

Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based care setting

Emergency situations, such as the current COVID-19 pandemic, present special circumstances in the delivery of care in long-term and community-based care settings. People receiving care or utilizing services in these settings are particularly vulnerable to complications due to their age and other concurrent medical conditions. Employees can also be affected in emergency situations. Maintaining operations in long-term and community-based care settings with the expected staffing shortages during any pandemic, epidemic or disaster can be very challenging. During this time, non-clinical staff may be needed to assist with care.

As indicated in the [Alzheimer's Association 2020 Alzheimer's Disease Facts & Figures](#), more than 5 million Americans age 65 and older are living with Alzheimer's dementia in 2020. People with Alzheimer's or other dementia make up a large proportion of all elderly people who receive long-term and community-based care. Overall, 48% of nursing home residents are living with Alzheimer's or other dementias. Among older adults in residential care settings, including assisted living, 42% or more have some form of Alzheimer's or other dementias. Many individuals with Alzheimer's or other dementias receive community-based services: 32% of individuals use home health services and 31% use adult day services.

Dementia is characterized by a group of symptoms that include a decline in cognitive abilities, loss of memory, poor judgment, changes in personality, disorientation and problems with abstract thinking. Alzheimer's disease is the most common cause of dementia, accounting for 60% to 80% of all cases. As the disease progresses, people living with dementia will need additional assistance to complete activities of daily living. Due to their decreased cognitive ability, they may require additional assistance and consideration during the implementation of an emergency plan.

PREVENTING ILLNESS

Persons living with dementia may have an impaired ability to follow or remember instructions, and may need reminders regarding:

- Hand-washing and moisturizing - consider a supervised hand-washing schedule.
- Covering nose and mouth during a sneeze or cough.
- Refraining from placing things in the mouth.
- Staying in a particular area.
- Taking medications appropriately.
- Adopting social distancing practices and refraining from sharing items.
- Following any other procedures that would require memory and judgment.

Tips for supporting persons living with dementia in long-term and community-based care settings

People living with dementia may become more confused, frustrated or even display an increase in dementia-related behaviors during a crisis. Individuals are often less able to adapt to changes in their environment, and may react to others' stress. It is recommended to try to minimize any changes in routine, environment and daily structure for individuals with dementia.

Below are some suggestions to meet the needs of persons living with dementia during a major disease outbreak or disaster:

PROVIDE PERSON-CENTERED CARE

As stated in the Alzheimer's Association [Dementia Care Practice Recommendations](#), one of the most important steps in providing quality dementia care is to **know the person**. In the event of a major disease outbreak or disaster, this may be more difficult for temporary staff members or those working in a new department or other health care setting.

A nurse, or social worker or staff under the supervision of licensed clinicians should complete a personal information form, or use an existing one, and place it a visible location consistent with HIPAA guidelines. For example, documents can be placed inside a closet door or in a folder attached to the back of a door. This will allow all staff, including temporary or substitute staff members to quickly identify essential information about the person to help maintain a stable and comforting environment.

Information on the form can include:

- Individual's preferred name (and pronouns).
- Cultural background.
- Names of family and friends.
- Past hobbies and interests.
- Sleep habits.
- What upsets the person.
- What calms him or her down.
- Typical patterns of behavior.
- Normal daily structure and routines.
- Eating and drinking patterns and abilities.
- Religious or spiritual practices.
- Remaining abilities, motor skills, verbal processing and communication abilities and methods.

Sharing information about a person with the care team is very important in terms of providing quality, consistent and effective care. Given the care team may change frequently during a pandemic or disaster, briefing meetings at the start of the shift will allow the staff to share pertinent information about those receiving care.

Advance planning

Planning for the future is an important part of person-centered care. Advance planning is important to ensure an individual's wishes regarding treatment and care options are fulfilled.

- Be aware of a person's advance directives and ensure they follow the person if a transfer is necessary.
- Ensuring individuals' advance directives, Provider Orders for Life-Sustaining Treatment (POLST), and other documents are all up to date with current documented wishes, and physician orders are consistent with these wishes.

HELP KEEP FAMILIES AND FRIENDS CONNECTED

People living with dementia may need help communicating with their families and loved ones during a crisis. For example, for persons with dementia living in a residential care setting, families might schedule a telephone or video call to keep connected and/or send notes for the person to read along with photos.

Providers should consider developing a "What You Should Know" fact sheet to explain what families and friends and staff need to know in the event of an emergency. It should include information on how families can receive updates or talk to a care provider about the person living with dementia. It is also important to note what adaptive devices are necessary and available for the individual, e.g., hearing aids and eyeglasses.

Remember that each family is unique, and for some people their closest supporters may not be biological or legal family members, but friends or community members.

ASSIST WITH EATING AND DRINKING

Persons living with dementia may need assistance with eating and drinking. This may include use of verbal, visual or tactile cues, such as high contrast dinnerware, adaptive utensils, graded approaches and modeling behavior. It is especially important for people with dementia to maintain their strength when there is risk of contracting a virus. Staff should familiarize themselves with the person's eating and drinking patterns and abilities. They may need to be reminded or prompted to drink and eat as they might not be able to recognize hunger or thirst. Sitting and talking with the person with dementia during meal times may improve intake.

Any evidence of difficulty in swallowing should be assessed by appropriately licensed clinical staff. Licensed or trained personnel should assist and monitor all persons with dementia who have been identified as having a choking risk or a history of swallowing difficulties.

