is due to dementia. Memory loss and/or confusion may be a result of many conditions, some of which are reversible. If you or someone you know has memory loss or confusion that's getting worse, it's important to talk with a health care professional about it. If it does turn out to be dementia, there are steps you can take to live well, and plan for a future with it.

Dementia affects each person differently, but symptoms typically include increasing memory loss, confusion, and disorientation. Changes in the brain can also impact how individuals interpret what they see, hear, feel, taste or smell, and their sense of time, place and judgment – each of which can impact safety.

The best environment for a person with memory loss or dementia is one that helps them feel as independent and supported as possible. For people with dementia wanting to stay at home, it's key to find the right balance between independence and safety - and to anticipate changes. With creativity and flexibility, it's possible to make adaptations that make the home safer and less stressful for all.

This "info kit" is a resource for family members and caregivers to assist in evaluating the home and taking steps to promote safety over the course of dementia. Materials highlight information and tips related to the following:

1. Home Safety
2. Falls Prevention
3. Driving
4. Wandering
5. Emergency Preparedness
6. Elder Abuse & Financial Exploitation

You may click on the links provided below each resource to view or print the information yourself. When a computer icon appears, the information is intended to be viewed online, and not in a printable format.

## Long Term Supports and Services Subcommittee

- Submitted by subcommittee Chair, Bob LeRoy
- Implementing Recommendations within Goals 4 and 6

**Recommendation 4.A.1:** Create a Washington State-specific “Roadmap” for family caregivers providing information about what to expect over time to help plan for the future.

### **Year End Accomplishments, 12/31/2016:**

- Reviewed material and resources from several organizations.
- Solicited and received input from full DAC regarding preliminary concept/content draft.
- Completed revised draft.
- Selected graphic designer to develop a user-friendly PDF version.

**Status:** Nearly COMPLETE (Graphic design in process)

### **2017 Timeline:**

- March 2017 - Complete pdf version of Roadmap
- June 2018 - Complete an online version of Roadmap

### **Ongoing Work:**

1. Work with graphic designer, Public Awareness and Community Readiness Subcommittee, other partners to complete a print and online version of Roadmap.
2. Develop plan for promoting and sustaining Roadmap.

**Greatest Challenge:** Sustainability of Roadmap in printed and online versions.

**Project Team:** Lead: Todd Larson; Members: Cindy Balbuena, Kim Boon, Lynne Korte, Jerry Reilly, Lauri St. Ours, Rep. Steve Tharinger

**Recommendations 4.C.2 and 4.E.1:** Expand and promote implementation of early stage memory loss (ESML) groups for people with cognitive impairment/dementia and their care partners, and develop information about models of social engagement such as Alzheimer’s Cafes, Zoo Walks, Museum/Arts (“here:now”) programs, etc.

**Year End Accomplishments, 12/31/2016:**

- Developed catalogue of current ESML groups with two categories: evidence informed and emerging service models.
- Collected feedback about ESML needs from participants at Alzheimer’s Association Town Halls.

**Status:** Ongoing.

**2017 Timeline:**

- April 2017 - Complete guidance for communities interested in ESML programming.

**Ongoing Work:**

1. Develop guidance for communities interested in developing ESML programs focused on support, advocacy, and dementia-friendly models.
2. Engage partners to expand awareness and availability of ESML groups and programs, particularly beyond Puget Sound.

**Challenge:** Beyond Puget Sound, lack of capacity in partners to increase community awareness and in communities to begin or sustain programs.

**Project Team:** Lead: Cara Lauer; Members: Patricia Hunter, Bob Le Roy



**Recommendations 4.F.1. and 4.G.1:** Identify and engage leaders and organizations of diverse populations to explore needs for education and support, and engage tribal representatives to explore the needs of tribal families caring for people with dementia to develop culturally relevant supports and services.

**Year End Accomplishments, 12/31/2016**

- Decided to initiate outreach to diverse communities in phases, beginning with Native Americans, then African American and Hispanic.
- Developed set of outreach questions.
- Identified tribal points-of-contact.
- Created and distributed “Dear Tribal” letter.

**Status:** Ongoing.

**2017 Timeline:**

- March 2017 - Complete initial outreach to identified points-of-contact in Native American community.
- April 2017 - Initiate outreach to African American community.
- October 2017 - Initiate outreach to Hispanic community.

**Ongoing Work:**

1. Create master list of contacts in Native American community.
2. Complete initial and follow-up contacts.
3. Compile and analyze responses to outreach questions; identify themes, gaps, and needs.
4. Determine next steps in engagement of Native American community.
5. Initiate outreach to African American community.
6. Initiate outreach to Hispanic community.

**Challenge:** Developing cohesive strategy to engage diverse tribal leadership willing to provide input regarding needs in their communities.

**Project Team:** Leaders: Aziz Aladin, Emma Medicine White Crow, Bob LeRoy; Members: Marietta Bobba, Christine Kubiak, Yolanda Lovato, Karen Winston, Shelly Zylstra

**Recommendation 6.A.2:** Identify and promote existing models of care coordination services for individuals living in the community and their family caregivers, such as Health Homes, geriatric care managers, and Alzheimer’s Association Care Navigators.

