



Alzheimer's Disease and Related Dementias in Primary Care

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Office of Clinical & Preventive Services

Indian Health Service

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Objectives

- Examine Alzheimer's disease and related dementias and its relevance in Indian Health
- Identify best practices in the comprehensive care of those living with dementia and their caregivers
- Access IHS resources and supports available to address Alzheimer's disease and related dementias in Indian Country



Nana's Story

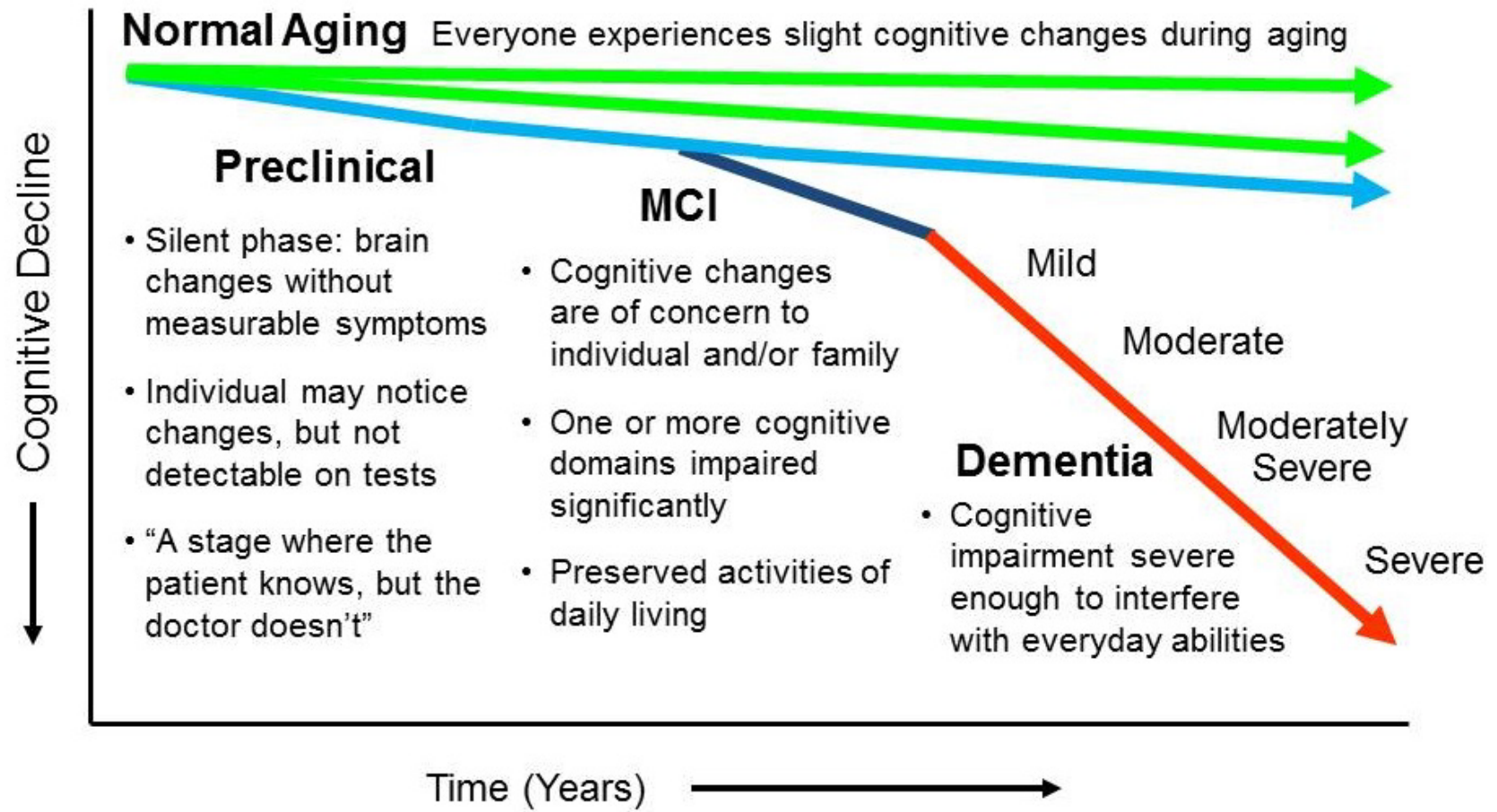
“Now, at times, she thinks that Dad is out fishing and will be home soon. In some ways, this is good, because she does not always have to know that he is gone, and continuously have to suffer the pain that loss can bring after a lifetime like theirs together.

But there are many times that she is totally lucid and knows that he is not with her, but is waiting for her to be with him when her time comes too. We have as a family kept Nana in her home, in the surroundings most familiar to her.

There, every day she is close to all of her family who love her and accept her, wherever she may be mentally. She knows that she is home, and that she is safe and loved, despite her confusion.”

Marquart K. **Nana**. *The IHS Primary Care Provider*. Vol 29 No. 5. May 2004.

Cognitive Changes Continuum



Mild Cognitive Impairment - MCI & Mild Neurocognitive Disorder (DSM V)

- Cognitive complaint (self-reported or informant)
- Objective cognitive impairment on test
- No impairment of daily function
- Absence of delirium
- Progression from MCI to dementia occurs ~ 10% of cases in 1 year for ages 65+



Major Neurocognitive Disorder (DSM-V) or Dementia - Details

- **Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains**
 - Learning and memory
 - Executive function
 - Complex attention
 - Perceptual-motor
 - Social cognition
- **Cognitive deficits must interfere with independence in everyday activities (ADLs and IADLs)**
 - Minimally, assistance should be required with complex instrumental activities of daily living, such as paying bills or managing medications.
- **Cognitive deficits must not occur exclusively in the context of delirium**
- **Cognitive deficits are not explained by another mental disorder (e.g. major depressive disorder, schizophrenia)**



Major Neurocognitive Disorder (DSM-V) or Dementia - Simplified

- **Cognitive decline** over baseline affecting learning and memory and or other ways of thinking, problem-solving, and organization.
- Interferes with **function** – activities of daily living
- Not delirium
- No other mental illness can explain it



Symptoms for Mild and Major Neurocognitive Disorders (DSM-V)

- Apathy
- Anxiety
- Agitation / aggression
- Depression
- Elation
- Confusion
- Insomnia (difficulty sleeping)
- Hypersomnia (oversleeping)
- Wandering
- Disinhibition
- Hyperphagia (extreme hunger or eating)
- Hoarding
- Hallucinations
- Delusions



