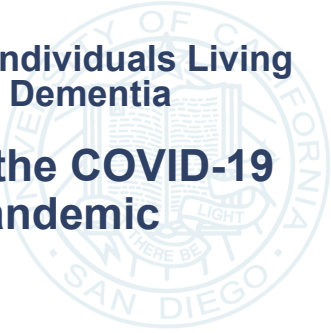


Caring for Individuals Living with Dementia During the COVID-19 Pandemic



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Daniel D. Sewell, MD, DFAPA

Professor of Clinical Psychiatry
Associate Vice Chair for Geriatric Psychiatry
Co-Director of the Division of Geriatric Psychiatry
Co-Director, Memory Aging and Resilience Clinic
Clerkship Director, Psychiatry 426 Geropsychiatry
University of California, San Diego
and
Past President
American Association for Geriatric Psychiatry

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Disclosures

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 - The George G. Glenner Alzheimer's Family Centers, Inc.
 - Medical and Scientific Advisory Board of Alzheimer's San Diego
 - Chair, Disease Management & Mental Health Subcommittee, Clinical Roundtable, San Diego County's Alzheimer's Project
 - The Brain Health Alliance, Inc.

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Lecture Outline

- Introduction including background and key points
- The impact of COVID-19 on those living with dementia
- The impact of COVID-19 on those caring for someone living with dementia
- Mitigating the negative impact of COVID-19 on those living with dementia and on those caring for someone living with dementia
- Summary

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Current COVID Impact

(November 9, 2020, 1:24 PM)

	Confirmed Cases	Deaths	Recovered
San Diego	60,169	908	
California	981,000	17,980	
USA	10.1 million	238 million	5,062,602
World	50.1 million	1.26 million	33.2 million

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The Future With COVID-19

- The development and release of one or more successful vaccines will have a very significant impact.
- Exactly when the first vaccine will be approved is not known.
- The current plan for releasing vaccine involves stratification of those who are most at risk either due to occupation or pre-existing conditions and vulnerability.
- No one knows for sure, but it may be at least another year before enough people have been vaccinated to create herd immunity.
- Once herd immunity exists, we will be able to return to life as it was before the pandemic (mostly).

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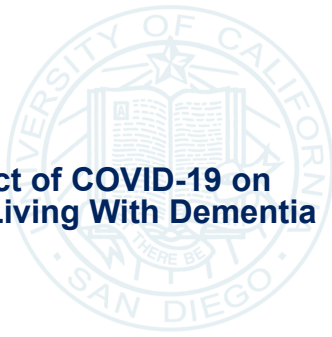
Six Key Points

- 1) The most important goal is to prevent exposure to COVID-19 which requires all of us to remain vigilant and to continue taking precautions to prevent infection.
- 2) We need to plan for COVID-19 having an ongoing, significant impact on our lives, and the lives of those for whom we care, for at least another year. As a result, care givers must pace their efforts and be even more committed to self-care and avoiding burn out.
- 3) COVID-19 has resulted in significant additional stress on caregivers WHILE many of the usual programs and supports are no longer available to individuals living with dementia and their caregivers. Some, however, are returning.
- 4) Necessary adaptations for individuals who have dementia and are living at home include: following the CDC guidelines, promptly seeking evaluation of behavioral symptoms, building/enlarging a caregiving team, improving communication, developing & using a structured activity program at home, and engaging community and technology resources.
- 5) Necessary adaptations in congregate living environments include: Strict screening of all staff, requirement of flu shots for all staff, prohibition of visitors, allowing for visitors only when this can occur outdoors, use of PPE and cohorting residents/patients.
- 6) Some aspects of caring well for individuals living with dementia have not changed. For example, new or rapidly worsening behavioral symptoms in an older patient should be considered a sign of an underlying medical illness until proven otherwise.

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The Impact of COVID-19 on Individuals Living With Dementia

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Medical Concerns

- Individuals living with dementia are in a high risk group based on:
 - Older age
 - At least one serious medical illness (dementia)
 - Not understanding/remembering/abiding by the CDC recommendations
- The most important goal is to prevent infection with COVID-19 by avoiding exposure
- COVID-19 affects different people in different ways and symptoms may vary between mild symptoms to severe illness.
- Symptoms of COVID-19 infection may appear 2-14 days after exposure:

• Cough	-New loss of taste or smell
• Sore throat	-Headache
• Shortness of breath	-Nausea
• Difficulty breathing	-Diarrhea
• Congestion or runny nose	-Fever
• Muscle or body aches	-Fatigue

