

Community Resources for Dementia

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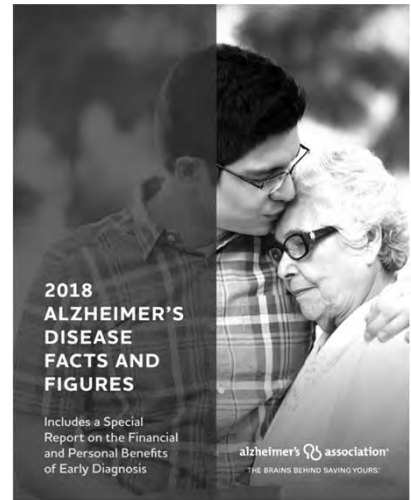
UW NW GWEC Geriatric Health Series
February 26, 2019

Outline

- Dementia Facts & Figures
- National and State Alzheimer's Disease Plans
- Dementia-Friendly Communities
- Dementia Supports & Services
- Questions

Dementia Facts & Figures

- Estimated 5.7 million Americans live with Alzheimer's or other dementias
- Another person diagnosed every 65 seconds
- Prevalence anticipated to more than double by 2050
- 1 in 3 seniors dies with Alzheimer's or other dementias
- Alzheimer's disease is the 6th leading cause of death
- 16.1 million Americans care for a loved one with Alzheimer's or other dementias



Source: 2018 Alzheimer's Disease Facts and Figures, Alzheimer's Association

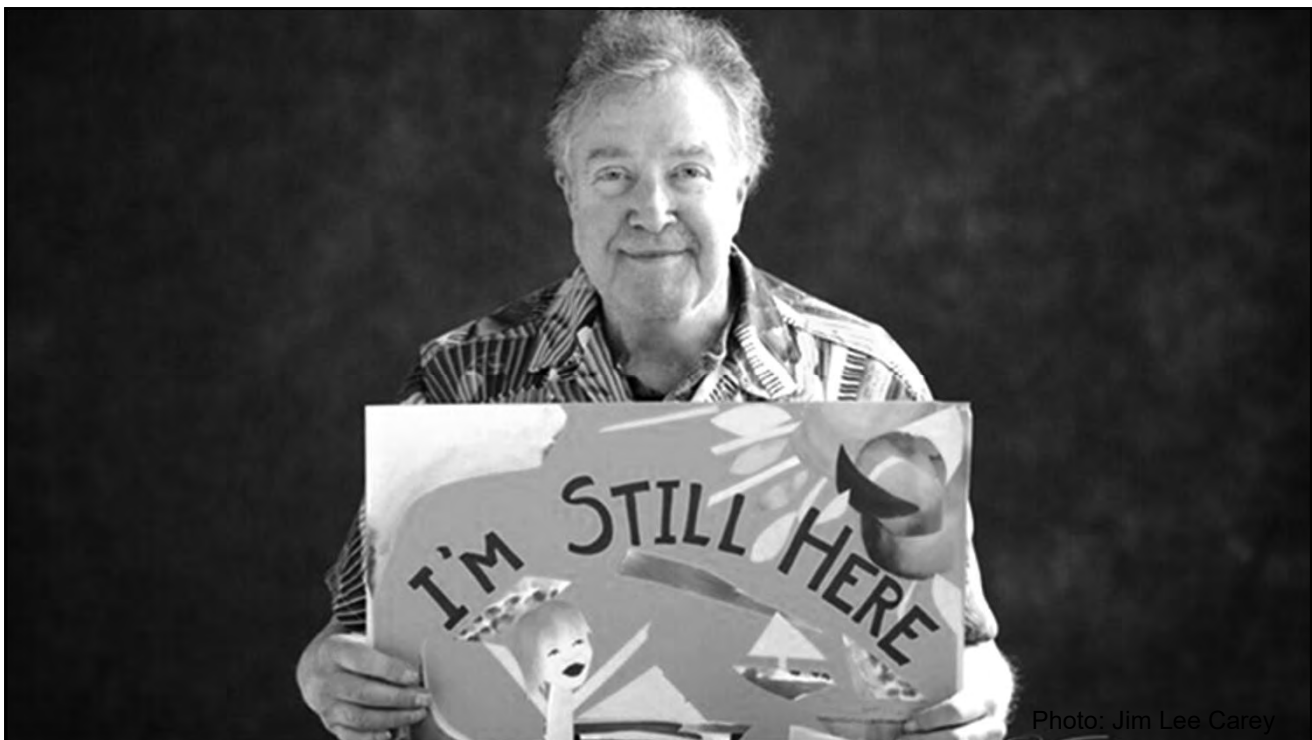
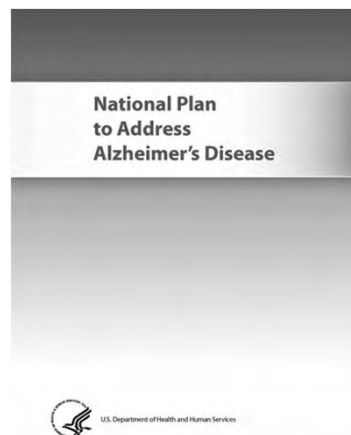


