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Information Session Workbook

The International Association for Indigenous Aging (IA²) is the administrator for Dementia Friends for American Indian and Alaska Native Communities.
www.AIANBrainHealth.org

Welcome to Dementia Friends!

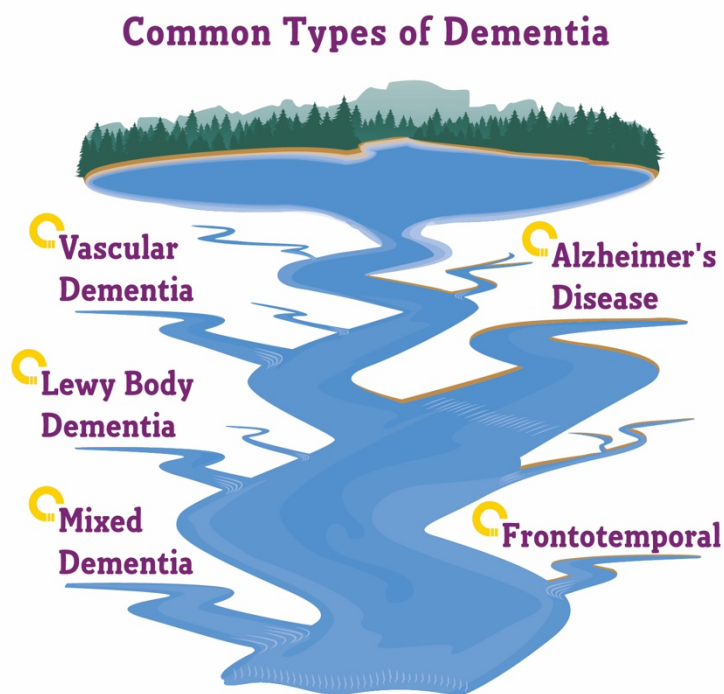
- **American Indian and Alaska Native people living with dementia need to be understood and supported in their communities.**
- **You can help by becoming a Dementia Friend in your community.**
- **Visit www.dementiafriendsusa.org to learn more!**

Dementia: What You Should Know

Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities.

Alzheimer's disease is the most common type of dementia and accounts for 60 to 80 percent of cases. Other types of dementia include Lewy body, frontotemporal, vascular, and mixed dementias. Mixed dementia means living with more than one type of dementia at the same time.

Certain types of traumatic brain injury may increase the risk of developing Alzheimer's or another type of dementia years after the injury takes place. Other risk factors include high blood pressure, heart disease, diabetes, and hearing loss.



Can We Reduce the Risk of Dementia?

Yes! Native people and communities have many strengths and great resiliency drawn from their cultures and traditional ways of life, for example: a strong sense of community and support, hope, general coping skills, traditional cultural and spiritual practices, and ethnic pride.

However, American Indian and Alaska Native cultures and traditions have been severely disrupted by discriminatory policies resulting in loss of land, forced assimilation, relocation, tribal termination, and historical trauma. These have contributed to higher rates of chronic disease and risk factors for developing memory problems. These risk factors include high blood pressure, diabetes, obesity, and commercial tobacco use, to name a few.

≈ 1 in 9 people 65+ in the U.S. will develop dementia
≈ 1 in 3 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

Some activities that promote resilience, re-build connections to our communities and cultures, and reduce risk for dementia include*:

- **Health Promotion:** Increasing traditional physical activity like dance, preparing and harvesting traditional foods and medicines, and maintaining overall healthy living practices
- **Cultural Practices:** Increasing knowledge and sharing of tribal history and cultural practices
- **Social and Emotional Well-being:** Increasing the sense of belonging to one's tribe, and the sense of connection to culture through beading, artwork, practicing song, and intergenerational interactions

In addition to reducing risk, these same strategies can help people living with dementia to live well, and we can each play a role in helping them stay connected to these types of opportunities. Hope doesn't end with a dementia diagnosis.

*Adapted from: <https://www.cdc.gov/healthytribes/tribalpractices.htm>

Sources: <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>,

<https://www.cdc.gov/aging/data/infographic/index.html>, and Mayeda, et al, (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. <https://doi.org/10.1016/j.jalz.2015.12.007>,

The River: A Story about the Progression of Dementia

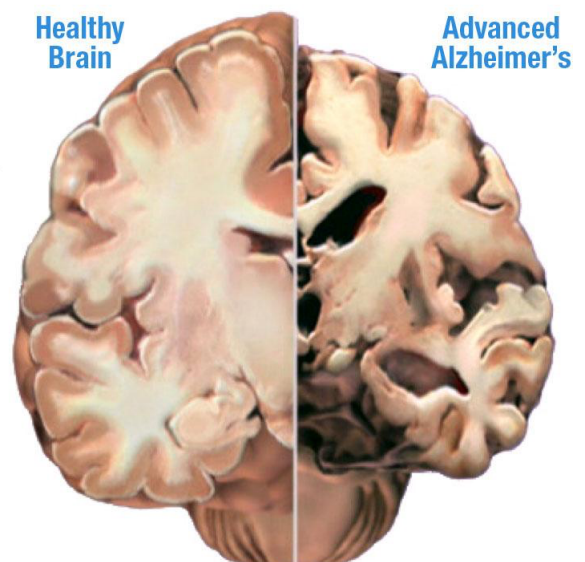
For every human being, life is like a river. The constant flow of water represents our daily experiences, from routine and familiar to those that take us by surprise. If we are lucky enough to live a long life, we will experience the river in each of the four seasons: spring, summer, fall, and winter.

