



Dementia Friendly Nevada (DFNV) Statewide Meeting

Tuesday, May 25, 2021 | 3:00 – 5:00 PM PST | Zoom Videoconference

In attendance: Jennifer Carson, Casey Acklin, Chuck McClatchey, Mekai Smedley, Mike Tracy, Mary Lee Fulkerson, Susan Hirsch, Jodi Qualls, Phil Kalsman, Tonya Brum, Carla Eben, Tessa Swigart, Charae Wamsley-Gipson, Michelle Harden, Michael Magney, Kat Hartley, Gini Cunningham, Alex Crocket, Byron Goynes

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:

- Michelle Harden, MPA, BOLD Public Health Program Coordinator, PopulationHealth and Wellness, Nevada Division of Public and Behavioral Health
- Tessa Swigart, PhD, Public Health Communications Specialist, Nevada PublicHealth Training Center, UNR
- Mekai Smedley, DEER Program, UNR, and AmeriCorps VISTA for DFNV

* = Please see attachments that were sent with the meeting agenda.

Meeting Agenda (notes are included in green)

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:
 - Name
 - Role in supporting people living with dementia and/or family care partners
 - What is one piece of advice you'd give to citizens of Douglas County as they launch a new dementia-friendly community group this summer?

- 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^{f*}
 - **Mobilizing Belief #3:** 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.
 - Let's hear from 2 members about why this Mobilizing Belief is so important.

Chuck McClatchey: It is so important to empower people living with dementia, because it's incredible what people can do when they are afforded the opportunities to do so.

Susan Hirsch: For people toward the end of their dementia, there is still so much potential for communication and meaning. Even for people who cannot speak, facial expressions and other mechanisms of communication can be employed. We should talk directly to people, even if we know they probably won't be able to respond. Everyone deserves that respect.

Michael Magney: None of us like to be spoken about as if we don't exist, as if we're not there. It's incredibly frustrating to have people talking about you, or people like you, and not even acknowledging that you might have some things to say yourself. "Nothing about us without us" applies fully to people living with dementia and family care partners, and to us here at Dementia Friendly Nevada.

Jennifer Carson: It's so important for us to have the assumption that people can contribute, because if we don't open the opportunity for people to contribute, they won't.

2. Learn (30 min – 10 mins per topic)

a. DFNV Program updates

- **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
 - Revising curriculum for Tribes in partnership with the International Association for Indigenous Aging (IA²). We will be presenting this revised curriculum at the 2021 National Indian Council on Aging Conference, being held in Sparks, NV during the first week of August.
 - Over 1,300 Dementia Friends across our state!

- **Dementia Conversations**
 - **Dementia Conversations with Chuck and Jennifer***

everyMonday from 10:00 – 11:30 AM via Zoom

- **Dementia Conversations with Nancy and Kat*** every Friday from 1:00 – 2:30 PM via Zoom
- In the works: **Dementia Conversations Recorded**
 - a. Promotional “episode” recorded and will be available on the DFNV website soon!
- Collaboratively developed Dementia Conversations Group Guidelines have been posted to the Dementia Conversations webpage.
- Three stories published on Dementia Conversations!
 - a. https://www.nextavenue.org/communities-redefine-dementia-narrative/?utm_source=share&utm_medium=email&utm_campaign=&utm_term=.email_article_share
 - b. <https://homecareassistance.com/blog/common-dementia-misconceptions>
 - c. https://daanow.org/resolute-examples-of-choosing-hope/?mc_cid=fd54923a7f&mc_eid=fb7b043c15
- **BOLD Public Health Program** updates
 - Welcome Michelle Harden, MPA; Population Health and Wellness, BOLD Coordinator!

Michelle will offer full time support to the DEER Program, DFNV, and all things dementia and Alzheimer’s related with regard to the CDC BOLD grant.

Michelle will help us make sure that dementia is a part of all other types of public health conversations, and integrate our work with other DPBH efforts.

Michelle will also help us contextualize dementia within more of a life-course perspective, including prioritizing discussions about brain health and modifiable risk factors for dementia.

- Summary of findings from our three recent focus groups with people living with dementia, family care partners, and professionals in the field
- Spanish translation of DFNV website and materials
- New webpages for the DFNV website: online resources(completed with ongoing updates), brain health (underdevelopment), and strategies for family care partners (upcoming)
- New DFNV Community Group: Douglas County! Welcome to themovement!

