# Louise Ryan Regional Administrator Region X

(aka Alaska, Idaho, Oregon, Washington)

# **Administration for Community Living**

### **Dementia & Elder Abuse**

It's complicated – no victim blaming ... just data

- About 1/3<sup>rd</sup> of victims of abuse have dementia or mental impairment
- Up to 2/3<sup>rd</sup> of people with dementia experience abuse or financial exploitation
- Unique risks:
  - caregiver stress and burden
  - existing abusive, violent, or poor relationships
  - behavior changes from dementia



96% of people living with dementia had at least one episode of aggressive behavior in a 10-year study

# **Caregiving for People with Dementia**

#### CAREGIVING AMONG AMERICAN INDIAN/ALASKA NATIVE ADULTS

1 in 3



- Majority of people live in community (not nursing home)
- 85% cared for by family or friends > caregiver
- Most caregivers are women
- Impact
  - Financial quit job, lose insurance, less income
  - Physical 74% can't maintain their own health, more chronic diseases, poor health, more likely to die early
  - Quality of life 60% have high stress or "burden" over years, 40% suffer from depression
- Caregiver burden is risk factor for elder abuse

# **Dementia & Elder Abuse Stats**

# It's complicated...



Informal caregivers abuse of people with dementia

60% - 78%



Paid caregivers (staff) abuse of people with dementia

78%



Resident to resident abuse in care facilities

- 98% staff have witnessed
- 65% of perpetrators have dementia





Abuse BY people with dementia of caregivers (informal + staff)

33% informal

# How to Help Reduce Elder Abuse for People with Dementia (Jolie's Thoughts)

- Community awareness and education about dementia reduce stigma / shame of diagnosis
- Early diagnosis to give caregivers and people with dementia time to prep
- MORE professional services and supports for caregivers SOONER:
  - respite care (#1 in our surveys)
  - education (disease, stages, behavior management, etc.)
  - skills training
  - counseling/therapy
  - self-care and relaxation training
  - fixes for the home environment
- Learning to communicate and support people with dementia and caregivers as a COMMUNITY – building "dementia capable" communities



# Dementia & American Indian Communities:

Risk Reduction and Health Promotion

Jolie Crowder, PhD, MSN, RN, CCM

May 18, 2022

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# Welcome



Dr. Jolie Crowder, Senior Project Director, IA<sup>2</sup>

## **Overview**

About IA<sup>2</sup>
 About Brain Health
 Healthy Heart, Healthy Brain & Other Tools
 Dementia in Indian Country
 Resources

# About IA<sup>2</sup>

The International Association for Indigenous Aging, a 501(c)3 non-profit educational association, works to:

- Ensure the provision of appropriate and quality services and resources for indigenous elders
- Expand opportunities for elders' involvement in environmentalism, community participation, health maintenance, volunteerism/civic engagement, consumerism, senior enterprise
- Enhance the protection of the rights of elders including their freedom from abuse and neglect and their right to autonomy
- Educate the public, policymakers and practitioners about the status of indigenous elders
- Improve the status of older people worldwide, especially indigenous populations
   www.iasquared.org

# National Healthy Brain Initiative Award

Develop a national project that identifies and incorporates locally tailored, culturally relevant information resources to address disparities in the burden of Alzheimer's disease and related dementias (ADRD) among American Indian and Alaska Native (AI/AN) populations.

Advance	Community engagement and capacity building
Promote	Healthy cognitive aging strategies across the lifespan
Foster	Dementia-capable tribal communities
Promote	Strategies from the Road Map for Indian Country

Our approach to this work is built on our belief in **values that** promote **tribal sovereignty** over work in local communities, **respect** cultural traditions and knowledge while encouraging innovation, recognize the importance of mutually beneficial collaborations and partnerships, and acknowledge the rights of sovereign tribal nations to work in a way that honors their culture, diversity, and traditions.



# **Brain Health**

"... a state of complete physical, mental, and social wellbeing through the continuous development and exercise of the brain."

