

### Linking Age-Friendly to Dementia-Friendly in Winnemucca

It started with a simple request: help regular customers, many of them older women, get their hair done at a downtown salon.

In rural Winnemucca, many of its 8,000 Nevada citizens have lived there for decades, so people know their neighbors, and planning decisions are made as much with a handshake as a city ordinance.

So what was the best way to help these women get their hair fixed?

Townsfolk agreed that for people living with physical and/or cognitive impairment, losing the ability to drive represents a major hit to both independence and dignity. In fact, members of a family caregiver support group for people living with dementia asked their group facilitator: "How do you take a driver's license away without being the villain?"

That facilitator was Gini Cunningham, long respected in the city for her civic efforts as well as her understanding of aging. Cunningham also writes a long-standing column on dementia for the local paper.

As always, she sprang into action.

In September of 2015, Cunningham quickly organized a town hall meeting with a panel of ten city officials representing law enforcement, the city council, the district attorney's office, and even the CEO of the local hospital. Thirty local citizens also attended to explore the rising challenges facing aging members of the Winnemucca community. Along with other concerns, transportation was on the front of their minds.

Cunningham, in collaboration with other interested and engaged citizens of Winnemucca, urged the city to provide the needed handicap zone for bus parking in front of the hair salon, and with approval from then-mayor Di An Putnam and the city council, they were off.

"It showed the seniors that a community cared about them," says Putnam.

Starting from a simple desire to support elders, this grassroots effort became the first step in Winnemucca's application to become a sanctioned AARP "age friendly community."

Since AARP encourages cities to bring together a wide spectrum of stakeholders to work together on age-friendly initiatives, Cunningham also reached out to the local library system, various religious and civic organizations, and other influential groups.

AARP's age-friendly guidelines list eight sectors — including housing, transportation, and health — and suggest starting with just two or three. But Cunningham had other plans; Winnemucca wanted to target all eight.

"A lot of their setup and organizational process takes more time," says Cunningham, speaking of AARP. "We were willing to move a lot faster."

Instead of just a handful, the town established 22 goals and within two years had either completed or made significant headway on nearly all of them — a testament to Cunningham's determination and the small, tight-knit community's ability to collaborate and mobilize.

Thanks to their efforts, Winnemucca now has resting benches, weekly concierge bus services, a fitness park designed for elders, and dozens more improvements in infrastructure and community services.

Today, AARP considers Winnemucca one of the most age-friendly rural cities in the country.

Two years after that first meeting, in 2017 Cunningham and colleagues became aware of the national dementia-friendly movement and signed on as one of Dementia Friendly Nevada's original Community Action Groups.

And they had a huge head start.

"When we implemented our dementia-friendly goals, we just laid them over our existing age-friendly ones since a lot of them are related," says Cunningham.

There are an estimated 300-500 people living with dementia in the greater Winnemucca area, many of them living alone.

"It's hard to say because we're still dragging the stigma and misunderstandings of dementia out of the closet," says Cunningham.

And just like Winnemucca's age-friendly efforts, the city has launched its dementia-friendly efforts with astounding success.

So far, the city has completed seven Dementia Friends information sessions to help citizens better understand dementia and how to interact with people living with dementia. So far, 150 people have been trained, including crisis intervention personnel, social workers, and school counselors.

Once a month, held at local partner Humboldt General Hospital, is the one-hour informal support group, *Let's Talk About It*, which welcomes questions about dementia from community members. Cunningham says this is especially important since fear and denial around dementia are so prevalent — not just in Winnemucca but everywhere. In the past, people saw her on the street and quickly veered off in another direction.

"They thought I was contagious," she jokes. "There's the Alzheimer's lady! Run! Run!"

Winnemucca also introduced the WAM program — Wellness, Art and Music — which meets twice a month to engage people living with dementia while allowing their care partners respite. For two hours, participants rotate from art projects to puzzles and music then a walk or stretch "to get the blood flowing," says Cunningham.

One of Winnemucca's biggest successes is *Music & Memory*, which Cunningham helped implement after seeing the movie *Alive Inside* in 2015. Documenting the use of iPods in long-term care communities, the movie illuminates the power of music to rekindle both memories and a passion for life.

In response, members of the Winnemucca Pink Ladies Auxiliary bought iPods for 25 residents at a local skilled nursing facility. Next, city cheerleaders interviewed the residents about their music preferences, played snippets of various songs, and populated the iPods with the selected tunes. The facility's activity director Robin Moore quickly discovered that this personalized music calmed residents, eased their pain, and made them happier overall.

With so many projects percolating in Winnemucca, what is its key to success?

"We have wonderful team members who deeply care," says Cunningham of her fellow Community Action Group members.

Winnemucca is one of the rare communities that has embraced both age-friendly and dementia-friendly efforts to great effect, and has even produced the

290-page resource guide “Age- and Dementia-Friendly Winnemucca and Humboldt County.”

A group with the same name meets monthly, joining the varied organizations and activities at the intersection of aging and dementia.

“There is a concerted effort to help and provide information to seniors and all those families living with a connection to dementia,” says Cunningham.

Of the two, has its age-friendly or dementia-friendly efforts been more successful?

Cunningham happily reports the winner: “It’s a tie.”



## ***Mobilizing Beliefs***

Dementia Friendly Nevada is guided by a deep belief that each person living with dementia remains, and will always remain, a full human being and his or her rights as a citizen are, and shall always be, intact. To guide dementia-friendly and inclusive efforts, we offer a set of **mobilizing beliefs**, which can help serve as a type of ethical roadmap for restoring and ensuring fundamental rights and opportunities to people living with dementia who have been disenfranchised by a prevalent view that discounts and diminishes their value and potential contributions to our communities and state.

1. People are ***living*** with dementia. In order to support each person in living with dementia, we must destigmatize dementia and see beyond the common tragedy narrative. People can live well with dementia when they are afforded with opportunities for meaning, purpose and growth.
2. People living with dementia are not their diagnosis. Person-first language should replace labels such as 'dementia sufferer' or 'Alzheimer's patient'. Such labels perpetuate an 'us versus them' mentality. In truth, *all* human beings are forgetful; some are just more forgetful than others.
3. If you know one person living with dementia, you only know one person living with dementia. Generalizations based on notions of 'age' or 'stage' are limiting and often wrong. Understanding the experience of living with dementia requires understanding each person as a unique human being.
4. People living with dementia are the genuine experts in the experience of dementia. Their perspectives, wishes and preferences should always be sought and respected in the decisions that affect their lives. Truly engaging each person living with dementia as a legitimate contributor to his or her own experience opens a world of possibilities.
5. People living with dementia can and do communicate and express themselves meaningfully across the entire continuum of the disease experience. It is

important that care partners and community members develop the ability to listen with more than their ears and to speak with more than their words.

6. Contrary to the increased use of the term, there is no such thing as “behavioral and psychosocial symptoms of dementia” (BPSDs). So-called “behaviors” are actually a form of communication; communicating identity, preferences and/or unmet needs. Instead of pathologizing behaviors, care partners and professionals should seek to understand and validate personal expressions, actions and reactions.
7. Sometimes, what makes care partners feel safe and secure makes people living with dementia feel trapped and anxious, including locked environments.
8. “Redirection” is a code-word for distracting, manipulating or charming someone living with dementia into doing what *you* want them to do. Instead, care partners and community members should respond supportively and seek to understand the world from another person’s perspective.
9. Just as the Americans with Disabilities Act ensures ramps for people living with physical disabilities, it should also ensure that communities provide adaptations and supports (i.e., cognitive ramps) for people living with dementia and other cognitive disabilities.
10. Communities and service agencies need to offer affordable, accessible and proactive community-based supports and services. The more energy and resources devoted to community-based supports and services, the less need there is for expensive and reactive interventions and institutional care settings.
11. People living with dementia should never be segregated, like convicted criminals. Each citizen has the right to live freely and safely in the community of their choosing. Even in circumstances where a person requires additional support due to cognitive impairment, the living environments offered should be normalized, inclusive and not merely ‘homelike’ but an actual home, without restrictions or restraints on one’s freedom. There are many ways to guarantee safety besides locked doors.
12. Persons living with dementia should have access to affordable person- and relationship-centered residential care and support that nurtures each person’s

well-being and upholds their right to autonomous decision making to the fullest extent possible. This requires an appropriate care partner to resident ratio.

13. Though most forms of dementia are degenerative, people living with dementia can continue to grow and thrive when care partners and organizations avoid the tendency to medicalize, sterilize and surveil all aspects of everyday life.
14. Supporting engagement, autonomy and partnerships with people living with dementia will promote improvements to their quality of life and well-being, and strengthen the social fabric of communities. Elders need communities and communities need elders.