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Medical Concerns

- COVID-19 treatment will almost certainly complicate the course of illness of someone living with dementia
- Medications
 - Dexamethasone: Mania, delirium depression, psychosis
 - Remdesivir: Delirium*
 - Regeneron: Administered IV and may cause fever, chills, chest pain, shortness of breath
 - Inhalers
 - Antibiotics or other medications with anticholinergic side effects
- Hospitalization
 - If needed, even more challenging for individuals living with dementia because visitors are not allowed. **Simulated presence therapy.**
 - May require ICU care
 - Care providers wearing PPE

*Grein, J, Ohnagari, N, Shin, D, Diaz, G, Asperges, E, Castagna, A, et al. (2020). Compassionate use of regdesivir for patients with severe Covid-19. New England Journal of Medicine 2020. doi: 10.1056/NEJMed2007016. [Epub ahead of print]

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Psychiatric Concerns

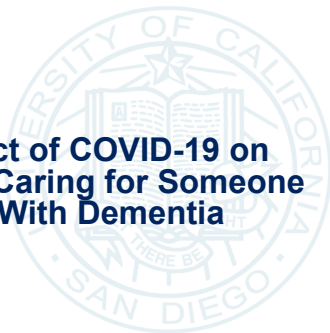
- COVID-19 is responsible for an increase in anxiety and depression symptoms and disorders. **Brain fog.**
- Other primary psychiatric disorders may also be impacted by COVID-19. COVID-19 related stress may trigger individuals with conditions like schizophrenia or substance abuse and dependency to have recurrent symptoms/episodes.
- The increase in psychiatric problems due to COVID-19 is related to:
 - Fear of infection
 - Social isolation/loneliness
 - Inability to work/diminished sense of purpose
 - Financial stress
 - Decreased opportunities to exercise
 - Decreased mobility
 - Decreased access to enjoyable activities and hobbies
 - Boredom

†: Psychiatric symptoms require prompt evaluation

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The Impact of COVID-19 on Individuals Caring for Someone Living With Dementia



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The Impact of COVID-19 on Caregivers

- Many care givers are also in a high risk for COVID-19 infection due to:
 - Older age
 - At least one chronic illness
 - Chronic stress prior to COVID-19
 - Added stress due to COVID-19
 - Added stress due to the challenges of caring for someone living with dementia during the COVID-19 pandemic
 - Decreased availability of supportive services

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The Impact of COVID-19 on Caregivers

- The impact of COVID-19 on caregivers are really too numerous to list. A partial list includes:
 - Every aspect of daily life is now more complicated and demanding of time and energy
 - Respite options for caregivers are reduced
 - Members of an informal caregiving team may not have as much time as they did before COVID-19 (e.g. increased time with children)
 - Caregivers for hire are more difficult to find
 - Caregivers for hire may not be conscientious about COVID-19 risk reduction measures and require additional supervision
 - New caregivers may not be well received by the individual with dementia
 - Caregiving is more difficult because all care must be provided at home (every lunch must be made, every activity must be planned and executed, clinician video visits are not well-accepted, every trip to the store requires more planning, etc.)

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Six Strategies to Mitigating the Impact of COVID-19 on Individuals and Caregivers

Strategies for mitigating the impact of COVID-19 on individuals living with dementia and their caregivers include:

- 1) Following the CDC guidelines for preventing COVID-19 transmission
- 2) Promptly evaluating and treating behavioral symptoms. This is even more important than ever because doing so will help protect caregivers from burn out.
- 3) Building a caregiving team/expanding the caregiving team
- 4) Learning and utilizing optimal communication approaches when caring for a person with dementia
- 5) Creating an optimal environment that includes structure and activities
- 6) Using community, online resources and other technologies to their fullest
 - Some community resources never went away (e.g. online learning modules)
 - Some went away temporarily but are coming back (e.g. assisted living communities are once again admitting residents, home health)
 - COVID-19 adaptations have been made which allow safety to be maintained in spite of COVID-19 e.g. video visits

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Helping the Person Living with Dementia Follow the CDC Guidelines

- Provide extra written reminders regarding important hygienic practices.
- Consider placing signs in the bathroom and elsewhere to remind people with dementia to wash their hands with soap for 20 seconds.
- Demonstrate thorough hand-washing.
- Alcohol-based hand sanitizer with at least 60% alcohol can be a quick alternative to hand-washing if the person with dementia cannot get to a sink or wash his/her hands easily.
- Request prescriptions for a greater number of days than usual to reduce trips to the pharmacy.
- Think ahead and make alternative plans for the person with dementia should adult day care, respite, etc. be modified or cancelled in response to COVID-19.
- Think ahead and make alternative plans for care management if the primary caregiver should become sick.

