

Alzheimer's Association  
Campaign for Quality Residential Care

# Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes

Phase 3 End-of-Life Care



Building consensus on  
quality care for people  
living with dementia

alzheimer's  association®

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The Alzheimer's Association is the leading voluntary health organization in Alzheimer research, care and support.

Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

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# Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes – Phase 3 End-of-Life Care

Edited by Jane Tilly, Dr.P.H.; Peter Reed, Ph.D.; Elizabeth Gould, M.S.W.; and Abel Fok

For more than 25 years, the Alzheimer's Association has been committed to advancing Alzheimer research and enhancing the care, education and support for individuals affected by the disease. Building on our tradition of advocacy to improve the quality of life for people with dementia, in 2005 we launched the Alzheimer's Association Campaign for Quality Residential Care to improve the quality of care for residents with dementia in assisted living and nursing homes.

More than 50 percent of residents in assisted living and nursing homes have some form of dementia or cognitive impairment, and that number is increasing every day. To better respond to their needs, we have joined with leaders in dementia care to develop the evidence-based *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. These recommendations are the foundation of our multiyear campaign.

Phase 1 of the recommendations focuses on the basics of good dementia care, food and fluid consumption, pain management and social engagement. Phase 2 covers wandering, falls and physical restraints. Phase 3 covers end-of-life care practices and issues.

To date, more than 30 leading health and senior care organizations have expressed their support and acceptance of one or more phases of the Dementia Care Practice Recommendations. We are grateful to these organizations for their counsel during development of the recommendations and for helping achieve consensus in our priority care areas.

## STRATEGIES FOR QUALITY RESIDENTIAL CARE

All aspects of our Quality Care Campaign — from the selection of priority care practice areas to development of recommendations, educational programming and advocacy — are based on the best available evidence on effective dementia care in residential settings. We are using four strategies to achieve the overall campaign goal:

- To encourage adoption of recommended practices in assisted living residences and nursing homes, we are advocating with dementia care providers.
- To ensure incorporation of the practice recommendations into quality assurance systems for nursing homes and assisted living residences, we are working with federal and state policy makers.
- To encourage quality care among providers, we are offering training and education programs to all levels of care staff in assisted living residences and nursing homes.
- To empower people with dementia and family caregivers to make informed decisions, we have developed the Alzheimer's Association CareFinder™. This interactive, online tool is educating consumers on how to select an assisted living residence or nursing home and how to advocate for quality care within a residence.

# Phase 3



# Introduction to the Dementia Care Practice Recommendations

## Phase 3

The Alzheimer's Association Dementia Care Practice Recommendations are based on the latest evidence in dementia care research and the experience of care experts.

The Association used two primary sources of research evidence to develop the Phase 3 practice recommendations on end-of-life care. An Association-sponsored literature review, *End-of-life Care for People with Dementia in Residential Care Settings*, by Ladislav Volicer, M.D., Ph.D., summarizes current peer-reviewed research relevant to end-of-life care for residents with severe dementia. To extend the knowledge gained through this literature review, Association staff member Jane Tilly, Dr.P.H., with Abel Fok, wrote *Quality End-of-life Care for Individuals with Dementia in Assisted Living and Nursing Homes and Public Policy Barriers to Delivering This Care*, which describes what practitioners, providers, professionals and researchers believe constitutes high-quality end-of-life care for residents with dementia.

Dementia care experts and professional staff from the entire Association, representatives of more than 30 national associations and other experts used the evidence in a consensus-building process to translate the research into specific recommendations for end-of-life dementia care in assisted living residences and nursing homes.

Underlying the end-of-life care practice recommendations is a person-centered approach to dementia care, which involves tailoring care to the abilities and changing needs of each resident. Recommended practices for end-of-life care include communication and decision-making strategies, assessment and care of physical and behavioral symptoms, psychosocial and spiritual support of residents and family, staff training and acknowledgment of resident death.

The recommendations emphasize the importance of consistency in individualized or person-centered care approaches, development of relationships between staff and residents and increasing staff knowledge of individual resident needs, abilities and preferences. Successful implementation of the recommendations depends on having a sufficient number of staff trained in end-of-life care for residents with dementia.

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## Organizations Supporting the Dementia Care Practice Recommendations, Phase 3

AARP	National Association of Social Workers
American Academy of Hospice and Palliative Medicine	National Center for Assisted Living
American Assisted Living Nurses Association	National Citizens' Coalition for Nursing Home Reform
American Association for Geriatric Psychiatry	National Conference of Gerontological Nurse Practitioners
American Association of Homes and Services for the Aging	National Gerontological Nursing Association
American Association of Nurse Assessment Coordinators	National Hospice and Palliative Care Organization
American College of Health Care Administrators	Paralyzed Veterans of America
American Dietetic Association	Service Employees International Union
American Health Care Association	Supportive Care Coalition
American Medical Directors Association	
American Occupational Therapy Association	The American Speech Language Hearing Association accepts the recommendations.
American Pain Foundation	
American Physical Therapy Association	
American Seniors Housing Association	The American Bar Association's Commission on Law and Aging and the American Health Lawyers Association provided invaluable legal expertise during the development of the Alzheimer's Association practice recommendations on end-of-life care for residents with dementia.
American Society of Consultant Pharmacists	
American Therapeutic Recreation Association	
Assisted Living Federation of America	
Catholic Health Association of the United States	
Consumer Consortium on Assisted Living	
Hospice and Palliative Nurses Association	
National Association of Activity Professionals	
National Association of Directors of Nursing Administration/Long Term Care	

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We are enlisting the support of these and other organizations, as well as consumers and policy makers, to help us reach the goal of our Campaign for Quality Residential Care — to enhance the quality of life of people with dementia by improving the quality of dementia care in assisted living residences and nursing homes.