While each of these mobilizing beliefs are represented in various ways by Dementia Friendly Nevada, the responsibility to ensure that all people living with dementia are respected and valued as active citizens and important members of our communities resides with all community members and leaders.

### Friends' Day Out: A Peer Support and Respite Innovation in Elko

For two years, Cheryl Poll prayed that she'd find something to replace her previous work as a facilitator of a program that served families in crisis. For years, she taught the Family Wellness program, "Survival Skills for Healthy Families," a series of six two-hour sessions that offered practical tools for healthy family interactions.

She loved it.

Yet when the local juvenile center lost funding for the program, Poll was devastated: "I just have a heart for helping families."

Then one Friday, she got a phone call from a close friend with some exciting news. There was a new peer support program in town aimed at older adults living with dementia, and they needed a facilitator. The program was called Friends' Day Out.

"She knew I was looking for something else to continue to offer my experience in a positive way in the community," recalls Poll. "I thought, oh my gosh, this is an answer to a prayer."

Following a Dementia Community Assessment, Dementia Friendly Elko, one of Nevada's six dementia-friendly community action groups, identified two big gaps: a support group for people living with dementia, and community-based respite support for family care partners. Group members decided to address both gaps with one new program, Friends Day Out, which features an evidence-based mutual peer support program called Java Music Club. Working in partnership with the Terrace and Ruby View, who provides the location, and Nevada Rural RSVP, who provides the volunteers, Dementia Friendly Elko developed the weekly Friends' Day Out to include a shared meal, peer support and socialization for people living with dementia, and a much-needed 3 to 4 hour respite break for family care partners.



When Poll learned of this new volunteer opportunity, she texted, emailed and phoned Steven Nichols who for the past month had made the 10-hour round trip from Carson City to facilitate Friends' Day Out every Friday in Elko. As the Innovations Project Respite Program Director for the Nevada Rural Counties RSVP Program, which provides aging services to rural areas, Nichols had helped replicate and launch the program in Carson City and was now spreading it to rural areas throughout the state.

With no previous aging experience, but plenty of people skills and enthusiasm, Nichols had contacted the creator of the Java Music Club to learn everything possible about the program, which expertly engages older adults with its blend of music, stories and personal reminiscences. With each session focusing on a unique theme, Nichols recalls the first time he introduced a topic.

"I didn't tell anyone what the day's theme was," he says. "I just pulled it out of the envelope. People were so excited. It was like the Academy Awards."

Now Nichols and Poll both have great experience hosting Friends' Day Out and have found the joy of the Java Music Club extends beyond their weekly program.

Originally offered for people living with dementia, "The caregivers have so much fun, they want to stay, too" laughs Poll.

Each week a different theme is presented — "Animals," "Acceptance," "Changes," "Grandparents," "Making Amends" — with an accompanying photo and quotes. Stories are shared, followed by songs that match the theme. Most people sing along, but the program also includes a number of easily-played percussion instruments ranging from egg shakers to bells and chimes.

A key element is the talking stick, which is used during discussions to ensure only one person speaks at a time. With her long history in family communication, Poll says that those who think they're communicating often aren't, or are not well heard.

"It's never too late to teach those communication skills," she says. From past experience when families learned these tools "I saw kids and parents just light up." Elders are much the same.

"Once they get this talking stick in their hand, they feel empowered because they have the full attention of everyone," says Nichols.

“It gives them an ability to express themselves without having someone tell them ‘Oh you shouldn’t say that,’” echoes Poll. “It’s kind of magical when you see it happen.”

Since Poll took over the Friends’ Day Out in Elko, there have been a handful of dependable regulars, including a woman who survived a brain aneurysm who attends with her husband.

“She looks forward to the class on Friday, because it’s helped her have a mind shift and look on the positive side,” says Poll. “She’s now one of the most positive and happy people in the group. And she loves to play the chimes!”

And there are even more benefits.

“What I’ve seen in Java Music is that people who haven’t communicated much are coming out of their shell,” adds Poll. “They’re more willing to communicate from their heart.”

She recounts a story shared by one elder man, a care partner for his wife, who never liked the dog his son left at the house when he went off to college. Yet eventually the dog became one of his best friends.

“This whole program can really touch people and help them heal,” says Poll.

Meanwhile, both Poll and Nichols are aware of the benefits Java Music Club offers to them personally.

“It’s changed my life, this program,” says Nichols, “It’s made me want to serve.”

“When you’re helping others, you heal and help yourself,” says Poll.

### Bravo Zulu: Getting to a Job ‘Well Done’ in Dementia Care and Support

While care partner training in the context of dementia is becoming increasingly sensitive to the needs of different cultures or groups, it is still rare to find culturally-sensitive supports for former military personnel.

So when the Nevada Department of Veterans Services reached out to Dementia Friendly Nevada co-facilitator Dr. Jennifer Carson to create a training for its Veterans-in-Care initiative, she was all in — and all ears.

About half of America’s 20 million veterans are over 65 and, increasingly, support for these elder veterans—often living with disabilities—is provided by civilian healthcare providers who have little if any military cultural competence.

In order to build a training programs centered on veterans, it was first necessary to learn how caring for veterans — including veterans with dementia — is different than caring for civilian elders. For Carson, it turned out to be far more educational, and subtle, than she ever imagined.

Veterans were clearly a population with specific needs, and military service was central to their identities as elders. To do their jobs well, care partners of veterans would need to learn about their military past, and thus would need to ask questions.

What was their military experience? Which branch did they serve in? When and where did they serve? What their MOS (military occupational specialty)? How did military service affect their lives? Have they experienced post-traumatic stress?

“It’s not just enough to know this elder was a veteran,” says Carson. “We have to go deeper.”

Veterans are steeped in a culture that rewards overcoming physical and emotional pain are often less likely to cry, report discomfort, or ask for help. With that in mind, Carson worked with the Nevada Department of Veterans Services

office along with the Nevada State Veterans Home in Boulder City, NV, to create a training that would eventually support Nevada's more than 200,000 veterans.

The person- and relationship-centered training was given the moniker Bravo Zulu, originally a naval signal for "job well done!" Since its inception, the "Bravo Zulu" signal has been delivered via flag hoist or radio by senior United States Navy, Marine Corps, or Coast Guard troops to acknowledge outstanding performance.

The Bravo Zulu training itself furnishes learners with a deep understanding of veteran experiences and communication, including a segment on "Military Culture 101." Care partners learn that when someone is frightened, it's instinctive to offer human touch or a hug, however since veterans may misinterpret physical contact as threat—which can trigger trauma—uttering military phrases can be just as useful, such as "You're safe," "I'm not leaving you," "It's all clear," or "Stand down."

Central to the Bravo Zulu curriculum is the concept that in order to be a good care partner, it is essential to treat elders like VIPS: *Value* their personhood, relationships and culture; treat them as unique *Individuals*; look at the world from the *Perspective* of the person; and provide a positive and supportive *Social* environment.

So far, Carson has offered the free 12-hour relationship-based training six times. Recently, with support from a Geriatrics Workforce Enhancement Program (GWEP) grant via the Sanford Center on Aging at the University of Nevada, Reno, Carson is now working with Dementia Friendly Nevada's six community action groups to provide the training across the state.

"Through the GWEP, we can now offer Bravo Zulu four times a year for five years. We plan to alternate urban and rural offerings, providing community members, many of whom are family care partners, with free, comprehensive dementia education close to home," reports Carson.

In 2019, she trained members of Dementia Friendly Pahrump along with Age- and Dementia-Friendly Winnemucca. In 2020, she will provide the training in partnership with Dementia Friendly Elko, Dementia Friendly Washoe County, Dementia Friendly Southern Nevada Urban, and a second offering with Winnemucca.

Originally developed with Nevada veterans in mind, Bravo Zulu can also be customized for care partners of all elders, replacing veteran culture with other cultural considerations.

Carson is especially thankful for the opportunity to learn about an underserved population.

“I’ve learned so much through developing and teaching this course,” she says. “For 30 years I’ve been providing care and support to veterans without really understanding military culture. But now that I know better, I will do better.”



## Community is the Answer

A Weekly Blog By Dementia Friendly Nevada

### Dementia Friendly Nevada: Fostering Inclusion across the State

Dementia Friendly America (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 care partners. The DFA movement began in September 2015 following the White House Conference on Aging and is based upon Minnesota's statewide successful initiative, ACT on Alzheimer's. As momentum grew and the winds blew west, something intriguing happened. Nevada's network of aging services professionals insisted it become a collaborative effort throughout the state.

Nevada is aging faster than any other in the continental United States, according to a 2018 comparison by U.S. News & World Report. (Only Alaska is aging faster.) Officials estimate that nearly 50,000 of Nevada citizens are living with dementia, and that number is projected to increase 36% over the next five years.