**Year End Accomplishments, 12/31/2016**

- Came to consensus on what is meant by care coordination.
- Completed format for inventory detailing existing care coordination resources.

**Status:** Ongoing

**2017 Timeline:**

- May 2017 - Complete inventory of resources available through current systems.
- June 2017 - Identify gaps or areas of opportunity to increase awareness of existing services or to provide services.

**Ongoing Work:**

1. Inventory and summarize publicly available benefits for care coordination.
2. Inventory and summarize care coordination models available through hospice and palliative care.
3. Identify gaps in services that do not meet care coordination needs of individuals with dementia and their caregivers.

**Challenge:** Confusion about what is meant by care coordination and how to access it.

**Project Team:** Lead: LeighBeth Merrick; Members: Susan Engels, John Ficker, Jullie Gray, Maureen Linehan, Mary Lynn Pannen, Mimi Pattison

## Health-Medical Subcommittee

- Submitted by subcommittee Chair, Kris Rhoads
- Implementing Recommendations within Goals 5 and 7

**Recommendation 5.A.1:** Convene an expert panel to identify and endorse a set of evidence-based standards for diagnosis, treatment, supportive care and advance planning for people with dementia.

### Year End Accomplishments, 12/31/2016:

- Identification of the Robert Bree Collaborative as the optimal venue through which to convene an expert panel to identify/endorse guidelines.
- This process included development of a "pitch" for why this topic should be selected by the collaborative for 2017, agreed upon talking points, and outreach to Bree leadership before the meeting.
- DAC members presented at Bree meetings in July and September to advocate for dementia care as a topic.
- DAC members identified potential content experts for the workgroup and have successfully populated the majority of members on the workgroup. Invitations were sent out by the Bree Collaborative to 22 possible members on 12/9/16 with confirmed representation from the DAC including Kris Rhoads (chair of the Bree workgroup), Nancy Isenberg, Tatiana Sadak, Myriam Marquez, and possibly Debbie Hunter.
- Project team members continued to identify existing dementia care guidelines from associations, states, and other medical groups, resulting in a document that will be provided to the Bree Collaborative workgroup.

**Status:** Partial completion. Convening the group will meet criteria for the first part of the recommendation, with endorsement by the end of 2017.

### 2017 Timeline:

- January 2017 - The initial Bree Collaborative Dementia Care Workgroup will convene at the Bree program office on January 11th.
- The workgroup will meet for approximately 9 months.

**Challenges:** The major challenges in this process were working with the timeline and structure of an outside organization and the uncertainty of these efforts resulting in a positive outcome. A second area of challenge relates to the logistics of convening a group of busy and already extended individuals, despite their interests and desire to do such work.

**Project Team:** Kris Rhoads, Amanda Avalos, Sumie Jayadev, Lynne Korte, Christine Seymour

**Recommendation 5.B.2:** Identify and recommend several validated, brief cognitive screening tools.

**Year End Accomplishments, 12/31/2016**

- Clarification of the anticipated product as a position paper outlining the importance of objective cognitive screening in primary and specialty care settings to also include the need for caregiver assessment and a recommendations and guidance around pathways for abnormal results.
- Completed a literature review on available screening measures, review of practice parameters and recommendations, best practice models and some preliminary examination of current practice parameters.
- An outline and expanded draft of the position paper has been created and will be completed by January 30 after feedback from both the project team and the DAC overall.

**Status:** Nearly COMPLETE (by 1/30/17).

**Timeline:**

- January 2017 - Integrate this paper into the DAC website
- Other dissemination work will be ongoing, as will integration into ongoing work by the Bree Collaborative and additional recommendations.

**Challenges:** The major challenge in this process was carving out the time to complete what were otherwise fairly concrete and straightforward components. There is also degree of challenge related to balancing quality of screening instruments/tools with the realities of clinical practice in multiple settings.

**Project Team:** Kris Rhoads, Lynne Korte, Aimee Ford

**Recommendation 5.E.1:** Promote understanding and effective utilization of (a) Medicare Annual Wellness Visit which includes objective cognitive assessment/screening; and (b) Complex care management (CCM) codes for care coordination services, and advance care planning codes for individuals at end of life.

**Year End Accomplishments, 12/31/2016:**

- Clarification on the nature and structure of the Medicare annual wellness visit, as well as clarification that this visit may be one of many venues at which cognitive screening can take place.
- Preliminary investigations into utilization rates and some organizational structures around the visit, as well as possible financial ramifications and incentives.
- This work identified the importance of completion or at least significant progress on recommendations 5A1 and 5B2 as well as the need for more information and partnerships across organizations to clarify how this type of visit is integrated into clinical care.

**Status:** Ongoing

**Challenges:** The major challenge in this process has been related to clarity around the Medicare Annual Wellness Visit itself, including focus, operators, how cognitive screening fits within it, as well as current practice indifferent organizations.

An ongoing challenge with this recommendation is finding a project team leader who has the expertise needed to move this forward.