# Dementia Issues for End-of-Life Care

## Dementia Issues

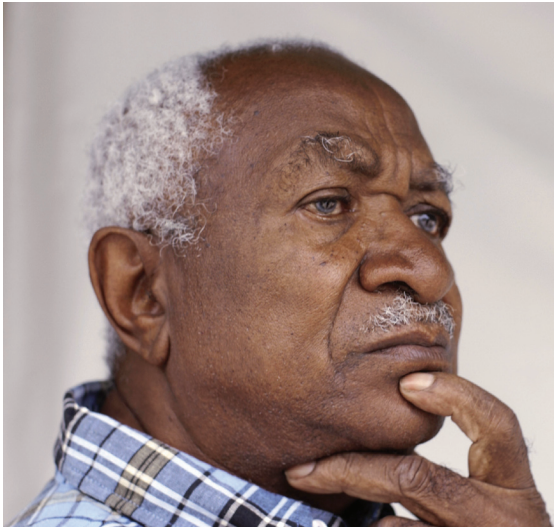
On receiving a diagnosis of dementia, many issues must be considered, including the resident's preferences regarding end-of-life care. Discussion with a resident about his or her preferences across many areas should begin as soon as possible after the dementia diagnosis is known. This is particularly true for decisions about end-of-life care. Loss of memory, judgment and speech make those decisions more difficult as the disease progresses.

The losses associated with dementia often result in a transition to a nursing home or assisted living residence. Sometimes residents choose hospice services while in one of these residential settings. Available research indicates that about 67 percent of dementia-related deaths occur in nursing homes. Analysis of nursing home data from the late 1990s in New York showed that at nursing home admission, only 1 percent of residents with advanced dementia who died within a year were thought to have a life expectancy of less than six months, while 71 percent of them died within this time frame. Twenty-five percent of the residents with advanced dementia received tube feeding, 49 percent received laboratory tests, 11 percent had restraints, and 10 percent had intravenous therapy. These data indicate that provision of palliative care could be improved for those who are dying with dementia.

Research from New York and Michigan (1997–2000) showed that 5.7 percent of nursing home residents with advanced dementia who died within a year of admission were referred to hospice services. National data from 2002 indicate that use of hospice among those who died with dementia is higher. In addition, hospices are increasingly involved in end-of-life care for people with dementia because they have broadened their admission criteria to include non-cancer diagnoses such as Alzheimer's disease and other forms of dementia.

Assisted living residences have a role in end-of-life care, too. Many states allow hospices to serve people in assisted living residences. In these cases, the residences and hospice services work together to serve the person dying with dementia.

The following practice recommendations are designed to improve the dying experience for people with dementia and build upon recommendations developed by the Alzheimer's Association in Phases 1 and 2 of *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. The earlier recommendations focus on many relevant areas of care, including the basics of good dementia care, food and fluid intake, social engagement, pain management, falls, wandering and restraints. The recommendations included in Phase 3 offer suggestions for addressing issues unique to people with dementia at the end of life.



### **DEFINITIONS OF TERMS**

Phase 3 end-of-life care recommendations use a number of terms that have varying definitions in the literature. In these recommendations, we define these terms as follows:

- **Active dying** for people with dementia may include total body system failure (including kidney shutdown), changes in skin color and texture and changes in the temperature of the extremities. The person may be unresponsive or comatose and have an expected life span of days, rather than weeks.
- **Advance directives** are legal documents that enable people to plan for and communicate their wishes about end-of-life care when they are unable to do so. A living will states a person's wishes about use of life-sustaining medical treatments at the end of life. A durable power of attorney for health care allows people to appoint someone to make medical treatment decisions on their behalf. Both types of documents are critical to ensuring that a resident's wishes are respected. However, the durable power of attorney for health care is the most flexible because the person with the power of attorney can make decisions about care that a living will may not address. In addition, the durable power of attorney helps ensure that the proxy decision maker is the person selected by the resident.



- **Care team** means the group of people who work together to plan, determine and implement a resident's care plan. This group may include the resident, family members, person who is able to make care decisions on behalf of the resident, professionals and staff involved in care, as well as those who provide spiritual support. The care team may include professionals outside the residential setting, such as geriatric care managers and hospice staff.
- **End-of-life care** means health and/or long-term care, which focuses on comforting the resident and includes provision of palliative or hospice services preceding death. The length of time preceding death, which is considered end of life, is different for every individual. Predicting time until death for most terminal conditions, including dementia, is inexact.
- **Family** includes people who are related to a resident, or who are not related but play a significant role in the resident's life.
- **Hospice care** in the United States is palliative care for individuals who are terminally ill with an expected survival of six months or less. Hospice is a benefit of Medicare, most state Medicaid programs and many private health insurance plans.
- **Palliative care** is designed to alleviate physical, emotional and spiritual suffering and enhance a resident's quality of life, rather than cure a disease or medical condition. Palliative care focuses on providing comfort to a suffering individual and his or her family. People who receive palliative care may or may not be terminally ill, and they do not have to forego curative treatment.
- **Proxy decision maker** is someone who makes medical decisions for a resident if the resident is unable to do so. The proxy decision maker should be someone chosen by the resident and is typically a close relative or a personal friend. This person should know the resident well and be someone the resident trusts. If the resident does not appoint a proxy decision maker, many states designate a priority order of default decision makers. State law varies on how default decision makers are designated. We use the term proxy decision maker as a general category that includes persons with a durable power of attorney for health care, guardians and default decision makers.
- In **severe or late-stage dementia**, individuals often lose the ability to carry out daily activities, swallow and move. Sometimes these individuals lose the ability to speak. People with severe dementia often lose interest in eating and drinking and may lose weight.
- **Spiritual support** means care that helps residents and their families find meaning and comfort at the end of life that is consistent with their philosophical or religious values or outlook on life.