Nevada's dementia-friendly movement began when aging services organizations knitted together a network of interested advocates. It included the state's Aging and Disability Services Division (ADSD), Nevada's two Alzheimer's Association chapters, Nevada AARP, the Cleveland Clinic Lou Ruvo Center for Brain Health, Nevada Rural RSVP, and the Sanford Center on Aging. Also invited were other members of the aging services network, including: University of Nevada, Reno researchers; faith-based organizations; law enforcement officials; first responders; and members of the business community.

A preliminary meeting was held in 2016 connecting participants north and south with a video link between Las Vegas and capitol Carson City, which welcomed partners from nearby Reno.

“It was a very good cross-section of people,” says Mary Liveratti, who with a 30-year history in Nevada aging services later became Chair of the Dementia Friendly Nevada Statewide Workgroup.

Of the many issues first discussed, one was whether to split Nevada into north and south, but that was quickly overruled to ensure the state worked holistically. Central to the meeting was a review of a dementia grant available from the federal Administration for Community Living — critical seed funds needed to launch Nevada’s efforts.

Over the next five months a group of five committed grant writers led by ADSD’s Jeff Doucet worked tirelessly to submit a solid proposal, and a few months later, ADSD was awarded the ACL grant.

Dementia Friendly Nevada (DFNV) used the \$1.2 million, three-year grant money to initially fund four community action groups, or CAGs: Dementia Friendly Washoe County; Dementia Friendly Southern Nevada Urban (i.e., Clark County); Age- and Dementia-Friendly Winnemucca; and Dementia Friendly Elko. In 2017, two more CAGs joined the statewide effort, Dementia Friendly Pahrump and the Pyramid Lake Paiute Tribe’s Pesa Soaname Advisory Group.

Each CAG received seed money of \$10,000. Upon completion of Dementia Community Assessment, which illuminated strengths, gaps and top priorities for their area, each CAG used their funding to mobile community-driven goals.

“The needs in Washoe County are very different than those in Las Vegas, Winnemucca or Elko,” says Dr. Jennifer Carson, who joined DFNV as its lead facilitator, directly supporting four of Nevada’s six CAGs. Director of the Dementia Engagement, Education and Research Program at the University of Nevada, Reno, Carson traveled throughout the state helping the CAG’s get off the ground by offering guidance and resources.

Meanwhile, the DFNV Statewide Workgroup continued to meet and eventually created a set of “mobilizing beliefs” that are among the most progressive in the country.

Committed to a ‘nothing about us without us’ approach, “All community action groups are committed to including people living with dementia as our partners in decision making. They are the true experts on the lived experience of dementia,” says Carson.

Since DFNV's inception there have been a steady stream of successes. For example, Washoe County has created a weekly dementia-friendly partner dance class and monthly peer support opportunity. Southern Nevada Urban has developed sector-specific Community Awareness Trainings and provided hundreds of cognitive screens in the community. Winnemucca has fused its age-friendly and dementia-friendly efforts into a single powerful initiative with dozens of impactful goals. The Pesa Soomame Advisory Group hosted a landmark Tribal Summit on Brain Health and Dementia targeting American Indians throughout Nevada. Pahrump hosted a community screening of a research-based drama about dementia for 65 community members and provided a 10-week care partner education series. Elko launched a weekly, volunteer-driven peer support and respite program called Friend's Day Out. And these are just a few examples.

Five of the six CAG's embraced Dementia Friends awareness training, while the sixth, Dementia Friendly Southern Nevada Urban, created a unique program targeting specific sectors of community. Champions have been trained in each community to deliver the programs.

In other words, each community has created unique local dementia programs while receiving statewide support and inspiration from one another.

"The communities have to be the drivers," says Carson. "It's not outsiders coming in with their ideas for transformation. Instead, local community members know what works best in their community."

DFNV's partners remain deeply appreciative of the state's collaborative nature.

"Dementia Friendly Nevada has been a joy because people north and south, statewide, have been willing to share ideas and resources," says Liveratti.

One of many examples is how Dementia Friendly Southern Nevada Urban used some of their funding not only to create its own website, but included all the CAGs in the process, under a Dementia Friendly Nevada umbrella. Now each CAG has its own webpage.

"Being able to partner with colleagues from around our state has made advocating for change a more inspiring endeavor," says LeeAnn Mandarino, who co-facilitates Dementia Friendly Southern Urban, headquartered in Las Vegas. "Collaborating with people who share the same mission and values strengthens our work and effectiveness. We share the same government and the same laws



and regulations, so working together to advocate for policies has helped set a solid foundation for creating a state that takes care of one of its most vulnerable populations – individuals with dementia.”

Carson is further complimentary of the CAG co-facilitators, with special appreciation for DFNV Statewide Workgroup Chair, Liveratti.

“She’s a collaborative leader who knows people in every community and resources available across the state,” says Carson. “She’s definitely foundational to our success.”

Carson also credits ADSD for their leadership role in convening this successful statewide initiative.

“Our partners at ADSD live the value of inclusion.”



## Community is the Answer

A Weekly Blog By Dementia Friendly Nevada

### You Can Never Have Too Many (Dementia) Friends

When Dementia Friendly Nevada launched in 2016, each of its Community Action Groups made local dementia awareness a priority. The program of choice? Dementia Friends.

Originally developed in the UK, and licensed by Dementia Friends USA, the Dementia Friends program aims to help community members learn what it's like to live with dementia and how all community members can play a supportive role. The program has now welcomed 61,000 Dementia Friends across the country.

From 2017-2019, Dementia Friendly Nevada has trained almost 700 new Dementia Friends in the state, including 74 trainers known as Dementia Friends Champions.

The benefits of Dementia Friends information sessions are enormous and spread exponentially. The 60- to 90-minute session helps educate citizens on recognizing dementia in the community, how to talk to people living with dementia, and ways to support them.

"With a little bit of education, people will walk *toward* people living with dementia instead of walk away," says Dr. Jennifer Caron, co-facilitator for Dementia Friendly Nevada. Carson is also the state's official Master Champion for the program and is licensed to train all of its Dementia Friends Champions.

Because Dementia Friends are more aware of dementia in their community, they are also able to educate others and spread the word to overcome rampant misinformation and stigma. Besides being more patient with family, friends and neighbors living with dementia, Dementia Friends are more likely to become involved with dementia-friendly efforts in their communities.

Washoe County currently leads Nevada's Dementia Friends education efforts. Members of Dementia Friendly Washoe County host information sessions for a wide variety of audiences, including monthly sessions at the Sparks library

and Osher Lifelong Learning Institute, as well as sessions for local aging services professionals, students from the University of Nevada, Reno, and participants of the weekly Dementia Friendly Nature Walks who are living with dementia.

“Just because a person has been diagnosed, doesn’t mean they know a lot about dementia. So they’re excited to learn this new information about a condition they’re living with,” says Carson.

In Southern Nevada, Dementia Friendly Pahrump has trained dozens of Dementia Friends, including 23 Search and Rescue volunteers who are often the first contact for people living with dementia who have gotten lost. Others trained include volunteers for the Nevada Rural Counties Retired & Senior Volunteer Program (RSVP), as well as the co-directors at the local senior center.

“Everyone I have trained has been receptive, interested and surprised at some of the information,” says Jan Lindsay, former co-facilitator of Dementia Friendly Pahrump.

In rural Winnemucca, 150 Dementia Friends have been trained, including care partners, social workers, and school counselors. Training sessions have also been held for law enforcement personnel and other first responders.

In Elko, a Dementia Friends information is offered monthly at the Terrace at Ruby View, a local “Senior and Active Lifestyle Center.” It has also been offered at a local retirement community “so residents can better help their neighbors,” says Carson. ROTC cadets who often provide public service for older adults have also received the training.

Dementia Friends has additionally been provided to members of the Pyramid Lake Paiute Tribe, which participates in Dementia Friendly Nevada as the Pesa Soaname Advisory Group (“pesa sooname” is a Northern Paiute phrase that translates to “good think”). Dementia Friends USA has worked closely with Dementia Friendly Minnesota to adapt the training for Native groups by using culturally appropriate metaphors.

Of the six community action groups in Dementia Friendly Nevada, only Dementia Friendly Southern Nevada Urban has opted for other community awareness education, constructing a sector-specific program of their own.

Carson says that while the Dementia Friends training lasts only an hour, even the smallest amount of education is immensely helpful.

“There’s a real lack of understanding about dementia, so a one-hour session with empowering content can really make a big difference.” Then she ponders, “Imagine, there are currently 47,000 people living with dementia in Nevada. What if we had an equal number of Dementia Friends? That’s something to work toward.”

### Birth of Pahrump's Dementia Film Series

For some it was their first time talking about it. For others, watching the movie was a welcome catharsis. For others still, it was a painful but important way to spend an hour.

That was the reaction to *Cracked: New Light on Dementia*, the filmed version of a play that screened to a crowd of 65 in rural Pahrump, Nevada, in May of 2019.

