WASHINGTON STATE PLAN TO ADDRESS ALZHEIMER’S DISEASE AND OTHER DEMENTIAS

AGE/DEMENTIA FRIENDLY FORUM—SPOKANE
• LYNNE KORTE, AGING AND LONG TERM SUPPORT ADMINISTRATION

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DEMENTIA BY THE NUMBERS

WASHINGTON STATE

- Alzheimer’s disease = 3rd leading cause of death
- 110,000 people currently living with dementia
- 324,000 unpaid family caregivers
- 181% increase in next 25 years
In 2010, 13% of residents age 65+
In 2030, 21% of residents age 65+
In 2015 7,949 people 65+ w/ AD
In 2030, 14,209 people 65+ w/ AD
DEMENTIA BY THE NUMBERS

More than half of Washingtonians with “memory loss that is getting worse” have NOT talked to their doctor about it.

Less than 50% of people with dementia receive a formal diagnosis.

The average annual Medicaid payments per Medicare beneficiaries with dementia were **twenty-three times** as great as those without dementia.

At diagnosis, less than **10%** are referred to organizations like the Alzheimer’s Association for support or information.

African Americans are 2x more likely than whites to have dementia. Hispanic/Latinos 1.5 times as likely.
PLAN’S 7 GOALS

1. Increase public awareness, engagement and education.
2. Prepare communities for significant growth in the dementia population.
3. Ensure well-being and safety of people living with dementia and their family caregivers.
4. Ensure access to comprehensive supports for family caregivers.
5. Identify dementia early and provide dementia-capable evidence-based health care.
6. Ensure dementia-capable long-term services and supports are available in the setting of choice.
7. Promote innovation and research related to causes of and effective interventions for dementia.
2016 – 2018 ACTIVITIES

- Next generation group formed
  - Public-private partnership
- Focus on what we can do
  - Through heightened collaboration
- Within existing resources
HEALTH AND MEDICAL

Problems
Families report challenges not only in attaining a diagnosis, but with receiving post-diagnostic support, assistance with ongoing care challenges, and referrals.

Dementia is drastically underdiagnosed.

ACCOMPLISHMENTS – Recommendations 5A1, 5B2

- DAC approached the Bree Collaborative to convene expert panel to establish evidence-based recommendations for primary care
- Final Report & Recommendations for AD and Other Dementias released Nov 15, 2017
- Developed position paper on cognitive screening tools for primary care
- Identified background, tools and guidance

Brief Cognitive Screening Tools for Primary Care Practice

Abstract
Early detection and diagnosis of Alzheimer’s disease and other cognitive impairment presents as a critical issue facing primary and specialty care providers in Washington State. In order to address the gaps and challenges faced by providers, the Dementia Action Collaborative offers the current...
IDENTIFY AND ENDORSE EVIDENCE-BASED STANDARDS

ACCOMPLISHMENT – Recommendations 5A1/5E3

BREE’s AD Report and Recommendations address 6 categories for primary care practitioners

- Diagnosis
- Ongoing Care and Support/Management
- Advance Care Planning and Palliative Care
- Transitions to Higher Levels of Care
- Transitions between community and hospital
- Screening for Delirium Risk

Dementia is a long journey. Families are often unclear what to expect and where to turn. They need a basic, but thorough road map to guide important action steps and to know where to find help along the way.

Supports for people in early stages is critical to allow for education, adjustment and planning.

