



Dementia Friendly Nevada (DFNV) Statewide Meeting

Tuesday, August 24, 2021 | 3:00 – 5:00 PM Pacific | Zoom Videoconference

In attendance: Jennifer Carson, Chuck McClatchey, Cori Stauffer, Kate Ingalsby, Barbara Payne, Phil Kalsman, Peter Reed, Chuck Duarte, Mordechai Lavi, Denise Hund, Rebecca Hepworth, Donna Thorson, Mary Lee Fulkerson, and 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, 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:

- Michelle Harden, MPA, BOLD Public Health Program Coordinator, Population Health and Wellness, Nevada Division of Public and Behavioral Health
- Mekai Smedley, DEER Program, UNR, and AmeriCorps VISTA for DFNV

Note: Please mute yourself when you are not speaking
and take personal breaks as needed.

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

Meeting notes included in green.

Dementia Friendly Nevada is supported through funding from the Nevada Aging and Disability Services Division and the Nevada Division of Public and Behavioral Health.

Meeting Agenda

1. **Welcome** (20 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:

- Name
- Role in supporting people living with dementia and/or family care partners
- One thing you think medical providers should know about dementia
 - The basics: what is dementia, and how does it differ from normal aging?
 - A person who just received a diagnosis of dementia is the same person when they leave the provider's office as when they walked in.
 - There's hope after diagnosis. People can and do live well with dementia for a long time!
 - It is untrue to say that when someone is diagnosed "there is nothing we can do". There is SO much available in terms of community resources to help support quality of life and well-being!
 - The importance of early detection and diagnosis, providing the opportunity for care planning and advocacy early-on.
 - The importance of accurate testing and the difficulty of scheduling these tests. What do you do in the meantime while waiting for appointments?
 - I am not my disease. I am a living and happy individual.

- I would like for medical professionals to take their time. Listen. In the ER, find out what is really wrong – don't assume people are "crazy."
- Medical providers should be helping to alleviate the stigma surrounding Alzheimer's and other dementias.
- Medical providers should know more about how to reduce the stigma of diagnosis and talk with their patients about ways they can discuss their diagnosis with others in their life.
- Have patience with your patients!

b. Let's warm the soil and have some fun on Zoom!

c. Review Dementia Friendly Nevada mission and meeting purpose

- 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 #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 identify, preferences, and/or unmet needs. Instead of pathologizing behaviors, care partners and professionals should seek to understand and validate personal expressions, actions, and reactions.
- Let's hear from 2 members about why this Mobilizing Belief is so important.

- Chuck McClatchey: People living with dementia have other needs that might cause them to say certain things or do certain things. If everything is attributed to the dementia, people living with dementia might never have had their needs recognized or met.
- Peter Reed: My grandmother was living with dementia in an assisted living community. She would spend all of her time walking around the building because she loved to walk. The staff, however, labeled her as a “wanderer.” Eventually they kicked her out of the community because of her “behaviors”; she was flushing clothing down the toilet. I don’t know why she was doing that, but the point is that the staff never asked themselves what the reason was. Maybe she was bored. Maybe she mistook the toilet for a laundry machine, and was just trying to help. Whatever the reason, if the staff had worked to understand her and her actions, she might have been able to keep her home.
- Chuck Duarte: Understanding a person’s communication requires time, and requires patience. We have to be patient, and put in the effort needed to look past the surface level “behavior” and see the meaning. We also need to support people in taking that time, such as in the case of first responders. It needs to be an option for them.

2. **Quick updates: Dementia Friends** (10 min)

- a. Dementia Friendly Nevada worked with the International Association for Indigenous Aging to launch “Dementia Friends for American Indian and Alaska Native Communities” at the recent National Indian Council on Aging conference.

- 9 Dementia Friends Champions were trained, and can now provide Dementia Friends Information Sessions in their communities across the country.

3. **Learn: Project ECHO Person-Centered Dementia Care Series** (30 min)

a. Welcome Dr. Mordechai Lavi, Geriatrician, Sanford Center for Aging

- Dr. Mordechai Lavi joined the University of Nevada Reno, School of Medicine faculty in September 2017. He specializes in the care of adults 65 and older. He practices outpatient geriatric medicine through the Sanford Center for Aging. He has been the medical director of Project ECHO Nevada since July 2018 and recently took on the role of medical director for clinical services at the Sanford Center for Aging in early 2021. He lives in Central Reno with his wife, son, and dog Scarlett. He enjoys spending time traveling and brewing beer.

b. The person-centered dementia care series through Project ECHO is available **for free** to all Nevada primary care practices. Using real case studies from their own work, provider teams will learn how to more effectively develop care plans for patients diagnosed with dementia.

4. **Reflect** (30 min)

- a. Let's look at responses from the chat box about things our members think medical providers should know about dementia. Do you have any additional thoughts to share?
- b. What are your reflections on current primary care experiences for people living with dementia?
- c. In what ways might this Project ECHO person-centered dementia care series positively impact the experiences that people living with dementia have with their primary care providers in your community?

- Combined reflections based on the above three discussion questions:
 - Question from Chuck Duarte: **What is the goal of this person-centered dementia care series through Project ECHO?** Response: To work with providers to pave the way toward approaching patients living with dementia from a more holistic perspective. To change what provider care teams see and respond to in the patients they see who live with dementia. This most certainly involves improving the diagnostic experience for people living with dementia, and also promoting early diagnosis for people who may be living with dementia.
 - Question from Chuck McClatchey: **Have you thought about having a session of the series where providers can meet and talk to people living with dementia?** Response: That specific educational method is a little bit outside the scope of Project ECHO, but it is absolutely valuable. We should definitely look into how to refer providers to other resources in Nevada where they might find such an experience, such as through Dementia Friendly Nevada.
 - We need to make education like this incentivized and/or required through policy measures.

5. Strategize (20 min)

- a. How can we best spread the word about this Project ECHO person-centered dementia care series across the state?
 - **Some suggested outreach options:**
 - Medical societies and medical associations
 - Las Vegas Heals
 - Hospital Associations

6. Explore: New Meeting Time

- a. We will be distributing a Doodle poll to all Dementia Friendly Nevada members within the next week with some options of new meeting times for our recurring monthly Dementia Friendly Nevada Statewide Meeting.

- Doodle poll:

https://doodle.com/poll/e8yn3x6wfamdpiva?utm_source=poll&utm_medium=link

7. Share (5 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?
- Alzheimer's Association: **Walk to End Alzheimer's Disease**, modified in-person events!
 - October 2nd in Reno/Sparks
https://act.alz.org/site/TR?fr_id=14330&pg=entry
 - October 16th in Las Vegas
https://act.alz.org/site/TR/Walk2021/AZ-DesertSouthwest?fr_id=14290&pg=entry
 - Nevada Caregivers Coalition: November 18th virtual **Caregiver Recognition Event**
 - <https://nvcaregiverscoalition.com/2021-caregiver-recognition-virtual-event/>
 - Nominations due in October.
 - **This Dementia Life** – podcast hosted by Chuck McClatchey
 - Dementia Friendly Nevada episode!
<https://www.youtube.com/watch?v=h1k02qq-59U>

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