



Dementia Friendly Nevada (DFNV) Statewide Meeting

Tuesday, February 23, 2021 | 3:00 – 5:00 PM PST | Zoom Videoconference

In Attendance: Jennifer Carson, Phyllis Fehr, Joan Lee, Chuck McClatchey, Mary Lee Fulkerson, Tessa Swigart, Dave Baldrige, Mary Liveratti, Pia Kontos, Leslie Fuller, Niki Rubarth, Tom Waters, Peter Reed, Mary Fridley, Susan Hirsch, Kat Hartley, Nicolette Ketchum, Kaleigh Behrendt, Cory Lutz, Pam Shields, Alex Crocket, LeeAnn Mandarin, Gini Cunningham, Charles Duarte, Casey Acklin, Kate Ingalsby, Cara Schaefer, Katrina Fowler, Tonya Brum, Laurie Riley

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 Mandarin, 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 notes are included in green.

Meeting Agenda

1. **Welcome**

- 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. Role in supporting people living with dementia and/or family care partners
 - ii. What is one fun Zoom-based activity that you have participated in that we might be able to do together at a future meeting?

- Bingo
- Painting class with wine
- Trivial Pursuit
- Costume contest
- Scavenger hunt.

- a. 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.

- b. Review one Dementia Friendly Nevada Mobilizing Belief*

Number 7: Sometimes what makes care partners feel safe and secure make people who have dementia feel unsafe and uncomfortable.

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

Tonya Brum: Spoke about an experience with a friend who was trying to protect her husband but also wrestling to ensure she was upholding his agency. It's so hard to make choices that are best for everyone involved.

Leslie Fuller: It's so important to put yourself into the shoes of others and imagine how it would feel to constantly not be able to go out or have a sense of freedom.

Mary Liveratti: Spoke about balance and the supports to a sense of safety, being able to accommodate others and understand the want rather than what you think they need.

Tom Waters: Everyone's comfort level is different, and everyone's safety needs are different. There's no one-size-fits-all solution.

2. Learn

a. Brief program updates:

i. **Dementia Friends***

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

We recently trained two new Dementia Friends Champions (Mekai Smedley and Sara Suzuki) who will be largely focused on bringing the Dementia Friends Information Session to Nevada's Tribes.

ii. **Dementia Conversations**

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

iii. **BOLD Public Health Program** updates

1. The Dementia Friendly Nevada website has been fully reviewed and revised for ADA-compliance and alignment with age- and dementia-friendly design principles.

2. We have sent the full website (including all downloadable materials) to the Nevada Public Health Training Center for translation into Spanish, which will be completed by the end of April 2021.
- b. Guest presentation about **Reimagining Dementia: A Creative Coalition for Justice*** from Dr. Pia Kontos, researcher/advocate, and Phyllis Fehr, international dementia rights advocate (diagnosed with early-onset Alzheimer's in 2012)
- i. Example of Reimagining Dementia One-Minute Show and Tell
 - ii. Example of the 'I Am 'poem:
 - I am (your name),
 - I am a member of Dementia Friendly Nevada because (something you want to change/achieve),
 - I am (a place or activity that is special to you),
 - I am reimagining dementia by (something that you're doing to reimagine dementia),
 - I am (your name),
 - I am (a feeling you have now).
 - iii. To join Reimagining Dementia:
https://docs.google.com/forms/d/e/1FAIpQLSdhaUshwLJT2F6Ety_fu5LRDhwYhVM1H3w2KJ0nC0Y94tNpw/viewform

The members of the Reimagining Dementia Creative Coalition for Justice are committed to addressing injustices that people with dementia face. Many COVID-related deaths have occurred in nursing homes, and the lack of media coverage on the matter is due largely to stigma. To achieve justice requires education and respect at every level of society.

The coalition has created relationships with over 450 members from over 23 countries, including people living with dementia, policy figures, family care partners, aging services professionals, and others. They are using the arts to address social injustice and to promote compassion.

- i. **Reflect:** What lessons might Dementia Friendly Nevada learn from, and share with, Reimagining Dementia?

Due to time constraints, a formal conversation on this topic was skipped in favor of a more general discussion about the Reimagining Dementia coalition.

- c. Guest presentation about the **Nevada State Legislative Agenda*** from Mary Liveratti, Chair of the DFNV Statewide Workgroup and the Alzheimer's Association of Northern Nevada Public Policy and Advocacy Committee, and Charles Duarte, former Medicaid Administrator for Nevada and Hawaii

All legislative advocacy is still virtual, with no information as to when it will go back to face-to-face. Current advocacy priorities include:

Protecting respite care funding for family care partners of people living with dementia

Renewing public education funding for Alzheimer's disease awareness. Nevada is addressing Alzheimer's disease as a public health crisis with a public awareness campaign.

Promoting Medicaid coverage for dementia care planning

Covering all Medicaid home and community-based services.

Nursing home Personal Needs Allowance (PNA) increases (The federal minimum PNA is \$30 per month)

Improving staffing ratios in long-term care communities

Establishing home-delivered meals as covered by Medicaid

Flexible sick leave

Personalized Legislative Tracking: Allows you to track bills and budgets that are of interest to you and subsequently tag and create notes on your tracked items.

Here is the link to register for the Alzheimer's Association Advocacy Day <https://p2a.co/emf27vk>

Questions? Feel free to email Chuck Duarte at ccduarte@alz.org, or call his cell at 775-781-1603.

Please direct any personalized legislative tracking questions to publications@lcb.state.nv.us or call 775-684-6835 or long distance within Nevada 877-873-2648.

Advocacy at the Nevada legislature and information on legislative activity is available on the NV legislative website: www.leg.state.nv.us

Information on dementia and care partner advocacy issues are available at Alzheimer's Association website: www.alz.impact.org. Select Nevada for state-specific information.

- i. **Reflect:** What policy initiative(s) sound most important to you, and what action will you take toward advocacy on those issues?

Due to time constraints, a formal conversation on this topic was skipped in favor of a broader discussion on legislation.

3. Share

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

Recurring courses presented by the Alzheimer's Association; a flyer is attached to the email through which these notes were distributed.

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