



Photo courtesy Chickasaw Nation

SUPPORTING DEMENTIA CAREGIVERS

A HEALTHY BRAIN INITIATIVE ISSUE MAP

The *Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples* is a guide focused on addressing dementia in American Indian and Alaska Native (AI/AN) communities.

Find the HBI Road Map for AI/AN Peoples and additional tools, resources and data at: alz.org/HBIRoadMapAIAN



**HEALTHYBRAIN
INITIATIVE**
Road Map Series

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PUBLIC HEALTH AND DEMENTIA CAREGIVING

A strength of AI/AN cultures is that they hold great esteem for Elders and are likely to take care of their Elders at home.¹ A strong public health response in tertiary prevention can help maintain the health, well-being and independence of people living with dementia and their caregivers and reduce associated costs.

Caregivers for people living with dementia often assist with activities of daily living such as personal care, household management, medication and health care management and coordination of financial matters. Caregivers also play an important day-to-day role in helping to reduce potential challenges such as wandering, medication mistakes, difficulties in paying bills and potential for dangerous situations.

As mild cognitive impairment progresses, disruption to memory, thinking and everyday life can range from mild to severe. Providing caregivers with resources and information about their important role and available support can help them maintain their own health and well-being.²

Specific approaches to support caregivers include providing education, helping manage dementia-related symptoms, improving social support for caregivers and providing respite from caregiving duties. Some approaches also aim to delay nursing home admission of the person with dementia by providing caregivers with skills and resources (emotional, social, psychological and/ or technological) to continue caring for their relatives, friends or neighbors at home. Respite programs can actively involve caregivers and be tailored and flexible to meet the specific and evolving needs, culture, and customs of people living with dementia.

Tertiary prevention strategies can connect the person living with dementia and their caregivers to treatment and support services to help preserve their independence and quality of life for as long as possible.

Compelling Data:

- One in four AI/AN adults are caregivers³ and 5.4% of AI/AN adults reported that they are caregivers of people living with dementia.⁴
- More than half (53.2%) of AI/AN caregivers of people living with dementia provide at least 20 hours of care per week and 60.3% have provided care for at least two years.³
- Among AI/AN caregivers of people living with dementia, 23.4% also have a child in the home, meaning they are caring for both a child or grandchild as well as an older adult with dementia (often referred to as the “sandwich generation”).³
- More than one-fourth (27%) of AI/AN caregivers of people living with dementia report being treated with less respect than others by health care providers.⁵

Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. The recipients of care can live either in the community or institutional settings, range from children to older adults and have chronic illnesses or disabling conditions. Because of their partnership with people living with dementia in making joint decisions to enhance their care and quality of life, caregivers can also be referred to as “care partners” or “carers.” Because caregiving is a common part of AI/AN family culture, the term caregiver is not often used. Many tribal nations do not have a specific word for caregiving, using community, family or Elder helper instead. A caregiver can be a direct family member, friend or relative and is often more than one person.

Tertiary prevention is managing a disease and its symptoms to slow the progression and prevent or reduce negative health effects and maintain quality of life. It also encompasses prevention of complications, support for caregivers and management of comorbidities (other diseases or conditions that a person has at the same time, such as diabetes or heart disease).

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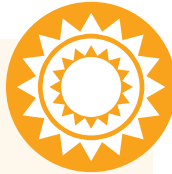
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DEMENTIA CAREGIVING ACTION AGENDA

The *Healthy Brain Initiative: Road Map for American Indian and Alaska Native Peoples* offers actions to improve brain health throughout life. It promotes health equity by using a strength-based approach that honors the diverse AI/AN cultures and incorporates the indigenous determinants of health. Actions within each domain help tribes, nations, pueblos, bands, villages and urban Indian organizations better support dementia caregivers.