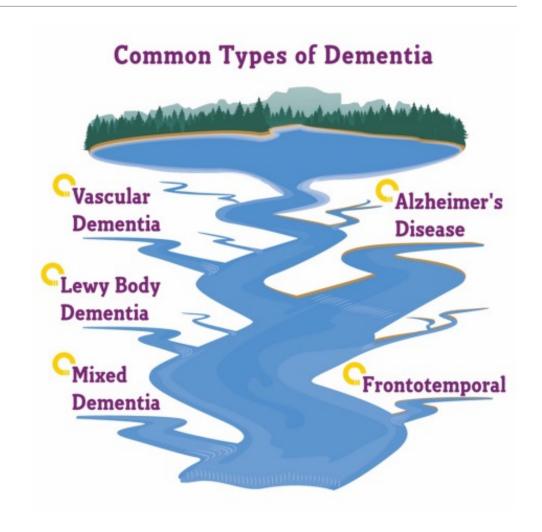
--Lancet Article

"Brain Health is an emerging and growing concept that encompasses neural development, plasticity, functioning, and recovery across the life course."

--World Health Organization

## **Dementia: What You Should Know**

- Not a specific disease
- Overall term
- Many symptoms
- Loss of memory or other thinking skills
- Severe changes affect the ability to do everyday activities
- Alzheimer's disease is thought to be the most common type



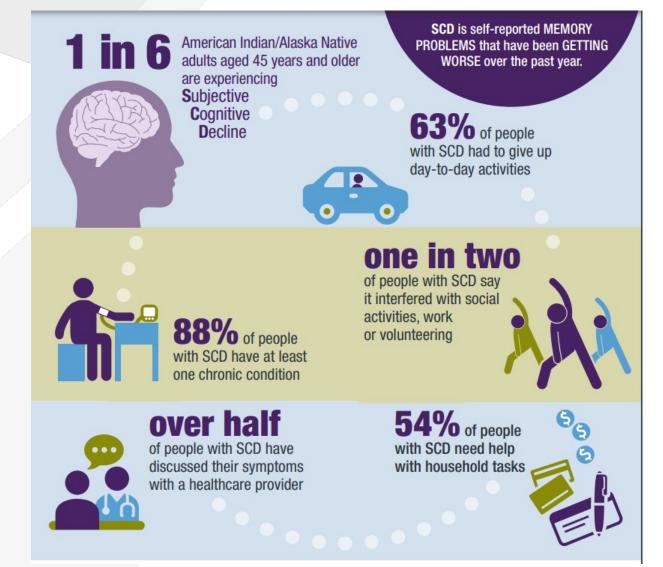
# Dementia in American Indian and Alaska Native Peoples



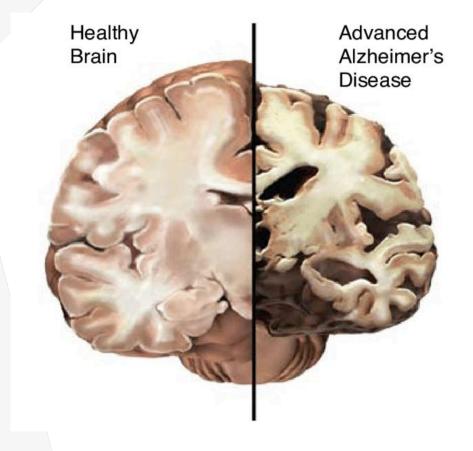
- ~ 1 in 9 people 65+ in the U.S. will develop dementia
- ~ 3 in 9 American Indian and Alaska Native people 65+ will develop dementia
- ~ 1 in 6 American Indian and Alaska Native people 45+ report memory problems getting worse

Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & dementia: the journal of the Alzheimer's Association*, 12(3), 216–224. https://doi.org/10.1016/j.jalz.2015.12.007; https://www.alz.org/media/Documents/alzheimers-facts-and-figures-special-report.pdf

# Memory Issues Don't Just Impact Older Adults



Dementia is caused by diseases or injuries of the brain. The left is a healthy brain. The right is a brain of a person living with advanced Alzheimer's disease. When the cells of the brain are damaged, they cannot function effectively.