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Recognizing and Responding Appropriately to Behavior Changes

- Behavior changes are a form of communication.
- When a person with dementia experiences a change in behavior the first goal is to determine the meaning or message being communicated.
- Sometimes the meaning or message will be simple or obvious but sometimes it may take a while to understand.
- Even though we are living through the COVID-19 pandemic, individuals living with dementia remain vulnerable to behavioral problems and the triggers for behavioral symptoms remain the same.
- Remember that the emotions and stress of a caregiver will likely be passed to the person who is living with dementia.
- Promptly evaluating and treating behavioral symptoms is even more important than ever because doing so will help protect caregivers from burn out.

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Possible Medical Causes of Behavioral Symptoms in a Person Living with Dementia

- Delirium
- Exacerbation of pre-existing medical illness
- Onset of new medical problem
- Medication toxicity (e.g. polypharmacy or suboptimal prescribing)
- Drug or alcohol intoxication
- Drug or alcohol withdrawal
- Exacerbation of pre-existing psychiatric illness
- Onset of a new psychiatric illness

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Create a Caregiving Team

- Share the caregiving burden with as many family members & friends as possible. This strategy helps protect any given family member or friend from stress related illnesses or burn out.
- Make a list of family members (and friends and neighbors) who are willing and able to help and what special skills and talents they possess.
- Give family members specific tasks or assignments that, when possible, exploit their strengths and talents.
- Family members and friends may be able to help without entering the home. Examples include:
 - Leaving meals on the front porch
 - Taking care of errands
 - Walking the dog
 - Mowing the lawn
 - Doing the laundry

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Create a Caregiving Team

- Assign out-of-town family members tasks that do not require them to be geographically close to the patient:
 - using email to keep all those interested in the family member with dementia informed
 - designing and maintaining a phone tree for efficient communication
- Keep in mind that caring for a family member with Alzheimer's or one of the other dementia illnesses can be extremely stressful and that stress has a tendency to cause psychological regression.
- Anticipate that long-standing patterns of behavior and communication between family members may be intensified by the stress of the situation.

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Create a Caregiving Team

- Periodically solicit feedback and offer praise and thanks
- Strive for open honest communication
- Encourage all involved family members to become as educated as possible about the type of dementia that is impacting their loved one, in general, and the strengths, weaknesses, preferences, needs and priorities of the afflicted family member, in particular
- Encourage care giving family members to attend **virtual** support groups

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Create a Caregiving Team

- Do not hesitate to set limits if a particular family member is saying or doing things that hurt more than help
- Monitor each care giving family member for signs of physical or psychiatric illness or burn out
- Depending on the family members role, insist that each person has vacations from their caregiving duties
- Establish clear lines of authority and communication
- Encourage (require?) care giving family members to attend an **online** course on how best to communicate with and assist someone who has dementia (e.g. Teepa Snow teepasnow.com)

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The Challenge of Caring for an Individual Living with Dementia at Home

- Contact the home health care provider and ask them to explain their protocols to reduce the spread of COVID-19.
- Check the home health care professional's temperature before they enter your home. Anyone with a temperature over 100.4° F should be excluded from providing care.
- Ask health care professionals if they have been exposed to anyone who has tested positive and if so, do not allow them into your home.
- Ensure that the health care professional washes their hands upon arrival and regularly throughout their time in your home.
- Ask the health care professionals to wear a mask.
- Be aware that bringing anyone into your home increases the risk of spreading COVID-19, even if CDC guidance is followed.
- Require private care givers to eat at a different time than the individual living with dementia.

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Successful Communication

“The most important thing in communication is hearing what isn't said.”

--Peter Drucker, an Austrian-born American management consultant (November 19, 1909 – November 11, 2005)

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Effective Communication

- Make one request at a time
- Speak clearly and slowly
- Allow time for the patient to respond
- Maintain eye contact
- Assume a comfortable posture with arms and hands relaxed
- Identify the patient's affect and verbalize this for him/her
- Time communications optimally based on circumstances (e.g. hunger, fatigue, background noise, etc.)
- Remember that even when words may no longer convey meaning volume, prosody and melody of speech may still convey information