### Accomplishments

- Created comprehensive yet simple to follow “Road Map”
- Online PDF version, print version – nearly 40,000 distributed already
- Created guidance for models of support - Webinars/Documents
  - Staying Connected
  - Alzheimer’s/Memory Cafes
  - Walking Programs
ACCOMPLISHMENT - Recommendations 1B2/4C2

- Inventoried programs across state
- Identified models with potential for and interest in replication
- Piloted Staying Connected (Spokane!)
- Created webinars and guidance documents to support
  - Alzheimer’s/Memory Cafes
  - Walking Programs
PUBLIC AWARENESS-COMMUNITY READINESS

ACCOMPLISHMENTS – Recommendations 1F1/2D2

- Encourage cognitive assessment among Asian Americans and Pacific Islanders
- Increase awareness of brain health in the African American community

National Asian Pacific Center on Aging and the UW Healthy Brain Research Network partnered; focus groups with Chinese and Japanese adults with older relatives - acceptability of messages concerned about cognitive health

DOH partnered with nonprofit Center for MultiCultural Health to tailor and disseminate brain health messages to African American audience

Identified 4 African American churches; sponsored “Memory Sundays” in June - brief presentation + Resource Table after services
ACCOMPLISHMENT – Recommendation 3A1
- Using existing federal grant and OAA funds
- ALTSA partnered with DOH and the Alzheimer’s Association to create a new online CHW module
  - Increase CHW awareness of: dementia and its impacts, age-related memory loss and possible warning signs of dementia
  - Promote referrals to appropriate supports
DEMENTIA FRIENDLY COMMUNITIES

Problems
Social stigma and barriers to inclusion can lead to shame, fear and isolation. This means they won’t get the help and services needed to help them stay safe and supported in their own homes.

Dementia also impacts safety. Families need help to balance independence and safety while they try to keep their loved ones at home.

ACCOMPLISHMENTS – Recommendation 2C1, 3B1
- Created Safety Info-Kit
- Developed Dementia-Friendly Communities fact sheets

Dementia-Friendly Communities
An Introduction for Washington State

Over 100,000 people in Washington state live with Alzheimer’s disease or other dementias, and that number continues to grow. For many people with memory loss, social stigma and barriers to inclusion can lead to shame, fear, and isolation. However, it doesn’t have to be this way. We recognize that people with memory loss are a vital part of our communities, and the need for strength and support. To do so, we’re joining the worldwide movement to build dementia-friendly communities.

Do you want to get involved? This introduction will help. Read on to learn more about the key elements of a dementia-friendly community, examples from our state and beyond, sample action steps, and additional resources.

What is a dementia-friendly community?
Put simply, a dementia-friendly community is one in which people with memory loss fully belong. People with memory loss remain actively involved in community life, knowing that whether riding the bus, going to the store, or volunteering at the elementary school, they and their loved ones will be met with respect, understanding, kindness and support. Community members are informed about dementia, equipped to be helpful as needed, and committed to inclusion. As a result, everyone enjoys a vibrant, connected community in which nobody is left out, everyone can fully participate and contribute, and everyone can fully belong.

As experts on their own experiences, your family, friends and neighbors with memory loss are the ones who can best define what would make your community more dementia-friendly. If you want to learn more, try asking: “What kinds of things help you feel you belong and can stay actively involved here in this community?” Let what you hear be your guide below: two Washington state advocates describe their own perspectives on dementia-friendly community:

“A dementia-friendly community is where people care for people with dementia. The point is respect — caring about people. I’ve lost, but I have many many friends in my apartment building. I told everyone at some point that I have Alzheimer’s, and they watched out for me.”

“Without the community, it’s easier for people to keep their loved ones at home.”

Debra, Tacoma
Myra, Seattle

Photo credit: Alzheimer’s Association
WHY AGE FRIENDLY? AARP LIVABLE COMMUNITIES

8 Domains of Livability

1. Outdoor spaces and buildings
2. Transportation
3. Housing
4. Social Participation
5. Respect and social inclusion
6. Civic participation and employment
7. Communication and information
8. Community and health services

World Health Organization’s Age-Friendly Cities and Communities Program
WHY THE DEMENTIA-FRIENDLY MOVEMENT?

- Stigma and fear
- Belief that “there’s no reason to get a diagnosis”
- Lack of disease knowledge and planning for the future of individuals/families
- Isolation of person and family
- Disconnected efforts and services for people with dementia
THINK DIFFERENTLY ABOUT DEMENTIA – WHAT WE CAN DO!