Pre-clinical

DEMENTIA

Umbrella term for loss of memory and other thinking abilities
severe enough to interfere with daily life

ALZHEIMER'S
60-80%

LEWY BODY
DEMENTIA 5%

FRONTOTEMPORAL
DEMENTIA 3%

MIXED DEMENTIA 50%

VASCULAR
DEMENTIA 5-10%

PARKINSON'S
DISEASE 4%

OTHER 3%

Relevance for Indian Country

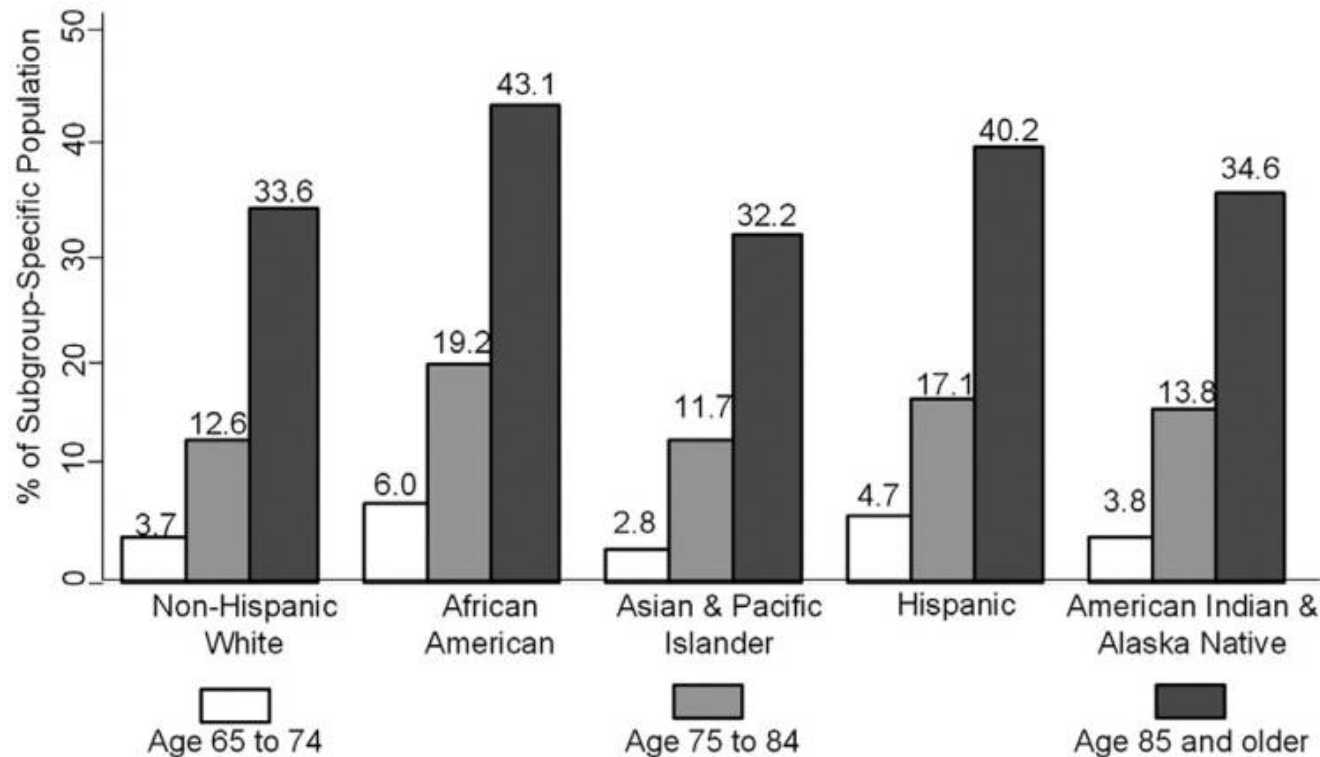
- Between 2014–2060, the number of AI/AN people 65+ living with dementia is projected to grow over five times
- In 2019-2020, one in six AI/AN people 45+ and older reported subjective cognitive decline (SCD) — that is, self-reported difficulties in memory or thinking
- Nearly six in ten of those with SCD had to give up some day-to-day activities because of cognitive problems
- Risk factors for dementia disproportionately impact Native people
- PLWD have higher healthcare costs & more complex care needs which puts unchecked demand on strained healthcare systems
- 1 in 3 American Indian and Alaska Native people are caregivers; over 50% of caregivers develop depression

Prevalence & Incidence of Dementia

- **Medicare:** 10.5% of AI/AN people with dementia diagnosis
- **Kaiser Permanente:** Incidence (new cases) among AI/AN people is 22.2/1000
 - 2nd only to African-Americans
 - 1 in 3 AI/AN people over 65 will develop dementia
- **Kaiser Permanente:** Incidence among AI/AN people with diabetes is 34/1000
 - 60% higher than Asians
- **Alberta Health & Wellness:** Prevalence among First Nations 7.5/1000 vs Non-First Nations 5.6/1000
 - Younger and male