E DOMAIN: ENGAGE COMMUNITIES AND SHARE KNOWLEDGE



- E-III Provide information on how to recognize signs of dementia and increase awareness of services, care, and social support for people living with dementia and their caregivers.
- E-IV Ensure caregivers have information about their important roles and how to support their own health and well-being.



W DOMAIN: BUILD A REPRESENTATIVE AND SKILLED WORKFORCE



- W-I Provide ongoing training to health care providers to support culturally centered and appropriate conversations about brain health and dementia.
- W-II Provide training to community health and direct service workers who work in AI/AN communities about brain health and the ways dementia disproportionately impacts those they serve.



M DOMAIN: MEASURE, EVALUATE AND USE DATA



- M-I Support data sovereignty through local data collection to help plan, implement and evaluate programs and approaches for dementia and caregiving in AI/AN communities.
- M-III Put data into action by sharing findings with AI/AN leaders, community members and organizations to help inform awareness efforts, resource needs, programs and policies.



P DOMAIN: STRENGTHEN POLICIES AND RELATIONSHIPS



- P-I Build relationships within and outside of the health and public health sectors to strengthen sustained commitments to brain health and its physical, mental, emotional and spiritual impacts across the life course.
- P-II Engage AI/AN leaders to increase awareness about the indigenous and social determinants of health associated with brain health, dementia and caregiving.
- P-III Equip AI/AN leaders with policy options to improve brain health across the life course and reduce stigma about dementia.

COMMUNITY IN ACTION: PUBLIC HEALTH SUPPORTING DEMENTIA CAREGIVERS

Absentee Shawnee Tribe, Oklahoma

The Absentee Shawnee Tribe and the Absentee Shawnee Tribal Health System is committed to supporting caregivers through culturally relevant programs that address the challenges of caring for loved ones with memory loss. Recognizing that many caregivers do not initially see themselves as such, the tribe actively works to raise awareness, provide essential training, and support caregiver self-care. They emphasize that caregivers must prioritize their own well-being in order to provide the best care for their loved ones.

The Savvy Caregiver in Indian Country program is a structured training that helps caregivers understand dementia, manage symptoms, and navigate behavioral challenges. Conducted in caregivers' homes, this six-session program ensures accessibility and flexibility for families with demanding caregiving responsibilities. Through checklists and discussions, participants gain a clearer understanding of their role and responsibilities, often recognizing for the first time the extensive duties they perform. Such duties include nursing, social work,

activity director, home companion, chief financial officer, administrator, safety officer, family counselor, and lawyer.

The Music & Memory program further supports caregivers by using personalized music to evoke memories and reduce agitation in individuals with dementia. These moments of joy not only enhance the quality of life for the person living with dementia, but also offer emotional relief to caregivers, reaffirming their efforts and strengthening their bond with their loved ones.

To address the physical, emotional, and mental toll of caregiving, the health system provides support for respite. Caregivers can choose known and trusted individuals, including family, to be with their loved one while they get some needed time for their own health and well-being.

Through these initiatives, the Absentee Shawnee Tribe and the Absentee Shawnee Tribal Health System are fostering a more resilient and powerful caregiving community.

In the *HBI: Road Map for AI/AN Peoples*, the image of a family by a river is used to illustrate prevention strategies at work in an AI/AN community. The story focuses on a woman moving through different phases of life. She begins healthy but then starts to show early signs of dementia and is ultimately diagnosed with Alzheimer's disease. Throughout her journey, she is supported by her family, community and culture.

In the third image of the story, the family has expanded to include a fourth generation. The woman is a great-grandmother and has been diagnosed with Alzheimer's disease. Her extended family, along with other tribal and community members, continue to help her stay connected to the land by supporting her and sharing a healthy traditional meal. They embrace their roles as caregivers, help her manage activities of daily life and support her continued involvement in the community. They respect her as an Elder and encourage her to continue to share her wisdom, language, stories and traditions with her family and community. They also support each other by sharing the responsibilities of caring for their loved one.