The title “Cracked” springs from lyrics by famed musician Leonard Cohen — “There is a crack in everything / That’s how the light gets in” — and was created by Collective Disruption: a team of Canadian performance artists and researchers. The team’s website declares: “The families struggle to see beyond the disease until they come to see that each of us has cracks as part of being human.”

While those in the aging field are intimately familiar with Alzheimer’s disease and other forms of dementia, to the general public that world is largely a mystery. Sponsored by Dementia Friendly Pahrump – one of six community action groups of Dementia Friendly Nevada – the film produced a range of emotional reactions from an audience of primarily family care partners, from validation and hope to sadness and, for some, remorse. One person left in tears.

“It was too much too soon for some people,” admits Jan Lindsay, who was then co-chair of Dementia Friendly Pahrump.

Yet most attendees clearly welcomed the chance to discuss the often taboo topic. Some arrived knowing absolutely nothing about dementia. One woman said she finally understood her husband’s struggle for the past three years. Some were confused by the film, which shifts between current reality and memories of the past, portraying the time disorientation experienced by many people living with dementia. In short, the drama was an embodied experience.

Following the film, Dr. Jennifer Carson, co-facilitator of Dementia Friendly Pahrump, and Barbara Payne, Dementia Friendly Pahrump member and volunteer family support group facilitator for the Alzheimer's Association, moderated a Q&A. The pair skillfully blended their personal observations and experiences with questions from the audience to create a free-flowing discussion that created an intimate environment around a difficult topic.

A special guest preceding the screening was former state senator Valerie Wiener, who served in the Nevada legislature from 1996 through 2012. Then serving as chair of Nevada's Task Force on Alzheimer's Disease (TFAD), Senator Wiener described the challenges of dementia, her work on the task force, and provided an overview of the 2019 Nevada State Plan for Alzheimer's Disease and Dementia.

After the screening, at the next Dementia Friendly Pahrump meeting, Jan suggested that in 2020 the group sponsor a quarterly film festival on aging and dementia, pointing out that film and video can often do what the written word cannot. Jan says feedback after the screening was positive and that she had spoken to many residents who wanted to see the film a second time. The film was illuminating for all, she adds, summarizing the event this way. "Get out there and get the information you need, so you have something to work with."

### Care Partnering in Cowboy Country

In many ways, Pahrump remains an 'Old West' town where cowboys walk the streets with guns slung around their waists in the "open carry" mecca of Nevada. Located an hour's drive west of Las Vegas, the town of 35,000 still embraces the spirit of independence where citizens are expected to pull themselves up by their own bootstraps.

It was into this culture of independence that Dementia Friendly Pahrump (DFP) decided it had to offer something the community desperately needed: a care partner support class for families navigating the challenges of dementia.

DFP members chose the 10-week *CarePro: Care Partners Reaching Out* education course because of its comprehensive education and support program. Two enthusiastic members from the DFP Community Action Group volunteered to teach the course in partnership with the Alzheimer's Association, and worked in tandem with the Association's Desert Southwest chapter for a spring 2017 launch.

But wildly independent Pahrump would not make it easy.

Despite a local newspaper, TV station, and radio outlet, the citizens of Pahrump share a familiar lament.

"For some reason it's just really hard to get news to people," says Jan Lindsay, who served as co-facilitator of DFP at that time.

Tonya Brum, one of the two CarePro volunteer instructors, agrees. "It doesn't matter what is out there, how many outlets are used to notify the community, the one thing I always hear is 'I didn't know about this.'"

Potentially as a result of these challenges, the need for aging support in Pahrump remains high.

"We're a town half full of seniors who need help," says Jan.

And so to market the CarePro caregiver support course, DFP members used a divide-and-conquer, in-person outreach strategy to over 23 organizations

throughout greater Nye County, assigning a volunteer to follow up with each one, and tallied the results on a spreadsheet.

“The Community Action Group worked really hard to spread the word about CarePro,” says Jan. “It was a significant outreach effort.”

Six family care partners completed the ten-week course, which included five in-person classes and five telephone coaching sessions on alternate weeks.

Co-instructor Karen Taylor says that hearing similar stories from others was extremely helpful to participants and “brought assurance that they are not on this journey alone, and need not take any of the sometimes painful outward expressions of people living with dementia personally.”

Since the course completion, Tonya has run into two of the women who took the class.

“Both commented on how much they got out of our class and how much they each enjoyed the interaction with the rest of the class,” she says. “Both are using the techniques we shared.”

Besides offering telephone support during alternate weeks, Irma Prettenhofer, manager of programs and services for the Alzheimer’s Association Desert Southwest, also made check-in calls each week and today continues to follow up with the participants. Tragically, two of the class participants lost their loved one soon after the course finished.

“I referred them to hospice and helped them through the difficult journey of letting go,” says Irma.

Karen says that after the emotional intimacy of sharing caregiving stories, many of the class participants are still in touch.

“CarePro gave them a common bond that far outlasted the ten-week session.” DFP is glad they worked so hard to bring this opportunity to town.



### If 'Thelma and Louise' Were Older and Wiser

About an hour's drive west of Las Vegas sits the rural town of Pahrump, which translated from its Native roots mean "water from rock." With extensive roots in indigenous history, the town is now predominantly white with an aging populous. In fact, Nye County is the oldest and largest county in the state of Nevada.

Jan Lindsay and Barbara Payne, both full-time volunteers in their 'retirement', joined Dementia Friendly Pahrump in 2017 when it became one of two Community Action Groups in southern Nevada focused on become more respectful, educated, supportive, and inclusive of people living with dementia and their family care partners.

Both women have backgrounds in aging services — Jan as a field representative for Nevada Rural Counties RSVP (Retired and Senior Volunteer Program), and Barbara as the volunteer facilitator for the local Alzheimer's Association support group. Barbara previously attended the same group when her husband, now deceased, was diagnosed with Alzheimer's disease in 2011.

So when Jan asked Barbara to join her for the 400-mile trek north to Pyramid Lake to attend the landmark 2019 Nevada Tribal Summit on Brain Health and Dementia, Payne was all in. A road trip was the ideal break both women needed.

It was also a perfect fit.

Jan no longer flew, and Barbara had a new car she wanted to break in. With her history of riding motorcycles and driving pilot cars for oversized truck loads, Barbara had always enjoyed watching the road unfurl beneath her wheels. Jan took charge of lodging and logistics. And somewhere in the back of their minds the two envisioned a modern day Thelma and Louise adventure.

Most important, both women were intrigued with the summit that lay ahead: a gathering of tribal members from across the state with a focus on discussing the topics of brain health and dementia within a Native context.

Jan is part Native American and has spent many hours in sweat lodges. She has also studied with the late Native American activist, author, and writer Dennis Banks, co-founder of the American Indian Movement.

As the trip began, the two talked about their families, work, aging, and dementia, sharing both stories and sorrows.

Barbara discussed her complaints with the healthcare system, including the doctor who once told her during an appointment “Hurry up, you only have two more minutes!” Jan described the local powwow she recently attended and the difficulty she has faced in being accepted as a part of the Native community when she does not outwardly look Native.

Once the two adventurers arrived at the summit, which was hosted by the Pyramid Lake Paiute Tribe’s Pesa Soomame Advisory Group (part of Dementia Friendly Nevada, and called Pesa Soomame for “good think”), Jan suddenly felt at home, reconnecting with her Cree roots in Canada.

Her favorite experience during the daylong event? The people.

“There’s a gentleness in Native towns I don’t find in many communities,” she says. In particular, she enjoyed the opening and closing traditional songs. “It just felt very comfortable.”

Barbara had an equally transcendent experience, although from a non-Native perspective — perhaps because as a child her father was a Boy Scout executive and had instilled in her a deep respect for Native customs and cultures.

Barbara especially loved that the event centered on elders, with each speaker referencing the importance of elders in Native communities. She recalls being recruited for lunch service: “Get some gloves and make a plate and serve it to the elders,” she was instructed.

The summit opened Barbara’s eyes to the true need for eldership.

“Respecting what an elder is, is something that really should be instilled in our population,” she says. “There’s such a wealth of information in the elder population that gets ignored. And that’s a shame.”

Barbara recalls in particular the poetic description of brain health offered by one of the summit speakers.

“Your heart is like the start of a free flowing river,” she says. “Veins and arteries that take blood away from and to the heart are like mini connected small streams that flow all through the body including the brain, feeding it with oxygen and energy. You have to work to keep the streams flowing through your body from becoming clogged, and the heart from being hurt.”

The return drive was more challenging than the trip north because the two women fought for rooms with travelers returning from the famed Burning Man festival. Still, they talked extensively and animatedly about all the new information they had learned, including the importance of elders in Native culture, and their sadness at the lack of respect for elders in mainstream society.

