Navigating COVID-19: Supporting Individuals with Dementia and their Caregivers

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Navigating COVID-19: Supporting Individuals with Dementia and their Caregivers
Support Statement

- This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to dually eligible beneficiaries, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar.

- To learn more about current efforts and resources, visit Resources for Integrated Care at: https://www.resourcesforintegratedcare.com or on Twitter @Integrate_Care
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Introductions

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■ Freddi Segal-Gidan, P.A., Ph.D.
  Director, USC-Rancho CADC
  Assistant Professor Clinical Neurology and Family Medicine, Keck School of Medicine of USC

■ Joseph Herrera, MSW
  Director, Outreach and Education, USC-Rancho CADC

■ Tom von Sternberg, MD
  Medical Director - Medicare, MSHO Care Management and Government Programs, HealthPartners
Learning Objectives

- Describe how COVID-19 may present in older adults with Alzheimer’s disease and related dementias (ADRD), and unique challenges facing individuals with ADRD and their caregivers during the COVID-19 public health emergency
- Identify strategies for supporting family and friend caregivers of older adults with ADRD during COVID-19 to build a daily routine, implement and use infection prevention measures, and plan ahead in case of COVID-19 diagnosis
- Identify key considerations for providing care to people with ADRD diagnosed with COVID-19 across health care settings
Webinar Outline

- Polls
- Dually Eligible Beneficiaries, ADRD, and COVID-19
- COVID-19 – Considerations for People with ADRD and their Caregivers
- Considerations for Providers and Health Care Systems
- Supporting People with ADRD and Caregivers at Home during COVID-19
- Role of Health Plans in Supporting Members with ADRD during COVID-19
- Resources during COVID-19
- Audience Q&A
- Evaluation
- Resources
Dually Eligible Beneficiaries, ADRD, and COVID-19

Jennifer Schlesinger, MPH, CHES
Associate Vice President, Healthcare Services and Community Education, Alzheimer’s Los Angeles
Dually Eligible Beneficiaries and COVID-19

- The current COVID-19 emergency presents new and unique challenges for individuals diagnosed with Alzheimer’s disease and related dementias (ADRD)
- Challenges may be particularly pronounced for individuals dually eligible for Medicare and Medicaid
  - 23% of all dually eligible individuals have ADRD\(^1\)
  - Many dually eligible individuals have complex healthcare needs and unmet social needs, which can result in worse outcomes\(^2\)
ADRD and COVID-19 – Parallel Risk Factors for Dually Eligible Individuals

- People over 65, including many dually eligible individuals, are at increased risk for both ADRD and for COVID-19
  - Older age often results in worse COVID-19 outcomes, and case fatality rates increases with age\(^4,5\)
  - 80% of COVID-19 deaths in the United States are in people over 65\(^6\)

- People with ADRD often have multiple co-existing conditions, representing a greater risk for developing a serious COVID-19 infection\(^3\)
  - ADRD is often a hidden co-morbidity in older individuals with COVID-19 infections, particularly nursing home residents, who are especially vulnerable at this time\(^8\)

- Almost 50% of dually eligible individuals are of a racial or ethnic minority group\(^4\)
  - Older Hispanics/Latinos and Blacks/African Americans are one and a half to two times as likely to have ADRD than non-Hispanic whites\(^5\)
  - COVID-19 illness and death are disproportionally affecting racial and ethnic minority groups\(^6\)
49% of dually eligible individuals receive long-term services and supports (LTSS)\(^7\)

- 50% of people living in nursing homes have ADRD\(^8\)
- 27% of COVID-19 deaths occur in long-term care facilities\(^9\)

Home and community-based services help provide alternatives to nursing homes, but services may be limited due to COVID-19-related stay-at-home orders and physical distancing measures

- Reduced access to these services puts additional strain on families, as well as healthcare professionals
COVID-19 – Considerations for People with ADRD and their Caregivers

Freddi Segal-Gidan, P.A., Ph.D.
Director, USC-Rancho CADC
Assistant Professor Clinical Neurology and Family Medicine, Keck School of Medicine USC
Clinical Presentation of COVID-19 in People with ADRD