## Care Goals

- To use a person-centered, culturally sensitive approach to providing care that meets a resident's changing needs and respects his or her preferences regarding end-of-life care.
- To minimize the resident's physical, emotional and spiritual distress, while maximizing comfort and well-being in a manner consistent with an individual's preferences regarding end-of-life care.
- To ensure open and ongoing communication among the resident, proxy decision maker, family and care team so that all parties have a clear and common understanding of what constitutes optimal end-of-life care for the individual resident.
- To provide support to families, other residents and staff when an individual is dying and after death has occurred to help them achieve meaningful closure.
- Care plans need to be flexible enough to adapt to daily changes in a resident's needs and wishes.



# 1

## Communication with Residents and Family

- Close communication among the resident, proxy decision maker, family and broader care team is critical to ensuring the best possible end-of-life care and honoring the resident's preferences.
- It is important to consider communication difficulties and differences, including the cultural and linguistic background of a resident and family, and their ability to understand and express themselves.  
**EXAMPLE:** Residents and families may require additional time to respond to questions or to communicate with the broader care team to assure mutual understanding.  
**EXAMPLE:** Short sentences, visual cues or picture boards may be needed to help residents understand what is being communicated to them.  
**EXAMPLE:** Interpreters may be needed for non-English-speaking residents and their families.
- Residents with early and moderate stages of dementia who are dying of another disease may still be able to directly express their preferences for care and treatment.
- Residents with advanced dementia frequently communicate nonverbally through their behaviors, including their reactions to care (e.g., facial expressions and body movements). Thus, effective communication at the end of life involves staff understanding a resident's behaviors and communicating using methods that the individual can understand, such as gentle touch, direct eye contact, smiles and pleasant tone of voice. Even if there is little expectation that a resident will understand the words, it is best to tell residents what is happening before touching them.
- Advance planning issues and resident care goals are essential topics for discussions among the resident, the proxy decision maker, the family and the broader care team.
- Residents, proxy decision makers and families are able to make considered and informed decisions regarding end-of-life care when they are educated about the course of dementia and the benefits and burdens of different care options.  
**NOTE:** These parties may need education about the differences between palliative care and Medicare and Medicaid hospice benefits. In addition, they need to know the availability of Medicaid hospice benefits in their states and hospices in their localities. Residence leadership and staff can play an important role in finding and offering information about these issues.
- Residents, proxy decision makers and families need a complete understanding of residence policies and situations that would cause an individual's transfer to another residence or a different part of the same residence. This is critical to understanding the limits on the type of care available at the end of life in a particular residence and what to do when an individual is discharged. For example, all parties, including hospital staff and discharge planners, need to understand whether the residence:
  - Discharges individuals who require aggressive feeding interventions, such as artificial nutrition
  - Requires individuals who wish to remain in the residence to hire personal care assistants as cognitive function declines
  - Works with local hospice agencies so prospective residents and their families understand any limitations on access to hospice services prior to admission  
**NOTE:** Some states do not allow assisted living residences to admit or retain individuals who have chosen hospice.
- Offers palliative care when residents are dying

### **TIMING OF COMMUNICATION**

Effective communication about end-of-life care occurs among the resident, proxy decision maker, family and broader care team, including the physician, during the admission process if possible. Effective communication recognizes and respects the cultural background and spiritual beliefs of the resident and family.

**NOTE:** Since dementia is a terminal condition, communication about these issues should start at the time of diagnosis. However, communication among residents, their families and the broader care team usually starts with the admission process since this is the first point of contact among all parties.

- Communication is ongoing as dementia progresses so that the resident, proxy decision maker, family and the broader care team understand how a resident's functional and health status is changing and what these changes mean for the resident's ongoing care.

**NOTE:** This is particularly important before the resident shows symptoms associated with active dying so that the family knows what to expect. At this point, they will likely need more information and counseling. Hospice staff with expertise in dementia care can be helpful in educating and counseling the family about the dying process.

- Regularly scheduled care planning meetings that involve the resident, proxy decision maker, family and the broader care team facilitate communication about end-of-life care and help ensure that care is person-centered and adapted to the resident's changing condition.

**NOTE:** Care planning meetings are most effective when they are held at times convenient for the resident and family so they can attend in person or via a telephone conference call.



**NOTE:** When a resident receives hospice services, the hospice nurse or care coordinator generally attends care planning meetings. Care plans reflect the hospice philosophy and specify which providers and staff are responsible for each aspect of the resident's plan.

- Families of dying residents benefit from ready access to the broader care team and team members who are approachable and responsive to family needs and questions.

## 2

## Decision Making

- Discussions about care and treatment decisions are of critical importance because of the progressive and inevitable decline associated with dementia, as well as the potential for moral dilemmas to surround end-of-life care. Peer-reviewed research has shown that many medical interventions produce either no benefit or have detrimental effects on people with advanced dementia. In addition, effective treatment for conditions such as severe pain may be perceived as hastening death, although current research shows otherwise. Thus, it is important for residents, proxy decision makers and families to understand the benefits and burdens of care and treatments so they can make informed decisions. It is also important for the residence to have and apply policies and procedures regarding implementation of care and treatment decisions.
- At admission, federal law governing participation in Medicare and Medicaid requires most health care facilities to document whether residents have advance directives and to provide residents with information about their decision-making rights. These provisions generally do not apply to assisted living residences.
- During the initial assessment and care planning process, it is important to discuss the resident's preferences regarding end-of-life decisions and any related doctors' orders such as "comfort care only," "do not resuscitate," "do not hospitalize" or "do not intubate." These orders are designed to prevent reviving, hospitalizing or inserting a tube to help a resident breathe when he or she is dying.
- If planning for end-of-life decisions does not take place upon admission, residence staff can discuss these decisions with the individual with dementia, proxy decision maker and family as soon as possible after the individual's admission to allow everyone time to adjust to the resident's new living

environment. This adjustment time also allows the resident, proxy decision maker and family to begin building a relationship with the broader care team, which is conducive to an effective care planning process.

