

Alzheimer's Disease and Related Dementias



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Tribal-AL TSA-HCS-AAA Spring Summit

May 19th, 2021

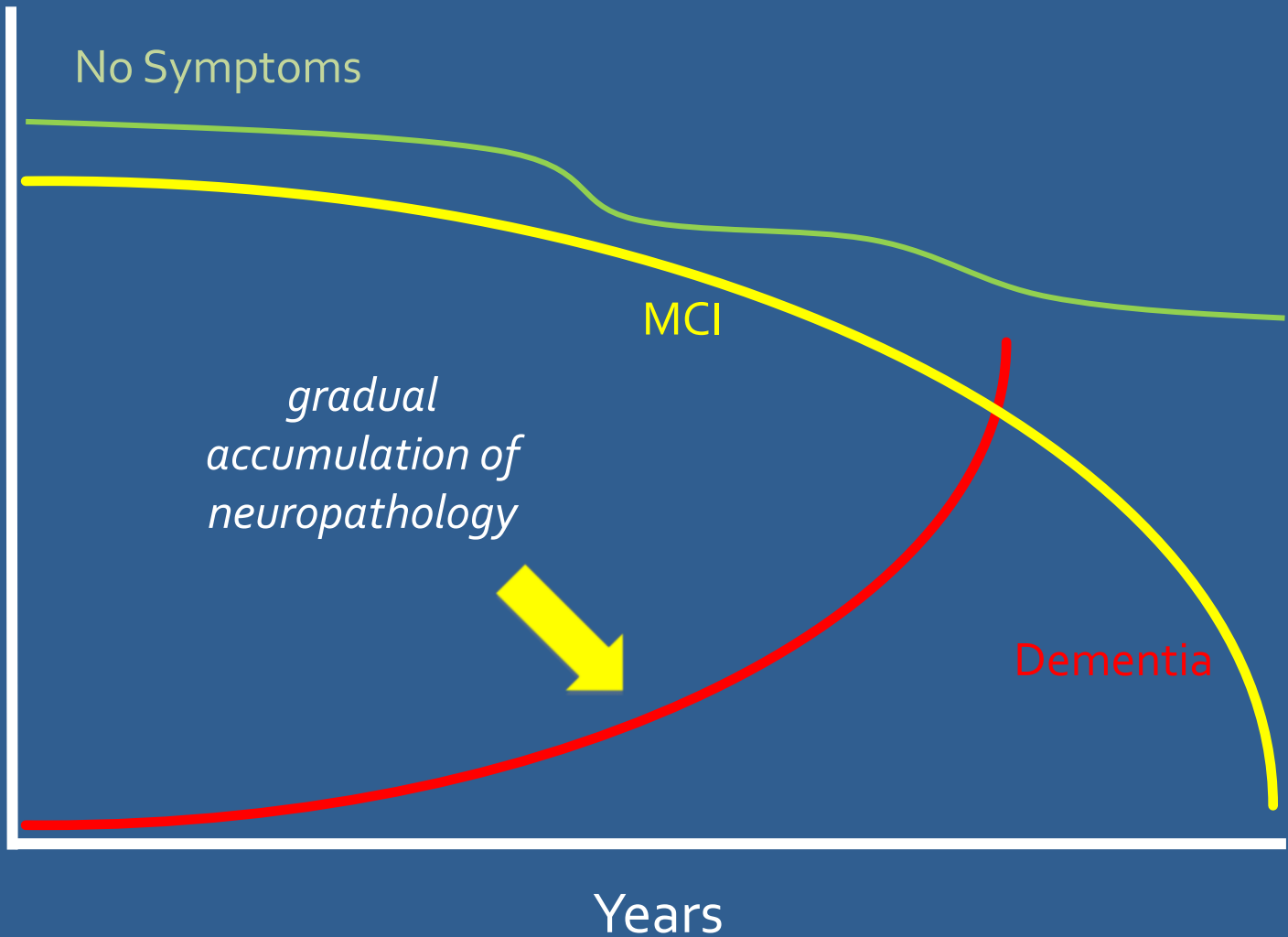
Presentation Overview



- Context
 - What's Normal, What's Not?
 - Trends
 - Health and Health Care Disparities
- Treatment
 - Prevention
 - Non-pharmacological
- Programs and Services Update
 - Project ECHO
 - Virtual and In-Person Resources

What's Normal, What's Not?