3. **Reflect** (30 min)

a. **Topic: Format and structure of in-person DFNV Community Group meetings.** With the possibility of in-person Community Group meetings on the near horizon, let's take some time to reflect on the format and structure of our previous monthly Community Group meetings. Some questions to consider:

- What worked, what didn't work, and how could they be changed or strengthened to promote effective, dementia-inclusive community engagement?

For Community Group meetings, strategically invite people living with dementia and family care partners into the discussion. People who work in the medical field and in emergencies services should also join the conversation.

Identify a target audience and then identify how to cater to that audience.

Have structure, but allow everyone to speak freely and feel heard as well.

Be proactive with meeting time and spend that time completing important tasks so as not to rely on members to meet outside of monthly Community Group meetings.

- Where and when will the in-person meetings be located (need large, well ventilated rooms)?

Many members expressed hesitation about meeting in-person, at least for now.

Members felt we should view this time as a transition period, being open to change. Having an option to join local Community Group meetings by Zoom—in addition to attending in-person—might be best for now, while people become more comfortable meeting in person.

The transition back to in-person meetings will look different and will proceed at different speeds in each Dementia Friendly Nevada community, and all such transitions will follow local, state, and federal guidelines.

- How will we practice good social distancing?
- Who will be invited to attend, and how will we invite them?
- What role should our statewide Zoom-based meetings continue to play once our local Community Groups have relaunched?

Although going back in-person meetings is important to revitalize the Community Groups, continuing to have these monthly zoom meetings is essential for anyone who might not feel comfortable going into in-person public settings, and to keep the statewide network connected.

4. **Strategize** (40 min – 20 mins per topic)

- a. **Topic: Latinx outreach and engagement.** Now that we have the DFNV website translated into Spanish and have translated key program materials, how do we best distribute these materials to Latinx communities across Nevada? How do we begin to develop capacity to offer DFNV programs in Spanish, such as Dementia Friends information sessions and Dementia Conversations? What other Spanish-speaking programs and services can we help promote as part of our outreach?

Perhaps hold a one-time focus group, minimal commitment, so that we can begin to understand how we can better connect with Spanish-speaking communities. “Nothing about us without us” applies here too! Ask Latinx communities the best approach to outreach and engagement.

Reach out to Spanish speaking students at UNR.

Find local champions in the Spanish-speaking communities who can bring information to community members.

Thinking about Latinx outreach is the perfect opportunity to connect with faith-based communities, which is something we have long wanted.

- b. **Topic: Revitalizing Community Groups through a DFNV Road Show.** The DFNV Support Team is considering the possibility of doing a statewide DFNV Road Show (possibly with Dr. Al Power, depending on the dates), with stops in each DFNV community and an engaging social media campaign, to revitalize our DFNV Community Groups and statewide movement. What ideas do you have for how to make this Road Show a success? What ideas do you have for stirring up excitement and visibility in your community?

There should be publicity leading the Road Show (ahead of time) and then also publicity following it. Promoting it as a “trip around the state” is what is going to make it meaningful. Bring a camera on the Road Show! Compile it into a video, and talk to PBS so that it will be shown over and over and over again.

Create a social media campaign similar to the “Humans of New York” project: people living with dementia and family care partners could be featured on a social media account, with a compelling portrait photo of them and a paragraph or two of a direct, emotionally moving quote.

- This idea could be combined with longer-form storytelling as well, to create further content to share on the DFNV website.

Use the Road Show as an opportunity to provide outdoor demonstrations of our programs: Dementia Friends, Dementia Conversations, and Java Music Club.

The Road Show may also be a great opportunity to bring in brain health. We can provide information on brain-healthy diets and lifestyles at the community events, while also physically exemplifying a brain-healthy existence!

Regarding venues:

- We want a public space so that we can engage with people in the community who want to connect with us but may not know they want to connect with us!
- We should avoid anywhere that is already connected in any way to dementia. We are trying to break that bond and reach out beyond those preconceived notions. We need places that aren't steeped in stigma.

5. 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?

See resources attached to the email in which these notes were distributed.

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