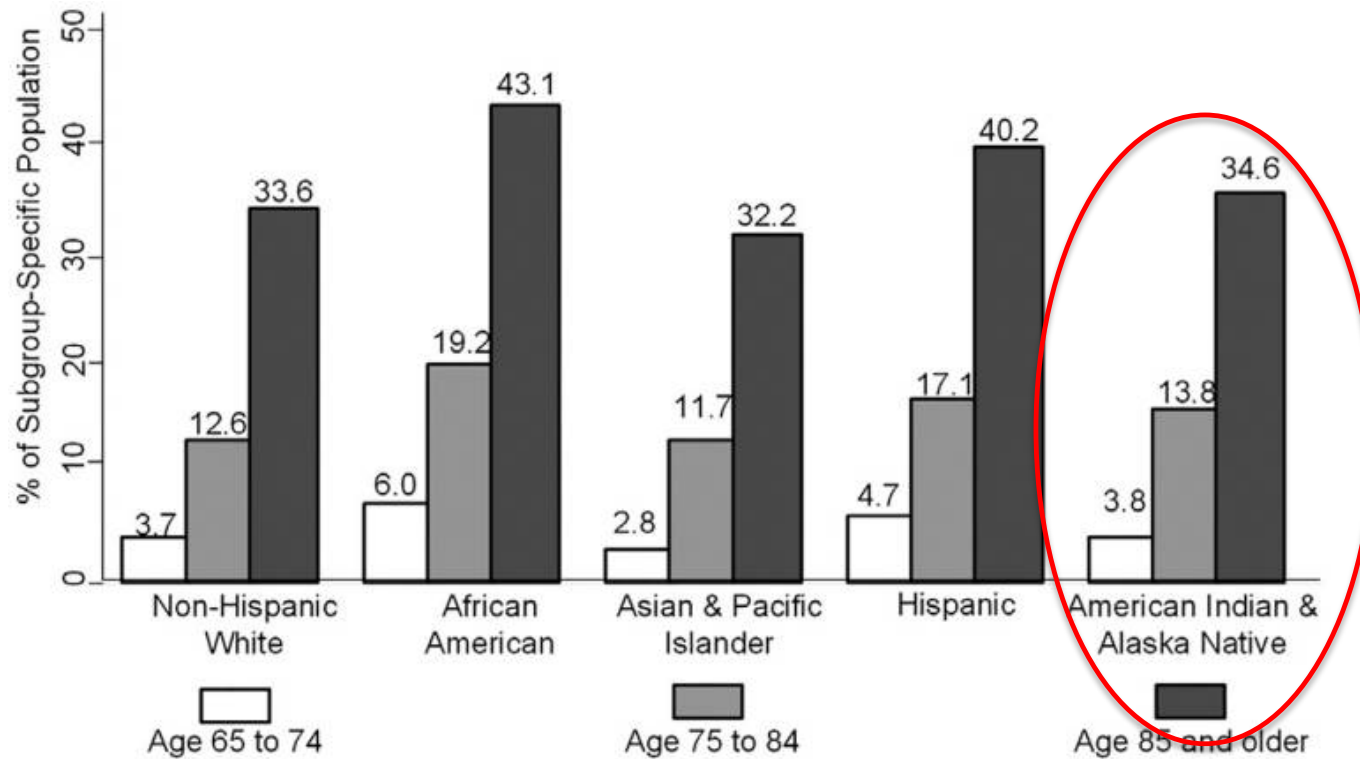
Citations: The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. Jacklin KM, et al. Can J Public Health. 2012 Nov 8;104(1):e39-44; Matthews, Kevin A et al. "Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥ 65 years." Alzheimer's & dementia : the journal of the Alzheimer's Association vol. 15,1 (2019): 17-24.; Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimers Dement. 2016 Mar;12(3):216-24.. Epub 2016 Feb 11.; Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimers Dement. 2016 Mar;12(3):216-24. doi: 10.1016/j.jalz.2015.12.007. Epub 2016 Feb 11. PMID: 26874595; PMCID: PMC4969071.

Dementia Increases with Age



Estimated prevalence of Alzheimer's disease and related dementias in the US Population aged ≥65 years, by sex and race and ethnicity; United States, 2014.

Dementia Increases with Age



Estimated prevalence of Alzheimer's disease and related dementias in the US Population aged ≥ 65 years, by sex and race and ethnicity; United States, 2014.

Under-diagnosis of Dementia

- Many large population-based studies are based on billing or EHR data which requires diagnosis
- Globally, 62% of dementia cases are undiagnosed
- Native, Hispanic, Asian, & Pacific Islander population is 2.5 times more likely to be undiagnosed than non-Hispanic White (adj model)
- **Possible causes:**
 - Difference in (lack of) knowledge
 - False belief that dementia represents “normal aging”
 - Clinician failure to recognize dementia
 - Cultural bias in cognitive assessment tools
 - Racial or ethnic differences in family support and expectation of function

Population-based Dementia Risk Factors for Native People (CDC, 2021)

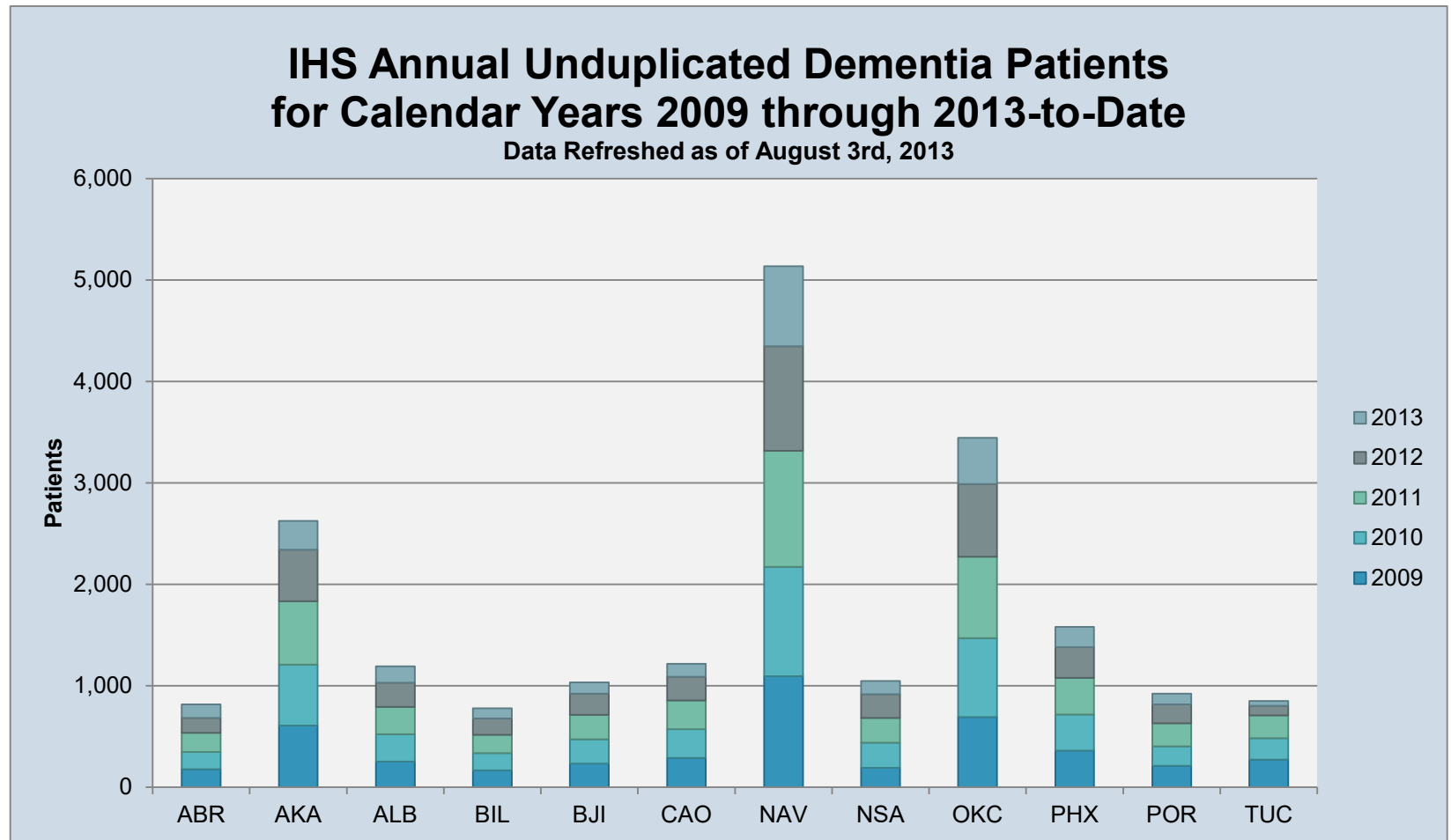
Causes of Death	Age-adjusted death ratios: Non-Hispanic AI/AN to Non-Hispanic White
Chronic liver disease and cirrhosis	4.06
Diabetes	2.54
Unintentional injury (including head injuries)	1.95
Kidney disease	1.84
Hypertensive disease	1.29
Heart disease	1.20
Cerebrovascular Diseases (stroke)	1.19