Did the two women think of Thelma and Louise during their trip?

Jan loved the film, especially that two women had the courage to “get out there and do what they wanted to do.” Barbara most remembers the moment that the two women threw their arms in the air and screamed in joy.

Yet the most important part of their adventure was learning more about aging, dementia, brain health, and one another.

“I got to know her a whole lot better,” says Barbara.

Barbara was so moved by the experience — especially the respect for Native elders — that when she returned to southern Nevada and gave a report on the summit to Dementia Friendly Southern Nevada Urban (another Dementia Friendly Nevada Community Action Group), she began with the Northern Paiute phrase for good day: “Pesa Tabeno.”

### A Collaboration to Provide Cognitive Screenings

It was exactly how change is supposed to happen.

During a 2018 meeting of Dementia Friendly Southern Nevada Urban (DFSNU) in Las Vegas, stakeholders discussed ways of reaching into the community to perform basic memory screenings. All agreed it was a great idea and an important step in early detection.

The problem was a common one. Too many older adults at risk of dementia lived in underserved communities or had difficulties accessing a clinician.

Attending the meeting was Susan Farris, a program manager in the Education Department at the Cleveland Clinic Lou Ruvo Center for Brain Health. She and her colleagues knew that if patients couldn't get to the doctor's office, healthcare professionals would have to go where the patients were.

When Farris noticed two professors from a nearby nursing school at the monthly DDSNU meeting, she pulled them aside and asked them a question.

"Would you like us to train your nursing students to do basic cognitive screenings?" she asked. The duo, from the College of Southern Nevada, responded with an enthusiastic "Yes."

And so began a fruitful collaboration that eventually welcomed a second nursing school — the University of Nevada, Las Vegas — that has sent nursing students to conduct memory screenings throughout southern Nevada, typically inside senior centers and faith-based communities.

Farris says the basic screenings are intended to offer general indicators like that at a health fair — not make a diagnosis. Based on the results, an onsite professional counselor is available at each event, with additional information from organizations specializing in aging services and dementia, including comprehensive cognitive assessment.

“The goal of this is to bring education and awareness and start a conversation,” says Farris, who oversees the clinic’s student and trainee education. “A lot of people have never had any sort of screening for their cognition.”

With the collaboration between DFSNU, the Cleveland Clinic and the two nursing schools, the screenings are proving an effective way of reaching out to older adults with limited access to healthcare. In 2018-2019, nurses at 10 events screened nearly 400 people.

The process is a simple one.

First, the nursing students are trained by Cleveland Clinic staff to use the Brief Alzheimer Screen (BAS). It includes a series of basic questions that include memorizing and repeating three words — “apple, table, penny” — spelling “world” backwards, and naming as many animals as possible in 30 seconds.

After the screening, scores are assessed onsite by Cleveland Clinic staff — typically Farris and two others. For those with questions who request a consultation — which happens for those scoring both low and high — they can meet immediately with a Cleveland Clinic faculty member for post-screening counseling. (Scores of 24 and above are considered “normal,” while scores of 23 and under suggest further testing from a health professional.)

Afterwards, volunteers from DFSNU are onsite to answer additional questions: the Cleveland Clinic’s Healthy Brains Initiative offers information on ways to optimize brain health; the local chapter of the Alzheimer’s Association answers questions about the disease and outlines its programs to support people living with dementia and their care partners; and Nevada Senior Services, which offers details on a wide array of services including housing, transportation and respite care.

Farris emphasizes that organizers want to make sure any concerns are addressed immediately.

“We didn’t want anyone to score below 24 and just leave,” she says. Instead, organizers hope citizens will be encouraged to seek further information: “You know, it might be good for me to get tested.”

So far, the highest turnout has been at a Catholic church immediately following mass. A total of 83 parishioners were screened by 16 nursing students.

While initial funding for the screenings has now ended, Farris says the screenings will continue nevertheless because of continued need.

“We know that not everyone can come to us, so our goal is to get out in the community,” she says. “We really want to get out there in locations that are underrepresented or underserved.” And through the power of collaboration, this important service will continue.

### Online Dementia Training for First Responders

Aging specialists throughout Nevada were excited when the state recently mandated all first responders receive behavioral health training. This has proven particularly important since elders living with certain types of dementia may mistakenly be misdiagnosed as psychotic, drunk or — worst of all — be accused of criminal behavior.

Responding to this mandate, Dementia Friendly Southern Nevada Urban, based in Las Vegas, has produced behavioral health training that targets first responders such as police, fire, and emergency medical personnel. The free training is available to anyone online at [DementiaFirstResponseNV.com](http://DementiaFirstResponseNV.com). Recipients can also collect four continuing education credits.

“Our goal is to get them to understand how to diagnose, refer out, and treat if needed,” says LeeAnn Mandarin, co-facilitator for Dementia Friendly Southern Nevada Urban. “We provide needed knowledge and resources.” Mandarin, Program Manager for education, outreach, and advocacy at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas, offers an example of the kind of confusion that can occur. “Imagine a man in his fifties,” she says, “whose life has suddenly fallen apart. He may lose job after job and even become homeless. His behavior may be erratic — even aggressive — and he may be arrested for the first time in his life. Yet this criminal behavior may actually be frontotemporal dementia. For many people with this form of dementia, so-called ‘criminal behavior’ is the first presentation of their brain disease.”

Another type of dementia can manifest as hallucinations. First response personnel may react to this as a psychotic episode without considering that Lewy Body dementia (LBD) may be the cause. Medicating someone with LBD with anti-psychotic medications can cause a severe reaction, temporary coma, or even death.

“When we’re able to train first responders, they can then offer the correct intervention,” says Kate Ingalsby, Mandarino’s fellow co-facilitator of Dementia Friendly Southern Nevada Urban and regional director of the Alzheimer’s Association, Desert Southwest Chapter, Southern Nevada region.

Because of the new law requiring behavioral health training, local first responders are now reaching out to Dementia Friendly Nevada, the Alzheimer’s Association, and the Lou Ruvo Center to receive the needed training. Ingalsby says that the training is particularly helpful in rural areas where access to education is limited. The first responder training developed by Dementia Friendly Southern Nevada Urban provides easy online access.

“It allows for flexibility in first responders’ busy work schedules and allows organizations additional time to spend helping clients and communities face the challenges dementia can present,” says Ingalsby.” The online training utilizes real life scenarios that help first responders recognize the signs of dementia they may encounter in any given day.”

The response to the online first responder training has been overwhelmingly positive, says Ingalsby, who believes that such a training is long overdue. “Behavioral health, including dementia, is just beginning to get the attention it deserves.”





## Community is the Answer

A Weekly Blog By Dementia Friendly Nevada

### Raising Awareness in Las Vegas

Las Vegas is more than just a tourist town; it's home to everyday people who experience the same joys and sorrows as those in any American city, and that includes aging and dementia.

When Las Vegas stakeholders launched Dementia Friendly Southern Nevada Urban (DFSNU) in 2016, community surveys revealed dementia awareness was a top priority.

"We saw an education program that North Carolina was doing, and we knew about the *Dementia Friends USA* program, but we decided to create our own program, one we thought would be a good fit for our community," says Susan Hirsch, a member of the DFSNU Community Action Group and a leader in outreach efforts.

A customized Las Vegas training program had to address a broad range of needs across multiple sectors. The goal was to offer information to raise awareness about dementia for businesses, faith-based organization, social services agencies, and community groups. In fact, the group hoped to reach all community members that serve and interact with persons with dementia. It also had to be mindful of the needs of tourists as Las Vegas welcomes 40 million tourists annually, including people living with dementia.

The resulting Community Awareness Training, or CAT, was designed with three initial sectors in mind, starting with business.

"In many ways our business sector has been the most challenging for us," says Hirsch, a program manager at the Cleveland Clinic Lou Ruvo Center for Brain Health. Why? Because there was so much to explain. Most people living with dementia live in the community and may already be customers of local businesses. Dementia training can help businesses better serve existing

customers, by enhancing their customer service practices and also attracting new customers, helping to bring value to a business as well as the community.

Next, the group created training for faith-based communities, basing the training on the template they created for businesses and swapping out examples and scenarios. And in this arena committed to service, they found traction.

Hirsch recalls an 18-member brainstorming session at a church that included suggestions for “prayer buddies” along with a variety of other great ideas. “It wasn’t just awareness,” recalls Hirsch. “It was like an epiphany.”

The third and final sector targeted social service and community organizations ranging from healthcare to housing, parks and recreation, the airport, and beyond. “We are beginning to roll this out now that we have the right tools to do so,” says Hirsch.

Creating templates for each sector proved the most time-consuming aspect of the program development, and highlighted the most effective tool of all. “When we do our training we tell lots of stories,” says Hirsch. “It’s through stories people can relate to the training.”