- Discussions about end-of-life care are ongoing and always involve the resident, proxy decision maker and family to the degree possible. Regular care planning meetings provide an opportunity to revisit care decisions that have been made to see if they are still appropriate.

### PROXY DECISION MAKER

- No amount of advance planning can anticipate all the care decisions that must be made during the course of a resident's dementia. All 50 states and the District of Columbia permit the designation of proxy decision makers who can make the decisions as they believe the resident would have made them or, in the absence of such information, in the best interest of the resident.

**NOTE:** Since the rights of proxy decision makers vary from state to state, staff can play an important role in helping residents and families ensure that they are well informed and have access to information about advance directives.

**NOTE:** A diagnosis of dementia does not necessarily mean the person lacks decision-making capacity, so the person should be involved in his or her own care planning as much as possible.

**NOTE:** By having a properly designated proxy decision maker, complications that arise from disagreements among family members may be more easily resolved.

- Ideally, the proxy decision maker is someone who knows the resident's values and preferences regarding care at the end of life and will take into account the individual's cultural and spiritual beliefs about end-of-life care.
- If the resident agrees, the proxy decision maker can be part of care discussions even before assuming the decision-making role. This enables the proxy decision maker to become familiar with the resident's condition, preferences and care.
- The proxy decision maker will need appropriate information and, possibly, further education from the broader care team when considering the trade-off between the goals of prolonging life or maximizing comfort after a medical crisis or major change in the resident's condition. Needed information includes the benefits and burdens of the various interventions for someone with dementia at the end of life.
- State law determines who serves as the decision maker if no proxy has been previously designated by the individual, so residences should be familiar with the law in their state. If no such law exists, providers may rely on family members to the extent that this is customary practice.
- Residents with advanced dementia who do not have family caregivers or others who can serve as decision makers may need assistance identifying individuals to make decisions on their behalf.

**NOTE:** Some states have public guardianship programs for people who cannot manage their affairs and who have no family or proxy decision maker. These programs may enable guardians to make care decisions. Guardians are empowered only to the extent spelled out in the court's order of guardianship. Courts may also appoint private parties, such as attorneys, to serve as guardians.

- If family members disagree about care decisions and there is no proxy decision maker or advance directive, alternative dispute resolution can be useful in achieving resolution before seeking legal guardianship. Alternative dispute resolution can involve mediation or a residence's ethics committee, when one is available.

**EXAMPLE:** The residence may establish an ethics committee or join other providers to do so. These committees can help resolve crucial care issues when family members disagree about what care is appropriate for their loved one.

#### **TOOLS FOR ADVANCE PLANNING**

- On admission, it is critical for the nursing home or assisted living residence to obtain signed copies of existing advance directives, include them in the resident's record and make them available to the entire care team. These documents should be acceptable in the state where the resident lives and accompany residents if they are transferred to another residence or to a hospital. Even if the document fails to meet state law requirements for a valid statutory advance directive, it still may provide valuable guidance about the resident's wishes.
- Staff members can help prepare the resident, proxy decision maker and family for end-of-life care discussions by providing them with materials, such as advance directives or workbooks, which help them work through advance planning decisions and care options. Staff can also discuss these issues with the resident, proxy decision maker and family, or provide referrals to groups that can provide counseling on these issues. Follow-up discussions need to take into account differences in attitudes toward death and medical treatments at the end of life.

**EXAMPLE:** Provide residents, proxy decision makers and families with access to advance directive materials that are specific to their states and counties, as requirements can vary among localities.

**EXAMPLE:** Provide easy-to-understand and translated materials when appropriate and feasible.

- Residents should be able to reconsider their advance planning decisions over time as long as they retain the cognitive capacity to do so.

#### **CONTENT OF CARE PLANNING MEETINGS**

- Determining the goals of the resident and family for end-of-life care provides a framework for the care team and enables it to tailor care to the resident's needs and preferences.

**EXAMPLE:** Some nursing homes and assisted living residences are using "I centered" care plans that discuss various aspects of care from the perspective of the resident. For activities of daily living, one might have a care plan that reads "When helping me to eat, I prefer you to stand on my right so that I can better hear you." Or, "When I am restless, I respond best if there is soothing music playing. My favorite composer is Brahms and the CD is in my top drawer."

- When meeting with the resident, proxy decision maker or family, the broader care team can discuss potential medical crises and treatment alternatives, and make decisions about the best course of action based on the resident's condition. The attending physician or other clinical practitioners play an important role in such discussions. Interpreter services will make these discussions meaningful for those who do not speak English.
- It is important that residents and families consider the following care decisions and the relationship of each of them to the resident's care goals during planning for the end of life:
  - Cardiopulmonary resuscitation
  - Invasive medical procedures and tests (e.g., surgery, blood tests, dialysis)
  - Hospitalization
  - Use of intensive care units and ventilators
  - Artificial nutrition/hydration
  - Use of antibiotics
  - Use of preventive health screenings, medications and dietary restrictions



**EXAMPLE:** Colonoscopies and mammograms may not be advisable for residents who are at the end of life and cannot benefit from or understand these sometimes uncomfortable procedures.