Prevalence of Selected Modifiable Risk Factors Among AI/AN Adults Aged ≥45

TABLE 1. Prevalence of selected modifiable risk factors* among adults aged ≥45 years, by selected characteristics and subjective cognitive decline† status — Behavioral Risk Factor Surveillance System, United States,§ 2019

	Sample No. (%)	Prevalence of risk factors, % (95% CI)							
		High blood pressure	Not meeting aerobic physical activity guideline	Obesity	Diabetes	Depressio n	Current cigarette smoking	Hearing loss	Binge drinking
American Indian or Alaska Native, non- Hispanic	2,059 (1.2)	54.1 (48.7– 59.5) ^{††} 2nd Highest	59.8 (55.1– 64.6) ^{††} Highest	39.4 (34.4– 44.4) 2nd Highest	24.7 (20.7– 28.7) ^{††} 2nd Highest	22.9 (18.0– 27.8) 2nd Highest	26.5 (21.8– 31.1) ^{††} Highest	17.5 (12.9– 22.1) ^{††} Highest	9.6 (6.8– 12.4)

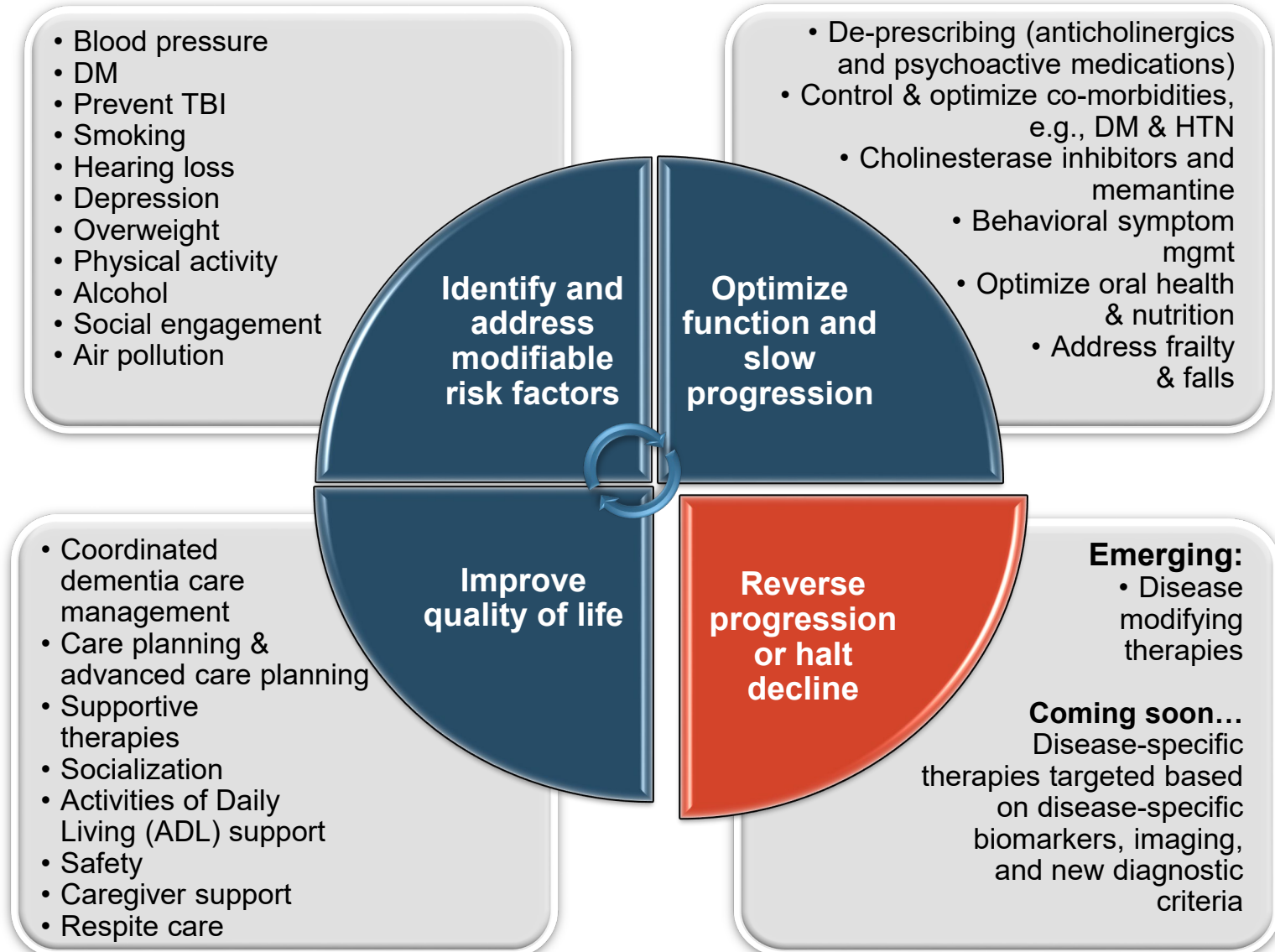
In Every Region of IHS There Are Persons With Dementia Diagnoses