Photo: Jim Lee Carey

National Alzheimer's Disease Plan

- Mandated in 2011 National Alzheimer's Project Act (NAPA)
- Approved in 2012
- Addresses various challenges including stigma and social isolation, and the need for caregiver support
- 5 Goals for Prevention and Support:
 - Prevent and Effectively Treat Alzheimer's Disease by 2025
 - Optimize Care Quality and Efficiency
 - **Expand Supports for People with Alzheimer's Disease and Their Families**
 - Enhance Public Awareness and Engagement
 - Track Progress and Drive Improvement



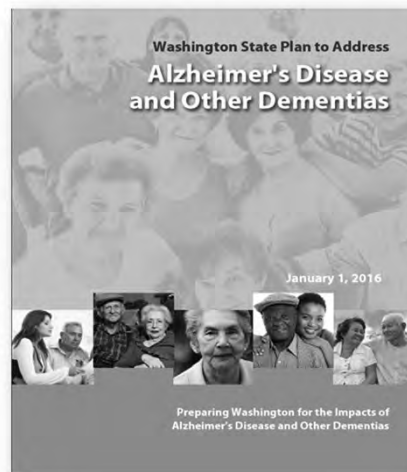
National AD Plan - Sample Strategy/Actions

- Strategy 3.B: Enable Family Caregivers to Continue to Provide Care while Maintaining Their Own Health and Well-Being
 - Action 3.B.1: Develop and disseminate evidence-based interventions for people with Alzheimer's disease and related dementias and their caregivers
 - Action 3.B.2: Provide effective caregiver interventions through Alzheimer's disease and related dementias-capable systems
 - Action 3.B.3: Collaborate to share information on long-term services and supports with Tribal providers
 - Action 3.B.4: Continue to promote use of the National Alzheimer's Call Center to provide information, advice and support to people with dementia or their caregivers
 - Action 3.B.5: Make behavioral symptom management education and training available to caregivers
 - Action 3.B.6: Examine technological solutions to support family caregivers

Washington State Alzheimer's Disease Plan

- 2014: Alzheimer's Disease Working Group formed by the state legislature
 - 37 key stakeholders
 - Public-private partnership
 - Tasked with making recommendations for priority action steps

- 2016: Washington State Plan to Address Alzheimer's Disease and Other Dementias released and approved



7 Goals



Dementia Action Collaborative

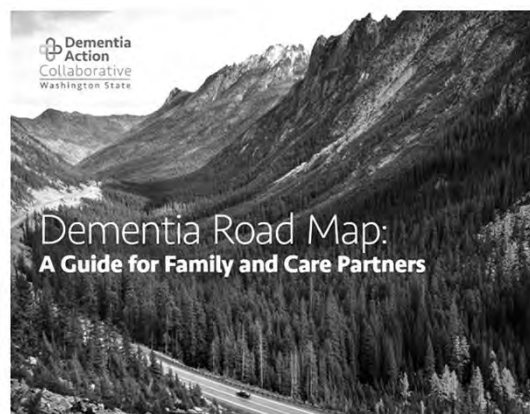
- April 2016: DAC convened
- Focus on what can be done through heightened collaboration within existing resources
- Three subcommittees
 - Health & Medical
 - Long Term Services and Supports
 - Public Awareness & Community Readiness