Spring is early childhood, when the river is new to us and we are just learning about all the fish, birds, and animals that connect with it. Summer is our experience from childhood to adulthood, when we transition from relying on others to navigating the water and harvesting for ourselves. Fall is adulthood, when we know the river and its resources and dangers well enough to provide for others, raise children, and chart our own course in the world. Winter is elderhood, when we have acquired the deepest knowledge and wisdom, but also start to experience changes from the aging of our bodies.

Dementia is like navigating a river freezing in a long winter storm, or even a blizzard. Storms can come in any season, although they are most common and most severe in winter. The wind and snow make it harder to see and hear the water. Everyday life—the natural flow of the water—becomes harder to navigate. Thinking activities that used to be easy, like planning a fishing trip, buying bait, planning meals for the trip, and reaching out to others to join the activity, become increasingly difficult. However, even at the start of a winter storm, emotional experiences and feelings remain strong; for example: the love of fishing, the memory of the sunlight bouncing off the rippling current, and the joy of company.

The longer a person lives with dementia, the thicker the ice on the river can become. The everyday flow of experiences beneath the surface is more difficult to reach and navigate without help. Eventually, even deep and lifelong emotional and spiritual connections are harder to access through the thickening ice.

This story of a river in a long winter storm helps explain the experience of dementia. Facts, recent memories, and complex thinking become harder to reach in the thickening ice, while deeper memories and emotions continue to flow under the surface.



Early Signs of Dementia vs. Normal Aging

Everyone slows down as they get older, both in body and mind. But big changes with memory, thinking, communication, or solving problems that make it hard to get through the day **don't happen to everyone**. These could be signs of early dementia. With most types of dementia, these changes happen slowly.

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

Sources: www.alz.org/10-signs-symptoms-alzheimers-dementia.asp and University of Wyoming *10 Early Signs of Abnormal Memory Changes* created in collaboration with Eastern Shoshone and Northern Arapaho tribal members.

Broken Sentences Worksheet and Six Key Messages

Match the sentences in Column 1 to Column 2 by drawing a line from each sentence *beginning* to the corresponding sentence *ending*. You should end up with **six sentences** that make sense and become Dementia Friends' "Six Key Messages about Dementia."

Column 1	Column 2
1. Dementia is caused by...	A. ...more common as people get older, but it is not a normal part of healthy aging.
2. There are things you can do to...	B. ...diseases of or injuries to the brain.
3. Dementia becomes...	C. ... live well, especially with their community's support.
4. Dementia is not...	D. ... reduce the risk of developing dementia.
5. People living with dementia can...	E. ... just about having memory problems.
6. A person living with dementia is...	F. ... a full being—worthy of respect—and is a vital part of their community.

Everyday Tasks

Write a step-by-step list to complete a task you do every day or a lot.
Make sure that someone reading your list could follow
the instructions successfully to complete the task.

People living with dementia sometimes need assistance to complete daily tasks. Some people might benefit from simple reminders, while others might require verbal and/or physical cueing or assistance. It's important to provide the right amount of support to maximize the abilities a person still has. In this activity, we broke down a common task into a series of steps. To help support a person living with dementia, cueing or assistance might be necessary at any or all steps. It's important to provide the missing information or necessary assistance one step at a time. It is also important not to take-over steps of the task the person can do for themselves without assistance.

How to Communicate with People Living with Dementia

Consider the following tips when communicating with a person living with dementia.

Treat the person with dignity and respect. Avoid talking past the person as if they aren't there.

Be aware of your own feelings. Your tone of voice and body language communicate your attitude.

Be patient and supportive. Let the person know that you are listening and trying to understand. If the task or topic is too overwhelming at the moment, you can stop and go back to it later.

Offer comfort and reassurance. If the person is having trouble communicating, let them know that it's okay and encourage the person to continue.

Avoid criticizing or correcting. Don't tell the person what was said was incorrect. Instead, listen and try to find the meaning in what is being said.

Avoid arguing. If the person says something you don't agree with, let it be. Arguing usually only makes things worse and often increases agitation for the person living with dementia.

Offer a guess. If the person uses the wrong word or cannot find a word, you can try guessing the right word. But again, first be patient, offer reassurance, and give them a chance to think. Sometimes, if you understand what the person means, finding the right word may not be necessary.

Encourage nonverbal communication. If you don't understand what is being said, ask the person to point or gesture.