**Project Team:** Kris Rhoads, Leslie Emerick, Charissa Fotinos, Tatiana Sadak, Lynne Korte

## For more information

Go to the Dementia Action Collaborative webpage:

<https://www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan>

## Appreciation

The Dementia Action Collaborative leadership would like to express gratitude to the Joint Legislative Executive Committee on Aging (JLEC) for their support, and to our many partner organizations and project team members – this work could not happen without this collective dedication, expertise and talent.

## Dementia Action Collaborative (DAC) Roster 2016

- **Aziz Aladin**, Budget Analyst | Washington State Developmental Disabilities Council
- **Basia Belza, PhD, RN**, Lead, Coordinating Center, Healthy Brain Research Network, Adjunct Professor, School of Public Health | University of Washington
- **Dave Budd**, Director, Full Life Care | Representing Adult Day Services
- **Leslie Emerick**, Director of Public Policy and Outreach | Washington State Hospice and Palliative Care Organization
- **Eric Erickson**, Executive Director | Washington Home Care Coalition
- **John Ficker**, Executive Director | Adult Family Home Council
- **Charissa Fotinos, MD**, Office of the Chief Medical Officer | Washington State Health Care Authority
- **Carla Calogero, JD**, Elderlaw Section Chair, Washington State Bar Association
- **Debbie Hunter**, Consumer, family caregiver
- **Patricia Hunter**, State LTC Ombuds
- **Suman Jayadev, MD**, Alzheimer's Disease Research Center | University of Washington
- **Arlene Johnson**, Consumer, family caregiver
- **Senator Karen Keiser**, Health Care Committee | Washington State Senate
- **Todd Larson**, Consumer, family caregiver
- **Kathy Lofy, MD**, State Health Officer | Department of Health (DOH)
- **Bob LeRoy, Long Term Supports and Services Subcommittee Chair**, President | Alzheimer's Association of Western & Central Washington
- **Maureen Linehan**, Division Director | Aging & Disability Services of King County | Representing Area Agencies on Aging
- **Cathleen MacCaul**, Advocacy Director, AARP Washington
- **Myriam Marquez**, Consumer
- **Jason McGill**, Health Care Policy Advisor | Governor's Executive Policy Office
- **Emma Medicine White Crow**, Chair of the Washington State Governor's Interagency Council on Health Disparities
- **LeighBeth Merrick**, Director of Senior Living & Community Services | Leading Age Washington
- **Diane Oakes**, Director | Washington Dental Service Foundation
- **Bill Moss, Dementia Action Collaborative Chair**, Assistant Secretary | Aging and Long-Term Support Administration | Department of Social and Health Services (DSHS)
- **Marilyn (Mimi) Pattison, MD**, Medical Director | Franciscan Hospice and Palliative Care
- **Jerry Reilly**, (Former) Director | ElderCare Alliance
- **Kristoffer Rhoads, PhD, Health-Medical Care Subcommittee Chair**, Clinical Neuropsychologist, Memory and Brain Wellness Center | University of Washington
- **Martha (Marty) Richards, LICSW**, Social Worker | Professional caregiver of person(s) with Alzheimer's
- **Tatiana Sadak, PhD, ARNP, RN**, Assistant Professor, Geriatric Mental Health and Neurodegenerative Disorders | University of Washington
- **Christine Seymour**, Director of Advocacy | Hearing Loss Association of WA
- **Kathy Sitker**, (Former) Executive Director | Alzheimer Society of Washington
- **Bruce Smith, MD**, Executive Medical Director, Regence Blue Shield of Washington

- **Lauri St. Ours**, Director, Governmental & Legislative Affairs | Washington Health Care Association (WHCA)
- **Representative Steve Tharinger**, Health Care and Wellness Committee | Washington State House of Representatives
- **Robert Wellington**, Consumer
- **Cheryl Townsend Winter, DDS, Public Awareness - Community Readiness Subcommittee Chair**, State Council on Aging

## DAC Subcommittee/Project Team Members

- **Amanda Avalos**, Health Care Authority
- **Cindy Balbuena**, Consumer, family caregiver
- **Marigrace Becker**, UW Memory and Brain Wellness Center
- **Marietta Bobba**, Aging and Long Term Support Administration
- **Selena Bolotin**, Qualis Health
- **Kim Boon**, Northwest Regional Council
- **Susan Engels**, Aging and Long Term Support Administration
- **Marci Getz**, Washington State Department of Health
- **Jullie Gray**, Aging Wisdom
- **Hilarie Hauptman**, Aging and Long Term Support Administration
- **Christine Kubiak**, Residential Care Services, Aging and Long Term Support Administration
- **Cara Lauer**, Elderwise
- **Karen Lewis**, Washington Dental Service Foundation
- **Joel Loiacono**, Alzheimer's Association
- **Yolanda Lovato**, Aging and Long Term Care of Eastern Washington
- **Mary Lynn Pannen**, Sound Options
- **Luisa Parada Estrada**, Developmental Disabilities Administration, DSHS

## Staff Support

- Lynne Korte, Aging and Long Term Support Administration
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