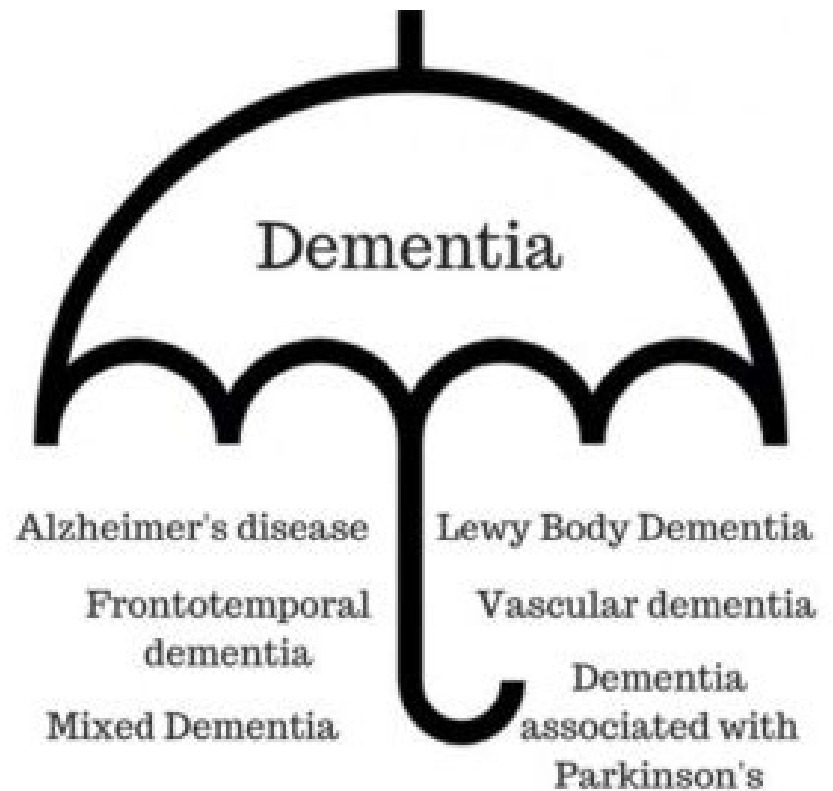
Cognitive Function



Alzheimer's and Dementia

Dementia is not a “disease” itself – it is a general term that describes a set of symptoms caused by a variety of diseases or conditions.

Alzheimer's is the most common disease causing dementia.



Dementia: What are the Differences?

	Alzheimer's Disease	Vascular Dementia	Dementia with Lewy bodies	Frontotemporal Dementia
Prevalence	60–80%	15-30%	12-20%	10-15%
Early Symptoms	<ul style="list-style-type: none"> Memory loss Executive dysfunction Aphasia Apraxia Apathy/Depression Poor insight 	<ul style="list-style-type: none"> Slow processing speed Poor attention Less memory impairment Poor acquisition/learning Apathy/Depression 	<ul style="list-style-type: none"> Visual hallucinations Muscle rigidity Parkinsonism Tremors Fluctuating cognition Visuospatial problems Memory loss 	<ul style="list-style-type: none"> Behavioral issues Personality change Attention problems Executive dysfunction Language problems
Cortical Changes	<ul style="list-style-type: none"> Temporal (medial) Parietal Frontal 	<ul style="list-style-type: none"> Cortical Subcortical Lesion-specific 	<ul style="list-style-type: none"> Parietal/Occipital Frontal Temporal 	<ul style="list-style-type: none"> Frontal Temporal (anterior)
Course	Progressive, gradual	Progressive, gradual or stepwise	Progressive, fluctuations	Progressive, rapid
Associated Factors	<ul style="list-style-type: none"> Beta-amyloid (plaques) Tau (tangles) 	<ul style="list-style-type: none"> Microvascular ischemic Hemorrhagic infarct Ischemic infarct Hypoperfusion 	<ul style="list-style-type: none"> Alpha-synuclein (Lewy bodies) 	<ul style="list-style-type: none"> Tau TDP-43

Alzheimer's and Dementia Worldwide

(Population = 7.6 billion)

- 46.8 million people worldwide living with dementia in 2015
 - 50 million people in 2017
 - 75 million in 2030
 - 131.5 million in 2050.
- 9.9 million new cases of dementia each year worldwide
 - One case every 3.2 seconds
 - 345,600 since Monday
- 58% in low and middle income countries
 - 68% in 2050
- 75% are undiagnosed
 - 55% in the US
 - 90% in India

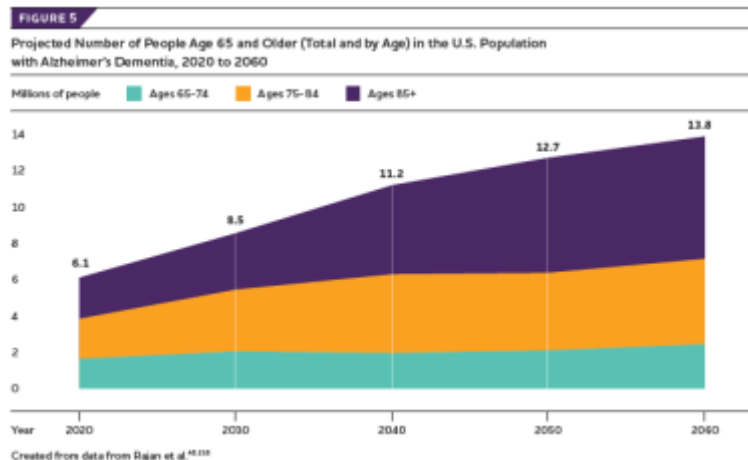


2021 US Facts and Figures

- 6,200,000 Americans with Alzheimer's
- 5,000,000 with MCI
 - 50% due to AD
- 15,000,000 with SCI