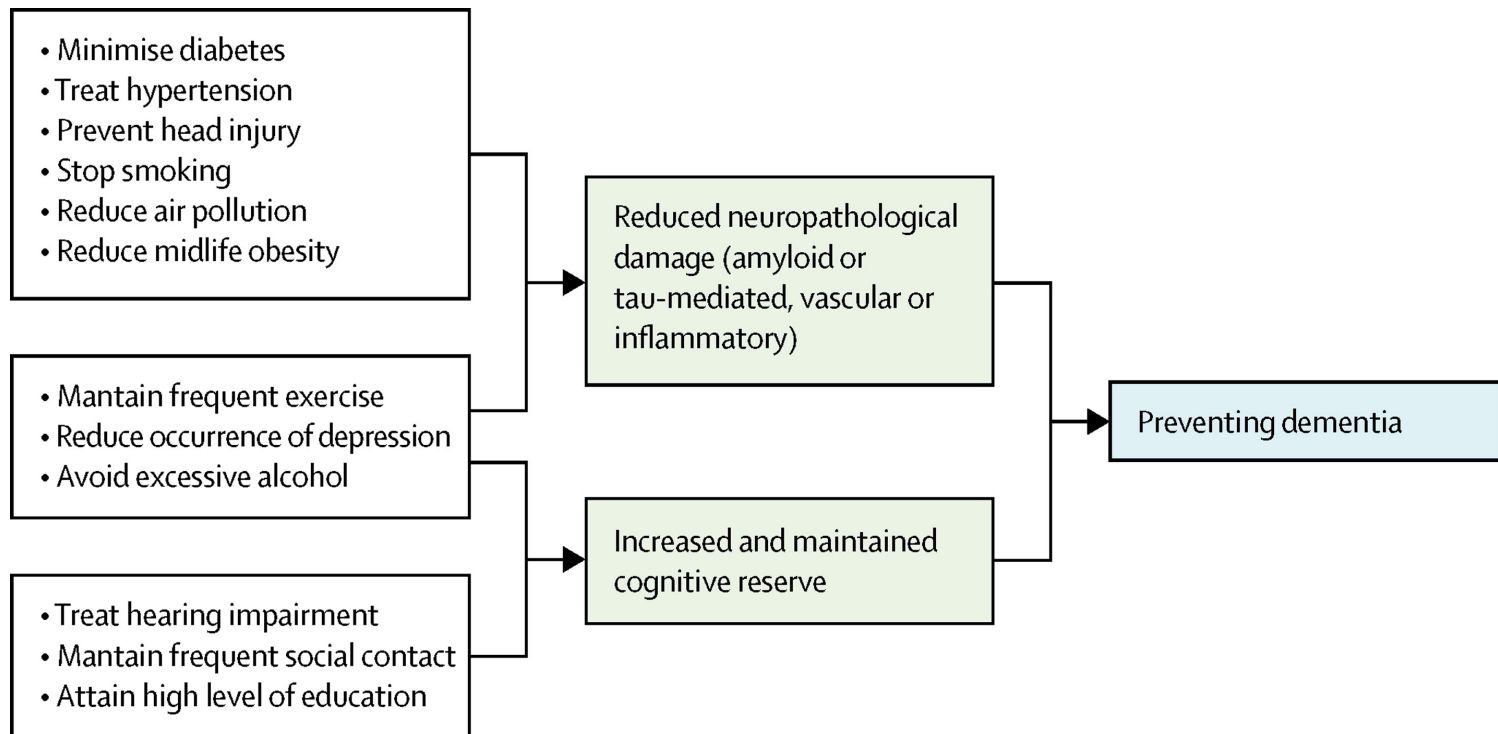


Dementia Detection & Diagnosis

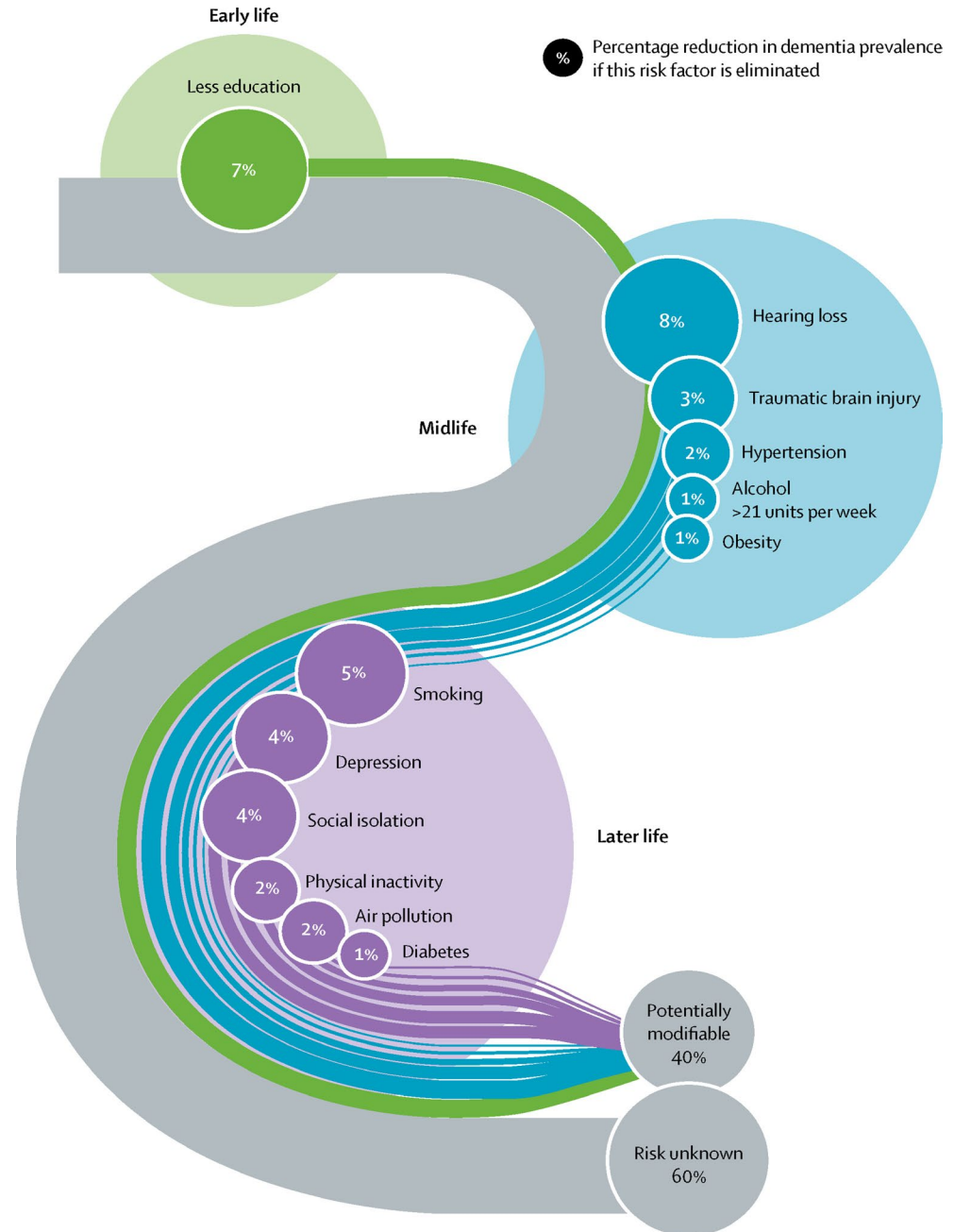
Goals of Early Recognition, Diagnosis, & Care