www.dshs.wa.gov/altsa/dementia-action-collaborative

Sample Progress to Date

- Produced comprehensive yet simple to follow “Road Map”
 - Online PDF version, print version
 - Nearly 40,000 distributed already
- Created and distributed Dementia-Friendly Communities fact sheet



www.dshs.wa.gov/altsa/dementia-action-collaborative

Sample Progress to Date

- Created guidance for models of support - Webinars/How-to Guides
 - Alzheimer's/Memory Cafes
 - Memory Loss Walking Programs
- Dementia Safety Info Kit
- Legal Resources (In Progress)



The Alzheimer's Café Model

An Introduction for Washington State



Friendships Blossom at the Alzheimer's Café at the Frye, Frye Art Museum, Seattle WA. Photo: Gill Tarnelius

www.dshs.wa.gov/altsa/dementia-action-collaborative

Dementia-Friendly Communities



Regions, cities or neighborhoods in which people with dementia are respected, included and empowered to remain active participants and contributors in community life.

Dementia-Friendly Communities



Myriam, Seattle

"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 Alzheimer's, and they watch out for me."

Photo credits: Alzheimer's Association



Bob, Tacoma

"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 acceptance, patience and respect. I feel good about it."

Staying Active, Staying Social

"At one point my doctor told me, 'Stay active and stay social.'

That's the best advice I've gotten anywhere!"

-Mary F, living with memory loss,
Seattle, WA



Alzheimer's Cafe Model

- Model established in 1997 by Dutch psychiatrist Bere Miesen; came to US in 2008 with Dr. Jytte Lokvig
- Monthly social gathering for persons with memory loss, family and friends
- Take place in welcoming community spaces like restaurants, coffee shops, libraries, museums, faith congregations
- Purpose of American model is social connection. European model includes education/discussion.
- Over 200 Alzheimer's Cafe events in the US.
- View national listing here: <http://alzheimerscafe.com>



First Alzheimer's Cafe in Washington State. Photo: Greenwood Senior Center

Alzheimer's Cafe Model



Alzheimer's Cafe at the Frye. Photo: Olli Tumelius

"Alzheimer's Cafés are especially beneficial to people who have been newly diagnosed with Alzheimer's and their caregivers. As you interact with others, you can find out what they have gone through and learn what to expect, in a friendly, informal atmosphere."

-Bob W, Guest at Tacoma area Alzheimer's Cafés

Alzheimer's Cafe Model



Alzheimer's Cafe at Elmer's Restaurant.
Photo: Lutheran Community Services Northwest.

"The world of a caregiver can become very small. Friends stay more distant since they are doing other things you no longer can do with them. So to be able to go out for a great restaurant meal with a group of others going through many of the same things as you is really a treat!"

-Mary S, Guest at the Mill Creek Supper Club, Battle Ground, WA

Momentia Movement



A grassroots movement empowering people with memory loss and their loved ones to stay active and connected in the community.

www.momentiasattle.org

Gallery Tours at the Frye Art Museum



https://fryemuseum.org/creative_aging/
Photo: Olli Tumelius

Walking Group at Woodland Park Zoo



Seattle Zoo Walk, Alzheimer's Association
www.alzwa.org

"The social aspect of the zoo walks is our favorite part. It is a place where my husband can feel comfortable just being himself."

"For me, the bond that has been created with the other care partners has been a wonderful support system and many deep friendships have been formed."

– Paula S, care partner

Improv Workshop with Taproot Theatre



"Family members with Alzheimer's never lose their imagination. They are still a gift in your life when you are able to do things with them like improv, that bring out the beauty in their mind."