- Recognize benefits of diagnosis - and that early detection is key
- Create acceptance, hope and empowerment
- Promote greater connection with others
- Increase understanding of dementia and services available
- Increase family engagement in legal, financial and advance care planning
- Create community supports/collaborations to help individuals live at home for as long as possible
DEMENTIA-FRIENDLY COMMUNITIES

- Created fact sheets
- Outreach to libraries and recreation associations
- Survey to explore and create opportunities for statewide resource sharing and networking
  - Alzheimer’s Café Webinars
    - January 24 & Oct 23, 2018
    - Register: https://tinyurl.com/AlzCafeWebinar
  - Dementia-Friendly Walking Groups – May 24, 2018
  - Dementia-Friendly Programming: Overcoming Obstacles – Nov 8, 2018
    - Register: https://tinyurl.com/DFProgramsWebinar

Dementia-Friendly Communities
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Do you want to get involved? This introduction will help! Read on to learn more about the key elements of a dementia-friendly community, examples from our state and beyond, sample action steps, and additional resources.

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As experts on their own experience, your family, friends and neighbors with memory loss are the ones who can best define what would make your own community more dementia-friendly. If you want to learn more, try asking: “What kinds of things help you feel belong and can stay actively involved here in this community?” Let what you hear be your guide!

Below, two Washington state advocates describe their own perspectives on dementia-friendly communities:

“Awareness and respect of persons with dementia and their caregivers help us feel comfortable. There are people in the community where I go routinely (like Denny’s, or volunteering at the golf course) who are aware of my dementia. I am treated with

“A dementia-friendly community is where people care for people with dementia. The point is respect - caring about people. I live alone, but I have many, many friends in my apartment building. I tell everyone at some point that I have dementia. My friends know me and the house is wonderful.
Shopping List

- Chicken
- Cheese
- Bread
- Eggs
- Milk
- Butter
- Biscuits
- Juice
- Salad
- Ham
- Tea
What would you want?
DEMENTIA FRIENDLY COMMUNITIES IN WA

- Are respected
- Can participate confidently in their communities
- Stay connected to their family, friends and neighbors
- Enjoy meaningful lives, with access to education, recreation, work or volunteer opportunities, cultural enrichment, and more
- Have a voice in their community
- Have access to early diagnosis and post-diagnostic resources
- Have transportation options
- Have community housing options
- Can navigate neighborhoods and public spaces
Minnesotans working together on the impacts of Alzheimer’s

http://actonalz.org/
Dementia Friendly Toolkit

The ACT on Alzheimer’s® Dementia-Friendly Communities Toolkit has four phases that guide communities in adopting dementia-friendly practices across the community.
DEMENTIA FRIENDLY TOOLKIT - WISCONSIN

- Using the Toolkit
- Shifting our perceptions of dementia
- Dementia-friendly communities
- Public health as a key partner
- Dementia’s impact
- Specific strategies for…
  - Business sector
  - Community organizations
  - Health sector
  - Public service sector
Fostering Dementia Friendliness

Communities across the country are stepping up to support a growing number of individuals with dementia and their family and friend care partners

Shaping a Movement

Dementia Friendly America is a multi-sector collaborative on a mission to foster "dementia friendly" communities

http://www.dfamerica.org/about-dfa-1/

The Dementia Friendly America Initiative

Through the work of over 35 national, leading organizations, the Dementia Friendly America initiative is catalyzing a movement to more effectively support and serve those across America.
Dementia Friendly Toolkit Overview

In a dementia friendly community, every part of the community plays a role and works together to create a dementia friendly culture.