# Early Signs of Dementia Vs. Normal Aging

Normal Aging	10 Early Signs and Symptoms
Sometimes forgetting names or appointments but remembering them later	Memory loss that disrupts daily life
Making occasional errors when balancing a checkbook	Challenges in planning or solving problems
Needing occasional help to use a microwave or record a TV show	Difficulty with familiar tasks at home or at work
Forgetting the day of the week but being able to recall it later	Confusion with time or place
Vision changes related to cataracts	Trouble understanding visual information
Sometimes having trouble finding the right word	Confusion with understanding and communicating thoughts verbally
Losing things from time to time and retracing steps to find them	Misplacing things and losing the ability to retrace steps to find them
Making a bad decision once in a while	Experiencing more slips in judgment or acting impulsively
Sometimes feeling weary of work, family, and social obligations	Withdrawing from work or social activities
Developing very specific ways of doing things and preferring routines	Changes in mood and personality

# Promote Resilience, Re-build Connections & Reduce Risk

- Health Promotion: traditional physical activity (dance and drum), preparing and harvesting traditional foods and medicine
- Cultural Practices: increase knowledge and share oral tribal history and cultural practices, learn and teach language
- Social and Emotional Well-being: sense of connection to culture, beading, artwork, practicing song, intergenerational events

# Why Healthy Heart, Healthy Brain?

 "Chronic hypertension is the most prevalent and pernicious risk factor for cognitive impairment in aging."

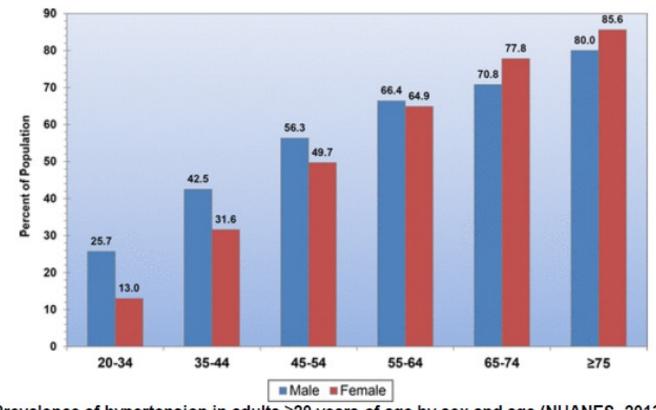
Daugherty, Seminars in Cell and Developmental Biology, <a href="https://doi.org/10.1016/j.semcdb.2021.03.002">https://doi.org/10.1016/j.semcdb.2021.03.002</a>

 80% of AD patients' brains have evidence for significant vascular pathology.

Liesz A. Science 2019;365(6450);223-224

# Over 116 Million People in US with High Blood Pressure

- High Blood Pressure = Systolic Blood Pressure > 130 mmHG
- AI/AN people 50% more likely than White people to have heart disease
- AI/AN people 10% more likely than White people to have high blood pressure



Prevalence of hypertension in adults ≥20 years of age by sex and age (NHANES, 2013–2016)

Benjamin et al, Circulation, 2019.

# Heart Health is Brain Health

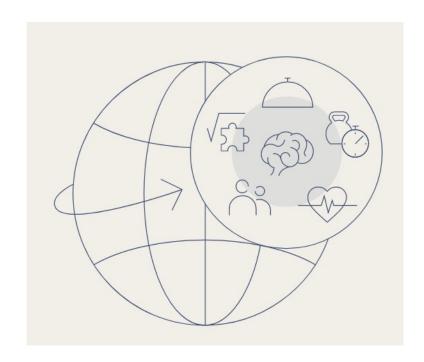
#### **HOW TO PREVENT HEART ATTACKS**



## What works for dementia risk reduction?

# "Multi component interventions"

The causes of dementia are complex, targeting several risk factors and interventions at the same time seems to produce the best preventive effects.