~ Katriz, caring for her father with dementia

Photo: Edmonds Center for the Arts. <http://taproottheatre.org/acting-studio/early-stage-memory-loss/>

Beyond Washington: Program Examples

- **Idaho**
 - Memory Cafe of Sandpoint: Contact pchristo@alz.org
- **Oregon**
 - artNOW at Portland Art Museum: <https://portlandartmuseum.org/artnow/>
 - Sing Here Now community choir:
https://www.alz.org/orswwa/helping_you/early-stage_programs/sing_here_now
- **Montana**
 - Art in the Moment at Missoula Art Museum:
<https://www.missoulaartmuseum.org/index.php/type/class/ID/951580a9e14f5d873fbf3c660f72f5a7/cID/6dd911c6/fuseaction/classes.detail.htm>
- **British Columbia**
 - Voices in Motion intergenerational choir:
<https://onlineacademiccommunity.uvic.ca/voicesinmotion/>



Life Beyond Diagnosis

“When I was diagnosed, I made some choices about how I was going to live my life. Because I didn’t know – and none of us know – how many good years we have left.

And so I just started to do the things that I love to do. I went to lots of places. I met wonderful friends.

There is LIFE after diagnosis! And it can be really wonderful.”

~Myriam M, Seattle, WA



Photo: Rachel Turner, Alzheimer's Association

The Role of Family Caregivers

- Unpaid family caregivers are the backbone of our long-term care system
- The best predictor of out of home placement is how the caregiver is doing
- Half of all caregivers have no outside help
- Only an estimated 10% to 20% use formal services



Caregivers for Persons with Dementia

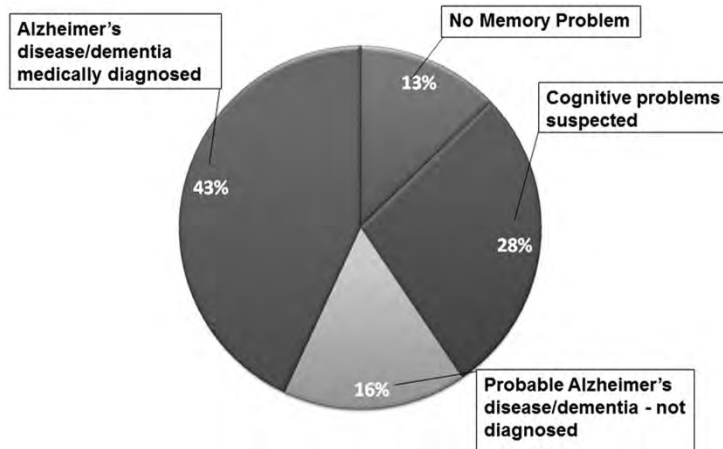
- Majority of persons with dementia are community-dwelling and are cared for by family and friends
- Provide an estimated 22 hours of care per week
- More likely to be providing care for five years or longer
- Majority are spouse/partners
- Approximately 2/3 are women
- 34% are 65+

Alzheimer's Association Facts & Figures, 2015

A Snapshot - Washington's TCARE® Process

- Is caregiver centered
- Measures levels of stress, burdens, depression, uplifts and identity discrepancy
- Creates a structured way to target services based on need

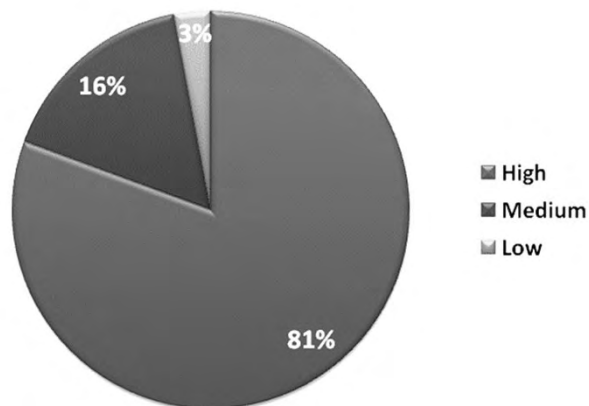
Cognitive Status of Care Receiver



Based on 304 TCARE® Screenings

Identity Discrepancy

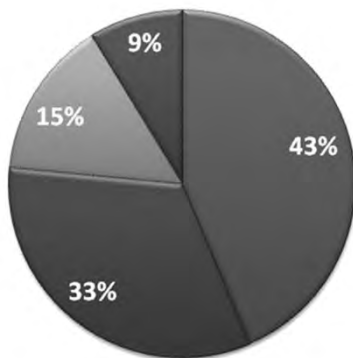
Measures the caregivers' feelings that their caregiving tasks/responsibilities are inconsistent with what they want to be doing in their relationship with care receiver.