**EXAMPLE:** Risks and benefits of medications may change when a resident has a limited amount of time to benefit from the positive effects.

**EXAMPLE:** Dietary restrictions may be modified when residents have difficulty swallowing or are not eating enough to maintain their weight.

**EXAMPLE:** Forgoing weighing the resident when he or she is actively dying.

- The resident's desires regarding end-of-life care, cultural and religious traditions, functional capabilities and health status affect care decisions. Therefore, the proxy decision maker and the family need information from the broader care team that will help them consider each decision. This information includes the potential benefits and burdens of each intervention.

**EXAMPLE:** Residents who cannot swallow and who suffer from repeated bouts with aspiration pneumonia may not be responsive to or benefit from yet another course of antibiotics.

**EXAMPLE:** Residents who cannot swallow may not benefit from artificial nutrition and hydration because these treatments may cause discomfort and increase the potential for aspiration.

**EXAMPLE:** Hospitalization of residents with dementia may be associated with a decline in their functioning.

- Decisions about the intervention options need to be part of the care plan and be translated into medical orders, when appropriate, to help ensure a resident's wishes are respected.
- As the resident's condition declines with the progression of dementia, care goals may change from curing coexisting conditions or preserving function to palliative care. It is important to re-evaluate and, if necessary, revise the care goals and decisions in regularly scheduled care planning meetings based on the resident's current status, desires regarding care and family input.

**EXAMPLE:** A person with dementia who has been eating with cueing may progress to needing hand-over-hand assistance during meals. When the person's condition worsens and swallowing is affected, thickened liquids given with natural feeding techniques may be appropriate. When the person does not know what to do with food substances in his or her mouth or cannot swallow, a decision for comfort may be made to stop feeding the patient. Under these circumstances, attempting to put food into the person's mouth can cause choking and aspiration pneumonia.

**NOTE:** Decisions should not be made without a recent objective assessment of a resident's functional and health status, which should occur at least quarterly or more frequently when a resident's condition changes.

- If a thoroughly informed resident, proxy decision maker or family decide on an aggressive or alternative medical intervention, or refuse treatment or care, the broader care team needs to make all feasible efforts to honor such a decision. However, the care team is not required to deliver treatment or care that is determined to be medically inappropriate.



# 3

## Care Provision, Coordination and Communication When Residents Choose Hospice Services



- When residents choose hospice care, effective staff training, care coordination and communication between the nursing home or assisted living residence and the hospice service help ensure the provision of high-quality end-of-life care. The goals of such systems are to ensure that:
  - Hospice and residence staff communicate with each other about the resident's life, current condition and care issues.
  - Hospice and residence staff determine which staff will be the primary source of communication with the family.
  - Hospice and residence care plans for residents are integrated.
  - Delivery of hospice services minimizes disruption of care routines and builds upon the residence staff's relationships with those with dementia.
  - Residents and families receive the appropriate balance of care from the residence and the hospice.
  - Hospice and residence staff provide training in each other's care provision when needed.
- **EXAMPLE:** Hospice staff can provide training to residential care staff that covers the types of care hospices provide and the role of the hospice team.
- Employees know how to address and resolve conflicts that may arise between residences and hospices, and employees have policies in place to resolve them.
- Residences include hospice services in their quality improvement monitoring and include hospice in quality improvement activities.

# 4

## Assessment and Care for Physical Symptoms, Including Pain

- Good end-of-life care for people with dementia ensures that residents are treated for pain and other physical symptoms that may cause discomfort. Under-treatment for these symptoms can occur when residents have difficulty communicating their discomfort or because staff skills in recognizing discomfort vary.

**NOTE:** Pain assessment and management for people with dementia is covered in detail in Phase 1 Practice Recommendations.

### CARE APPROACHES

- It is as important for staff to regularly assess and monitor a resident's physical symptoms and pain at the end of life as in any other stage of dementia.
- Regular assessment of physical distress is essential for pre-emptive treatment to prevent a condition from occurring in the first place, as well as to prevent secondary problems.

**EXAMPLE:** Maintaining good oral hygiene for residents can prevent a buildup of debris on dentures, and conditions such as tooth decay, mouth sores, unpleasant odors and gum disease, which in turn can affect food and fluid intake and overall health.

- Direct care workers may be the first to notice a resident's symptoms. Therefore, it is important to consider training direct care workers to recognize and report symptoms to their supervisors. Workers could use a checklist to observe a resident's comfort level at the end of life. The checklist may include such items as:
  - Change in behaviors, such as becoming more withdrawn or agitated
  - Change in mental status, such as increased confusion or lack of responsiveness
  - Verbal communication, such as yelling or calling out
  - Motor restlessness
  - Facial grimacing or teeth grinding
  - Gestures that may communicate distress
  - Rigidity of body posture and position or posturing of extremities
  - Labored breathing pattern
  - Changes in swallowing ability
  - Loss of appetite and thirst
  - Excessive thirst
  - Disturbed or restless sleep
  - Scratching or picking at skin or other body parts
  - Changes in skin condition, such as bruising, open or discolored areas
  - Excessive sweating
  - Dry mouth or problem with oral cleanliness
  - Excessive oral secretions or drooling
  - Accumulation of secretions (eyes, nose, lungs, genitalia)
  - Bowel patterns and incontinence
  - Change in general cleanliness, such as dirty nails, body odor, etc.
  - Change in grooming habits, such as unkempt hair, unbrushed teeth, etc.
- Residents in the end of life often have a limited range of expression. Staff who are more familiar with residents may be able to better identify change and assess a resident's condition. Consistent staff assignment is one approach that may help staff become more familiar with residents and anticipate their needs.