Hirsch tells of one couple who patronized a local restaurant for many years. Although the wife’s dementia had progressed to the point where she could no longer order for herself, the server made sure to speak directly to her, saying “That’s my favorite, too.”

Moreover, the restaurant did not have a family bathroom. So, if necessary, staff members would stand outside of one of the restrooms to ensure privacy for the couple.

“That made them feel like valued customers,” smiles Hirsch. “And that was always reflected in the tip.”

For another example, in the faith-based sector, a church may be interested in understanding ways to serve congregants with dementia and also recognize that attending services offers important respite for care partners as well.

“That’s the goal of dementia-friendly initiatives,” says Hirsch. “To help individuals and entities adapt the principles in ways that best serves their needs.”

The objectives of CAT—which is offered for free—are extensive: to provide a better understanding of dementia, to offer improved communication (such as approaching a person from the front, maintaining eye contact, and asking simple yes or no questions), to improve the physical environment (such as offering some

place for a person to sit to rest), and to recognize and support care partners. In sum, to make the Las Vegas area more dementia-friendly, one presentation at a time.

From the beginning, recalls Hirsch, they knew their best advocates would be people whose lives had been touched by dementia.

“We are starting to have referrals from people who attended awareness presentations and help us make connections with others.”

Hirsch lists a series of businesses and organizations who have participated in the training, from casinos to housing to entertainment.

“Part of the awareness is creating an understanding of why dementia training would be helpful,” says Hirsch. “We’re talking about an illness so feared people don’t even want to mention the word.”

Hirsch adds that Las Vegas is just getting started.

“Almost everybody can do something that makes their community more dementia-friendly.”

### Dance with Me

When he looked at the library's flyer announcing an outreach event for Dementia Friendly Washoe County, it piqued his curiosity. He knew a lot about aging since he'd covered it for seven years for the California Health Report – one of the few reporters nationally writing about aging full time — so Matt Perry wanted to know more.

The next day at the dance studio he attended, The Ballroom of Reno, he was standing next to one of its managers and told her about the dementia-friendly event. "What do you think of creating a dementia-friendly dance class here?" he asked. During his years writing about aging he considered dancing the best intervention to stop, delay, or perhaps even prevent dementia. It had everything elders needed in a single activity: physical movement, mental strategy, community connection, and musical immersion – which sparks several different parts of the brain. "Let's do it," she replied without hesitation.

At the outreach event, Perry discovered that in less than a week the monthly Dementia Friendly Washoe County (DFWC) meeting was being held. So he and two representatives from The Ballroom attended to present the dementia-friendly dance class idea. Immediately, DFWC partnered with the enthusiastic group and provided seed money to launch the class.

With help from the Alzheimer's Association, three couples were identified, two test classes were organized, and the first class was held just two months after the idea was conceived. It was a great success, and soon the dancers were beginning to see the benefits.

"She's begun to remember things from the past that were beyond her reach before dancing," says Mike Grimes of his wife Helen, a former dance teacher for many decades who now lives with Alzheimer's disease. "This class has been wonderful for us both."

Ron Brown, who is experiencing the beginnings of Alzheimer's disease, says he has two left feet. But he and wife Donna have discovered how much they enjoy partner dancing. In fact, after taking classes for a month, one evening at home when the power was out, they turned on battery-powered candles and a battery-powered radio. "We listened for a few minutes and Ron suggested we dance," says Donna. "Before taking dance class that would have been the last thing he would have said. We danced close and held onto each other after a song was over and waited for the next song." And she adds that dancing has spilled over onto other parts of their lives. "A day doesn't go by that we don't pass each other with a little smile, a little touch for each other, or a little kiss."

Research shows that partner dancing is a highly effective intervention for elders facing physical and cognitive changes. It can reduce joint pain, improve mental clarity, and secure emotional bonds. It's most beneficial when done three or four times per week, so repetition is key.

In 2020, The Ballroom, in partnership with DFWC, has ambitious expansion plans so that more elders can participate and hopefully dance several times per week to obtain maximum benefits. The Ballroom plans to offer the class six times per week by April, and 12 times per week by the end of the year.

The popular class has quickly gained both momentum and notoriety. It was recently featured on the local TV show, *Aging and Awesome*:

<https://dementiafriendlynevada.org/communities/washoe/news-in-washoe/>

"Everyone has just improved so dramatically," says lead dance instructor Desiree Reid. "And not just physically but mentally as well. You can see the improvement with everyone week to week."

"This is the most wonderful collaboration I've ever been involved with," says Perry. "Between The Ballroom and Dementia Friendly Washoe County, we've been able to move quickly to create something that everyone loves and really makes a difference for those with dementia and their care partners."

Donna Brown makes it even more personal. "Dance has been a great addition to our life!"



## Community is the Answer

A Weekly Blog By Dementia Friendly Nevada

### Dementia-Friendly Nature Walks in Reno

For more than five years, in Reno's most popular city park, Dementia-Friendly Nature Walks has offered weekly walks for elders that blend physical exercise with an expanded appreciation of nature and an opportunity for peer support.

Formerly known as the Idlewild Health Walks, the walks were initially launched as a collaboration between the Sanford Center for Aging (at the University of Nevada, Reno) and the Truckee Meadows Parks Foundation. This year, the two organizations sought a new partner – Dementia Friendly Washoe County – in an effort to strategically reimagine the walks and ensure that they are accessible to *all* elders, including people living with dementia.

This new partnership also brought a new name to the program, highlighting its commitment to inclusivity: Dementia Friendly Nature Walks.

Each Tuesday morning, about 10 older adults and their care partners participate in the walks, which are led and supported by volunteers from all three organizations and boast a volunteer-to-participant ratio of nearly 1-to-1. The half-to full-mile walks have two different routes: either alongside the Truckee River or past the ponds inside the park.

Besides the walks themselves, trained naturalists from the Truckee Meadows Parks Foundation borrow from their study of phenology to discuss the life cycles of plants and animals and how both are influenced by the changing seasons.

"They're very knowledgeable and point things out to us," says Pauline Morales, whose doctor suggested the walks after she was diagnosed with early-stage Alzheimer's disease. Morales especially enjoys the time spent with others outdoors: "Just being around other people and walking and meeting all the people I walk with."

“She absolutely loves it,” says her daughter and care partner Lori Burdick. “It’s not something she would do on her own.”

Carter Norris, an AmeriCorps VISTA volunteer at the Sanford Center for Aging, says the walks provide not only exercise and community but a break from often predictable schedules.

“People get really different things out of the walk,” says Norris, the center’s Volunteer and Community Partnerships Coordinator

The walks started in 2014 when Jennifer Baker from the Sanford Center for Aging discovered *Dementia Adventures* in the United Kingdom — a program in which people living with dementia can retain a sense of adventure by connecting with the outdoors. She approached the Truckee Meadows Park Foundation with a similar idea, and the walks were born.

Norris says the walks have evolved over time and today emphasize both accessibility and socialization. There are two wheelchairs available for each walk, and walking groups of friends tend to form readily. “We’re trying to encourage conversation,” says Norris.

The walks have proven helpful to everyone involved, including the volunteers, who have learned more about aging and dementia and each have attended the Dementia Friends information session, provided by Dementia Friendly Washoe County.

Without any previous experience in aging, Norris admits she was at first nervous about working with elders living with dementia. Today, the walks are often the high point of her week; spending time in nature with elders. “I love their company so much.”

### The Open Door Café: A Gathering Place for Peer Support

It's no secret that people living with dementia and their care partners often experience frustration and social isolation. Clearly, the need for human connection remains powerful after a dementia diagnosis. So, when Reno-based Dementia Friendly Washoe County (DFWC) first asked its community what it needed to ease the challenges of dementia, peer support was high on the list. People living with dementia desperately wanted an outlet, a place to talk. In fact, they wanted to talk with others in the same situation instead of talking to aging services professionals. They knew where to find information about dementia; now, they craved friendship and camaraderie.

And so a year after the creation of DFWC, the volunteer-driven organization launched the Open Door Café in downtown Reno. Held monthly for 90 minutes, the "café" is actually a gathering place where people living with dementia and their care partners can talk about their experiences with dementia... or not.

"That's what's so powerful about the Open Door Café," says Casey Acklin, who organizes the event as an AmeriCorps VISTA volunteer for DFWC. "That support and understanding is there, but if they don't want to talk about dementia they don't have to. It can be support or friendship. If they want to talk about swimming in the summer up at Lake Tahoe, they can do that."

"It's a place where I can feel normal and share experiences with others with similar conditions — and we can laugh at ourselves," says Terry Bostick. "We can feel more normal and accepted. We don't have to be as much on our guard about not repeating ourselves."