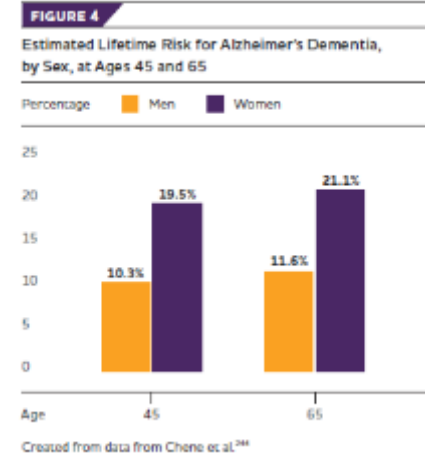
- 11.3% general risk after age 65
 - 65-74 = 5.3%
 - 75-84 = 13.8%
 - 82+ = 34.6%

- 45% with a diagnosis
 - <50% disclosed
 - <50% of providers with standard protocols



Differential Risk Factors

- Significant gender disparities
 - ~66% of PlwD are women
 - 1 in 5 for women, 1 in 10 for men
 - Biological?
 - Survival bias?
 - APOE-4 and estrogen?
 - Education, occupation and health behaviors?



- Significant racial and ethnic disparities
 - 2:1 for older Blacks
 - 1.5:1 for older Hispanics
 - ?:1 for American Indian/Alaska Natives
 - Issues of “ethnic gloss”
 - Importance of comorbid conditions, socioeconomic, health care literacy, access, adversity, discrimination, poverty, stress, structural and institutional racism

TABLE 3
Percentage of African Americans and European Americans with Specified APOE Pairs

APOE Pair	African Americans*	European Americans*
e3/e3	45.2	63.4
e3/e4	28.6	21.4
e3/e2	15.1	10.2
e2/e4	5.7	2.4
e4/e4	4.5	2.4
e2/e2	0.7	0.2

Race, Ethnicity and Alzheimer's in America

- Health vs. health care disparities
- Social determinants of health
 - Housing uncertainty
 - Food insecurity
- Implicit bias
- Language barriers
- Low health literacy
- Undermined trust and access to clinical care and research



Race, Ethnicity and Alzheimer's in America

- 40% of Native Americans perceive race/ethnicity as a barrier to care
- 63% of Native caregivers have experienced discrimination in health care
 - 9% regularly, 33% from time to time
 - Feeling not listened to (31%)
 - Provider acted like you were not smart (43%)
- 53% believe that cognitive impairment is a normal part of aging
- 35% of Native Americans believe they will not live long enough

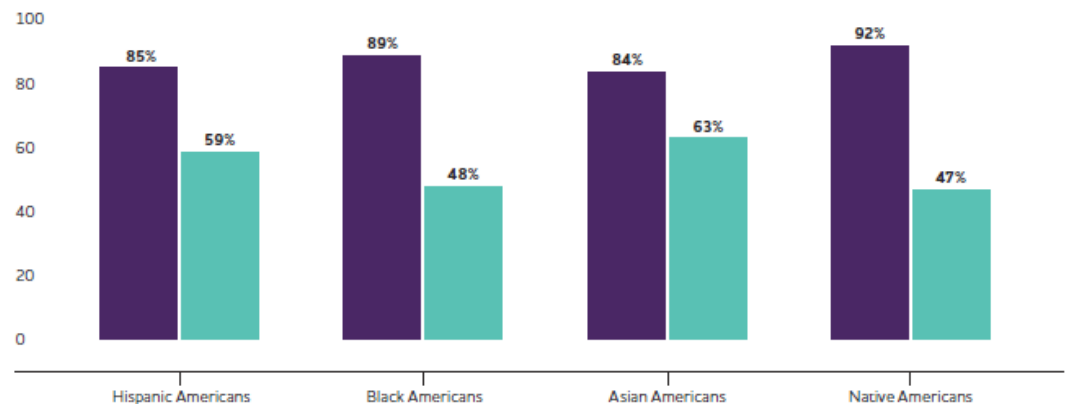
FIGURE 19

Access to Health Care Providers Who Understand Racial and Ethnic Backgrounds Among U.S. Adults

■ Important for Alzheimer's or dementia health care providers to understand a (race/ethnicity) person's ethnic or racial background

■ Confident that (race/ethnicity) patients currently have access to providers who understand their ethnic or racial background

Percentage



Addressing Disparities

- Cultural Competence, implicit bias
 - Education/Training
 - Staff, providers, systems
- Increasing Diversity in Dementia Care
 - Start in medical school
 - Improving representation in primary care
 - Low in specialties such as geriatrics and neurology
- Increasing Diversity in Clinical Trials
- Building relationships to restore trust
 - Partnerships with community based organizations
 - Community stakeholders
 - HBI Road Map for Indian Country
 - Improve culturally appropriate materials and outreach
 - Bi-directional learning

