



## Q&A and Resources

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### **Person-Centered Supports for People with Dementia Living in the Community**

*An NCAPPS Webinar from November 2020*

#### ***Q1: What is a Memory Café?***

**Cynthia:** Memory cafes have been popping up across the United States (and abroad) as places where those with dementia and care partners can enjoy social activities and interactions. Some memory cafes are sponsored by the area Offices for the Aging. Some are being sponsored by faith communities and still others, by service organizations in the community. Some Memory Cafes do not charge participants and instead rely on grants and donations to cover their costs. Others may charge a participant/ per use fee. Many require an intake or a preregistration where an assessment is done of participants and to obtain both contact and basic health information- for safety's sake.. Some memory cafes are open daily for a several hours. Others are open less frequently- perhaps twice a month.. Many memory cafes require that a person living with dementia be accompanied by a care partner. Others welcome all living with dementia and do not require a care partner. If you are considering visiting a memory café, call ahead to check with the requirements, the hours, and other helpful information. Also check to ensure that the staff and volunteers have been trained in basic dementia care and basic first aid. Memory cafes go by different names such as “friendship clubs” but their goals are similar: to provide a gathering place for people living with dementia and care partners to have fun, to engage with others, and express themselves in a safe and caring environment.

#### ***Q2: If they cannot communicate effectively, is this due to misuse of words, memories, other?***

**Cameron:** Challenges in communication for persons with dementia have a variety of causes. Difficulty finding the words you want is common, and frustration at not having the word available adds to the difficulty. It is like having a word “on the tip of my tongue” – something all of us have experienced. It’s just that it can occur more often in persons with dementia. Sometimes this challenge at expressive communication is dealt with through the use of printed words and/or pictures or icon that a person can point at to assist with letting them express themselves. Speech pathologists use a device called a language board this way. Older adults with dementia also communicate through tone of voice and nonverbal signals, which is why it is important to monitor these forms of communication, to speak slowly so that you give the person time to process information, speak face-to-face and at their eye level, etc.

The Alzheimer’s Association has a web page that addresses this topic in more detail:



[https://www.alz.org/help-support/caregiving/daily-care/communications?gclid=EAlalQobChMIqbn7wKzO7QIVZVXVCh0vPwrqEAAAYiAAEgL4ZvD\\_BwE](https://www.alz.org/help-support/caregiving/daily-care/communications?gclid=EAlalQobChMIqbn7wKzO7QIVZVXVCh0vPwrqEAAAYiAAEgL4ZvD_BwE)

***Q3: My family have recently been noticing some signs [of dementia] with my mother, how would you recommend addressing this?***

**Cameron:** First, it would be important to have a discussion with your mother about this. What specifically are you noticing that are causes of concern? Does your mother notice them too? Is she concerned about them if she does?

Does your mother have a primary care physician? If so, has she discussed any of these things with her physician?

It is important to get information about what signs are generally indicative of dementia. The Alzheimer's Association has information on this, and possibly could provide some guidance on next steps.

I also would look into groups like Dementia Alliance International and ask people who have a diagnosis of dementia what might be the best way to approach this topic with your mother.

***Q4: Brian your story is so humbling....do you know any webinars/peer support groups for families that are helping loved ones with Alzheimer's?***

**Answered in chat:** The Alzheimer's Association has all sorts of webinars and engagement programs. You can find them at [communityresourcefinder.org](http://communityresourcefinder.org). My chapter has early engagement programs online most Fridays at 11 am and many support groups are meeting regularly over Zoom and via the phone. We also have a wonderful message board for caregivers and or people with dementia at [ALZconnected.org](http://ALZconnected.org); anyone can email me at [cprudhomme@alz.org](mailto:cprudhomme@alz.org) or call our helpline 1-800-272-3900 24 hours a day!

***Q5: I'd love to hear more about speech path as a diagnostic tool and how it can help improve functioning for people with dementia***

**Answered in chat:** [We had a question about the role of speech pathologists in supporting people with dementia. Here is one resource as a start.] Not Cured ... But Improved: As communication deteriorates for clients with Alzheimer's dementia, we can step in with conversational and memory supports that maximize their functioning.: The ASHA Leader: Vol 21, No 6

<https://leader.pubs.asha.org/doi/10.1044/leader.FTR1.21062016.44>



***Q6: I wanted to know if the Alzheimer's disease affects people who already have mental illness e.g. schizophrenia or bi-polar disorders more than the general population?***

**Cameron:** Persons with Alzheimer's disease or other forms of dementia also can develop or already have other psychiatric disturbances. This makes treatment and communication even more challenging.