Possible Mechanisms for Enhancing or Maintaining Cognitive Reserve & Risk Reduction of Potentially Modifiable Risk Factors in Dementia



Population Attributable Fraction (PAF) of Potentially Modifiable Risk Factors for Dementia





Detection – 10 Warning Signs

We think about Cognitive Impairment when we see...

1. Memory loss that affects daily life
2. Trouble planning or solving problems
3. Get confused about time, date, or where you are
4. Daily tasks are getting harder, e.g., driving
5. Trouble with how your eyesight and thinking work together gets worse
6. New trouble talking or writing
7. Lose and cannot find things
8. Notice changes in mood or personality
9. Act different and more poor choices
10. Pull away from friends and family because it is harder to keep up



10
SIGNS

**OF THINKING OR MEMORY CHANGES
THAT MIGHT BE DEMENTIA**

As we get older, we may slow down a bit.

This is a normal part of aging. Changes in memory or thinking that make it harder to get through the day, are not a normal part of aging. **These may be early signs of dementia.**

Because American Indian and Alaska Native people have a high risk of dementia, it is important to know the warning signs.



Do you have any of these 10 signs? If so, talk to your doctor.

- 01 Memory loss that affects your daily life.** You may:
 - Forget events or important dates
 - Repeat yourself
 - Rely more often on lists or sticky notes to remember
- 02 Trouble planning or solving problems.** You may have a harder time:
 - Paying bills
 - Cooking recipes you have used for years
- 03 Get confused about the time, date, or where you are.**
- 04 Daily tasks are getting harder, including:**
 - Driving
 - Making a grocery list or going shopping
- 05 Trouble with how your eyesight and thinking work together that gets worse.** This includes:
 - Tripping, falls, or problems with your balance
 - Spilling or dropping things more
- 06 New trouble talking or writing.** You may have a harder time finding the words you want to say. For example, you may say "that thing on your wrist that tells time" instead of "watch."
- 07 Lose and cannot find things.** For example, you:
 - Can't find the coffee pot that you use every day
 - Might put your car keys in the freezer
- 08 Notice changes in mood or personality,** such as being:
 - Easily mad or sad in everyday situations
 - More fearful (scared) or suspicious (not trusting)
- 09 Act different and make poor choices.** You may:
 - Spend money you do not have or be a scam victim
 - Stop washing up regularly or pay less attention to how you look
 - Forget to take care of your pet
- 10 Pull away from friends and family because it is harder to keep up.** You may not want to do things you used to enjoy, like sporting events, church, music, or sex.



American Indian and Alaska Native people have a high risk of dementia.



Big changes in memory or thinking that make it hard to get through the day are not a normal part of aging.



People with one or more of these 10 signs should talk to their doctor to find the cause. It is not always dementia.



Early dementia diagnosis gives you a chance to get care and plan your future.



**AMERICAN INDIAN
and ALASKA NATIVE**
RESOURCE CENTER FOR BRAIN HEALTH

To learn more, visit:

www.AIANBrainHealth.org
www.cdc.gov/aging

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Detection – Risk Factors

We think about Cognitive Impairment with...

- **Non-modifiable risk factors**
 - Age
 - Family history
 - Genetics
- **Older patients**
 - 3% of adults aged 70 to 74 had dementia vs 22% of adults aged 85 to 89 vs 33% of adults aged 90 and older*
 - Trisomy 21 / Down Syndrome – 55% aged 40-49, 77% aged 60-69**
- **Middle aged & older patients with additional risk factors**
 - Long-standing diabetes
 - Chronic kidney disease
 - Vascular disease – CVD, Significant CAD, PVD
 - Chronic liver disease
 - History of alcohol or other substance abuse
 - History of significant or repetitive head trauma
 - Depression
 - Sensory issues, e.g., hearing loss