**NOTE:** Regardless of the staffing structure, thorough and regular reporting of information about residents verbally and in the resident's chart will help ensure that the individual receives consistent care.

- Regular consultation with family can provide valuable information about how the resident typically communicates discomfort.
- Comfort-care approaches to physical symptoms can be beneficial.

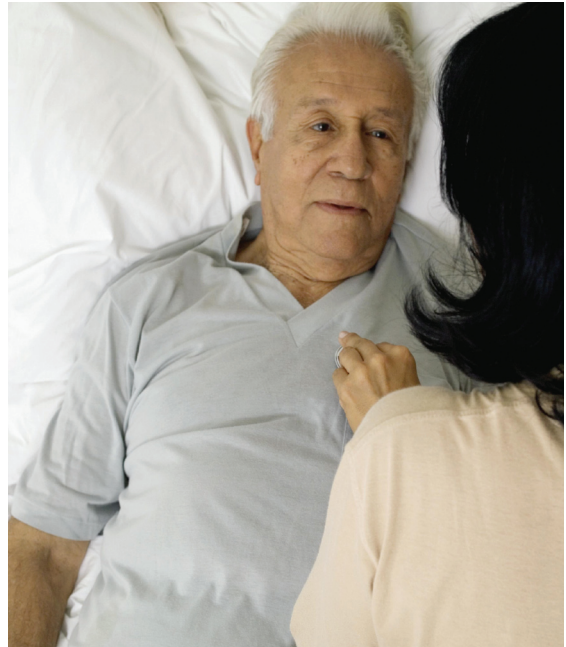
**EXAMPLE:** Oxygen or an oscillating fan set on low and aimed toward the resident can produce enough moving air to make breathing easier.

**EXAMPLE:** Resident's dry mouth can be moisturized by frequent oral swabbing and cleaning, or artificial saliva spray.

**EXAMPLE:** Difficulty with swallowing can be addressed by hands-on assistance with eating, changing food texture or increasing the thickness of liquids.

**NOTE:** Syringe feeding is not an acceptable practice in most situations and should not be used for those with swallowing difficulties because it is an unsafe practice for this group.

**EXAMPLE:** Sometimes just holding the resident's hand will provide some comfort when the source of distress is unknown.



#### **IMPORTANCE OF PAIN ASSESSMENT AND CARE PLANNING**

- There are many pain scales and tools available for assessment at end of life for people with dementia. Staff can try various types to determine which ones work most effectively for any given resident with dementia. Once an appropriate pain scale is determined for an individual resident, consistent use of the same pain scale is best, until the resident's condition deteriorates to the point where the scale is no longer useful.
- Effective care plans are updated when pain symptoms get worse and current pain management is not working.

# 5

## Assessment and Care for Behavioral Symptoms

- At the end of life, behavioral changes may indicate distress, so investigating the cause of any change is important.

**NOTE:** Staff awareness of the impact of resident behavior changes on family is important as well. The frequent inability of people with dementia at the end of life to communicate can be upsetting to family members when they realize that their loved one is dying.

### ASSESSMENT

- Direct care workers may be the first to notice a resident's behavioral and psychological symptoms. Therefore, it is important to consider training direct care workers to recognize and report the symptoms to their supervisors. For example, workers could use a checklist, including such items as:
  - Changes in attention span
  - Changes in level of arousal (distractible, inattentive, fluctuating arousal, variably alert)
  - Psychomotor agitation
  - Changes in mood/affect (depressed, anxious, fearful)
  - Hallucinations (visual, auditory, tactile)
  - Withdrawal from others
  - Groaning or calling out
  - Facial grimacing
  - Striking out or other physical gestures of discomfort or distress
- It is important to determine whether a particular resident's behavior is due to a known cause (e.g., medication effect) or a change in health or emotional conditions (e.g., dehydration, pain or depression) that requires assessment and possible treatment.

### CARE APPROACHES

- Once the underlying cause for the behavior has been addressed, behavioral interventions should only be pursued if a particular behavioral symptom is found to be distressing for the resident involved or poses a risk or harm to the resident or others.

**EXAMPLE:** Using a psychotropic medication to sedate a resident who has verbal outbursts without evidence that these outbursts are causing harm or distress to the resident is inappropriate. This particular use of psychotropic medication may be a form of restraint limited by federal and state regulations governing nursing homes and assisted living. Instead, the care team needs to investigate the reasons behind the outbursts and address those needs. In this example, the resident had untreated pain.
- It is best to first try to address behaviors of concern through care or environmental interventions (i.e., nonpharmacological approaches). These interventions address unmet physical and psychological needs and eliminate or reduce environmental irritants.

**EXAMPLE:** Using gentle caregiving techniques, including warnings before touching a person or beginning care, apologies for causing distress, keeping the person covered and warm, etc.

**EXAMPLE:** Providing companionship for a resident who is isolated. Companionship can come through use of residence staff; hospice staff, if the resident has chosen hospice; or volunteers.

**EXAMPLE:** Altering the environment for comfort, such as providing a calm environment, soft music and privacy, may help to minimize a resident's restlessness at the end of life.

# 6

## Psychosocial and Spiritual Support of Residents

- While residences need to meet the daily physical needs of individuals with dementia, their psychosocial and spiritual needs at the end of life also require attention.
- Residents with dementia are able to derive a sense of comfort from familiar and meaningful interactions. Members of the care team can enhance a resident's quality of life by assuming that the resident benefits from positive interactions, even though he or she may be incapable of responding to them. Quality of life for residents with dementia depends on the quality of the interaction and relationships they have with direct care staff.

