Tips and Best Practices for Helping People Living with Dementia Stay Socially Engaged and Connected
Webinar Instructions

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• All participants are muted.

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Chat Feature
• The Chat feature allows webinar attendees, the host, co-hosts and panelists to communicate for the duration of the webinar.

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• The recording will be available on www.engagingolderadults.org.
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USAGing

- USAGing represents and supports the national network of Area Agencies on Aging and advocates for the Title VI Native American Aging Programs that help older adults and people with disabilities live with optimal health, well-being, independence and dignity in their homes and communities.
- [https://www.usaging.org/](https://www.usaging.org/)
Overview of engAGED

• National effort to increase social engagement among older adults, people with disabilities and their caregivers
• Administered by USAging
• Funded by the U.S. Administration on Aging, which is part of the Administration for Community Living
• Broad-based Project Advisory Committee
• www.engagingolderadults.org
Connect With Us!

- [www.engagingolderadults.org](http://www.engagingolderadults.org)
- Facebook: @engAGEDCenter
- Twitter: @engAGEDCenter
- [info@engagingolderadults.org](mailto:info@engagingolderadults.org)
Presenters

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Caitlin Torrence, Ph.D  
Research Associate, CU Office for Research and Organizational Development

Bailey Dull  
Director, Golden Corner Respite Care Center
Fostering Social Engagement in DFA Communities

Mary Ek, Director, USAging
Darya Rahbar, Program Manager, USAging
The Growing Need

More than 6 million Americans are living with Alzheimer’s.

Over 11 million Americans provide unpaid care for people with Alzheimer’s or other dementias.

These caregivers provided more than 18 billion hours valued at nearly $340 billion.

Number and Ages of People 65 or Older with Alzheimer’s Dementia, 2023*

- Total: 6.7 Million
- 65-74 years: 1.79 million (26.7%)
- 75-84 years: 2.54 million (37.9%)
- 85+ years: 2.37 million (35.4%)

*Percentages do not total 100 due to rounding. Created from data from Rajan et al.52,222
Dementia & Risk for Social Isolation and Loneliness

Stigma

- Can lead to lack of confidence
- Hesitance to let people know about diagnosis
- Can lead to loss of friendships or make it difficult to form new ones

Support networks and interaction

- People struggle to know how to support people living with dementia
- Lack of support can intensify feelings of isolation
- For many people who live alone, support from family and friends is vital

Activities and engagement

- Many people stop engaging in regular activities, which can contribute to loneliness
- Diminished confidence can lead to a loss of independence
Dementia Friendly America

- Dementia Friendly America (DFA) launched in 2015.
- Goal is to ensure that communities and individuals across the U.S. are equipped to support people living with dementia and their caregivers.
- Two primary initiatives within DFA:
  - Dementia-friendly communities (community-wide impact)
  - Dementia Friends (individual-focused impact)
- Modeled after Minnesota’s ACT on Alzheimer’s
- USAging is fiscal agent and program administrator for DFA.
- Guided by a National Council of 35+ national leading organizations
- [www.dfamerica.org](http://www.dfamerica.org) and [www.dementiafriendsusa.org](http://www.dementiafriendsusa.org)
What is a Dementia Friendly Community

• A dementia friendly community is informed, safe and respectful of individuals with dementia, their families and care partners and provides supportive options that foster quality of life.

• Joining the DFA network means a community is working to become more dementia friendly
  • Community approach (involving at least 3 sectors of community)
  • Including people with dementia and their care partners in planning
  • Adopting dementia friendly practices and goals
Social Engagement in DFA Communities

**Nevada**
Dementia Conversations

[Image: https://dementiafriendlynevada.org/dementia-conversations/]

**Minnesota**
The Remember Project

[Image: https://rememberproject.org/]

**Denton County, TX**
Dementia Friendly Nature Walks
Dementia Friendly Worship

[Image: https://dementiafriendlydentoncounty.org/programs]
Avenues for Creative Engagement

Opening Minds through Art
https://scrippssoma.org/

Time Slips
https://www.timeslips.org/

Giving Voice Chorus
https://givingvoicechorus.org/

Story Corps Memory Loss Initiative
https://storycorps.org/discover/memory-loss-initiative/
DFA Network Reach

- **41 States** have communities that are members of the DFA Network
- There are **over 400 DFA Communities** across the country.
- **23 State-led Efforts**: Alabama, Arizona, Arkansas, Delaware, Florida, Georgia, Hawaii, Illinois, Indiana, Iowa, Maine, Massachusetts, Minnesota, Mississippi, Nebraska, Nevada, New Hampshire, New York, North Carolina, Oklahoma, Utah, Virginia, West Virginia, Wisconsin
• Dementia Friends USA is part of a global social awareness movement.

• Participants attend a Dementia Friends champion-led session to learn about what it’s like to live with dementia and turns that understanding into action.

