



Dementia Friendly Nevada (DFNV) Statewide Meeting  
Tuesday, April 27, 2021 | 3:00 – 5:00 PM PST | Zoom Videoconference

In attendance: Tonya Brum, Susan Hirsch, Alex Crocket, Anakaren Lamas, Anthony Murphy, Carla Eben, Chuck McClatchey, Cori Stauffer, Gini Cunningham, Jocelyn Martinez, Kaleigh Behrendt, Kat Hartley, Kate Ingalsby, LeeAnn Mandarino, Leslie Fuller, Mary Lee Fulkerson, Michelle Harden, Niki Rubarth, Pamela Shields, Phil Kalsman, Riley Franco, Tom Waters, Tracey Bowles, Mekai Smedley, Brian Browne, Tessa Swigart, Casey Acklin

**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

## 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:
  - Name
  - Role in supporting people living with dementia and/or family care partners
  - What is one misconception that is generally held about dementia or about people living with dementia?

That people with dementia cannot continue to grow past their diagnosis

That people living with dementia are helpless and not driven, or cannot do things on their own

That people living with dementia can no longer be contributing members to society

- 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\*
  - Let's hear from 2 members about why this Mobilizing Belief is so important. Number Seven "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.

Chuck McClatchey: The reality truly is that sometimes people do all the wrong things for all the right reasons.

Leslie Fuller: Working at a long-term care community caused her to continually consider how she would feel if the situation were reversed.

Tonya Brum: Every care partnership looks different. There are so many different types of dementia, and each person's experience with dementia will be unique. On top of that, care partnerships in rural and urban areas take different forms.

## 2. Learn

a. Brief program updates (15 min)

- **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
- **Community Awareness Training**
  - Completed trainings with McCarran International Airport!

The Community Awareness Training is a central framework that can be adapted to any sector.

The training includes the individual stories of people living with dementia as well as their care partners.

- **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

- In the works: **Dementia Conversations Recorded!**
- **BOLD Public Health Program** updates
  - We are 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.

b. Research and Clinical Trials (45 minutes)

- Brian Browne: Participating in Clinical Trials

Brian@dementiacareeducation.com

- Brian Browne, MS, CSA is the president of Dementia Care Education, the Editor of Dementia Care News, and a research consultant for the Cleveland Clinic.

He possesses over 20 years of experience in the field of cognitive science, Alzheimer's, and dementia. He is an expert in Alzheimer's/dementia research, clinical trials, aging, cultural competency, caregiver strategies, and dementia training and education. His research interests include examining the role of modifiable risk factors and lifestyle intervention to prevent cognitive decline in Alzheimer's and novel methods to increase clinical trial participation.

It all starts with a question. Humans are naturally inquisitive. We do research to collect data to answer the questions that we have.

There are three main study designs:

- Outcomes-based
- Survey research
- Randomized control studies

The history of clinical trials goes back to the 1600's. By 1950, the British Research Council had developed a systematic methodology for studying and evaluating clinical interventions.

Components of clinical trials:

- Must use human subjects
- Must have a control group
- Must focus on the unintended effects of the intervention
- Must review existing scientific data and build on those data
- Must control for potential biases

Research terms:

- Randomized: schemes used to assign participants to one group or the other
- Nonrandomized: "All with X disease are cases, others are controls."
- Protocol: the study design and instructions
- Blinded: study participants do not know what treatment group they are in
- Double blinded: neither participants nor researchers know the treatment groups
- Placebo: an inactive pill with no therapeutic value

Ethics of clinical trials:

- Respect for persons: treatment of persons as autonomous beings
- Beneficence: weighing potential good vs. potential bad outcomes
- Justice: treatment of all fairly, and all equally share benefits and risks

Study ethics are ensured through the Institutional Review Board.

Clinical trials must involve informed consent, which itself must include:

- Why the research is being done
- What will be done
- Risks and benefits
- Other treatments available
- Assurance that participants can withdraw anytime

Children, people who are mentally impaired, and people living with advanced dementia are not thought to have autonomy to give informed consent.

It is crucial that research includes people of all ethnicities, cultures, and backgrounds. This is the only way to ensure that interventions work for everyone.

- LeeAnn Mandarino, Cleveland Clinic Lou Ruvo Center for Brain Health; and Co-Facilitator of Dementia Friendly Southern Nevada Urban
  - Alzheimer's Disease Neuroimaging Initiative (ADNI)

ADNI is a longitudinal study to identify biomarkers of Alzheimer's Disease. The aim is to detect Alzheimer's Disease as early as possible, to track progression with biomarkers, to establish new diagnostic methods, and to continue to make data available to all scientists free of charge.

- Alzheimer's Disease Research Center (ADRC)

31 centers across the country, in 20 states. These centers help with diagnosis and provide dementia-related services.

The Cleveland Clinic Lou Ruvo Center for Brain Health is one of four exploratory ADRCs, and the Cleveland Clinic's center is specifically focused on rural and smaller-town Nevada.

There is much need in our state. Nevada has 40 geriatricians; to serve the population, we need 160-480. Additionally, Alzheimer's Disease is more common in rural communities, and Nevada's geography is primarily rural.

Participants in the ADRC's studies have access to programs, consultations, and educational opportunities.

The goal of the program is to build rural infrastructure, creating a referral network and partnering with local providers.

- Diversity and research

### **Reflect** (30 min)

- c. What hopes are raised up when thinking about research and clinical trials? What questions or concerns come to mind?

What is considered rural?

- Population less than 50,000, and quite a distance from a main urban center. Indian reservations are included, however for ADNI, Black and LatinX populations are prioritized.

- d. How knowledgeable do you feel about research opportunities broadly, and more specifically here in Nevada? What is the most useful way for Dementia

Friendly Nevada to provide information about future research opportunities?

Facebook was identified to be a very useful mechanism of communicating information about clinical trials. Newspapers were mentioned as well. However, all methods should be used if possible.

3. **Share** (15 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?

- **Life Enhancing Activities for Family Caregivers (LEAF)**
  - Anakaren Lamas, Director, Site Operations & Recruitment, Recruitment Partners LLC.
- Dementia Friendly Nevada Engagement Event
  - Arts-based opportunity to build community!
  - Monday, May 10<sup>th</sup>, 4:00 – 5:30 PM

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