**NOTE:** Involvement of hospice or geriatric care managers can bring additional resources for psychosocial and spiritual support of the resident.

### PSYCHOSOCIAL SUPPORT

- Providing appropriate support to dying residents with severe dementia involves staff, family and volunteers learning and communicating as much as possible about the resident's life story, preferences and abilities, and honoring the resident's needs, desires and cultural backgrounds.
  - EXAMPLE:** Encouraging Spanish-speaking staff or volunteers to converse in that language with residents whose first language is Spanish.
  - EXAMPLE:** Playing violin music for a resident who played this instrument in an orchestra.
  - EXAMPLE:** Stimulating the senses by giving the resident the opportunity to smell freshly baked bread or a meal being prepared if they enjoyed cooking.
  - EXAMPLE:** Bringing in fabric swatches to touch and feel for a resident who used to sew.
- Some residents will not have family who can be with them as they are dying. In these instances, residence-based volunteer programs can help ensure that these individuals have companionship

during this critical time. Residences also can help ensure that these individuals have access to hospice services, if they want them and the services are available. In addition to their regular staff, hospices frequently offer volunteers as part of their services.

### SPIRITUAL SUPPORT

- Staff need to know as much as possible about whether an individual has cultural or religious values or a certain outlook toward the end of life. Staff can provide the best support when they know which practices are most significant to the individual resident. Family and friends, when they are available, are likely to have this information and need to be consulted about care plans that address spiritual support.
- If proxy decision makers and individuals with dementia so desire, the residence can help them access chaplains, other clergy or advisors and involve these people in care planning when appropriate.
- Offering access to a nondenominational chapel or a quiet setting for reflection and meditation on-site can help residents, family members and staff as they deal with end-of-life issues.
- Spiritual support is part of discussions about palliative and hospice care. Access to hospice and palliative care can be particularly helpful in providing expertise regarding the complicated psychosocial and spiritual support needs that residents and families may have.

## **PSYCHOSOCIAL AND SPIRITUAL SUPPORT OF FAMILY**

- For family members and loved ones, grieving for a person with dementia may be a prolonged, ongoing experience marked by conflicting emotions. The debilitating nature of dementia causes grief at multiple stages, beginning with diagnosis. Grief also may be experienced when a resident is first placed in a nursing residence and then by the unavoidable decline and eventual death of the individual.
- Proxy decision makers may experience guilt in planning and implementing the end-of-life care choices they must make on behalf of their loved ones. The interdisciplinary care team plays an important role in providing access to psychosocial and spiritual support for family throughout the grieving process. Some families may require referral to a professional, such as a trained grief counselor, or if there is disagreement about care, someone skilled in conflict resolution.
- Family members may desire psychosocial and spiritual support when a resident is actively dying. During this time, a staff member trained in providing support to families, such as a counselor, social worker, chaplain or nurse, can help educate and guide the family through the resident's dying process and ultimate death.

**EXAMPLE:** A knowledgeable nurse can inform the family and allay their fears about the signs of approaching death, such as changes in respiration and skin color.

**EXAMPLE:** A trained staff member can counsel the family at all stages of the disease and grieving process.

**EXAMPLE:** A trained staff member can set up a support group at the residence, when possible.
- Providing information to families about the signs and symptoms of dying will help them to have a

better understanding of what their loved ones are experiencing. The signs and symptoms identified may include:

- Decreased need for food and drink because body functions are gradually slowing down.
  - Difficulty swallowing. The mouth will become drier and needs to be moistened.
  - Increased sleeping and more difficulty in waking up.
  - Increased restlessness.
  - Decreased urine output as kidneys slow down.
  - Breathing may sound moist because of relaxed vocal cords and a small amount of oral secretions collecting at back of throat.
  - Change in breathing patterns, with 10-30 second periods of no breathing, referred to as apnea.
  - Moaning sounds, which may not necessarily signify pain.
  - Arms and legs may become cool to the touch and bluish in color. There also may be mottling (reddish blue blotches) on the underside of the hands and feet. The underside of the body may be somewhat darker in color. These physical signs are a result of the slowing down of blood circulation and do not necessarily indicate that the person is too cold.
  - Fevers may occur.
- Sharing information with the family about what will happen immediately following death is important. For example, who will be called first, what will happen to the body, how long (hours or days) the family has to take away the resident's belongings.

# 7

## Family Participation in Resident's End-of-life Care

- Family members are an important part of the care team and often derive satisfaction in knowing that they can still help with the care and comfort of their loved ones. To facilitate this, staff may provide suggestions for activities that the family members can engage in with the resident.

**EXAMPLE:** Direct care staff can teach the family how to regularly moisten the resident's mouth and how to massage the resident's hands and feet.

**EXAMPLE:** Encourage family members to play music that the resident enjoys or read aloud passages from the resident's favorite book.

**EXAMPLE:** Encourage families to bring in pictures and items familiar to the resident so that they and staff can use them to connect to the resident and provide the comfort of familiar objects.

**EXAMPLE:** Activities staff can give the family ideas for providing comfort to the resident, such as hand holding, massaging the hands, playing soothing music, etc.

**EXAMPLE:** Families can offer reassurance and continue to talk to their loved one in a soothing voice because it can be calming for the resident.

- Soliciting input from the proxy decision maker or family regarding care options and development of a care plan helps them know that they are contributing to the well-being of the resident.
- Members of the broader care team may not always be available when family members visit a residence. The residence can encourage family members to pose concerns and questions about end-of-life care for the broader team to answer by facilitating communication and contact.

**EXAMPLE:** Provide a logbook or an e-mail address to use in correspondence.

**EXAMPLE:** Exchange telephone numbers to make communication easier between staff and family.

- Members of the broader care team can show support for the family while the resident dies.