• Active in 30 states/territories through sub-license process
139,000+ Dementia Friends Across the U.S.
Contact Information

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dfamerica.org
dementiafriendsusa.org

Follow us on social media:
  • @dfamerica_ on Twitter
  • Search for Dementia Friendly America on Facebook
Memory Cafés

engAGED webinar: Tips and Best Practices for Helping People Living with Dementia Stay Socially Engaged and Connected

June 7, 2023

For more than 150 years, Jewish Family & Children’s Service has been helping individuals and families build a strong foundation for resilience and well-being across the lifespan.
Beth Soltzberg, LICSW, MBA
Jewish Family & Children’s Service, Greater Boston
• Coordinator, JF&CS Memory Café
• Founder/Director, JF&CS Memory Café Percolator
• Lead, Dementia Friends Massachusetts
• Leadership Team, Dementia Friendly Massachusetts
What we’ll cover

• 1-minute intro to memory cafés
• JF&CS Memory Café – why it works
• Percolator and other resources to help you start or sustain your own memory café
Key principles and aims of memory cafés

• Focus on social connection
• For people living with dementia and care partners
• For people with dementia due to any medical cause, at any stage of disease progression
• No one is asked their diagnosis
• Tailored to language and community, local interests/needs
JF&CS Memory Café
Assessing Impact:
Program Improvement vs. Outcomes

If you already received this survey by email and completed it electronically, then you do not need to complete this paper survey.

Dear JF&CS Memory Cafe Participant,

Please take a few moments to share your ideas and suggestions about the JF&CS Memory Cafe. Your responses will help us to improve this program. Your responses are anonymous.

We have learned over the past two years that some participants prefer in-person gatherings and some prefer virtual gatherings. We are exploring ways to meet everyone’s needs, including some in-person gatherings, as safety permits. Please let us know what you prefer.

1. How do you prefer to attend the JF&CS Memory Cafe? Choose the option that fits you best. Note that our in-person location is JF&CS headquarters, 1481 Main Street in Waltham. Please check one response below:
   - I can only attend if the gathering is held in-person. I cannot attend virtual gatherings.
   - I can only attend if the gathering is held virtually. I cannot attend in-person gatherings.
   - I could attend either in-person or virtual gatherings.
   - Other comments:

2. Please answer if you responded that you could attend either in-person or virtual (JF choose above, otherwise skip this question).
   - Do you have a preference for Memory Cafe gatherings? Please check one response below:
   - In-person
   - Virtually
   - Neutral, either in-person or virtual is fine with me.
"We Don't Feel so Alone": A Qualitative Study of Virtual Memory Cafés to Support Social Connectedness Among Individuals Living With Dementia and Care Partners During COVID-19, Masoud et al, 2021.

Five key themes were identified: (1) Reprieve; (2) What is still possible; (3) Connectedness; (4) Inclusivity; and (5) Value added (cognitive stimulation, education about dementia, learning about resources, helping others)

Full text here: 
Impact – participants who are living with dementia

• “It gives me a feeling of home.”

• “I love to know that this is not an end for me but the beginning of a different lifestyle.”

• I’ve made so many friends here. This is what we need – a place where we’re treated like everybody else.”
Impact – care partners

• “Joe is ready to come back next month. It is the first positive activity I have had in months.”

• “It was so good for me to see Dad having a good time and me being able to relax for a while!!! Thanks for all the pampering, too, I needed that!!!!”

• “For my husband who is living with younger Onset Alz, it truly is a "reset" button for him as no matter how his day starts, once we arrive he becomes calm and engaged. For me, it gives me a wonderful way to fill our hours with meaningful and enriching actives and wonderful social engagement opportunities”
Impact – volunteers

• Memory café has taught me the beauty and importance of a population that people my age tend to ignore.”

• Caring for people with dementia will be one of the most significant responsibilities of our generation …I find it both heart-warming and humbling to recognize that we must work at this together, in community…”
Make new friends – and help keep the old ones
Percolator resources: www.jfcsboston.org/Percolator

• All resources are FREE!
• Toolkit on starting/running in-person café; virtual/hybrid supplement
• Join our mailing list and Google group!
• Quarterly idea exchanges – next one is June 14!
• PSA videos in English, Spanish, Portuguese
• Guest artist directory
• Guide to encourage leadership and participation
• Many how-to videos; TEDx talk
Additional Resources

- engAGED Innovation Hub and 2023 What Works [https://www.engagingolderadults.org/hub](https://www.engagingolderadults.org/hub)


Individual or Regional Cafés

- [Massachusetts Memory Café Directory](http://www.memorycafedirectory.com)

- [Fox Valley Memory Project Cafés, Wisconsin](http://www.memorycafedirectory.com) and [Library Memory Project, Wisconsin](http://www.librarymemoryproject.org)