The café concept is loosely based on "memory cafés" that originated in Chicago and that offered events and activities — a place to go for people living with dementia. In Reno, the Peer Support Action Team, a subcommittee of DFWC, considered the template set by memory cafés, which begins with planned



activities for each gathering. But local attendees actually wanted something different, asking for more *unstructured* time. And so instead of a planned set of activities, the Open Door Café begins with what Acklin calls an “icebreaker” question to get people talking.

“What we’ve been trying to do with these icebreaker questions is make them simple but meaningful,” he says. Recent icebreaker topics included the importance of community, gratitude and simple pleasures. The icebreaker typically lasts for 15-20 minutes; after that conversations are more freeform. “Sometimes they continue on the theme of the icebreaker and sometimes they don’t,” says Acklin. After the icebreaker, smaller groups often form spontaneously.

Typically about 12 people attend the Open Door Café each month — light snacks are provided by a local restaurant — with four or five couples considered “regulars.” Organizers hope to double that participation in the coming year.

Acklin says while there are local support groups for care partners, the Open Door Café fills a desperate need for people living with dementia. “I like being able to connect with my friends,” says Linda Stacyr. “Everyone shows up at the same time, which makes it easier.”

“They don’t say it directly, but it’s clear people feel like they’ve lost community or companionship in their lives,” says Acklin. “And over and over and over again participants say how much they appreciate having a real community to come to once a month.”

“The people there are so nice and kind and understanding,” says Bostick. “That makes us feel normal and accepted.”

Acklin asserts that the success of the program depends largely on the involvement of people living with dementia and their care partners. “The majority of the reason it’s so successful is that it’s been designed alongside people living with dementia,” says Acklin. “It’s not a formulaic implementation of an interventionist program. It’s a program *by* people living with dementia *for* people living with dementia and their care partners.”



## Community is the Answer

A Weekly Blog By Dementia Friendly Nevada

### A Landmark Dementia Event for Nevada Tribes

Understanding of dementia in the United States is just beginning to blossom, yet within Native communities it's almost nonexistent. So when Pyramid Lake Paiute tribal member Carla Eben stumbled upon a dementia training course in 2017, she realized virtually nobody in her community knew about dementia's causes, its challenges, and what it means to have a dementia-inclusive community. So she took it upon herself to be a lightning rod, not just for her tribe but for tribal communities throughout Nevada.

Toward that end, Eben teamed up with Dr. Jennifer Carson, Director of the Dementia Engagement, Education, and Research Program at the University of Nevada, Reno, to launch a Community Action Group as part of Dementia Friendly Nevada. They called their group the Pesa Soaname Advisory Group; "pesa sooname" is Northern Paiute for "good think."

Within two years, the Pesa Soaname Advisory Group became the host of a landmark event in the United States: the nation's first Tribal Summit on Brain Health and Dementia, held at Pyramid Lake just an hour north of Reno. The daylong summit welcomed 114 participants from 14 tribes who heard presentations by national dementia experts, shared stories within wisdom circles, and ate a heart-healthy, brain-healthy lunch.

The summit joined Pesa Soaname's dementia-friendly efforts with the rest of Nevada's tribal communities, so during its planning stages, Carson asked Eben how to best honor tribal traditions. Eben described an elder abuse conference she'd attended in Colorado which they could use as a template. "She was really excited that we'd follow basic native protocol," says Eben. "She kept telling me 'This is your event - how do you want it?'"

Following Native tradition, the summit began with an opening prayer, traditional Northern Paiute song, and color guard to establish a mood of

reverence for those attending and for “all our relations,” past, present, and future.

Central to the summit were explorations of dementia and brain health from expert speakers, most of whom were Native, followed by Q&A. “Wisdom circles” continued the discussion to ensure everyone in attendance had a chance to participate, an essential aspect of tribal culture.

Since one in three American Indians will experience some form of dementia, many questions revolved around the rising incidence of dementia, which is exacerbated by obesity, heart disease and diabetes — common risk factors within tribal communities.

To help address these questions was Dave Baldrige (Cherokee), who heads the International Association for Indigenous Aging. He was followed by consultant Mike Splaine, the two discussing their cutting-edge dementia guide *Road Map for Indian Country* which they helped create in collaboration with the Alzheimer’s Association and the Centers for Disease Control and Prevention (CDC). The road map is part of the CDC’s national Healthy Brain Initiative.

“There are very few tribes with programs or resources in place to help people with dementia and their caregivers, and that includes Indian Health Service,” said Baldrige. “That’s why we created the *Road Map for Indian Country* — to begin these conversations and encourage local planning.”

Baldrige cited estimates that from 2014-2060, the number of American Indians and Alaskan Natives 65 and older with dementia is expected to multiply by five times.

The afternoon session featured presentations by Dr. J. Neil Henderson (Oklahoma Choctaw), the executive director of Memory Keepers Medical Discovery Team on Health Disparities, and Dr. Peter Reed, director of the Sanford Center for Aging.

Henderson described the peril of walking into grocery stores loaded with nutritional nightmares that are recipes for poor brain health.

“Grocery stores aren’t looking out for your best interests,” warned Henderson. “When you walk into that grocery store, be afraid.”

Henderson said that common foods like sugar can be neurotoxic when consumed in excess. He also asked how ethical it was to promote sugary foods to children who don’t yet have the ability to think critically.

“When we see high rates of diabetes and know that it's linked to dementia,” he pointed out, “we have to ask, ‘How much dementia is induced by poor diet?’ Diabetes increases the risk of dementia, so when we cut back on diabetes, we cut back on dementia.”

Reed discussed the importance of a holistic approach to dementia assessment and care.

“Interdisciplinary team approaches to geriatrics are critical for gaining the full picture of an elder’s needs,” said Reed. “The Sanford Center Geriatrics Specialty Clinic offers a comprehensive assessment that seeks to identify all relevant aspects of an elder’s life—including physical, social, cognitive and environmental factors—to build a care plan addressing the whole person. These services are also available via telemedicine to support elders living in rural and tribal communities.”

Throughout the day, tribal elders were consistently front and center.

“It’s the first training I’ve been to that really helped me,” said Linda Eben-Jones, Carla Eben’s aunt, who is Northern Paiute.

Jones has been a care partner most of her life — for her grandfather who lived to 104, her mother, and her husband who passed away two years ago — and says dementia is not commonly discussed among tribal elders, so there’s both a lack of information and, for some, deep denial.

“It’s vital these tribal elders and their communities are aware of it,” she says. “They don’t want to admit they have this problem.”

Other attendees appreciated the focus on elder wisdom.

“There’s such a wealth of information in the elder population that gets ignored,” says Barbara Payne from Dementia Friendly Pahrump, who drove 400 miles away to attend the summit with a fellow Community Action Group colleague. “And that’s a shame.”

Payne also recalled the advice given about heart health.

“Your heart is like the start of a free-flowing river,” says Payne. “Veins and arteries that take blood away from and to the heart are like mini connected small streams that flow all through the body, including the brain, feeding it with oxygen and energy. You have to work to keep the streams flowing through your body from becoming clogged and the heart from being hurt.”

Like a bookend, the summit closed with a traditional prayer and song.

“It was such a powerful event,” recalls Carson. “It felt like a community really learning together.”

Baldrige also complimented Eben and the Pesa Soaname Advisory Group on the event.

“I consider Pyramid Lake a premier tribe in dementia education in the entire country.”

### Lighting the Fire of Advocacy in Indian Country

When Carla Eben received the email about a dementia training from her supervisor, she read it curiously. Dementia? Even though Eben is head of Pyramid Lake's Tribal Senior Services Program, she admits she knew almost nothing about the topic. Still, it piqued her interest since part of her job was to get more information for tribal care partners, and dementia was certainly something she needed to know more about.

The following week, Eben made the two-hour drive to the Winnemucca senior center. There, she joined 10 others around a U-shaped table listening to a woman from the Nevada Geriatric Education Center (NGEC) discuss Alzheimer's disease and other forms of dementia. Although Eben was most interested in the subject of hoarding, one of the other topics presented that day by the NGEC, the instructor also discussed different types of dementia, their progressions, and some strategies for effective care partnering.

Eben was shocked. This was all foreign territory for her, and based on their questions everyone else in the room knew far more than she did. And as a member of the Pyramid Lake Paiute Tribe, it was clear Eben was the only one in the room representing Indian Country. So when the day was over and the presenter was packing up, Eben walked up to her slowly.

"Do you ever offer these dementia information sessions to Indian Country?" she asked.

"We always invite them, but they never seem to come," the instructor responded while packing up her materials. Eben thought for a moment, then left silently.

"Those words rang in my head the whole two-hour drive home," recalls Eben. "And I thought to myself 'I'm going to change that.' That really lit the fire in me."

The next day Eben reached out to her tribal health clinic and asked about local dementia screenings or trainings. Nothing was scheduled, and dementia training wasn't anything Indian Health Services offered.