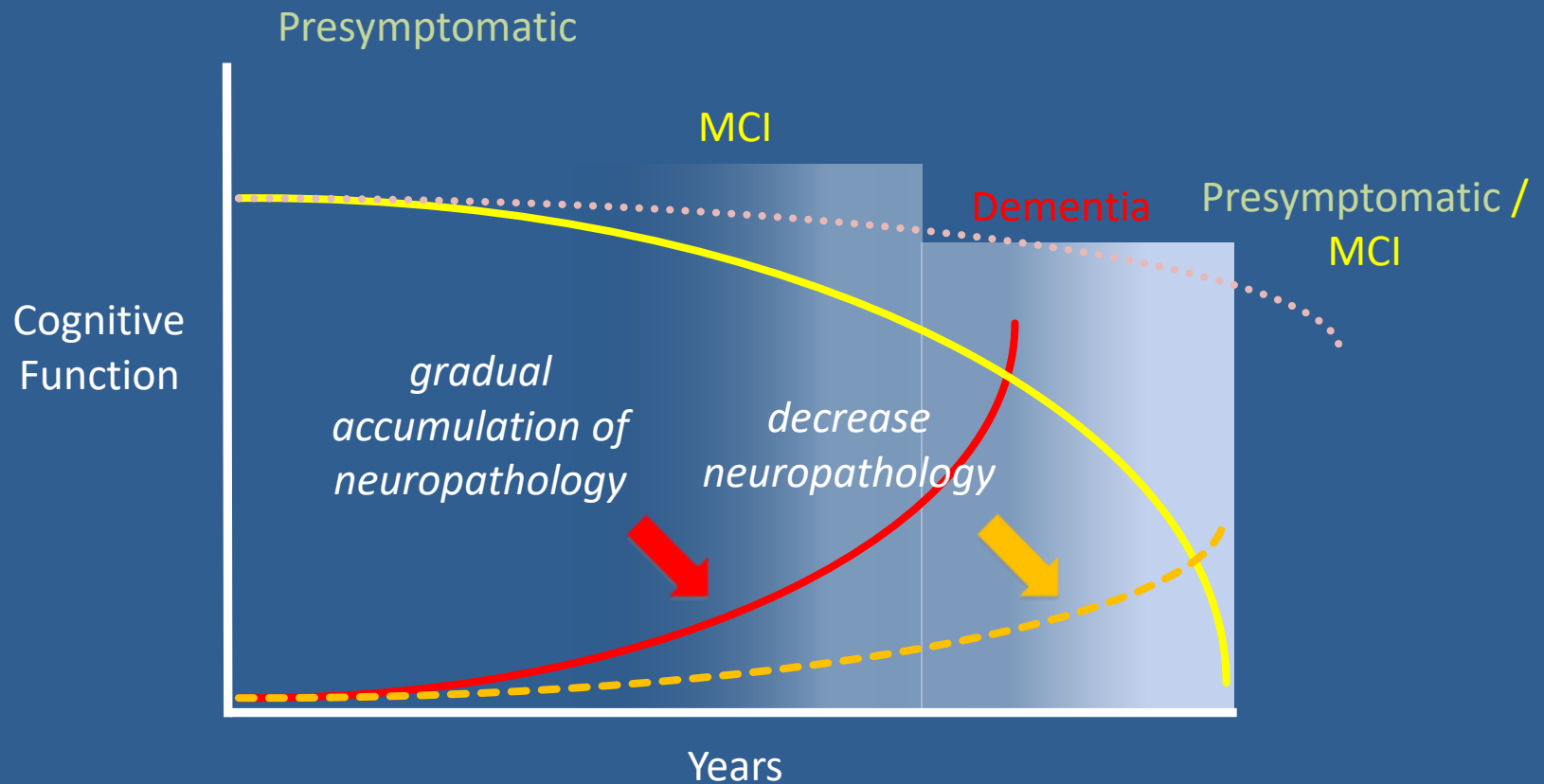


Alzheimer's in Washington State

- 120,000 cases in WA
 - 16.7% increase by 2025
- 3rd leading cause of death
 - 8th highest rate in the US
 - Mortality rate= 47.1
 - 16% increase during COVID-19
- Who provides care?
 - 295,000 unpaid caregivers
 - 132 geriatricians (399 needed to serve 10% of those 65+)
 - 426,000,000 hours = \$9.6 billion
 - \$250 million in additional health care costs