# Healthy Heart, Healthy Brain Resources

Available at https://iasquared.org/toolkit-healthy-heart-health-brain/







### **Public Service Announcements**

- A Healthy Heart is A Healthy Mind (30 seconds)
- Older Minds Matter in Indian Country (30 seconds)
- Take Action to Care for Your Heart and Mind (60 seconds)
- Talk with Your Doctor About Aging and Brain Health (60 seconds)



# **Native Caregiver Videos**

American Indian elders and caregivers share their experience with dementia and caregiving.



"I Can't Remember:

A Native Family's

Story of Dementia"





"One Day at a Time: Supporting
Tribal Caregivers and Elders with
Dementia"

## **Urban Audience Version from NCUIH**

#### Keeping Wisdom Keepers Healthy



#### Recognizing the Signs of Alzheimer's in Wisdom Keepers

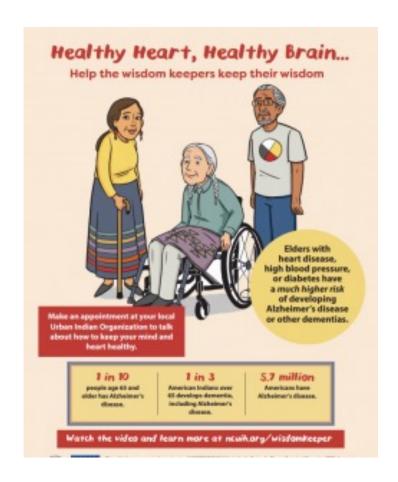


#### Wisdom Keepers Living Healthfully with Alzheimer's



#### National Council of Urban Indian Health Wisdom Keeper Webpage

- Healthy Heart, Healthy Brain Urban Flyer Adaptation
- Healthy Heart, Healthy Brain, Urban Poster Adaptation
- Animated Video: Keeping Wisdom Keepers Healthy
- •Animated Video: Recognizing the Signs of Alzheimer's in Wisdom Keepers
- Animated Video: Wisdom Keepers Living Healthfully with Alzheimer's
- Social Media Graphics Series: Early Detection Matters
- •Social Media Graphics Series: Help the Wisdom Keepers Keep Their Wisdom
- Social Media Graphics Series: Reduce Your Risk
- Download The Toolkit!





#### **Information Session**

June 7th

1:30 - 3:00 PM (EST)/ 10:30 - 12:00 PM (PT)

#### **About Dementia Friends:**

Dementia Friends is a global effort that aims to change how people view dementia. This program has been designed for American Indian and Alaska Native communities.

Dementia Friends helps to spread awareness, reduce stigma, and reduce risk.

#### **About the Sessions:**

Dementia Friends Information Sessions are designed to help you better understand dementia. These sessions are taught by Champions who have completed Champion training.

#### **Champion Training**

June 7th

3:30 - 6:00 PM (EST)/ 12:30 - 3:00 PM (PT)

#### Register at:

https://iasquared.org/dementiafriends/

## **Brain Health and Alzheimer's Awareness Month**

- Great opportunity to do some outreach, education, awareness
- We have \$250 printing stipends if you want hard copy materials
- Will have some social media messages for the month you can share or steal



# Resources

Activity	How to Access
Monthly e-news for ADRD for and by American Indian and Alaska Natives	Sign up now: http://eepurl.com/hfDl6n
Print-on-demand \$250 stipends for tribes for select resources (flyer, poster, provider guide)	https://www.surveymonkey.com/r/2021PrintRequest
Online brain health resource library	www.AIANBrainHealth.org
"Dementia Friends" adaptation for AI/AN communities	https://iasquared.org/dementia-friends/
Savvy Caregiver for Indian Country Resources	Resources on website
VA Training Referral - Addressing Behavioral Challenges of Dementia (ABCD) training program for I/T/U public health and aging staff; other resources	Email: jolie@iasquared.org

# www.AIANBrainHealth.org

