



Dementia Friendly Nevada (DFNV) Statewide Meeting
Tuesday, March 23, 2021 | 3:00 – 5:00 PM PST | Zoom Video Conference

In Attendance: Jennifer Carson, Mekai Smedley, Debbie Keay, Casey Acklin, Tracy Gibbs, Paula Anderson, Wendy Renault, Cory Lutz, Nicolette Ketchum, Mary Lee Fulkerson, Michael Magney, Gini Cunningham, Karen Robbins, Loretta Hillier, Kate Ingalsby, Laura Garcia, Anakaren Lamas, Peter Reed, Susan Hirsch, Jacqui Keating, Phyllis Fehr, Mary Burnett, Frances Morton-Chang, Mary Liveratti, Sara Suzuki, Nicole Mans, Laurie Riley, Anne Pizzacalla, LeeAnn Mandarino, Anthony Murphy, Clarabelle Lee, Byron Goynes, Erin Kingdom, Carina Stumpf, Jocelyn Martinez, Michelle Hardin, Cassandra Munoz, Carla Eben, Cathy Barrick, Kaleigh Behrendt, Alex Crocket

Co-Facilitators:

- Jennifer Carson, Director, Dementia Engagement, Education and Research (DEER) Program, UNR, and Program Director, DFNV
- Casey Acklin, Coordinator, DEER Program, UNR, and Program Coordinator, DFNV

Community Group Co-Facilitators:

- LeeAnn Mandarino, Kate Ingalsby, and Susan Hirsch, Cleveland Clinic Lou Ruvo Center for Brain Health, Dementia Friendly Southern Nevada Urban
- Tonya Brum, Nevada Rural Counties RSVP, Dementia Friendly Pahrump
- Carla Eben, Numaga Program, Pesa Soaname Advisory Group
- Gini Cunningham, Age- and Dementia-Friendly Winnemucca

Support:

- Tessa Swigart, PhD, Public Health Communications Specialist, Nevada Public Health Training Center, UNR
- Mekai Smedley, DEER Program, UNR, and AmeriCorps VISTA for DFNV

* = Please see attachments that were sent with this agenda.

Meeting Agenda

1. **Welcome** (15 min)

- a. As members are logging onto Zoom, please use the 'Chat Box' feature, using a single entry (hitting "return" only at the very end), to share your:
 - i. Name
 - ii. Role in supporting people living with dementia and/or family care partners
 - iii. Your favorite place in the world!
- b. Let's warm the soil and have some fun on Zoom!
- c. Review Dementia Friendly Nevada mission and meeting purpose
 - i. Mission: By working together, we aim to develop and promote communities that are **respectful, educated, supportive** and **inclusive** of persons **living** with dementia and their care partners.
- d. Review one Dementia Friendly Nevada Mobilizing Belief*

Mobilizing Belief Number 8: "Redirection" is a code-word for distancing, 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.

- i. Let's hear from 2 members about why this Mobilizing Belief is so important.

Mary Lee Fulkerson: We can't lock people in rooms and treat that as a solution. We must work *with* them!

Phyllis Fehr: We should always try to understand that people living with dementia have a different way of communicating, and we should meet them where they are at. Everything is communication! Redirection doesn't get to the "why" of the matter.

Sara Suzuki: Sometimes, providing some context can be extremely helpful to give someone the space to navigate their thoughts and their environment. A few extra minutes can go a long way toward creating a shared understanding.

2. Learn

a. Brief program updates (15 min)

i. **Dementia Friends***

- Monthly session on the third Wednesday of each month from 12:00 – 1:00 PM via Zoom
- Looking for additional, invited online opportunities

ii. **Dementia Conversations**

- **Dementia Conversations with Chuck and Jennifer*** every Monday from 10:00 – 11:30 AM via Zoom
- **Dementia Conversations with Nancy and Kat*** every Friday from 1:00 – 2:30 PM via Zoom
- Potential new idea: Dementia Conversations Recorded!

iii. **BOLD Public Health Program** updates

- We will be convening focus groups of people living with dementia, family care partners, and professionals to discuss gaps in existing public health and dementia messaging materials and identify potential new materials to develop.

iv. **Pesa Soaname Resource Notebooks**

- The Pesa Soaname Advisory Group is compiling resource notebooks (physical binders filled with dementia-related resource information) to distribute to each of Nevada's tribes.
- In addition to material focusing on dementia in Native communities broadly, the group hopes to include Nevada-specific information such as the Nevada Dementia Support Toolbox.