Treatment Targets



Prevention and Interventions



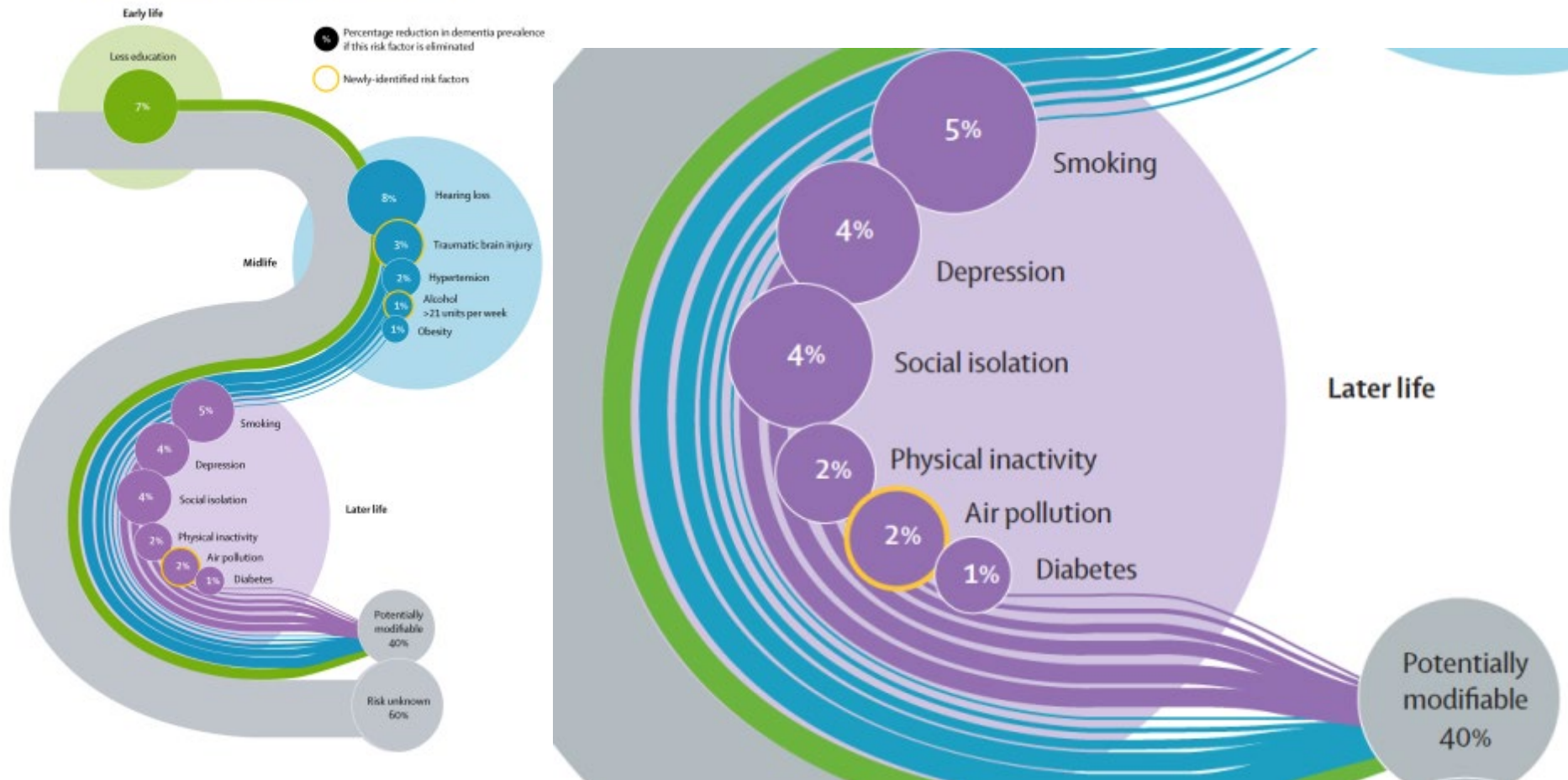
- Treatment of Modifiable Risk Factors
 - Cardiovascular
 - Sedentary lifestyle
 - Sleep disorders/disruption
 - Alcohol
- Medications
- Cardiovascular Exercise
- Cognitive Activation and Rehabilitation
- Dietary Interventions
- Meditation/Mindfulness-Based Stress Reduction
- Community Engagement and Socialization

Lancet Commission

Dementia Prevention, Intervention, and Care Livingston et al., 2020

Risk factors for dementia

An update to the Lancet Commission on Dementia prevention, intervention, and care presents a life-course model showing that 12 potentially modifiable risk factors account for around 40% of worldwide dementias



The Importance of Lifestyle

- Combining multiple healthy lifestyle factors may be more impactful for reducing dementia risk
 - Healthy diet
 - Moderate to vigorous physical activity
 - Light to moderate alcohol intake
 - Smoking
 - Cognitive stimulation
- 4 or 5 = 59% lower risk of Alzheimer's dementia
- 2 or 3 = 39% lower risk
- May even offset risk associated with genetics

Programs and Services

- Support groups/educational events
- Dementia Friendly Communities
- Momentia
 - Zoo/Garden walks
 - Alzheimer's cafes
 - Arts events
- Dementia Friends
- Intergenerational programs




Programs and Services



UW Memory and Brain Wellness Center Programs and Services

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Community Events & Programs

As part of our mission to promote the well-being of persons living with memory loss and their families, the Memory & Brain Wellness Center offers ^{Dementia Action Collaborative} events and programs. Note that during the COVID-19 outbreak, we are offering virtual support, education and engagement opportunities, offered by video or phone. Our in-person programs are temporarily on hold. For more information, please contact program manager Marigrace Becker at mbecker1@uw.edu or (206) 744-2190.