- [Memory Arts Café, NYC](http://www.memoryartscafe.org)
Contact Beth: bsoltzberg@jfcsboston.org
Social Engagement of Those with Dementia

The National Resource Center for Engaging Older Adults
Webinar 6-7-2023

Cheryl Dye, PhD. Clemson University, Institute for Engaged Aging
Caitlin Torrence, PhD., CU Office of Research and Organizational Development
Bailey Dull, MSML, Golden Corner Respite Care Program Director
Dementia Friendly America initiative

Community Assessment

Asset mapping

Collaboration, combination of resources

Brain Health Club

Golden Corner Respite Care Center
Dementia Friendly Communities

- Specialized residential options offering memory loss supports and services
- Dementia-aware and responsive legal and financial planning
- Welcoming and engaging communities of faith
- Dementia-aware and responsive banking practices
- Transportation, housing, and public spaces
- Understanding and supportive neighbors and community members
- Dementia informed local government emergency planning and first response
- Options that maximize independent living and sustain meaningful community engagement
- Businesses that foster customer service and environments that support customers with dementia and employee caregivers
- Health and long term care that promotes early diagnosis and specialized care and support throughout the care continuum
Assessment of Community Interest for Day Program

- Gathering of stakeholders
  - University faculty and students
  - Municipality / Church
  - AAA
  - Alzheimer’s Association
  - Community members
- Discussion of need
- Asset mapping & available locations
Values for Engaging Those with Dementia

• Day program with trained, compassionate staff,
• Respect for participant feelings & emotions, need to feel important and valued
• Social engagement with peers
• Activities - failure-free, variety – music, crafts, incorporation of individual interests
Solution – Combination of Resources

• University leadership, grant writing, and student contribution
• Graduate assistantship & undergraduate student funding
• Identification of location – church & closed senior center
• Collaboration with the church leadership / AAA site director
• Department on Aging Alzheimer's Resources Coordinating Center funds
• Respite waivers from the Alzheimer's Association
Establishment of Two Day Programs

- **Golden Corner Respite Care Program, established 2015**
  - Located within church,
  - Leadership by community board

- **Brain Health Club, established 2018**
  - Closed senior center that was renovated and reopened
  - Municipality and county resources
  - AAA services, after-school program, dementia day program

- Both programs originally staffed by CU students and doctoral student, currently part-time directors & community volunteers
Golden Corner Respite Care

- Arts and crafts
- Music
- Outside guests
- Brain games
- Application for funding to build a sensory garden
Central Community Center Renovation
<table>
<thead>
<tr>
<th>Participant outcomes</th>
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</thead>
<tbody>
<tr>
<td>• Cincinnati Observation Checklist</td>
</tr>
<tr>
<td>• Cohen-Mansfield Agitation Inventory</td>
</tr>
<tr>
<td>• Caregiver check-in</td>
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“My husband say today is the day that we go to the club”
Brain Health Club - Multigenerational programming

• Day program for those with dementia
• AAA services – congregate meal, exercise
• Daily after-school program for elementary students
In 2020, the Brain Health Club received an Aging Innovations and Achievement (AIA) Award from the National Association of Area Agencies on Aging.
Contact Information

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engAGED Resources

• New! 2023 What Works: Social Engagement Innovations and Best Practices
• Updated! A re-launched and updated Other resources:
  – Social Engagement Innovations Hub continues to grow
  – Community Awareness Toolkit
  – Tips for holding virtual events manual
  – Tips for hybrid events manual
  – Videos
  – Consumer brochures
• Monthly newsletter and blog
• www.engagingolderadults.org
Upcoming Social Media Campaign

• Taking place June 12-16
• Fill-in-the-blank social media campaign to show how individuals stay engaged
• Open to all! Aging Network and partner org staff, volunteers and consumers
How to Participate

• [www.engagingolderadults.org/2023-loneliness-awareness-week](http://www.engagingolderadults.org/2023-loneliness-awareness-week)

• Download the sign and add how you stay #SociallyengAGED

• Take a photo or make a video with your sign

• Post on social media with the hashtag #engAGEDandConnected and tag @engAGEDCenter
Commit to Connect

• Fostering a nationwide network of champions who are committed to addressing social isolation and loneliness
  • Online discussions
  • Communities of Practice
  • Engaging webinars
  • Peer Networking opportunities
  • Newsletter and resources

• Funded by ACL
• USAging serves as the Coordinating Center
• https://committoconnect.org/
Commit to Connect – Upcoming Webinar

• Date: Thursday, June 15
• Join Commit to Connect for a webinar highlighting state-level leadership in promoting social engagement and addressing social isolation and loneliness.
• Find out more information about the event and how to register on our website: www.committoconnect.org
Questions and Discussion

Please submit your questions or comments through the Q&A.
Join Us For More Discussion in the Office Hours!

Follow the Zoom link provided in the chat to join us now for Office Hours!

Thank you!