The Dementia-Friendly Toolkit guides communities through a research-informed process that fosters adoption of dementia friendly practices in all parts of community. The toolkit is designed to be flexible and adapt to fit a community’s needs and complement other project management processes. The four phases are: Convene, Engage, Analyze, and Act. Successful implementation of the community toolkit requires strong leadership, dedicated team members and well-developed work plans. The time commitment for completing the four phases varies and has ranged anywhere from six to eighteen months.

1. Phase 1: Convene key community leaders and members to understand dementia and its implications for your community. Then, form an Action Team.
2. Phase 2: Engage key leaders to assess current strengths and gaps in your community using a comprehensive engagement tool.
3. Phase 3: Analyze your community needs and determine the issues stakeholders are motivated to act on; then set community goals.
4. Phase 4: Act together to establish implementation plans for your goals and identify ways to measure progress.

Approximately 1-3 months  Approximately 2-6 months  Approximately 1-2 months  2 months - ongoing
Dementia Friends

Dementia Friends is a global movement that is changing the way people think, act, and talk about dementia. Developed by the Alzheimer’s Society in the United Kingdom, the Dementia Friends initiative is underway in Minnesota. By helping everyone in a community understand what dementia is and how it affects people, each of us can make a difference for people touched by dementia.
Is about community impact  Is about individual impact
HOW OR WHERE TO START? DEMENTIA FRIENDLY TEMPE

- Arizona’s first dementia friendly city
- Dementia Friendly America Action Team
- Formed Action Team led by Chamber of Commerce
- Weekly Memory Café at library where people with dementia and caregivers can meet others
- Dementia Friends training to educate community on how to support dementia friendly efforts
DEMENTIA FRIENDLY COMMUNITIES IN MINNESOTA

- International Falls
- Marshall
- Paynesville
- Sauk Rapids
- St. Cloud
- St. Paul African American Faith Community

Check out in-depth, evaluative reports on communities, as well as on other aspects of the ACT.
In 2014, Greater International Falls initiated the ACT on Alzheimer’s effort.

- Koochiching Aging Options, a local nonprofit, led the project.
- Key partners in the effort include representatives of:
  - a local long-term care facility
  - a health care provider
  - the faith community, and
  - the county’s public health agency
- The core team brought together a larger assembly of interested people to form the ACTion Team.

**Snapshot of Activities**

- Established the Koochiching Memory Café, which invites those living with dementia and their care partners to enjoy a social outing with education, refreshments, and activities.
- Offered Dementia Friends Information Sessions.
- Working with area clinics and related professionals to promote early screening.
- Established agreement with Koochiching Aging Options (KAO) to provide ongoing leadership for implementing the community’s ACT priorities.
- KAO hired a dementia support specialist as a single-point-of-contact for the community.
In September 2013, the Marshall Area Dementia Awareness Network became an Action Community for ACT on Alzheimer’s. ACTion Team members represent:

- aging services providers
- health care
- long-term care, adult day program
- the Area Agency on Aging, and
- local government.

**Action Priorities**

- Create a [community resource brochure](#) and dementia awareness business cards
- Offer Dementia Friends Information Sessions
- Host a monthly radio and television show
- Offer education to community and family caregivers
- [Create dementia-friendly community recreation and education programming at the YMCA](#)
- Host an ArtSage workshop

**Snapshot of Activities**

- The ACTion Team meets monthly and functions as the Marshall Area Dementia Awareness Network.
- Held Dementia Friends Information Sessions in Lincoln County.
- Conducted Virtual Dementia Tours at local nursing homes. Partnering with Avera Marshall Regional Medical Center to increase Virtual Dementia Tours offerings.
- Held a successful ArtSage workshop with 50 professional and family caregivers to learn how to use the arts to reach out to those with dementia.
- Plan to expand to a larger service area, including Lyon County. Future plans include community awareness events, Dementia Friends sessions, Virtual Dementia Tours in nursing homes, Rider Companion Program, collaboration with local clinics as to memory screenings, ongoing memory loss consultation, support groups and evidence based classes to assist family caregivers.
The Paynesville Area ACT on Alzheimer’s was formed in 2014. The ACTion Team is made up of representatives of:
- health care
- social service agencies
- the Paynesville Area Center, and
- those who are or have been a caregiver to someone living with dementia.