- COVID-19 can present as delirium and other cognitive changes in people with ADRD
  - Delirium is often a presentation of underlying hypoxia, a result of lack of oxygen flow to brain, due to the COVID-19 infection reducing respiratory function\(^{18}\)

- Delirium often presents as:\(^{19}\)
  - Change in consciousness (including sleeping very little, or sleeping for a longer period of the day)
  - Impaired attention
  - Sleep/wake cycle disturbance
  - Hallucinations
  - Emotional disturbances
Clinical Presentation of COVID-19 in People with ADRD (cont.)

- Caregivers should be aware that older adults with COVID-19 may not present with typical symptoms, such as cough and fever.\(^{20}\)
- If people with ADRD do experience symptoms, they may not be able to alert a caregiver.\(^{20}\)
- Changes in the following are potential signs of a COVID-19 infection:\(^{21}\)
  - **Cognition**
    - Increased confusion
    - Slower processing (e.g., inability to do things as quickly or difficulty in following directions)
  - **Function**
    - Decline in usual abilities (e.g., harder time dressing, toileting)
  - **Behavior**
    - Enhanced response may present as anxiety, agitation, or aggression
    - Hypoactive response may present as apathy, depression, fatigue, or increased sleep
Changes to Home Environment and Routines

- Majority of people with ADRD live at home, and home environments and routines are impacted by COVID-19
- During COVID-19, people with ADRD may:
  - Be unable to attend adult day programs
  - Be unable to go outside or on walks as often as they are used to
  - Nap more during the day
  - Experience difficulties in communicating with caregivers due to use of masks
  - Experience difficulties in understanding the pandemic and why these changes are occurring
  - Experience distress at wearing or trying to wear a mask
  - Experience distress if there is a change in caregiver
Changes to Home Environment and Routines (cont.)

- Home environment and routine changes can lead to behavior changes in people with ADRD, including:
  - Boredom, loneliness, and anxiety due physical distancing and cancelled/closed programming
  - Confusion and disorientation due to difficulty in understanding the pandemic and associated changes, including use of masks and changes in caregivers
  - Irritability and agitation due to frequent requests for handwashing and other infection control measures
  - Sleep difficulty and increased wandering and pacing associated with frequent daytime naps

- Caregivers and family members may be spending more time around the person with ADRD, and may develop an increased awareness of limitations of the person they are caring for
COVID-19 – Considerations for Providers and Health Care Systems

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Health Systems Supporting People with ADRD during COVID-19

- Health plans and providers can establish and implement specific strategies for working with the following populations:
  - For people with a known ADRD diagnosis:
    - Reach out to these individuals, their family, and caregivers to provide information on the signs of COVID-19 infection
    - Educate staff on how to handle a call about an infection that may be COVID-19
  - For people who may have ADRD, but are not diagnosed:
    - Establish steps to take if someone presents with delirium, confusion, changes in alertness, or other signs of ADRD
    - Consider if there is an underlying missed dementia
  - For people without an identified cognitive issue who present with delirium:
    - Recognize delirium is often the first presentation of underlying dementia, but that not everyone with delirium has known or undiagnosed dementia
Additional ways health plans and providers can support individuals with ADRD at the health system level include:

- Ensuring all levels of the health system are aware of the threat that COVID-19 presents to the ADRD population
  - Consider implementing geriatric interdisciplinary care teams
  - Look for opportunities for integration of dementia care across your organization
  - Use a dementia care navigator position to assist caregivers and families of patients with ADRD
  - Identify a primary contact person, and time for regular updates, for any hospitalized person with ADRD
Hospital and ICU Considerations for People with ADRD

- Minimizing hospitalizations and Intensive Care Unit (ICU) placements for people with ADRD is the goal
  - This requires family and caregiver support strategies, enhanced outreach, and sustained engagement with the person with ADRD and their family/caregiver prior to COVID-19 infection

- Prior to a potential hospitalization, families/caregiver(s) should develop a detailed plan in event of a COVID-19 admission
  - Include medication, co-morbidities, primary language, severity of dementia, and name and contact number for a family member or other primary contact person at the time of admission
  - If not provided at admission, request this information in order to deliver person-centered care
People with ADRD require different interventions than others receiving care in the hospital:

- Create a plan to prepare staff to care for people with ADRD in the ICU
  - Develop this plan with representatives of all staff who work in the ICU, including nurses, doctors, sanitation staff, etc.