- a. If you know of any resources that you think we should include, please send to Casey Acklin: cacklin@unr.edu

- b. International Exchange of Ideas! (60 min)

- i. **Presentation from Dementia Friendly Nevada**

- Introduction - Dementia Friendly Nevada (Jennifer Carson)

Dementia Friendly Nevada as a statewide effort has six community groups and two different funding sources: the Nevada Aging and Disability Services Division and the Nevada Division of Public and Behavioral Health

Nevada is one of only a handful of states that has embraced as a statewide effort toward becoming dementia-friendly-and-inclusive.

Dementia Friendly Nevada has—in many communities—used the Dementia Friends Information Session to increase dementia awareness. Evaluation of the Dementia Friends Information Session in Nevada showed a statistically significant increase in knowledge on post-session surveys compared to pre-session surveys.

The weekly Dementia Conversations series (offered on Mondays and Fridays each week) offers people living with dementia, family care partners, and interested community members an opportunity to talk with other experts of lived experience about what it means to live well with dementia.

Dementia Friendly Nevada shares resource information across the state via the Nevada Dementia Supports Toolbox, a document that details programs and services for people living with dementia and family care partners. Over the initial three

years of Dementia Friendly Nevada, sharing of the Toolbox increased utilization of included programs and services by nearly 900%

The Dementia Friendly Nevada website is being translated into Spanish so as to reach the 25% Nevadans who are native Spanish speakers.

- Dementia Friendly Pahrump (Tonya Brum)

Provided dementia education through the coordination of community film screenings combined with discussions on the topic of dementia

Developed a library and resource center with materials available for free checkout. Materials are available in Spanish and via multimedia, and many are developed by and for people living with dementia.

- Pesa Soaname Advisory Group (Carla Eben)

Focused on dementia and brain health awareness by educating elders and tribal department using the Dementia Friends Information Session program and by hosting educational events featuring local community partners.

Hosted the 2019 Nevada Tribal summit on Brain Health and Dementia in which 114 attendees—including representatives from 14 Tribes—gathered for a full day of information and discussion about brain health and dementia within a Native context.

- Dementia Friendly Southern Nevada, Urban (Kate Ingalsby, Susan Hirsch, LeeAnn Mandarino)

Launched on World Alzheimer's day (September 21st, 2016).

Hosted memory screenings, care partner and provider education conferences, and sector-specific dementia training that they developed from the ground up.

The "Dementia Training for First Responders" program is available online and offers physicians, nurses, social workers, and emergency services professionals an opportunity to learn not only about dementia, but about the specifics of numerous types of dementia. www.dementiafirstresponsenv.com

- Dementia Friendly Washoe County (Casey Acklin)

Dementia Friendly Washoe County launched a number of programs designed to open opportunities for peer support and active engagement for people living with dementia and family care partners.

- The Open Door Café: a monthly unstructured gathering place for people living with dementia and family care partners to simply *be* together in a welcoming and supportive environment
- The Java Music Club: a weekly peer support program for people living with dementia that uses music, quotes, and images to stimulate community-building discussion toward the goal of reducing social isolation and loneliness.
- Dance With Me: a weekly dementia-friendly partner ballroom dance class in which people living with dementia

and their care partners move their bodies, work their brains, and grow their relationships.

- Dementia Friendly Nature Walks: a partnership with the Truckee Meadows Parks Foundation and the Sanford Center for Aging in which people living with dementia and family care partners explore their local parks, learn about nature, and develop networks of peers who share their interest in the outdoors.

- Age- and Dementia-Friendly Winnemucca (Gini Cunningham)

Age- and Dementia Friendly Winnemucca has sought to create a more inclusive community for all Winnemucca citizens through a diversity of endeavors.

- Various community events, including a turkey trot, a sprint triathlon, The Alzheimer's Association's "The Longest Day", film screenings, and community presentations.
- The installation of an age-and dementia-friendly outdoor fitness park.
- Respite care programs
- Monthly ads in the local newspaper aimed toward building awareness of dementia.