**EXAMPLE:** Provide the family member with a pillow, blanket and recliner if he or she plans to stay the night.

**EXAMPLE:** Allow access and encourage family members to use a refrigerator at the residence.

**EXAMPLE:** Ask family members whether they are hungry or want some reading materials.

**EXAMPLE:** Provide "comfort carts" that can include: snacks, sandwiches, beverages, inspirational passages and books, a listing of places of worship in the area, a CD player with comforting music, massage aides and other items that can help family spend meaningful time with the resident.

- Some residences could provide the family and resident with a private room when the resident is actively dying.
- Residences could use a signal, such as a flower, to put on the door of the person who is actively dying to alert staff to be extra quiet in that area and to encourage staff to visit that individual and his or her family.
- Providers may also encourage the development of family support networks to connect those families that share the same experience in their role as caregivers and proxy decision makers. Family councils could play a role in this.

**NOTE:** If such a network or group does not exist in the residence, staff can refer families to the Alzheimer's Association or other caregiver support groups in the community.

- The involvement of hospice services can provide additional, experienced staff members who are skilled at meeting the grief and bereavement needs of family members.

# 8

## Staff Training

- Staff education and training is an essential part of the delivery of quality end-of-life care for individuals with dementia. It is important for staff members to adopt an attentive, anticipatory and investigative approach to caring for very vulnerable individuals who can no longer manage their own care.  
**NOTE:** Residences that have contracts with hospices or palliative care services may request the hospice to provide palliative care training to staff.
- Good preparation for the unique challenges of providing quality end-of-life care requires that staff have training in caring for people with dementia, which covers:
  - Dementia as a terminal illness
  - Effective communication with residents who have dementia
  - Communication with the resident, proxy decision maker and family regarding advance care planning, end-of-life decisions and when the resident has begun the dying process or has a prognosis of death
  - Culturally appropriate communication and care for residents and families
  - Need to honor advance directives and the treatment choices of proxy decision makers for legal and ethical reasons, despite one's personal beliefs about the appropriateness of care decisions
  - Physical and behavioral symptom assessment as well as pharmacological and nonpharmacological approaches to care at the end of life
  - A basic understanding of pharmacological approaches to symptom management
  - Approaches and goals of care (restorative-focused care versus comfort or palliative care)
  - Common symptoms associated with dementia and signs of impending death
  - Coordination among care teams, including hospice providers, when a resident chooses hospice
  - Understanding the grieving process and bereavement needs of a family with someone who has dementia
  - Support for the resident, family and other community members, including a roommate, while the resident is dying
  - Importance of spiritual support for everyone involved, including the resident, family, proxy decision maker, other residents and staff
- New or part-time staff members can benefit greatly by learning from experienced staff members who are familiar with dementia care at the end of life.  
**EXAMPLE:** A palliative care mentoring program, which pairs a new frontline or part-time staff member with an experienced staff member, can provide the opportunity for experienced staff members to share their knowledge, experience and skill.



# 9

## Acknowledgement of Death and Bereavement Services

- An essential part of quality end-of-life care is providing services and support to the family following the dignified death of a resident. Properly acknowledging a resident's death supports the care community as it grieves and celebrates the resident's life.
- There are several approaches that residences could use to respectfully acknowledge the death of an individual with dementia. Examples include:
  - Alert all staff members on duty that a resident has just died to ensure staff members do not walk into the resident's room unaware of his or her death.
  - Tell the resident's roommate, if applicable, about the death.
  - Place a "hold" on the resident's bed or room for a period of time out of respect for both the resident and family.
  - Place a flower on the resident's bed for a period of time.
  - Let other residents know of a death and when services will occur.
  - Occupy those who might be upset by the arrival of the mortuary with an activity.
  - Create a "memorial book" or "book of condolences" and place it in the lobby or foyer so that members of the community can pay tribute to the resident by writing words of encouragement for the family and signing their names.

**NOTE:** Families should have an opportunity to decide whether this is something they want.
  - Place the resident's photograph on a special "recognition wall" for several days to mark the passing of a member of the community, or place an obituary in the residence's newsletter.

**NOTE:** The use of resident pictures and personal information must comply with the federal Health Insurance Portability and Accountability Act's (HIPAA) privacy regulations.
- Assisted living residences and nursing homes, in coordination with hospice services, can recognize staff and family bereavement in a number of ways:
  - At the time of death, any available staff can join the family or others at the bedside for a short ceremony. Depending on the residence and the individual's preferences, there may be a reading of a prayer or a poem, or the group may join together in singing a familiar song as a way to honor the person's passing.
  - Send the family a condolence card signed by the broader care team and a card on the first-year anniversary of the resident's death.
  - Contact the family by phone to express concern for the family during their bereavement.

**NOTE:** Bereavement services for families are available from hospices for a year after a resident's death.
- Conduct periodic in-house memorial services to bring together current residents, family members and staff members to recognize and celebrate the lives of residents who have died. Staff can get the permission of families for the memorial service, help plan and officiate at the memorial, and provide anecdotes about their experiences with the resident.

**NOTE:** Resident memorial services give staff, residents and volunteers who have developed close relationships with a former resident an opportunity to grieve.

- Staff and residents need time to grieve and say goodbye to a resident they have cared for or lived with over the years.

**EXAMPLE:** Inform workers who have an emotional attachment to their residents about imminent death and provide them with an opportunity to be present and supportive during a resident's final hours and to say farewell.

**EXAMPLE:** Provide ways for staff to pay tribute to a resident who has died, such as writing a poem, creating a collage of photos or a time to share stories.

**EXAMPLE:** Provide residents with transportation to memorial services.





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