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Validation Therapy

- The need to be seen, heard and understood is a part of human nature and does not disappear simply because someone is living with dementia
- Individuals living with dementia may have problems with expressive and receptive aphasia
- Putting a thought, need or emotion into words for can sometimes be powerfully helpful
- Someone living with dementia may have preserved emotional intelligence
- When interacting with someone who is living with dementia strive to avoid triggering feelings of shame

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Redirection

- Represents an intentional thwarting of goal directed thought or behavior
- Goal is to help patient refocus in order to be more:
 - calm
 - cooperative
 - content
 - safe
- May trigger frustration or agitation
- Has two forms: simple and complex

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Simple Redirection

- **Simple redirection**
 - **Presentation of options:** “This door is closed but this door is open.”
 - **A compliment:** e.g. “My that’s a beautiful sweater!”
 - **A request for help:** e.g. “Please help me fold these towels.”
 - e.g. other possibly helpful distractions include: food, drink, music, humor.

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Complex Redirection

- **Complex redirection: 4 steps**
 - **Validate:** “You look worried.”
 - **Join:** “You’re looking for [fill in the appropriate item]. I’m trying to find [fill in an item]. Let’s look together...”
 - **Distract:** “Let’s look over there...”
 - **Redirect:** “That coffee smells good. Do you want a cup?”

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Complex Redirection

- Enter the agitated patient’s reality
- Approach in a calm manner
- Communicate your desire to help

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Structure and Stimulation

- In the scientific literature, these are described as “Nonpharmacological interventions.”
- In general, nonpharmacological interventions provide benefits to both patients and caregivers.
- Nonpharmacological interventions work best when individualized.
- Prevent wandering: structured activities prevent the boredom and uncertainty that may lead to wandering.
- Routines can be learned and then may reduce anxiety.
- A majority of studies report at least modest improvement (>91% of studies).

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Types of Activities

- Types of activities:
 - Physical fitness
 - Intellectual exercise
 - Emotional health
 - Spiritual needs
 - Enjoyment
 - **Simulated presence therapy**
- Note: Some activities may fit in more than one category

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Specific Activities

- Arts and crafts
- Baking
- Current events
- Exercise
- Gardening
- Grooming
- Music
- Pets
- Reminiscing

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Ways to Create a Non-threatening Environment

- Think of a non-threatening environment as “a **soothing environment**” and create this by:
 - Playing music or pleasant sounds e.g. ocean surf, singing bowl
 - Providing warmed blankets
 - Offering a security object (e.g. toy animal)
 - Providing opportunities for rest and privacy

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The Importance of Stimulating Environments

- The brain, in some ways, is like a muscle:
 - Regular use helps it stay quick and strong or even grow quicker and stronger
 - If not used, it grows slower and weaker
- Every one has different interests, talents, passions, hobbies
- A persons interests, talents etc. may evolve over the course of dementia
- The ideal environment presents a variety of activities and options
- When introducing an activity name items, demonstrate, encourage and reward

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Meaningful and Stimulating Activities for Any Stage of Dementia

- Reminiscence and life review
- Singing
- Dancing
- Telling jokes
- Reading
- Card games
- Table games
- Word games including crossword puzzles

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Possible Components of a Stimulating Environments

- Activity boxes
- Activity aprons
- Animals
- A workshop
- A garden
- A piano
- A library (large print books or magazines)

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Engaging Community Resources

- Some community resources never went away:
 - Resources through the phone like the Alzheimer's Association 24/7 helpline (800.272.3900) or the internet
- Community resources that were temporarily not available are returning
- One of a number of helpful sites on the web: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html>
- Congregate living options for patients who are living with dementia have made a number of adaptations:
 - Careful screening of staff members
 - Require staff members to obtain flu vaccines
 - Prohibiting outside visitors
 - Using PPE
 - Cohorting residents who test positive for COVID

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Six Key Points

- 1) The most important goal is to prevent exposure to COVID-19 which will require all of us to remain vigilant and to continue taking precautions to prevent infection.
- 2) We need to plan for COVID-19 having an ongoing, significant impact on our life for at least another year. As a result, care givers must pace their efforts and be even more committed to self-care and avoiding burn out.
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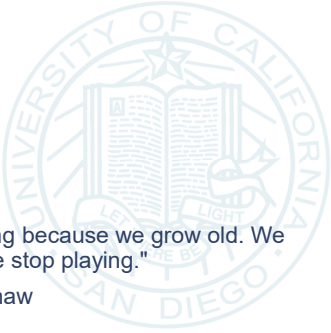
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Summary

"We don't stop playing because we grow old. We grow old because we stop playing."
--George Bernard Shaw




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Questions and Answers

Thank You!



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