- Personalize care
  - Request staff include a picture of their face and name on their gowns to help people with ADRD see the worker behind the personal protective equipment (PPE)
Hospital and ICU Considerations for People with ADRD (cont.)

- Isolation, use of gowns and masks, noise from machines, and general hospital noise can cause:
  - Confusion and insecurity
  - Sleep problems
  - Anxiety, agitation, hostility, and refusal of treatment
  - Hearing difficulties related to mask use

- Prepare for these behavioral changes by:
  - Assigning a care manager to provide additional bedside contact and direct communication with family/caregiver(s)
  - Using technology (e.g., FaceTime, iPads, Zoom, Skype) to improve communication between the person with ADRD and their family/caregiver(s)
    - Including training on this technology as part of expected practice for providers
Case Study: Mrs. C

Mrs. C phones and informs the primary care provider (PCP) that Mr. C, who has been diagnosed with Alzheimer’s disease (mild/early stage), fell in the bathroom three days ago, has been in bed sleeping a lot, is more confused, and today has a cough and fever of 100.0 F. She is worried he may have COVID-19 and is not sure what to do.
Case Study: Mrs. C (cont.)

- The PCP reassured Mrs. C that she did not need to call 911 or bring Mr. C to the hospital yet, based on his symptoms.
- The PCP shared education with Mrs. C about how to treat Mr. C aggressively at home with the following:
  - Antipyretic (Tylenol) to reduce fever
  - Hydration
  - Waking every few hours
- The PCP told Mrs. C to bring Mr. C to the hospital if:
  - He became unarousable
  - He was unable to walk to the bathroom
  - His fever escalated
Case Study: Mrs. C (cont.)

- Additionally, the PCP:
  - Discussed the possibility of testing (dependent on location, availability, and accessibility)
    - Testing for people with ADRD presents unique challenges, including cooperation needed for swabbing and for blood tests
  - Monitored progression by following up every two days
  - Recommended a home health assessment
Supporting People with ADRD and Caregivers at Home during COVID-19

Joseph Herrera, MSW
Director, Outreach and Education, USC-Rancho CADC
“Care for the Dyad”: Preventing acute infection in both the person with ADRD and the caregiver(s) is important.

Prevention measures may be challenging when caring for people with ADRD:

- Physical distancing is not possible for caregivers living in the home and difficult to do with any caregivers not living in the home who are entering the house.
- Use of PPE, such as gloves and masks, can be frightening or confusing for someone with ADRD.
- People with ADRD need extra reminders and support related to proper hygiene.
Preventive Measures for Caregivers

- Caregivers can help prevent COVID-19 infection by:
  - Posting written reminders related to hygiene around the house
  - Observing physical distancing when outside of the house
  - Cleaning and disinfecting all surfaces around the house regularly

- To minimize risk of transmission in households with two or more people:
  - Be hyper-vigilant about personal hygiene
  - Demonstrate proper hygiene practices frequently
  - Observe all infection guidelines before contact with person with ADRD
  - Observe physical distancing guidelines
Planning Ahead for a COVID-19 Infection in Caregivers

- To prepare for a possible COVID-19 infection in caregiver(s):
  - Identify and designate alternate caregiver(s)
    - Ensure the alternate caregiver’s information is readily available, including phone number, email address, etc.
    - Identify who will serve as the person with ADRD’s legal representative
  - If an alternate caregiver does formally take over as the person with ADRD’s legal representative:
    - This requires signing a new advance healthcare directive, updating a Power of Attorney (POA), or updating a living will
    - This must be completed while the person with ADRD still has decision-making capacity
    - Some states are allowing virtual notarization of POAs during COVID-19
Planning Ahead for a COVID-19 Infection in Caregivers (cont.)

