

## Planning for emergency or disaster situations: Caring for persons 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 facility training. The Alzheimer's Association®, in partnership with Healthcare Interactive, offers CARES® online interactive training featuring videos of real caregivers, families and people with dementia. In addition, the Association offers essentiALZ®, a certification program for individuals to receive recognition for their knowledge in quality dementia care practices. Visit [alz.org/essentiALZ](http://alz.org/essentiALZ) to learn more.*

Emergency situations, such as a pandemic, epidemic or disaster, present special circumstances for staff in long-term care facilities. Residents in long-term care facilities 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 be needed to assist with patient care.

Approximately 64 percent of all Medicare beneficiaries residing in a nursing home have Alzheimer's disease or another dementia. Among residents in assisted living programs, 42 percent or more have some form of dementia. Dementia is characterized by a group of symptoms that include a decline in cognitive abilities including loss of memory, poor judgment, changes in personality, disorientation and problems with abstract thinking. As the disease progresses, residents with dementia will need additional assistance in conducting activities of daily living. Due to their decreased cognitive ability, residents 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 the 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 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.

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### **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. It is recommended to try to minimize any changes in routine, environment and daily structure for residents with dementia.

Below are some areas of concern for residents 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. It is recommended that a personal information form be completed for each resident and placed in an easily accessible place, consistent with HIPAA guidelines.

For example, forms can be placed inside a closet door or in a folder attached to the back of a door. 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 can include:

- What the resident likes to be called.
- 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.

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

#### **2. Communication concerns**

Residents with dementia may need help communicating with their families during a crisis. In fact, it is recommended to inform residents’ families ahead of time about what to expect in case of a major disease outbreak, disaster or other emergency. Facilities should consider developing a “What You Should Know” fact sheet to explain what families need to know in the event of an emergency. For example, it might explain that instead of visiting in person, families can schedule a telephone call to keep connected and/or send notes for the resident to read along with photos. Facilities may also wish to offer to train volunteers before a crisis hits. It is also important to ensure that adaptive devices are available to the resident where appropriate, e.g., hearing aids and eyeglasses.

### 3. Nutrition and fluid intake concerns

Residents with dementia may need assistance with eating and drinking, which may include verbal, visual or tactile cues. It is especially important for residents to maintain their strength when there is risk of contracting influenza. Staff should familiarize themselves with the resident's eating and drinking patterns and abilities. 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 assessed appropriately by nursing staff with pertinent consultation as needed. 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.

### 4. Wandering

Wandering is aimless or purposeful motor activity that causes a social problem such as getting lost, leaving a safe environment or intruding in inappropriate places. The risk for wandering may increase when residents become upset, agitated or face stressful situations. Possible interventions include:

- Provide residents with safe spaces to wander.
- Secure the perimeter of areas with security personnel or security systems, if possible.
- Ensure that residents get regular exercise.
- Provide structured activities throughout the day.
- If non-pharmacological treatment options fail after they have been applied consistently, then medications may be appropriate when residents 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 resident's condition.

### Catastrophic Reactions

A catastrophic reaction occurs when a situation overloads the mental ability of the person 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 challenging behaviors or catastrophic reactions are as follows:

- 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 challenging 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 the 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.
- Understand that the individual may be expressing thoughts and feelings relative to their own reality, which may differ from generally acknowledged reality. The resident may be reacting to an event from their past. Offering reassurance and understanding, without challenging the resident's words, can be effective.
- Through behavioral observation and attempted interventions, try to determine what helps reduce exaggerated reactions and include this information in the resident's individualized plan of care.

Additional strategies and interventions may include:

- Moving the resident to a quiet area; consider having rocking chairs available.
- Sitting by the nursing station.
- Talking to particular 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 music or a tape of a familiar person.
- Looking at pictures or a book/magazine.
- Exercising or taking a walk.

Prevention of 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.

Prepared by:  
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