Based on 304 TCARE® Screenings

Intention to Place

Given Current Situation



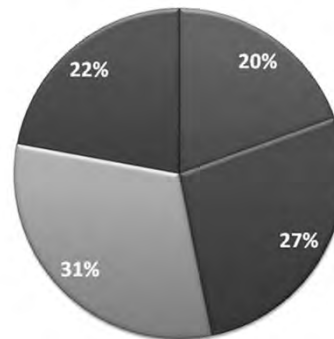
■ Screening
Definitely not

■ Screening
Probably not

■ Screening
Probably would

■ Screening
Definitely would

If Condition Worsens



■ Assessment
Definitely not

■ Assessment
Probably not

■ Assessment
Probably would

■ Assessment
Definitely would

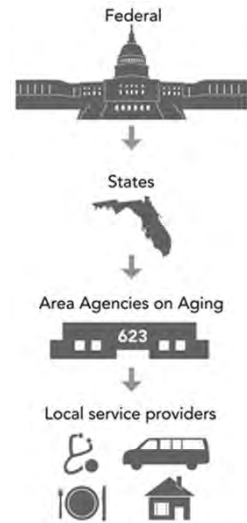
Based on 304 TCARE® Screenings and 267 TCARE® Assessments

Area Agencies on Aging - A National Network

- Nationally established in the 1973 Older Americans Act (OAA)
- Designated “on the ground” organizations charged with helping vulnerable older adults live with independence and dignity within their communities.
- There are 622 AAAs serving older adults in virtually every community in the nation.
- In a few small or sparsely populated states, the state serves the AAA function.

National Aging Network

- Administration on Aging - Federal Oversight
- State Units on Aging
- Local AAAs (service area can span more than one county)
- Contracted Service Providers
- Volunteers and Coalitions



Core Aging Network Programs and Services

- Supportive Services - information & assistance, transportation, adult day services
- Nutrition Services – home delivered meals, congregate meals
- Preventive Health Services – senior drug education, health promotion
- **National Family Caregiver Support Program**
- Elder Rights – elder abuse investigations, Long-Term Care Ombudsman Program National Demonstrations

The National Family Caregiver Support Program

- Unpaid family caregivers as service recipients
- Administered through the Aging Network
- Program design is guided by local and state planning processes
- Flexible package of high-value supportive services:
 - Information
 - Access Assistance
 - Counseling, Support Groups, Training
 - Respite
 - Supplemental Services

Eligible Service Recipients

- Family caregivers (18+) of older adults (60+)*
- Family caregivers (18+) of individuals with Alzheimer's disease/related dementia (any age)
- Grandparents and relative caregivers (55+) of children (under age 18)
- Grandparent and relative caregivers (55+) of adult children (18-59) with a disability

*some areas have expanded the program to serve family caregivers (18+) of adults (18+)



Program Impact

- 700,000 caregivers
- 1/3 work full time
- ¼ providing care for 5-10 years
- Primarily Women (73%)
- Caregivers are older themselves
 - 54% age 60+
 - 22% age 75+
- 17% live in rural areas
- Grandparents
 - 81% female
 - 84% age 60-74



National Evaluation

- Between 2013 and 2018 ACL undertook the first evaluation of the National Family Caregiver Support Program (NFCSP).
- The two-part evaluation included:
 - A process study to understand and document the strategies used to meet NFCSP goals
 - An outcome study to understand NFCSP caregiver outcomes including stress reduction and maintenance of the care recipient in the community

What We've Learned about Caregivers

Participants in National Family Caregiver Support Program report that their biggest challenges are:

- Stress (26%)
- Not enough self-time (16%)
- Financial burden (11%)

AAA services caregivers need the most:

- Information and assistance - 10%
- Caregiver education and training, individual counseling, support groups - 14%
- Respite care - 42 %
- Supplemental services - 10%
- Other (home health aide, physical therapist, homemaker services/house cleaning, and meals) - 25%

Findings

- Relationship between NFCSP service use and other services
- Difference in outcomes: NFCSP Caregivers vs. Comparison caregivers
- Association between NFCSP service amount and caregiver perception of program effectiveness