When approaching the person with dementia and starting a conversation:

- Keep in mind some people with dementia have trouble seeing or hearing. Come from the front, identify yourself, and keep good eye contact if that is something that is considered respectful and comfortable in your culture.
- If the person isn't standing, go down to eye level so they can see your face.
- Call the person by their preferred name.
- Use short, simple phrases and repeat information as needed. Ask one question at a time.
- Speak slowly and clearly, using a gentle and relaxed tone.
- Patiently wait for a response while the person takes time to process what you said.
- Help them know that they are still important, respected, and in control of their own lives.

During the conversation:

- Provide choices so they feel they still have power, but make them simple. For example, say "Do you want chocolate or vanilla ice cream," instead of asking "What kind of ice cream do you want?" Sometimes, too many choices can feel overwhelming.
- Provide a statement rather than ask a question. For example, say "I hope you had a wonderful day today!" instead of asking "What did you do today?" This opens a space for the person to provide information without putting them on the spot to recall specific details or facts.
- Avoid confusing and vague statements. Instead, speak directly; rather than saying "They're here for you." say "The taxi you asked me to arrange is here to take you home."

- Turn negatives into positives. Instead of saying, “Don't go there,” suggest, “Let's go here.” Instead of saying “You can't do that,” encourage “Let's try this.”
- Give visual cues. Point or touch the item you want the person to use or begin the task for them yourself.
- Avoid quizzing the person with questions like “Do you remember when...?” or “Do you remember who this person is?”
- Try using written notes or pictures as reminders if the person is able to understand them.

Six Key Messages

- Dementia is caused by diseases of or injuries to the brain.
- There are things you can do to reduce the risk of developing dementia.
- Dementia becomes more common as people get older, but is not a normal part of healthy aging.
- Dementia is not just about having memory problems.
- People living with dementia can live well, especially with their community's support.
- A person living with dementia is a full being—worthy of respect—and is a vital part of their community.

Turn Your Understanding into Action

Elders are the lifeblood of our culture. Elders living with dementia can continue as our leaders and storytellers, passing down traditions and language. They can serve as memory keepers, lend their wisdom, and continue as active members of American Indian and Alaska Native communities. There is much a Dementia Friend can do to protect this vital community resource.

As a Dementia Friend for American Indian and Alaska Native Communities, I will...

- _____ Focus on what people living with dementia CAN do throughout the progression of dementia, such as share traditional stories, teach the language of their community, or share their wisdom with younger generations
- _____ Include people who are living with dementia in the decisions affecting them; everyone has a right to express their voice and choice.
- _____ Get in touch and stay in touch with someone I know who is living with dementia.
- _____ Have empathy and be patient.
- _____ Be more understanding.
- _____ Use language and words that value people living with dementia.
- _____ Help someone living with dementia protect themselves from being exploited, abused, or ridiculed by others in the community.
- _____ Carry out this personal action (write your own action):

Resources in Your Community

Alzheimer's Association 24/7 Helpline: Serves people with memory loss, caregivers, health care professionals, general public, diverse populations, and concerned friends and family. Helpline provides referrals to local community programs and services, dementia-related education, crisis assistance and emotional support. (800) 272-3900 or www.alz.org

Lewy Body Dementia Association: a nonprofit organization dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and caregivers and promoting scientific advances. The Association's purposes are charitable, educational, and scientific. (800) 539-9767 or www.lbda.org

Dementia Action Alliance (DAA): provides hope and help to individuals and families living with dementia and information about how to live proactively with dementia. DAA offers services and peer supports including three weekly online discussion groups, two monthly podcasts, an online Resources Center, a national Speakers Bureau and other services. All DAA efforts and activities are shaped and informed by individuals living with dementia. (732) 212-9036 or www.daanow.org

Dementia Friendly America (DFA): DFA is a national network of communities, organizations and individuals seeking to ensure that communities across the U.S. are equipped to support people living with dementia and their caregivers. Dementia friendly communities foster the ability of people living with dementia to remain in community and engage and thrive in day to day living. To learn how to join the DFA network of communities, or to connect with your local community, visit www.dfamerica.org

National Indian Council on Aging (NICOA): a nonprofit organization founded by members of the National Tribal Chairmen's Association who called for a national organization focused on the needs of aging American Indian and Alaska Native elders. The mission of NICOA is to advocate for improved comprehensive health, social services and economic wellbeing for American Indian and Alaska Native elders. (505) 292-2001 or www.nicoa.org

IA² Healthy Brain Website: Resources and information including the Healthy Heart, Healthy Brain flyer for American Indian, Alaska Native, and Urban Indian communities on health promotion and steps we can take to reduce our risk for dementia. www.iasquard.org

Healthy Body, Healthier Brain: Includes resources and information for people with memory problems and other chronic health problems like high blood pressure, diabetes, or kidney disease including tips to reduce the risk for developing dementia. <https://www.cdc.gov/aging/publications/features/healthy-body-brain.html>

Eldercare Locator: Is a public service of the U.S. Administration on Aging connecting you to local services, supports, and information for older adults and their families on issues related to caregiving, health, housing, transportation, and more. Reach them at 1-800-677-1116 or <https://eldercare.acl.gov>

Local aging, senior center, or Title VI program

Local dementia support group

Tribal home health, public health, community health representative

Local dementia-friendly community group or effort