- Dementia Friendly Elko County (Jennifer Carson)

Dementia Friendly Elko County partnered with Nevada Rural Counties RSVP to launch "Friends' Day Out:" a respite opportunity with four hours of engaging programming for people living with dementia, including the evidence-based Java Music Club peer support program.

Multiple community events were held in Elko, one featuring a panel of professionals, people living with dementia, and family care partners to discuss dementia from various perspectives.

ii. **Presentation from *Empowering Dementia Friendly Communities Hamilton and Haldimand***

- Tracy Gibbs, Project Manager

The first step taken by the group was to engage community members in Hamilton and Haldimand in the creation of dementia-friendly action plans. Over 300 people participated in the efforts via one-to-one interviews and online surveys, in which community members were able to relay their experiences and challenges in community life along with ideas and solutions to becoming more dementia-inclusive.

Five themes emerged:

- Empowering people living with dementia
- Challenging stigma and building understanding
- Fostering social inclusion and participation
- Creating dementia-inclusive built environments and transportation
- Improving community responsiveness to crisis/COVID-19

The next step was to take action

- Five dementia-specific recommendations were integrated into the Hamilton Age-Friendly Plan.
- People living with dementia provided consultation on the plan.

The entire effort is led by “Lived Experience Leadership Teams” of people living with dementia.

The goal now is to continue learning and to share this successful process with the world!

- Phyllis Fehr, team leader, international dementia rights advocate (diagnosed with early-onset Alzheimer's in 2012)
- Debbie Keay, team leader, international dementia rights advocate (diagnosed with early-onset Alzheimer's in 2018)

Both Debbie and Phyllis spoke of their journeys with dementia and how they got to where they are now. They discussed the connections between family, career, growth, and feeling isolated within the community: not being able to complete day to day activities because of dementia. Joining international groups of people living dementia helped with the transition into accepting their diagnosis and feeling welcomed in their communities.

3. **Reflect** (20 min)

- a. What strengths do these two initiatives share?

They both focus on empowerment and inclusivity, trying to create new ways for people living with dementia and their family care partners to feel loved and appreciated.

They focus on interpersonal connections and developing long lasting relationships between community members. It's not just about providing information, but about showing community members how to implement that information. There's a strong focus on leadership, growth, and development.

- b. What creative approaches (to authentically engaging people living with dementia, to surmounting obstacles, to spreading awareness, etc.) taken by one initiative might apply to the other?

How do we go from a “project” to a “way of life” where being included in communities is simply part of living with dementia?

- It starts with policy change: uniting existing movements that are spread geographically into more amplified voices for change.
 - We must identify the policy initiatives that support the ways we hope communities will exist and do our best to support them!
- Education is essential, both for the public and for the government.

Empowering Dementia Friendly Communities Hamilton and Haldimand has employed a very effective infographic created by the Alzheimer’s Society that emphasizes the importance of changing mindsets and the roles that each community member can play.

- Carla Eben mentioned that such an infographic would be well-received in tribal communities.

4. **Share** (10 min)

a. Is there anything happening locally—or across the state or nation—that members of DFNV should know about and can possibly help promote?

i. **Life Enhancing Activities for Family Caregivers (LEAF)**

- Anakaren Lamas, Director, Site Operations & Recruitment, Recruitment Partners LLC

Life Enhancing Activities for Family Caregivers (LEAF) study: This study, funded through the National Institute on Aging and offered through Northwestern University and the University of California San Francisco, is seeking family care partners of people living with Alzheimer's disease in the United States as participants. It offers family care partners the opportunity to practice positive emotions that could help their overall well-being as they navigate care partnering responsibilities.

- Mather telephone topics

Mather telephone topics provides telephone-based or online access to interesting discussions and programs related to wellness, education, music, live performance, and more!

Browse topics and register here:

<https://matherlifeways.eventsair.com/MLCEPortal/community-initiatives-live-event/matherce/Calendar?location=Telephone%20Topics>

- Save the date! Dementia Friendly Nevada will be hosting an “I Am” Showcase event (details included in the flyer attached to the email in which these notes were distributed) on April 15th, 2020 from 4:00 – 5:30 PM.

Thank you for all that you do to make our communities and state dementia-friendly and inclusive!