**What We’re Doing for Our Community**
- Providing weekly assistance and education for shoppers at our local grocery store who have dementia
- Educating elementary and middle school students about dementia; planning to extend to high school students
- Providing Dementia Friends sessions upon request
- Assisting individuals and families with their dementia journey
- Starting a video histories program to share life stories with families

**Snapshot of Activities**
- Display public billboard to promote Paynesville as a dementia friendly community
- Provided Dementia Friends Information Session to emergency responders including firefighters and first responders, families, local organizations, school students and community members.
- Trained “Ollie,” the first dementia friendly therapy canine in Minnesota, to provide comfort and calming companionship to people with dementia.
- Provided educational presentations with expert speakers to physicians and healthcare professionals, caregivers, police,
- Providing Alzheimer’s emergency responders and firefighters friendly business training to city employees, Chamber of Commerce members and local businesses.
- Continue to distribute pamphlets about Alzheimer’s disease/dementia in local grocery store and have volunteers assist with shopping or provide “coffee and companionship” while the family caregiver shops
- Provide books and information materials to elementary, middle and high school libraries and teachers
After holding several ACT on Alzheimer’s convening meetings that included being informed by the Central Minnesota Council on Aging and the Cambridge ACT ACTion Team, the Sauk Rapids team was formed in 2014.

Community sectors represented on the team include:
- service club
- health care
- local government
- education
- Business
- nonprofit senior service provider
- community members

**Snapshot of Activities**

- Presented to the City Council, informing council members of what ACT is and how our city is taking steps to become dementia friendly.
- Trained 125+ **Dementia Friends**, working in senior housing, assisted living, and living in the community. Students and teachers at the high school are also Dementia Friends.
- Participated in an **Expo for Seniors** in St. Cloud with this year's theme of Dementia. Kim Campbell (Glen Campbell's wife) was keynote speaker.
- Trained all managers and staff of **Coborn’s Grocery** in ACT's Dementia Friendly @ Work; trained 60 employees.
- Developed and distributed “**Know the 10 Signs**” **bookmarks** containing community resource information. Created and disseminated “**awareness cards**” for caregivers and family members stating “Please be patient. I am with someone who has dementia.”
DEMENTIA FRIENDLY RESOURCES

APPROACHING ALZHEIMER’S First Responder Training

To register, go to: alz.org/firstresponders

The Alzheimer’s disease epidemic continues to grow. As a first responder, it’s critical to understanding how to best approach situations involving someone with Alzheimer’s disease.

Make your first response the right response!
Dementia Friendly Businesses and Organizations: Information for Starting a Local Initiative, provides information on the business benefits, criteria, content and best practices businesses can use to become more dementia friendly.

The DFA website also includes examples of dementia friendly business trainings such as the Dementia Friendly @ Work program, which can be offered by peers within an agency or business.

DFA partner Home Instead offers an Alzheimer’s Friendly Business online course.

These resources and more are available in the Dementia Friendly America Resources portal!
A grassroots movement empowering people living with memory loss and their loved ones to remain connected and active in the community.
MOVING FORWARD – AN OPPORTUNITY TO LEAD

- Connect/collaborate across sectors
- Include people living with dementia (family members)
- Find your champions and supporters
- Start with something do-able
- Use existing resources and tools
- Consider joining the Dementia Friendly America network of communities

Dementia Friendly Communities start with us!
MORE INFORMATION ON THE DEMENTIA ACTION COLLABORATIVE & OUR RESOURCES

It is amazing what you can accomplish when you don’t care who gets the credit.

Harry S. Truman

Lynne Korte, Program Manager
Aging and Long-Term Support Administration

- Lynne.Korte@dshs.wa.gov
- Washington State Alzheimer's Plan