Eben quickly learned that when it came to Indian country, the focus is on acute or immediate treatment. Dementia wasn't on anyone's radar. And while Native people might die from complications of Alzheimer's disease or other forms of dementia, the official death notice would list the cause as diabetes or heart disease.

Yet inside, Carla was still fired up. So she asked a friend at the nearby University of Nevada, Reno (UNR) to help track down someone who could assist the Pyramid Lake Paiute tribe with dementia training. A week later, she got the name of Dr. Jennifer Carson from UNR's Dementia Engagement, Education and Research (DEER) Program, who also happened to be lead facilitator for the state's Dementia Friendly Nevada (DFNV) initiative. Eben emailed her.

The two met, Carson thrilled because the state's dementia-friendly initiative hadn't yet connected with any of Nevada's tribes. Immediately, the two began working diligently to launch the Pesa Sooname Advisory Group, the Pyramid Lake Paiute Tribe's dementia-friendly Community Action Group within DFNV. The group first conducted a comprehensive dementia community needs survey with support from UNR's Sanford Center for Aging and then worked collaboratively to plan their first goals, including a statewide summit designed specifically to discuss dementia within a Native context.

While Dementia Friendly Nevada had already established four Community Action Groups— Washoe County, Elko, Winnemucca, and Southern Nevada Urban — they were looking to welcome more. After consulting with an approving Native elder, Eben and Carson decided to call their group Pesa Sooname, or “good think.” It seemed an appropriate way to respect elders while encouraging positive thinking and cognitive clarity. With that name, Pesa Sooname joined rural Pahrump – located an hour west of Las Vegas – as the two newest DFNV Community Action Groups.

Though the larger Dementia Friendly America (DFA) model targets sectors like hospitals, banks, retail stores and restaurants, many of these don't exist on tribal lands. Instead, the Pesa Sooname Advisory Group began to focus on tribal

departments like the health center, tribal court, and tribal administration. Their goals were to educate elders, care partners, and tribal departments.

Not only did Eben, Carson, and Pesa Sooname receive funding from the Nevada Aging and Disability Services Division (ADSD), through a grant from the Administration for Community Living, to work toward these goals, but a Dementia Friendly America representative acknowledged “You’re the only tribe across America that applied for a dementia-friendly grant and got it.”

Besides the ADSD funding, Eben also used an existing grant from the Older Americans Act (also known as Title VI) to work with Carson to educate Pyramid Lake’s elders, tribal department staff, and care partners.

Largely because of Eben’s efforts, the Pesa Sooname Advisory Group at Pyramid Lake has gained national recognition as a leader in dementia training and advocacy in Indian country. It’s also one of just four native communities spotlighted in the national Healthy Brain Initiative’s *Road Map for Indian Country* published by the Alzheimer’s Association and the Centers for Disease Control and Prevention.

Still, there was one more goal Eben wanted to reach in 2019. In August, the Pesa Sooname Advisory Group hosted 114 attendees at its inaugural Nevada Tribal Summit on Brain Health and Dementia, including representatives from 14 tribes.

Also at the summit was an old friend: the woman who first taught Eben about dementia, and who opened her eyes to the lack of representation from Native people in dementia education efforts. Eben thanked her as the two helped serve lunch to elder attendees.

“You were my inspiration,” Eben told her. “Had I not gone to your training, this would never have happened.”

Eben’s reputation as a dementia expert in tribal communities has become so strong that she was also asked to join a 2019 Older Americans Act panel in Minnesota focusing on dementia assistance in Indian country.

All of Eben’s hard work has also lit another spark. The National Indian Council on Aging (NICOA) has selected Sparks, Nevada for its 2020 American Indian Elders Conference where Eben and Carson will discuss their collaboration and provide a Dementia Friends information session to conference attendees.



Thanks to Eben, the fire of advocacy for elders living with dementia and their care partners burns bright at Pyramid Lake.

### Reducing Dementia Risk in Indian Country

After Dementia Friendly Nevada (DFNV) launched in 2017, each of its six Community Action Groups surveyed local stakeholders to discover what they most needed to help support community members living with dementia. For many communities, needs overlapped and centered on education, peer support, and better medical resources. The Pyramid Lake Paiute Tribe, however, had a unique focus: prevention (i.e., risk reduction).

Naming its dementia-friendly Community Action Group “Pesa Sooname” for “good think” – a bow to the Native desire for harmony as well as cognitive clarity – co-facilitator Carla Eben says tribal communities have very different priorities than their non-Native counterparts. While non-Native cultures tend to corral elders into long-term care, Native families will traditionally sacrifice personal comfort for the sake of their elders and care for them at home, which makes risk reduction in Indian country even more critical.

“People will drop what they’re doing,” says Eben, who heads Pyramid Lake’s Numaga Senior Services Program. “Even their career.”

Eben herself is the perfect example.

Fresh out of high school, Eben was studying to be a med tech at the Oregon Institute of Technology when she called home to check in on her ill grandmother. But when she called, she found grandma was home alone.

“Somebody is supposed to be with you all the time, and nobody’s there,” cried Eben. “I’m coming home.”

“But you only have two more months until summer break!” came the reply.

Despite her grandmother’s objections, Eben returned to Pyramid Lake where she was desperately needed.

In American Indian communities, rates of dementia are skyrocketing and are projected to not just double or triple but multiply by five between 2014 and

2060. One reason dementia rates are among the highest in Indian country is the high incidence of diabetes, obesity, and heart disease. Nutritional deficiencies are one of many factors contribute to dementia.

And since younger tribal members like Eben will dutifully set aside their own lives to care for revered elders, prevention is particularly crucial.

In fact, during its needs assessment, the Pesa Soomame Advisory Group estimated there were 28 people in the tribal community living with dementia — half of them living alone.

“This was a shock to us,” admits Eben.

While tribal members wanted to be educated about dementia, Eben quickly discovered nothing was available from the local clinic nor from Indian Health Service. So she had to create dementia supports.

Her initial idea was to launch an elders circle as part of Pesa Soomame to educate personnel from fire, police, emergency medical, health services, social services, victim services, and beyond — the entire community.

But it was challenging.

Eben would schedule the monthly meetings on a calendar at the local clinic but only a handful of people would show, including “an elder or two.” She would see people in the clinic parking lot and they would tell her they were too busy. Even members of her own staff would skip the meetings.

Thankfully, the one constant has been Dr. Jennifer Carson, co-facilitator of the Pesa Soomame Advisory Group and of Dementia Friendly Nevada, as well as Director of the Dementia Engagement, Education and Research Program at the University of Nevada, Reno. Carson and Eben have spent countless hours together, navigating the maze of dementia and aging, and together they have created a road map for education and outreach within the Pyramid Lake tribal community.

In 2019 Eben and her Pesa Soomame Community Action Group, with support from Carson, held four different education sessions on topics spanning dementia education to care partnering approaches, and reached nearly 50 elders, care partners, social services employees, and clinic staff.

In August, Eben and Carson also launched a landmark event: Nevada’s first Tribal Summit on Brain Health and Dementia, which brought together 14 tribes and 114 participants from across Nevada.

While the outreach has been fragmented, Eben continues to push forward. Carson remains impressed with Pesa Sooname's vision, and Eben's commitment and drive.

"They're the only Community Action Group that's working on the whole continuum, from risk reduction all the way through care and support," she says.

The Pesa Sooname Advisory Group has also garnered national attention. It's one of just four native communities spotlighted in the national Healthy Brain Initiative's *Road Map for Indian Country* published by the Alzheimer's Association and the Centers for Disease Control and Prevention.

Others nationwide have taken notice, too.

"Carla brought us all to attention through the recent collaboration [with Dementia Friendly Nevada] focusing on dementia and Alzheimer's disease," says Cynthia LaCounte, director of the Office for American Indians, Alaskan Natives and Native Hawaiian Programs for Health and Human Services' Administration on Aging and Administration for Community Living. "This is a relatively new area for Title VI programs, so Pyramid Lake has provided guidance to other tribes in this area... which is just how it should happen. The Tribes should lead the federal government to provide assistance to them."

Although the Pesa Sooname Advisory Group no longer has the same funding stream, Eben insists it will continue pushing forward with its efforts to educate the community. Putting the CDC *Road Map for Indian Country* into action, they already have dementia 'Talking Circles' scheduled for January, March and May.

Looking further into the future, Eben continues with her grand vision: more care partner education, an annual health fair, more memory screenings, a local care navigator for families experiencing Alzheimer's disease and other forms of dementia, a toolkit for tribal members to reference when a loved one is diagnosed with dementia, more elders accessing the coordinated care offerings from nearby Sanford Center on Aging, and an annual Tribal Summit on Brain Health and Dementia.

Despite the constant headwinds, Eben is determined to succeed. "I'm not giving up."