In addition, persons can have more than one form of dementia at the same time. This is why it is very useful to get a diagnosis from a geriatrician or other specialist who has expertise with the complexities of diagnosing older adults with multiple conditions.

***Q7: Any housing or memory care facilities that accept people with no income?***

**Cameron:** This probably would involve a facility within a state that has a program called a Medicaid waiver, which allows Medicaid to pay for a person to live in a place that is not a nursing home.

***Q8: For driving, when is a good time to consider stop driving? I had a neighbor who was escorted by police home because he had lost his way. Another who has others drive his cars for him because he is afraid to advocate for himself in driving.***

**Answered in chat:** We had a question about driving and dementia. From the National Institute on Aging:

"Signs that the person should stop driving include:

New dents and scratches on the car

Taking a long time to do a simple errand and not being able to explain why, which may indicate the person got lost

Two or more traffic tickets or increased car insurance premiums

Comments from friends and neighbors about driving

Speeding or sudden lane changes

Confusing the brake and gas pedals

Recommendations from a doctor to modify driving habits

Other health issues that may affect driving ability, such as changes in vision, hearing, or mobility.

Some people with memory problems decide on their own not to drive, while others may deny they have a problem." <https://www.nia.nih.gov/health/driving-safety-and-alzheimers-disease>



***Q9: I oversee a guardianship program and work closely with our state's adult protective services. Do you have suggestions for applying person-centered planning when working with people living with dementia who are experiencing abuse, neglect, financial exploitation, or self-neglect? How to balance the sometimes-conflicting goals of self-determination and dignity of risk with protection from harm?***

**Cameron:** I think the staff of the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) who organized this panel discussion would be an excellent resource for you.

***Q10: What advice would you have for family members who cannot see their parents during COVID and so everyone is missing the social connections, but we on the outside can't really tell what is going on with them? And their use of technology is spotty and the facility does not support them to use Zoom?***

**Answer in chat:** Consider using Google Duo as a way of communicating with family/friends etc. at a distance, but in real time.

***Q11: While I appreciate that these folks have been diagnosed with Alzheimer's, there are many more types of dementia. Can you address some of their differences?***

**Cameron:** The Alzheimer's Association has a useful handout on this topic. Here is the address for a downloadable pdf:  
<https://www.alz.org/media/Documents/inbrief-differentiating-dementias.pdf>

***Q12: Can you provide resources / literature on the Montessori approach to dementia / Alzheimer' care?***

**Answered in chat:** Dr. Camp has great resources on Montessori approach to Dementia here <https://www.cen4ard.com/product-category/books-manuals/>

***Q13: To Dr. Camp... Are there any studies that show person-centered practices extend the early stage of dementia, delay facility placement or help some other dependent variable?***

**Cameron:** There is little research on this topic, but it certainly needs to be done.



## **Resources**

Working/ Not working: [We have several questions about dignity of risk and how to be sure people remain healthy and safe. It becomes an on going discussion and is important for everyone to be heard. One resource that may be helpful is "what's working/not working"] <https://www.sdaus.com/copy-of-communication-chart-1>

Rural Dementia Caregiver Project: <https://caregiverproject.ucsf.edu/>

Dementia Action Alliance: [www.daanow.org](http://www.daanow.org)

Free COVID-19 Dementia Resources, Center For Applied Research In Dementia:

<https://www.cen4ard.com/what/free-resources/>

Alzheimer's Foundation of America: [www.alzfdn.org](http://www.alzfdn.org)

Alzheimer's association, Greater Maryland Chapter: <https://www.alz.org/maryland>

AGE of Central Texas: <https://ageofcentraltx.org/>

A-LIST, UsAgainstAlzheimer's: <https://www.usagainstalzheimer.org/networks/A-LIST>

InterCare: [www.myintercare.com](http://www.myintercare.com)

Memory Café Directory: <https://www.memorycafedirectory.com/what-is-a-memory-cafe/>

Alzheimer's Café: A Place for Patients, Caregivers to Recharge, Share Life Stories -

AARP Bulletin: <https://www.aarp.org/health/conditions-treatments/info-04-2011/alzheimers-cafe-a-place-to-recharge.html>

How to start a memory café: <https://www.memorycafedirectory.com/how-to-start-a-memory-cafe/>