

Question & Answer (Q&A): Navigating COVID-19: Supporting Individuals with Dementia and Their Caregivers

Webinar participants asked these questions during the June 2020 Navigating COVID-19: Supporting Individuals with Dementia and Their Caregivers webinar. We have edited speakers' responses for clarity. The webinar recording, slides, and transcript can be found on the Resources for Integrated Care website:

https://www.resourcesforintegratedcare.com/Older_Adults/2020_Webinar/COVID-19_Supporting_Individuals_with_Dementia_and_Caregivers

Featured Speakers:

- Freddi Segal-Gidan, PA, PhD; Director, University of Southern California USC-Rancho California Alzheimer's Disease Center (CADC); Associate Professor of Clinical Neurology and Family Medicine, Keck School of Medicine of USC
- Joseph Herrera, MSW; Director, Outreach and Education, USC-Rancho CADC
- Jennifer Schlesinger, MPH, CHES; Associate Vice President, Healthcare Services and Community Education, Alzheimer's Los Angeles
- Tom von Sternberg, MD; Senior Medical Director of Geriatrics, Home Care, and Hospice Case Management, HealthPartners

COVID-19 Prevention People With Alzheimer's Disease and Related Dementias (ADRD) and Their Caregivers

Q1: What are some strategies for COVID-19 infection control for people with ADRD?

Dr. Tom von Sternberg: There are several considerations related to COVID-19 infection control for people with ADRD. Instead of using a mask that loops around the ears or ties behind the head, try using a neck gaiter or other clothing that can be pulled up over the face like a turtleneck. If a mask covers the nose and mouth, it should suffice. Overall, I think delicate, calm, and reassuring reminders to wear masks can be helpful for individuals with ADRD.

However, we should adjust our expectations about the importance of a person with ADRD wearing a mask and focus instead on making sure that others around the person with ADRD are taking precautions. I think maintaining physical distancing and ensuring those near the person with ADRD are wearing masks is just as important, or more important, than relying on the person with ADRD to wear a mask.

Joseph Herrera: Caregivers can explain and demonstrate proper infection control protocols to the person with ADRD, including thorough handwashing and the use of alcohol-based hand

sanitizer if soap and water are not available. Additionally, care managers may suggest that the caregiver ask their pharmacy about home delivery or mail-in prescriptions to limit the caregiver's exposure to COVID-19. Generally, when suggesting infection control measures to caregivers, care managers should bear in mind that each family is unique and has distinct needs.

Q2: Due to loosening restrictions and states reopening, some family caregivers feel that the COVID-19 pandemic is "over" and that taking proper precautions is no longer as important. How can care managers reemphasize the importance of these measures?

Joseph Herrera: As of now, the pandemic is not over. The risk of infection is genuine, and the impact of COVID-19 has not changed, especially in vulnerable populations. COVID-19 has had a devastating effect on people with ADRD, as well as on their caregivers and families, and we need to protect everyone, including people with ADRD and others at high risk. Care managers can continue to encourage caregivers and family members to limit outings, wear a mask, wash hands frequently, avoid touching their face, observe social distancing, and stay home if they are feeling sick. Care managers can underscore that even if your state is officially "open," there is still a risk of infection.

Supporting Caregivers of People with ADRD During COVID-19

Q3: How can we best support families who are unable to visit or communicate with their loved ones in long-term care facilities that are closed to visitors during COVID-19?

Jennifer Schlesinger: Many families cannot visit their loved ones in long-term care facilities during the public health emergency, but facilities can still arrange virtual video (e.g., FaceTime, Zoom, Google Duo, Facebook Messenger, etc.) visits. Staff can provide a tablet and help with the technology, as someone with ADRD may be unable to navigate it on their own. Staff may also be able to coordinate a safe visit with the family, such as with the person with ADRD sitting near a window, and their family greeting them from outside. Families can also get creative and bring gift baskets with snacks, notes, drawings, lotions, or photos to comfort the person and help them feel at home.

The current public health emergency is exceptionally challenging, so I also want to suggest that families consider participating in a telephonic or virtual support group, especially if you can find one that's specifically for caregivers and families of people with ADRD in facilities. The public health emergency is a very challenging situation, and sharing with others can help.

Q4: What are good ways to check in with caregivers who are busy and may not have time to participate in something like a telephonic support group?

Joseph Herrera: I would suggest care managers develop a check-in system, even if it is just a quick text or phone call. Care managers can ask how the caregiver is doing, what challenges they are experiencing, and how to best support them. Technology is essential during the public health emergency and even if the caregiver does not have access to other technology, they most likely have access to a phone. The care manager can initiate contact and keep the caregiver and family informed about telephonic/virtual support groups, counseling, and educational events occurring online at different organizations. These programs can help caregivers connect and learn new information about managing their caregiving responsibilities. I would recommend that care managers stay informed about current policy by connecting to local and national advocacy organizations. Finally, care managers should remember that while caregivers may not always be able to initiate the contact, they likely still need assistance and support.