Virtual Support, Education & Engagement during the time of COVID-19

Virtual Coffee Chats for persons with memory loss/dementia

Make a cup of coffee or tea, and come together for an informal social time with others living with memory loss or dementia. Share how you're coping in the midst of COVID-19, and reflect on a different theme each week. Participate online or by phone, with a free application called "Zoom." Facilitated by program manager Marigrace Becker. Join for just one session, or multiple. Space is limited; sign up by the day before.

Tuesday, June 2, 10 - 11 a.m.

Tuesday, June 9, 10 - 11 a.m.

Tuesday, June 16, 10 - 11 a.m.

Tuesday, June 23, 10 - 11 a.m.

Tuesday, June 30, 10 - 11 a.m.

[Sign Up Here](#)

PEOPLE

Marigrace Becker, MSW

Program Manager of Community Education and Impact, MBWC

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Thomas J. Grabowski, MD

Professor, UW Departments of Radiology and Neurology | Medical Director and Neurologist, UW MBWC/ Director, UW Integrated Brain Imaging Center | Director PI/ Project 3 Leader, ADRC

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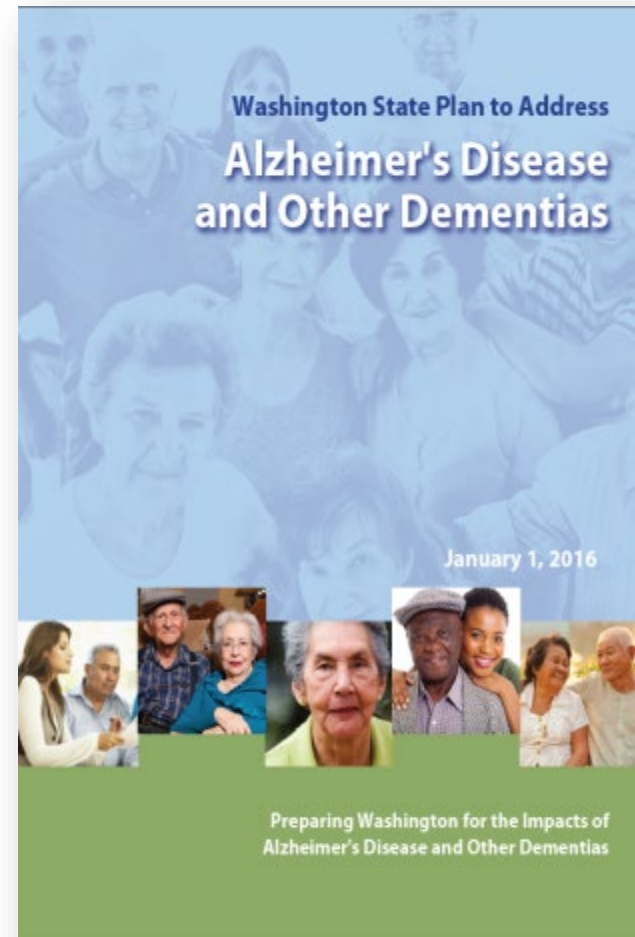
<https://depts.washington.edu/mbwc/events/community-events-programs>

UW Memory and Brain Wellness Center Programs and Services

- Virtual versions of our in-person programs
 - Coffee Chats for people living with memory loss/dementia
 - Caregiver Forums
 - Community Wellness Talks
 - Memory Loss: A Guide to Next Steps
 - Powerful Tools for Caregivers
 - Garden Discovery Walks
 - Healthy Brain Aging Seminars
- Phasing in in-person programs
 - Resource and Education Days
 - Strength for the Journey
 - SOAR (Shared Outdoor Adventures for Resilience)

Alzheimer's Washington State Plan

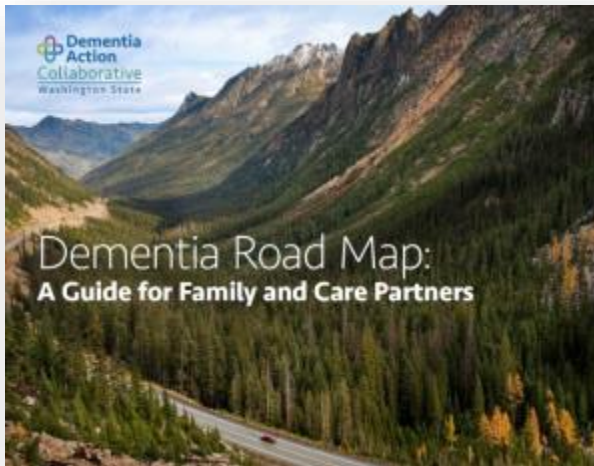
- **October 2013—Governor's Aging Summit**
- **February 2014—SSB6124**
- **July 2014—Alzheimer's Disease Working Group**
- **January 2016—Plan released**
- **February 2016—Plan accepted by Senate**
- **April 2016—Dementia Action Collaborative**
- **January 2017- Bree Collaborative Working Group**
- **November 2018- Budgetary "ask"**
- **July 2019 – Multiple projects funded**