- Compile a guide for potential alternate caregiver(s), including:
  - Medication management plan, including types of medication, dosage, and times to administer
  - Provider information
  - Notes on likes and dislikes, routines, and preferred foods, books, films, or other activities

- Decide if the person with ADRD can stay in place or elsewhere
  - Determine if there is enough room in the home for the caregiver to safely isolate in place
  - Consider how a change in location or caregivers may affect the person with ADRD
Create or update advance healthcare directives for both the caregiver(s) and the person with ADRD. Developing an advance healthcare directive includes:

- Identifying a legal representative
- Organizing any documentation that may be needed (e.g., living trust, advance directive, POA, will)
- Developing an information toolkit (including documentation of any medical issues, list of medications, and allergies)
- Caregivers will also need to identify who will care for the person with ADRD in case they become ill
COVID-19 Infections in Caregivers

- If the caregiver(s) develops a COVID-19 infection:
  - Isolate immediately to avoid contact with person with ADRD
  - Contact the alternate caregiver(s) to take over care. Be aware that bringing anyone into the home increases the risk of COVID-19 exposure/transmission, and address this risk by:
    - Requiring they check their temperature before entering the home
    - Requiring they wear a mask in the home
    - Determining if they have been exposed to anyone who has tested positive for COVID-19
    - Ensuring they wash their hands when entering the home and regularly throughout the day
    - Suggesting they disinfect frequently touched surfaces
In the event the person with ADRD becomes distressed by their typical caregiver’s absence

- Provide reassurance; “I’m here”
- Acknowledge loss: “I know you miss _____. I do too”
- Be positive: “You will see them again soon”
- Remember the person with ADRD doesn’t have the same sense of time
Considerations for Health Plans and Providers

- Health plans and providers can help to assist caregivers of adults with ADRD in their response to COVID-19 by:
  - Providing support in the face of additional caregiver burden
  - Identifying and supporting this population’s unique needs
  - Helping to develop daily routines
  - Providing support for first-time caregivers
  - Identifying considerations related to cultural competence
Supporting Caregivers

- Recognize that caregivers are also experiencing increased burden during this time

Help to support caregivers by:
- Addressing possible increased stress, depression, and anxiety
- Using a coaching/modeling technique to help develop responses to the person with ADRD
- Scheduling check-ins to provide support via telehealth, phone, or text

Encourage caregivers to:
- Identify family and friends who may be able to assist with caregiving responsibilities, even if not in-person
- Recognize and vocalize when they need this outside assistance
- Adjust expectations
  - Understand that infection control protocols like proper handwashing will be extremely difficult to achieve in this population
As the emotional and physical needs of people with ADRD may change as a result of COVID-19, coach caregivers in strategies for:

- Helping people with ADRD feel calm, safe, and secure
- Reassuring and redirecting people with ADRD
  - Preparing for normal activities to take longer than usual
  - Preparing to repeat yourself
  - Using “I” not “you”
  - Remembering to be adaptable and flexible
- Providing rewards, including favorite foods, music, games, and activities
Developing Routines

- Support caregivers in creating a routine and schedule, in order to minimize anxiety and behavior changes, such as:
  - Developing an in-home activity plan (e.g., arts and crafts, painting, playing music, gardening, watching family videos, etc.)
  - Turning tasks into a game (e.g., incorporating singing into handwashing)
  - Emphasizing the importance of maintaining a daily routine that includes:
    - Regular meal times
    - Scheduled activities throughout the day, including:
      - Video-chatting with loved ones
      - Watching favorite TV shows
      - Using telehealth for regular appointments with clinicians
    - Limited daytime naps
Supporting First-Time Caregivers

- Some family members have taken on caregiving responsibilities for the first time during COVID-19
  - Provide education about ADRD and COVID-19
    - Underscore that ADRD is more than just memory loss, and that there are also associated behavioral changes including anger, suspicion, confusion, agitation, etc.
  - Share tips on how to discuss potentially sensitive topics, including finances/bills
Supporting First-Time Caregivers (cont.)