Q5: In instances where nursing home care is likely the appropriate level of care for a person with ADRD, what can facilities do to reassure families concerned with COVID-19 infection risk?

Dr. Freddi Segal-Gidan: The key is open, frequent, and regular communication between the facility and the family. The facility should provide in writing what procedures they have put in place to minimize COVID-19 infection risks for their residents and staff, including what training personnel receive, how often it is repeated, and the name of a designated staff person who can answer any specific questions family members may have. The facility could also provide regular (I would suggest bi-weekly at a minimum) updates through email or telephone calls to family members about infection rates and changes in procedures. If possible, a daily text to family from the facility providing updates on numbers of residents and staff tested and number of positive tests would be ideal.

Q6: What recommendations do you have for families who are selecting facilities for their family members with dementia during COVID-19?

Dr. Tom von Sternberg: Although not a guarantee, a facility with a higher Five Star Quality Rating that accepts both Medicare and Medicaid has a better chance of operating with greater attention to COVID-19 infection control. The Five Star Quality Rating System, developed by the Centers for Medicare & Medicaid Services, assists consumers, families, and caregivers in comparing nursing homes, using ratings on a scale of one to five stars. More information on how to use Five Star Quality Ratings can be found [here](#).

Families can also review how a facility performs on state nursing home surveys; these should be publicly posted on the state Department of Health website. It would also be helpful to directly ask the facility administrator what trainings they have implemented related to infection control

and personal protective equipment (PPE) use, as well as how well stocked they are with PPE. Their answer will demonstrate how much attention they are paying to COVID-19 prevention.

Additional Resources

Q6: Do you have any recommendations on respite resources or supports that are available for caregivers of individuals with ADRD?

Jennifer Schlesinger: There are Alzheimer's organizations throughout the United States that provide a variety of supports and services to families. Some Alzheimer's organizations or caregiver support organizations may have respite funds available to help families in need. Some healthcare organizations also offer respite to families in need. Families who are in need of respite or other supports can contact their local Alzheimer's organization, some of which can be found using the [Alzheimer's Association Local Chapter Finder](#). There may also be other organizations that serve caregivers within the community that offer respite.

Joseph Herrera: Depending on your state of residence, there may be agencies or organizations that can provide paid hours of respite for the caregiver. I would encourage care managers to search for those organizations and have the contact information in their toolkit to assist caregivers. Care managers should have accurate and updated information tailored to the state and city where the caregiver resides. There are also home health organizations that can provide respite for a fee. For referrals, care managers can contact the nearest Alzheimer's service agency or organizations.

Additionally, the Alzheimer's Association has a [24-hour hotline](#) (800-272-3900) staffed with Social Workers to provide on-demand counseling, stress management, and other services, resources, and referrals.

Q7: Do you have any strategies for supporting caregivers of people with ADRD in using technology during COVID-19?

Joseph Herrera: COVID-19 has pushed people to use technology more. While social distancing is required to save lives, it creates numerous challenges, especially for caregivers and people with ADRD. However, caregivers who may have been wary of technology previously are now more aware of the benefits. Smartphones are being used at higher rates and in different ways, and many caregivers are learning more about using such devices, if they have access to them. The digital transformation they are going through, in part due to COVID-19, has enabled many caregivers to learn how to navigate the internet, social networks, and make video calls. Care managers can leverage caregivers' new skills to teach them how to access resources, support groups, on-demand counseling, and other services that require the use of technology.

Dr. Tom von Sternberg: HealthPartners offers iPads as a supplemental benefit to members and caregivers, as iPads can support caregiver education, care management, cognitive exercises, communication and video services, and safety promotion. However, not all members and caregivers are familiar with this technology, so we also offer technical support to help get them started.

Q8: Are there any resources related to ADRD and COVID-19 in languages other than English?

Jennifer Schlesinger: Alzheimer's Los Angeles has free, downloadable [caregiver tip sheets](#) on COVID-19 and dementia available in Spanish as well as English.

Joseph Herrera: Some excellent resources would be the [Alzheimer's Association](#), [AARP](#), the [Centers for Disease Control and Prevention](#) (CDC), [Us Against Alzheimer's](#), and the COVID-19 information phone number for the city where the caregiver resides. All of these organizations provide services in multiple languages and offer referrals and resources.

Dr. Freddi Segal-Gidan: Different communities have begun to develop materials about COVID-19 in different languages. The CDC produces online resources in [Spanish](#), [Chinese](#), [Korean](#), and [Vietnamese](#). They offer print materials in Spanish as well. Alzheimer's organizations in other countries have also developed materials in their respective languages, and some of these are posted on their websites.