Accomplishments: 2016 - 2020

- Convened an expert panel to identify evidence-based best practices
- Guidelines for diagnosis by primary care
- Dementia Road Map
- Safety toolkit
- Dementia-friendly community toolkit
- Alzheimer's Café Model: A How-To Guide
- Info for Asian Americans and African Americans
- Website "point of access" portal
 - www.memorylossinfowa.org
- Over \$1 million in state funding!
- Legal Planning toolkit
- COVID-19 resources
- Project ECHO- Dementia

Dementia Road Map: A Guide for Family and Care Partners



- Comprehensive yet simple to follow guidance document
- Online PDF version
- Print version – disseminated nearly **75,000** already
- Section on MCI
- Recently translated into Spanish

DAC COVID-19 Resources

DAC Info Sheet Dementia Caregivers Covid-19

May 1, 2021



Resources for Family Caregivers of People with Dementia during the COVID-19 Outbreak

Alzheimer's Association - Tips for Dementia Care

- [Tips for dementia caregivers at home](#)
- [Residential facility has an incidence of COVID-19](#)
- [Tips for individuals receiving home-based services](#)
- [Staying healthy](#)
- [Tips for caregivers of individuals in a residential care setting](#)

More info available at: [Covid-19 Tips for Dementia Care](#)

[COVID-19 Vaccine: Answers for Dementia Caregivers and People Living with Alzheimer's](#)

Upcoming webinars –

Community education programs are now online! Learn from the comfort and safety of your own home. Each free webinar is held live with time for Q&A. Full program descriptions and registration is [available on their website](#). Or call 800.272.3900.

- **Understanding Alzheimer's and Dementia** – May 3, 1 – 2:30 pm, May 19, 2 – 3:30 pm
- **Healthy Living for Your Brain and Body** – May 4, 1 – 2:30 pm
- **When Living at Home is No Longer an Option** – May 5, 3 – 4:30 pm
- **Living with Alzheimer's: For People with Alzheimer's – Part 1:** May 6, 1 – 3 pm; **Part 2:** May 20, 1 – 3 pm
- **Understanding & Responding to Dementia-Related Behavior** – May 6, 9 – 10:30 am; May 24, 3 – 4:30 pm
- **10 Warning Signs of Alzheimer's** – May 10, 3 – 4:30 pm; May 13, 1 – 2:30 pm
- **Legal and Financial Planning for Alzheimer's Disease** – May 11, 9:30 am – 12:00 pm; May 18, 4 – 5:30 pm; **Part 1:** May 19, 1 – 1:45 pm; **Part 2:** May 26, 1 – 1:45 pm
- **Dementia Conversations: Driving Doctor Visits, Legal & Financial Planning** - May 14, 11 am – 12:30 pm
- **Effective Communication Strategies** – May 17, 3 – 4:30 pm; May 26, 10 – 11:30 am
- **Living with Alzheimer's: For Younger Onset Alzheimer's** – May 27, 1 – 2:30 pm

- Virtual support groups
- Dementia education webinars
- Online resources
- Resources for staying active
- WA Family Caregiver Support Program
- Hearing loss and COVID-19
- Local, state, regional, national level resources and programs

UW Project ECHO - Dementia



- Moving knowledge, not people or providers
- Hub and spoke model
- All teach, all learn
- Case based & didactic
- Best practices
 - Medical
 - Programs and services
- Can be used for other best practices and programs
- Launched 6/12/20



UW Project ECHO - Dementia



We've provided 280
Instructional hours
June 2020 –May 2021

More than half of survey
Respondents plan to
change practice based
on learnings.

Current community

- 24 Sites
- 70 Providers



To find out more or to sign up, please contact Allyson Schrier, Program Coordinator: allysons@uw.edu
<https://depts.washington.edu/mbwc/resources/echo>

Resources



- Memory Loss Info WA
 - memorylossinfowa.org
- Dementia Action Collaborative/State Plan
 - www.dshs.wa.gov/altsa/dementia-action-collaborative
- Alzheimer's Association
 - Taking Action workbook:
http://www.alz.org/mnnd/documents/15_ALZ_Taking_Action_Workbook.pdf
 - Living Well workbook:
http://www.alz.org/mnnd/documents/15_ALZ_Living_Well_Workbook_Web.pdf
- Momentia Seattle
 - www.momentiasseattle.org
- Department of Health
 - <https://www.doh.wa.gov/YouandYourFamily/HealthyAging/AlzheimersDiseaseandDementia>

“I have a good life”

“After hearing the news, I just felt totally lost. But you know what, I have a good life. That sounds crazy, but I do!

I get out, I have fun, and I don't worry about Alzheimer's. Because if you can't fix it, then you have to find a way to live with it.

I've got a group of people who love me, and who stand by me, and that is what life is supposed to be.

I just want all the happiness I can have, and that's what I go for.”

~Alice P.

Bellevue, WA



Photo: Rachel Turner, Alzheimer's Association



Thank you for your attention!



Questions?