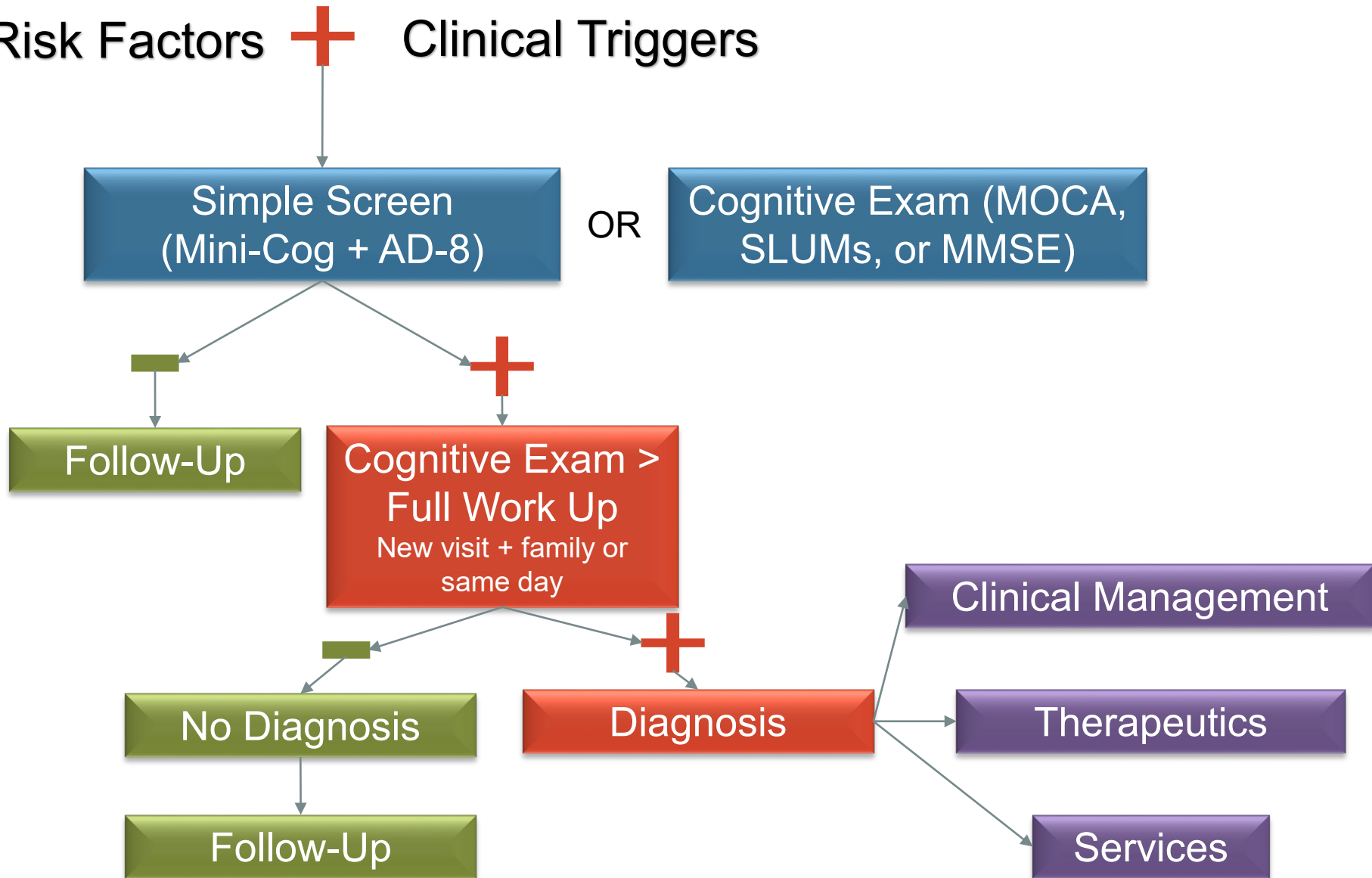
Detection – Clinical Triggers

We especially think about it when there is...

- Concern expressed by a patient or family member
- Decline in self-management of a chronic condition
- Vagueness in reporting of medical history or living situation
- Older patient struggling to understand in the absence of a language barrier or hearing deficit
- Delirium during acute illness
- Comprehensive prevention-oriented visit (e.g., a Medicare Annual Wellness Visit)

Detection to Comprehensive Care

Risk Factors + Clinical Triggers



Diagnosis

There might be cognitive impairment...Is there? How significant?

Cognitive Exam

- **Montreal Cognitive Assessment: MOCA**
 - No licensing fee for use - Certification required
 - Fee for 1-hour on-line training
 - <https://mocacognition.com/>
- **Saint Louis University Mental Status Exam: SLUMS**
 - No fee for use
 - Video training is free
 - <https://www.slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/assessment-tools/mental-status-exam.php>
- **Mini-Mental Status Exam: MMSE (Folstein)**
 - Relatively insensitive for Mild Cognitive Impairment and mild dementia
 - Very sensitive to education level
 - Copyright issues

All of the instruments assess:

Visuo-Spatial, Executive Function, Naming, Registration/Recall, Attention, Calculation, Fluency, Abstraction, Orientation

None are specifically validated in Native populations.

Diagnosis

There is cognitive impairment... Is it dementia?

Functional Status Assessment

- **Activities of Daily Living (ADLs)**
 - Grooming
 - Bathing
 - Dressing
 - Eating
 - Toileting
 - Ambulating
 - Transferring
- **Instrumental Activities of Daily Living (IADLs)**
 - Money management
 - Cleaning or hobbies
 - Medication management
 - Transportation
 - Cooking
 - Communication

Tools

- Lawton Instrumental Activities of Daily Living Scale
- Bristol Activities of Daily Living Scale
- **Katz Index of Independence in Activities of Daily Living**
- Functional Activities Questionnaire
- Functional Independence Measure Instrument
- **Barthel ADL Index**
- Bristol Activities of Daily Living Scale

Usually measured as: Independent / Needs help / Dependent

Diagnosis

There is cognitive impairment...Is it dementia?

1. **+ Objective examination of cognitive domains (e.g. MOCA, SLUMS, MMSE)**
2. **+ Functional status assessment**
3. **History**
 - Acute vs. chronic (acute c/w delirium, encephalopathy, trauma, stroke)
 - Fluctuating vs stable (fluctuating c/w delirium, encephalopathy)
 - Recent fall or trauma – no matter how minimal
 - Current or remote alcohol or substance use
 - Transient weakness, clumsiness, or confusion or syncope
 - Baseline cognitive function
4. **Physical Exam**
 - General appearance/hygiene – self-neglect
 - Hearing
 - Neurologic exam – especially weakness, gait, parkinsonian features, nystagmus
 - Cardiovascular exam – atrial fibrillation, CHF, murmur, PVD
5. **Diagnostics – *excluding other causes for cognitive impairment***
 - CBC, e'lytes, BUN/Cr, LFTs, B12, TSH. Consider RPR, HIV, others based on hx.
 - Imaging (non-contrast CT or MRI) for acute change or physical findings

Diagnosis

There is dementia... What kind is it?

ALZHEIMER'S 60-80%

Causes problems with memory, language and reasoning. 5% of cases start before age 65

LEWY BODY DEMENTIA 5%

Caused by Lewy Body proteins. Can include hallucinations and disordered sleep.

PARKINSON'S DISEASE 4%

Can give rise to dementia symptoms as the condition progresses

VASCULAR DEMENTIA 5-10%

Impaired judgment, difficulty with motor skills and balance. Heart disease and strokes increase the likelihood

FRONTOTEMPORAL DEMENTIA 3%

Personality changes and language problems. Most common onset between 45 and 60

OTHER 3%

Creutzfeld-Jacob, depression, multiple sclerosis, hippocampal sclerosis, alcohol induced, etc.

