
Planning for emergency or disaster situations: Caring for persons living with dementia in a residential community

Note: This document is designed as a guide for non-licensed staff and lay people who may become involved in direct care during a major disease outbreak or disaster. These are suggestions for 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 training.

Emergency situations, such as a pandemic, epidemic or disaster, present special circumstances for staff in long-term care communities. Residents in long-term care communities are particularly vulnerable to complications of influenza (the “flu”) due to their age and other concurrent medical conditions. Employees would also be affected by a serious flu outbreak. Maintaining operations in a long-term care setting with the expected staffing shortages during a pandemic, epidemic or disaster would be very challenging. During this time, non-clinical staff may need to assist with resident care.

Nearly half of all nursing home residents and more than 4 in 10 people in residential care communities are living with Alzheimer’s or another dementia. Dementia is characterized by a group of symptoms that include a decline in cognitive abilities which may include loss of memory, poor judgment, changes in personality, disorientation and problems with abstract thinking. As Alzheimer’s progresses, residents living with the disease will need additional assistance in performing activities of daily living such as eating, bathing, dressing, etc. Due to decreased cognitive ability, residents living with dementia may require additional assistance and consideration during the implementation of an emergency plan.

Prevention issues

Residents with dementia may have an impaired ability to follow or remember instructions regarding:

- Hand washing.
- Wearing a mask.
- Refraining from placing things in their mouth.
- Staying in a particular area.

- Taking medications appropriately.
- Following any other procedures that would require intact memory and judgment.

It is recommended that residents living with dementia be placed on a supervised “hand-washing schedule” followed by the use of moisturizer to avoid skin breakdown. Various approaches may be needed to ensure that these individuals use masks and remain in particular areas. This may require additional staff and volunteer training.

During plan implementation

Residents with dementia may become more agitated, frustrated or even display “catastrophic” reactions during a crisis. They are often less able to adapt to changes in their environment, so try to minimize any changes in routine, environment and daily structure.

Below are some areas of concern for residents living with dementia who may require special attention during a major disease outbreak or disaster, along with some potential approaches:

1. Person-centered care

One of the most important steps in providing quality dementia care is to get to know the resident. 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. Ask if the long-term care community has a personal information form for each resident and where it’s placed.

This will allow temporary or substitute staff members to quickly identify essential information about the resident to help maintain a stable and comforting environment. Information on the form that can be helpful includes:

- What name/nickname does the resident like to be called?
- What are his or her likes and dislikes?
- 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.

2. Communication concerns

Alzheimer's and other dementias gradually diminish a person's ability to communicate and will require patience, understanding and good listening skills. The strategies below can help you communicate with the person living with dementia and understand their needs better, especially in a crisis situation.

- Engage the person in one-on-one conversation in a quiet space that has minimal distractions. Speak slowly and clearly.
- Maintain eye contact. It shows you care about what he or she is saying.
- Give the person plenty of time to respond so he or she can think about what to say.
- Be patient and offer reassurance. It may encourage the person to explain his or her thoughts.
- Ask yes or no questions. For example, "Would you like some coffee?" rather than "What would you like to drink?"
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what the person says. Repeat what was said to clarify.
- Avoid arguing. If the person says something you don't agree with, let it be.

3. Nutrition and fluid intake concerns

Residents living with dementia may need assistance with eating and drinking, which may include verbal, visual or tactile cues. Residents may need to be reminded or prompted to drink and eat throughout the day, as they might not be able to recognize hunger or thirst. Sitting and talking with the resident during meal times may improve intake.

Any evidence of difficulty in swallowing should be communicated to the nursing staff and assessed appropriately. Licensed or trained personnel should assist and monitor all residents who have been identified as having a choking risk or a history of swallowing difficulties. Ask the nursing staff which residents may be at risk for choking or have a history of swallowing difficulties.

4. Wandering

Wandering and getting lost is common among people living with Alzheimer's or another dementia and can happen during any stage of the disease. The risk for wandering may increase when residents become upset, agitated or face stressful situations. Possible interventions include:

-
- Reassure the person that they are safe if they feel lost, abandoned or disoriented. If they want to leave to “go home” or “go to work,” use phrases to comfort them and validate their feelings. Avoid correcting the person. For example, say “We are staying here tonight. We are safe and I’ll be with you. We can go home in the morning after a good night’s rest.”
 - Ensure all basic needs are met. Has the person gone to the bathroom? Are they thirsty or hungry?
 - Avoid busy places that are confusing and can cause disorientation.
 - Provide supervision. Do not leave someone with dementia unsupervised in new or changed surroundings.

Catastrophic Reactions

A catastrophic reaction occurs when a situation overloads the mental ability of the person living with dementia to act appropriately. An exaggerated response to the situation may include striking out, screaming, making unreasonable accusations or becoming very agitated or emotional. One of the first steps in preventing and responding to a catastrophic reaction is to identify circumstances that may trigger potentially catastrophic behavior.

It is useful to attempt to identify the root cause of the behavior. Potential causes of dementia-related behaviors or catastrophic reactions include:

- Over-stimulation.
- Inadequate attention.
- Pain.
- Hunger.
- Fear.
- Depression.
- Inability to understand or misinterpretation of the environment.
- Panic reaction to an apparently new situation.
- Inability to express thoughts or feelings.

Strategies and interventions for responding to catastrophic reactions and other dementia-related behaviors include:

- Do not physically force the person to do something.
- Speak in a calm, low-pitched voice.
- Try to reduce excess stimulation.
- Rule out pain as a source of agitation.

-
- Validate the individual's emotions (i.e., focus on their feelings, not necessarily the content of what the person is saying). Sometimes the emotions being expressed are more important than what is being said. Look for the feelings behind the words. Affirming the resident's feelings may help calm them.
 - The person living with dementia may express thoughts and feelings that do not seem to be based in reality, but try to meet the person where they are. Keep in mind that the person is trying to make sense of his or her world with declining cognitive function. For instance, they may be reacting to an event from their past. Offering reassurance and understanding, without challenging the resident's words, can be effective.
 - Try to determine what helps keep the person calm and comfortable, and include this information in the person's individualized plan of care.

Additional strategies and interventions may include:

- Moving the resident to a quiet area; consider having them sit in a rocking chair if available.
- Sitting near others, such as by the nursing station.
- Talking to familiar staff or a special person.
- Relaxed breathing.
- Wrapping up in a warm blanket or placing a cool cloth on their neck or forehead.
- Listening to favorite music or watching a favorite movie.
- Looking at pictures, a book or magazine.
- Exercising or taking a walk.

Preventing catastrophic reactions can be difficult in a changing or chaotic environment; however, applying some of the following strategies may help:

- Regular verbal and written cueing to the environment can help, especially for new residents.
- Provide a consistent routine.
- Reduce clutter.
- Encourage the family to provide comforting objects or other familiar items from home.

TS-0049 | Updated January 2023