- Understand they may be overwhelmed
  - Be present with the caregiver
  - Acknowledge you understand how hard the situation is for them, and offer emotional and moral support
  - Underscore the importance of self care

- Reiterate that caregivers can receive support from others, even if physically distanced
  - Suggest reaching out to friends, family, the Alzheimer’s Association, AARP, the American Psychological Association, and other resources
COVID-19 Health Disparities

- The CDC reports that COVID-19 is disproportionately affecting African American, Latino, and Asian communities in terms of infection rates and mortality due to a combination of factors, including:
  - Reduced access to health care
  - Higher prevalence of chronic health conditions
  - Lower socioeconomic status
  - Higher likelihood of living in densely populated areas and areas with less access to healthy food
- COVID-19 and ADRD both disproportionately impact communities of color
Identifying Cultural Considerations

- In the event of a COVID-19 diagnosis in a person with ADRD, determine any potential cultural considerations by:
  - Identifying any religious beliefs that providers should consider, including:
    - Altruism when family member is ill
    - Belief that health will be restored
    - Power of prayer
  - Identifying multi-generational households, and the possibility of multiple family caregivers
  - Determining if the legal representative and caregiver are the same person in order to appropriately direct questions
Case Study: Mr. F

- Mr. F is in the hospital with COVID-19. He also has mid-stage Alzheimer’s disease. Mr. F’s family believes it is important to be by the bedside of their loved one when he is ill. This is especially important because Mr. F can become agitated when he is in an unfamiliar environment and with unfamiliar people.
Case Study: Mr. F (cont.)

- In order to support Mr. F and his family, providers:
  - Worked with the family to document necessary information, including:
    - Spiritual and religious needs
    - Knowledge of care needs, including needed assistances with bathing, eating, or toileting
    - Any communication challenges – verbal, non-verbal
    - Any previous issues with wandering, getting lost, falls, suspiciousness, or delusional behavior
  - Discussed Mr. F’s medical condition with his family using open and honest conversation
  - Anticipated that isolation could cause anxiety for both Mr. F and his family, and communicated with the family about Mr. F’s safety and wellbeing
Role of Health Plans in Supporting Members with ADRD during COVID-19

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HealthPartners, Inc.
HealthPartners Dementia-Friendly Care Model

- HealthPartners’ Minnesota Senior Health Options (MSHO) supports dementia-friendly care management and coordination
  - COVID-19 has only increased the need for dementia-friendly care practices, as people with ADRD and their families have increased needs during this time
- HealthPartners’ MSHO supports members with ADRD and their families through:
  - Proactively identifying the ADRD population
  - Offering dementia-friendly supplemental benefits
  - Providing dementia-specific education for case managers and care coordinators
  - Communicating with members with ADRD, their families and caregivers, and providers
Identifying the ADRD Population

- Proactively identify the member population with ADRD, as well as their caregivers, in order to connect them to support resources and supplemental benefits
  - This is a best practice in general but is especially important during COVID-19
  - Prioritize outreach to people with ADRD and their caregivers, as this population will have increased risks and gaps in care as a result of COVID-19
    - Outreach and identification can be supported by the use of claims data, health risk assessments (HRAs), and established care management assessments

Offering Dementia-Friendly Supplemental Benefits

- HealthPartners offers a variety of supplemental benefits to their general members that may be particularly supportive for people with ADRD and their caregivers, including:
  - Telephonic caregiver supports, including training, coaching, and counseling
  - Technology benefits, including iPads, personal emergency response systems, motion sensor-operated lighting, and animatronic cats
  - Nutrition services, including home-delivered meals

- COVID-19 has limited access to some supplemental benefits, including:
  - Day centers
  - Home-based services and education
  - Consistent transportation options
Educating Case Managers and Care Coordinators

- Provide education to case managers/care coordinators on dementia-friendly care coordination and management practices in a COVID-19 environment, including on:
  - Medication management
  - Supports and education for caregivers
  - Availability of day centers and community support resources
  - Advance directives and goals of care
  - Access to palliative care and hospice
  - Supplemental benefits that may be particular helpful for people with ADRD and their caregivers
Communication