MONITOR WALKING/UNSAFE WANDERING

Walking is a purposeful motor activity that promotes mobility and strength building. Unsafe wandering occurs when a person living with dementia gets lost, intrudes into inappropriate places or leaves a safe environment. The risk for unsafe wandering may increase when the person becomes upset, agitated or faces stressful situations. Possible interventions include:

- Provide persons with dementia safe spaces to walk about.
- Secure the perimeter of areas, if possible.
- Ensure that persons with dementia get regular exercise.
- Provide structured activities throughout the day.
- Spending time outdoors in a safe environment.

OBSERVE AND RESPOND TO DEMENTIA-RELATED BEHAVIORS

Behavior is a form of nonverbal communication for the person living with dementia. Dementia-related behaviors may be an option or response for a person living with dementia to communicate a feeling, unmet need or intention. These behaviors are triggered by the interaction between the individual and his or her social and physical environment. A response may include striking out, screaming, or becoming very agitated or emotional. The care provider's role is to observe and attempt to understand what the person living with dementia is trying to communicate.

It is useful to attempt to identify the root cause of the behavior. Potential causes of dementia-related behaviors are as follows:

- Pain.
- Hunger.
- Fear.
- Depression.
- Frustration.
- Loneliness, helplessness, boredom.
- Hallucinations.
- Overstimulation.
- Changes in environment or routine.
- Difficulty understanding or misinterpreting the environment.
- Difficulty expressing thoughts or feelings.
- Unfamiliarity with personal protective equipment or clothing, such as gowns or masks.

Strategies to observe and respond to dementia-related behaviors include:

- Rule out pain, thirst, hunger or the need to use the bathroom as a source of agitation.
- Speak in a calm low-pitched voice.
- Try to reduce excess stimulation.
- Ask others what works for them.
- Validate the individual's emotions, e.g., focus on the feelings, not necessarily the content of what the person is saying. Sometimes the emotions are more important than what is said. Look for the feelings behind the words. Affirming the person's feelings may help calm them.
- Understand that the individual may be expressing thoughts and feelings from their own reality, which may differ from generally acknowledged reality. They may be reacting to an event from their past. Offering reassurance and understanding, without challenging their words, can be effective.
- Through behavioral observation and attempted interventions, try to determine what helps meet the person's needs and include the information in the individualized plan of care.
- Be aware of past traumas (veterans, abuse survivors, survivors of large scale natural and human-caused disasters)
- Never physically force the person to do something.

Additional strategies and interventions may include:

- Offering a favorite food.
- Sharing photographs of family and friends.
- Listening to familiar music.
- Using an evidence-based therapy, such as aroma, bright light, validation, reminiscence, music or pet.
- Looking through books or magazines.

- Exercising or taking a walk.
- Providing purposeful tasks to be helpful.
- Connecting with family and friends using applications like Skype, FaceTime or other technology.
- Using technology applications to deliver individual and small group activities.
- Using relaxation techniques, such as deep breathing.
- Supporting their spiritual needs.
- Providing a warm blanket or placing a cool cloth on their neck or forehead.
- Talking to particular staff or a special person.
- Moving the person to a quiet area; consider having rocking chairs available.

If non-pharmacological practices are not effective after they have been used consistently, then medications may be appropriate when individuals living with dementia have severe symptoms or have the potential to harm themselves or others. Continued need for pharmacological treatment should be reassessed as required by the medication regimen or upon a change in the person's condition.

It can be difficult to anticipate and respond to dementia-related behaviors in a changing environment; however, applying some of the following strategies may help:

- Provide a consistent routine.
- Use person-centered care approaches for all individuals living with dementia during activities of daily living — every interaction or task is an opportunity for engagement.
- Promote sharing of person-centered information across the care team.
- Encourage all staff to treat individuals living with dementia with dignity and respect.
- Put the person before the task.

Crises can be challenging, especially for individuals living with dementia. With some careful planning and attention to the unique needs of those receiving care, professionals may feel more empowered to respond quickly and appropriately to support individuals living with dementia.

ALZHEIMER'S ASSOCIATION RESOURCES

24/7 Helpline (800.272.3900)

The Alzheimer's Association 24/7 Helpline partners with our chapter network across the United States to provide around-the-clock support and information to people with Alzheimer's and other dementias, family members, caregivers, health care professionals and the general public.

alz.org

The Alzheimer's Association website offers a wealth of resources and information for people living with the disease, caregivers and health care professionals.

For additional information, contact:

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CDC COVID-19 RESOURCES: GUIDANCE FOR RETIREMENT COMMUNITIES AND INDEPENDENT LIVING

- Guidance for Retirement Communities and Independent Living:
<https://www.cdc.gov/coronavirus/2019-ncov/community/retirement/index.html>
- Preventing the Spread of COVID-19 in Retirement Communities and Independent Living Facilities (Interim Guidance): <https://www.cdc.gov/coronavirus/2019-ncov/community/retirement/guidance-retirement-response.html>
- Coronavirus disease 2019 (COVID-19) Checklist: Older Persons:
<https://www.cdc.gov/coronavirus/2019-ncov/community/retirement/checklist.html>

Note: This document is designed as a reference to support all staff, including non-licensed staff and lay people who may become involved in direct care during a major disease outbreak or disaster. These are suggestions for quality care. It may be unrealistic to expect all items to be carried out in an emergency or disaster situation. This document is not a substitute for evidence-based training on how to care for persons living with dementia in long-term and community-based care settings.

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