Avison, C., Brock, D., Campione, J., Hassell, S., Rabinovich, B., Ritter, R., & Zembrak, K. [The Caregiver Outcome Evaluation Study of the National Family Caregiver Support Program.](#)

Insights from the Caregiving Community

- ACL also conducted a small, retrospective study of caregivers whose care recipient passed away.
- Caregivers who seek assistance and supports earlier in the process often find the experience to be more manageable than those who don't engage with services until later on in their caregiving journey
- Caregivers who frequently use respite and home health services experience more positive caregiving.
- Focus on the development of natural and peer supports

From Caregiver to Caregiver: The Wisdom and Insights of Former NFCSP Caregivers

Respite Care Models

There are opportunities to offer

- Formal Respite Care Services (in home, **adult day services**, overnight stays)

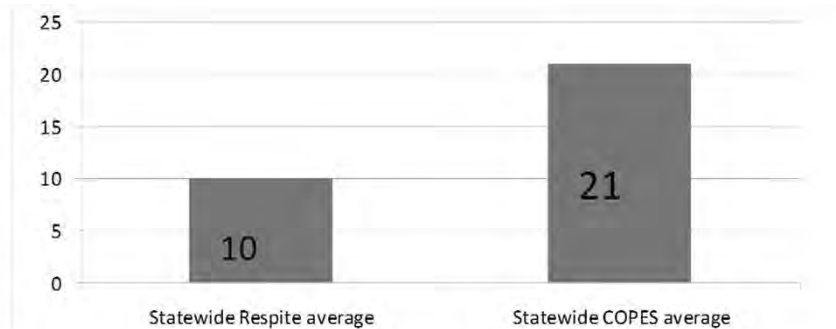
as well as,

- “little r” respite (informal support, volunteers, recreational programs...)

to provide alternate sources of care for caregivers to have much needed breaks.



Respite serves individuals with higher levels of cognitive impairment ...



MMSE scores: 24-30 Uncertain Cognitive Impairment
18-23 Mild to moderate Cognitive Impairment
0-17 Severe Cognitive

Caregiver support delays the need for most costly services

88% of care receivers in the Washington's Family Caregiver Support Program are functionally eligible for the COPES Medicaid waiver program

- Average annual cost for:
 - FCSP Clients - \$2,000
 - Medicaid Nursing Homes - \$52,800*
 - Community Based Services - \$25,200*

* includes medical costs

2009 TCARE Data

Connecting Patients To AAAs



The national Eldercare Locator toll-free hotline helps consumers connect to these local resources!

800.677.1116
www.eldercare.gov



The screenshot shows the Eldercare Locator website interface. At the top, there is a navigation bar with 'Home', 'About', and 'Resources' links. Below this, the search results for 'helena, MT' are displayed. A welcome message states: 'Welcome to the Search Results Page. Below is a listing of resources in your community that provide information and assistance for older adults and caregivers. To learn more about each type of agency access the [button] button located next to each service.' Below the message is a dropdown menu for 'Area Agencies On Aging' and a 'New Search' button. The main content area shows a listing for 'Rocky Mountain Area IV Area Agency on Aging' with the following details:

Address :	200 South Cruse Ave.
City :	Helena
State :	MT
Zip :	59624
Website :	http://www.rmdc.net
Contact Email :	juikerson@rmdc.net
Office Phone :	(406) 447-1680
Information Phone :	800 551-3191
State Phone :	(800) 551-3191
Languages :	English
Description :	primarily serve seniors and people with disabilities. Information and Assistance, SHIP counseling, Long term care ombudsman. Wide range of direct services to help seniors remain independent in their own homes. Legal assistance- long-term care- abuse prevention/intervention- meals & support services- health pr.
Hours :	8:00 AM - 5:00 PM - Mountain Time, M-F
Directions :	View on map

Other Nationwide Resources

- **Alzheimer's Association**
 - Information and support for people with Alzheimer's disease and their caregivers. Operates a 24/7 helpline and offers support groups & care navigator tools.
- **AARP**
 - Find free care guides, legal checklists, care options and an online community that supports all types of family caregivers.
- **Veterans Administration**
 - Support and services for families caring for veterans. Maintains a VA caregiver support line.

Questions?

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