MIXED DEMENTIA 50%

Several types of dementia contribute to symptoms. Most common in people over 85

Delivering the Diagnosis

- **General guidelines**
 - Family **MUST** be present whenever possible
 - Talk directly to the person with dementia
 - Summarize test results in plain language
 - Ask patient/family to repeat back what they have heard
 - Make sure all family members hear the same message, are on the same page
- **Address immediate problems and concerns**
 - Identify caregiver(s)
 - Assess capacity to make decisions
 - Address immediate safety concerns – especially driving, firearms, cooking, getting lost
- **Provide resources**
 - Local Alzheimer's Association chapter
 - Handouts and web-resources
- **Schedule Follow-up**
 - Answer questions related to diagnosis
 - Care planning
 - Steps to advance care planning for legal, financial, etc.
 - Connections to local resources



Delivering an Alzheimer's Disease Diagnosis

<https://www.youtube.com/watch?v=v2ZC5ZSZL8&t=2s>





**IHS resources to help
you care for those
living with dementia
and their caregivers**

GRANTS & Program Awards

Addressing Dementia in Indian Country: Models of Care

“...to support the development of models of comprehensive and sustainable dementia care and services in Tribal and Urban Indian communities that are responsive to the needs of persons living with dementia and their caregivers.”

2023

- 2023 Notice of Funding Opportunities (NOFO) announced March 29
- 2023 Program Awards (federal programs) announced April 6

2022 Awardees

- The Indian Health Board of Minneapolis, Inc.
- The Indian Health Council, Inc.
- The Nez Perce Tribal Health Authority
- The Northern Valley Indian Health

In-person meeting of IHS Grantees and ACL ADPI Tribal Grantees and the CDC BOLD grantee Northwest Portland Area Indian Health Board on April 11 & 12 at the ACL AI/AN/NH Title VI Director's meeting to connect and share vision, experience, resources.

2023 Funding Opportunities

Cooperative Agreements

- Funding Announcement Number: [HHS-2023-IHS-ALZ-0001](#)
- Eligibility: Tribes, Tribal Organizations, and Urban Indian Organizations. *Cannot be an existing Dementia program awardee*
- Federal Register Publication: [Addressing Dementia in Indian Country: Models of Care](#)
- Funding Amount: Awards of between \$100,000 and \$200,000 per year for 2 years
- Anticipate 6 awards
- Application period end date: **June 27, 2023**

Program Awards

- Eligibility: IHS Service Units working in partnership with the Tribe(s) and Nations that they serve under the condition that the Tribe(s) or Nations served by the IHS Service Unit have elected not to apply for a Cooperative Agreement (above)
- Application Materials: [Program Award Information & Fillable Application Template](#)
- 2 options for funding
 - 1) Comprehensive Model of Care: Up to \$200,000 per year for two years
 - 2) Programs and Services: Up to \$50,000 per year for two years
- Anticipate up to \$600,000 in awards
- Application period end date: **June 12, 2023**

Funding Opportunity Resources

- 1. IHS Alzheimer's website:** <https://www.ihs.gov/alzheimers/>
 - See “Planning Resources” on 2023 funding opp page:
<https://www.ihs.gov/alzheimers/fundingopps/2023fundingopp/>
- 2. [Grants.gov](https://www.grants.gov) Website**
 - Registration, application process for **grants/ cooperative agreements**
- 3. IHS Division of Grants Management**
 - <https://www.ihs.gov/dgm/>
- 4. IHS Elder Care team consultations**
 - Email jolie.crowder@ihs.gov

Upcoming ECHO Programs

Northwest Portland Area Indian Health Board (NPAIHB)

Indian Country ECHO Program

Funded by the IHS Alzheimer's Grant Program

Indian Country Dementia Clinical ECHO

- First session May 11, 2023 from 11am-12pm PT, and
- Continuing regularly the 2nd Thursday of each month at 11am PT
- Case-based learning to strengthen Primary Care knowledge and confidence to
 - Detect cognitive impairment
 - Diagnose Alzheimer's disease and related dementias
 - Manage care for American Indian and Alaska Native people living with dementia and their caregivers

Indian Country Dementia Caregiver Support ECHO

- First session June 22nd from 11am-12pm PT
- Continuing regularly on the 4th Thursday of every month at 11am PT
- Training and mentorship for Indian Health staff providing coaching and support for caregivers.
- Certificates of Completion will be provided

More Educational Opportunities

2022 Indian Health Geriatric Scholars Pilot

- 15 Scholars from 10 IHS, Tribal, and Urban programs
- Completing local improvement efforts in dementia detection and/or diagnosis (9), medication management (3), falls (1)
- Developing practicum/mentorship to support next steps in local improvement

2023 Indian Health Geriatric Scholars

- Recruitment in early summer

VA - Free Training for I/T/U Facilities, VA Office of Rural Health

- Rural Interdisciplinary Team Training (RITT)
- Addressing Behavioral Challenges in Dementia (ABCD)
- 1 - 2 day training, free to rural Indian Health (IHS and Tribal) programs serving AI/AN veterans/
- For more information email [Josea Kramer, PhD](mailto:Josea.Kramer, PhD) at BettyJo.Kramer@va.gov

The IHS Elder Care Team



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Thank you!

For more about Alzheimer's disease and other dementias and the IHS Alzheimer's Grants Program

Visit: <https://www.ihs.gov/alzheimers>

Join: [IHS Elder Care LISTSERV](#)

Reach out:

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Billing & Coding

The Mini-cog or other screen is usually part of another visit or exam.

For a diagnostic exam: **Cognitive Assessment Care Plan Services - CPT 99483**

Required elements

1. Cognition-focused evaluation including a pertinent history and exam
2. Medical decision-making of moderate or high complexity
3. Functional assessment including decision-making capacity
4. Use of standardized instruments to stage dementia
5. Medication reconciliation and review for high-risk medications, if applicable
6. Evaluation for neuropsychiatric and behavioral symptoms
7. Evaluation of safety, including motor vehicle operation
8. Identification of caregiver(s), caregiver knowledge, caregiver needs, social supports, and willingness of caregiver to take on caregiving tasks
9. Address palliative care needs, if applicable and consistent with beneficiary preference
10. Creation of a care plan, including initial plans to address any neuropsychiatric symptoms and referral to community resources as needed; – Care plan shared with the patient and /or caregiver with initial education and support.

Abbreviations

- **AI/AN** = American Indian/Alaska Native
- **AOR** = Authorized Organization Representative
- **COI** = Conflict of Interest
- **DCCS** = Division of Clinical and Community Services
- **DGM** = IHS Division of Grants Management
- **DTLL** = Dear Tribal Leader Letter
- **DUIOLL** = Dear Urban Indian Organization Letter
- **IHS** = Indian Health Service
- **NOFO** = Notice of Funding Opportunity (also known as FOA)
- **ORC** = Objective Review Committee
- **SAM.gov** = System for Award Management
- **UEI** = Unique Entity Identifier