Contact Information

Memory and Brain Wellness Center

<https://depts.washington.edu/mbwc/>

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Northwest Tribal Elders Project (NTEP)

Building Our Largest Dementia Infrastructure (BOLD)
Addressing Alzheimer's Disease and Related Dementia's (ADRD)



NORTHWEST PORTLAND AREA
INDIAN HEALTH BOARD
Indian Leadership for Indian Health

Project Introduction

- History of Northwest Tribal Elders Project
 - The board has had numerous projects
 - History of NW Tribal Elder's Committee
- Why did we apply for the ADRD funding
 - Education
 - Awareness
 - Tribal Support



Some Facts

- In 2015-2017, one in six AI/ANs aged 45 and older reported subjective cognitive decline (SCD), which are self-reported difficulties in thinking or remembering. Nearly two-thirds (63%) of those with SCD had to give up some day-to-day activities because of these cognitive problems.
- With dementia, it's not just the person with cognitive challenges dealing with the condition. Family members and friends feel the impact too.
- The number of older American Indians and Alaska Natives (AI/ANs) is increasing. An estimated 569,000 AI/ANs are aged 65 or older. This number is expected to triple over the next three decades.
- The number of AI/ANs living with dementia is also expected to increase. Between 2014-2060, the number of AI/ANs aged 65 and older living with dementia is projected to grow over five times.



Project Progress

- Presented to NPAIHB Elders Committee at QBM's
 - July 2020, October 2020
- Established an Tribal Advisory Committee (TAC) to make:
 - Recommendations to project staff
 - Guide workplan activities
 - Provide input on needs assessment
 - Provide input to strategic plan design
 - Identify key partners and communication strategies



ADRD Funding

- Northwest Portland Area Indian Health Board
 - CDC's Healthy Brain Initiative for Building our Largest Dementia Infrastructure (BOLD)
 - 3 – year capacity building cooperative agreement
- NEW Funding Announced from Indian Health Service
 - \$5million for 574 tribes



Year 1 Focus

- Needs Assessment and or survey - Target population
 - Tribal Communities
 - Tribal Leadership
 - ADRD Patient Caregivers
 - Health Care Providers/Professionals
- Develop a strategic plan improving awareness and education of ADRD
- Build community partners through engagement
- Identify culturally relevant support, resources and services
- Identify baseline data through existing and new partners



Tribal Community Outreach

- Engage with NPAIHB 43-Tribes in ID, OR, WA
- Learn about tribes level of education and awareness
- Recruit tribes for coalition
- Recruit tribal elders for public media interviews (Yr 2)
- WA Tribes – Savvy Caregivers Basic Training
 - Of the 29 Tribes, 15 were identified as attending the training



Successes and Challenges

- **Successes**

- Project Launch
- Introductions to local, state and National Alzheimer's Associations and Agencies working with ADRD
- Established TAC
- Contacted/identified 100% of NPAIHB Tribal Elder Program Coordinators
- Identify existing resources
- Identify Tribes trained in caregiving

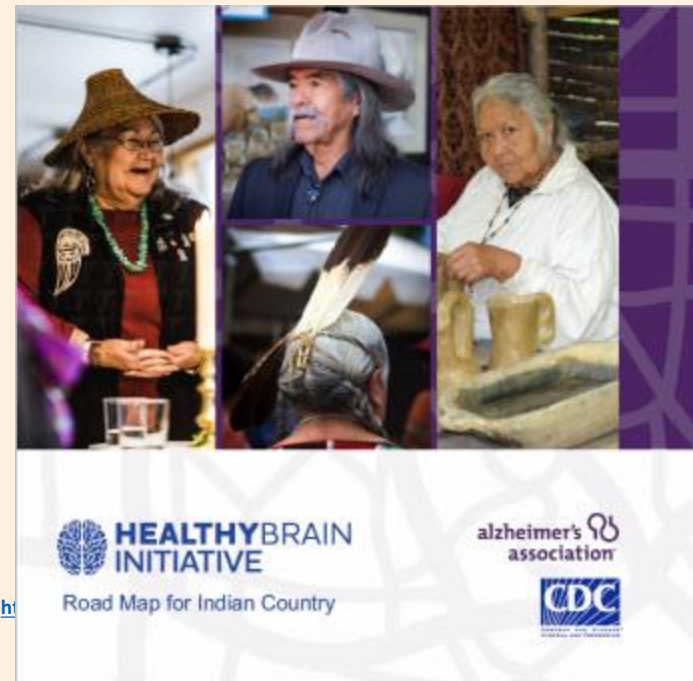
- **Challenges and Barriers**

- COVID-19 priority
- Shelter in place/telework impact on workforce
- Lack of partners working in ADRD with Indian Country
- Access to baseline data
- Tribes are at different levels of awareness and education
- Training and caregiver certification opportunities for Tribal members



Healthy Brain Initiative (HBI) Road Map for Indian Country (RMIC)

- Road Map Strategies for our project:
 - Educate and Empower Community Members
 - Collect and Use Data
 - Strengthen the Workforce
- Our Project workplan includes 4 of the RMIC



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