- Encourage strong and frequent communication between members, caregivers, families, case managers/care coordinators, and providers
  - Highlight the availability of various communication methods, including telephonic, Google Duo (allows for multiple people to video chat, can include an interpreter), and face-to-face with appropriate PPE
  - Communicate with caregivers and family members about COVID-19 related service disruptions to be aware of, including medication delivery, meals and other services, and transportation
  - Discuss goals of care and advance directives with the member, and their caregiver or family
  - Be aware of caregiver stress, and provide supports
    - Calm and comfort the caregiver
Individuals Living in Nursing Homes

- COVID-19 has particular implications for people with ADRD living in nursing home settings
  - Nursing homes may have differing levels of ability to respond to COVID-19 needs, depending on proximity of residents in shared rooms, staff working in multiple facilities, level of training and preparedness, access to testing, frequency of testing, and rates of asymptomatic testing
Supporting Members Living in Nursing Homes

- To support members with ADRD and their caregiver(s)/families, health plans can:
  - Counsel the caregiver(s)/families about the hospital experience of COVID-19, including information about admissions in people with advanced ADRD
  - Emphasize the importance of advance directives and goals of care, and support people with ADRD and their caregiver(s)/families in developing these materials
  - After a hospital stay, determine whether the person with ADRD wishes to return to a nursing home or another setting (at home, private facility, independent living)
    - Depends on how much support they need with Activities of Daily Living (ADLs), as well as available resources
  - Communicate about the availability of virtual/telephonic palliative care and hospice services, when appropriate
Resources during COVID-19

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Associate Vice President, Healthcare Services and Community Education, Alzheimer’s Los Angeles
ADRD Support During COVID-19

- Support from Alzheimer’s organizations is available nationwide
- Examples of supports from Alzheimer’s Los Angeles:
  - Web Chats
  - Telephonic care counseling
  - Virtual support groups
  - Virtual Alzheimer’s classes and caregiver education
  - Virtual activity programs
COVID-19 Caregiver Tip Sheets

COVID-19 is disrupting routines and turning care for someone with dementia into a potential nightmare for families. Below please find four tip sheets to help caregivers manage those living with dementia during these difficult times.

**English**
- HYGIENE
- PLANNING
- STRESS
- ROUTINES

**en Español**
- HIGIENE
- PLANES
- MANEJANDO EL ESTRES
- RUTINAS Y ACTIVIDADES

To download the tip sheets: [www.alzheimersla.org/covid-caregiver-tip-sheets/](http://www.alzheimersla.org/covid-caregiver-tip-sheets/)
Health Care Person-Centered Profile

The National Center on Advancing Person-Centered Practices and Systems, a joint initiative between the Administration for Community Living and the Centers for Medicare & Medicaid Service, has developed a Health Care Person-Centered Profile tool to assist with COVID-19 person-centered care planning.

The tool includes:

- A Health Care Information sheet for capturing brief and vital information about the person’s health status, contact information, and information related to the existence and location of advance directives.
- A Health Care Person-Centered Profile for describing who the person is, what is most important to the person, and how best to provide support.

The tool, instructions, and samples are available at: [https://ncapps.acl.gov/covid-19-resources.html](https://ncapps.acl.gov/covid-19-resources.html)
Questions and Answers

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Thank You for Attending!

- The video replay and slide presentation will be available at: https://www.resourcesforintegratedcare.com
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Webinar Evaluation Form

- Your feedback is very important! Please take a moment to complete a brief evaluation on the quality of the webinar. The survey will automatically appear on the screen approximately a minute after the conclusion of the presentation.

- We would also like to invite you to provide feedback on other RIC products as well as suggestions to inform the development of potential new resources: https://www.research.net/r/MVGNWVJ
Resources

- Alzheimer's Association National Website
  - Find your local chapter
- American Geriatrics Society Website
- Alzheimer's Los Angeles
Sources


Sources


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