

Alzheimer's Association
Campaign for Quality Residential Care

Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes



Building consensus on
quality care for people
living with dementia

alzheimer's  association®

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The Alzheimer's Association is the leading donor-supported, 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 – Phases 1 and 2

Edited by Jane Tilly, Dr.PH., and Peter Reed, Ph.D.

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 for improving the quality of life for people with dementia, we launched the Alzheimer's Association Campaign for Quality Residential Care in 2005.

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.

Each year we are focusing on a different set of care recommendations that can make a significant difference in an individual's quality of life. Phase 1 focuses on the basics of good dementia care and three care areas: food and fluid consumption, pain management and social engagement. Phase 2 covers three additional care areas — wandering, falls and physical restraints. In the next few years, we will add recommendations in new care areas, such as end-of-life care, and update recommendations as new evidence on effective care interventions becomes available.

To date, 26 leading organizations have expressed their support and acceptance of the Phase 1 Dementia Care Practice Recommendations and 24 have stood with us to support the Phase 2 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 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 encourage adoption of our recommended practices in assisted living residences and nursing homes, we are advocating with direct 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 their caregivers to make informed decisions, we have developed the Alzheimer's Association CareFinder™. This interactive online guide is educating consumers on how to recognize quality care, choose the best care options, and advocate for quality within a residence.

Phase 1

Introduction

Dementia Care Fundamentals

Food and Fluid Consumption

Pain Management

Social Engagement



Introduction to the Dementia Care Practice Recommendations

Phase 1

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

A three-year study, funded by the Alzheimer's Association and conducted by researchers at the University of North Carolina at Chapel Hill, explored staff and facility characteristics associated with quality of life for people with dementia in assisted living residences and nursing homes. Results from this study were published in *The Gerontologist* (October 2005).

The Association also conducted a comprehensive literature review, *Evidence on Interventions to Improve Quality of Care for Residents with Dementia in Assisted Living and Nursing Homes*, which critiques evidence on interventions designed to improve dementia care. Dementia care experts and professional staff from the entire Alzheimer's Association used this evidence and a consensus-building process to translate the research into specific recommendations for dementia care practices.

Included in the initial set of recommendations are the fundamentals for effective dementia care, which are based on person-centered care — care tailored to the abilities and changing needs of each resident.

Recommended practices for care include a comprehensive assessment and care planning as well as understanding behavior and effective communication. Strategies for implementing person-centered care rely on having effective staff approaches and an environment conducive to carrying out recommended care practices.

For the first year, the Alzheimer's Association chose three priority care areas where we believe intervention can make a significant difference in an individual's quality of life. The dementia care recommendations define goals for each care area and present strategies for achieving them.

Food and Fluid Consumption

Inadequate consumption or inappropriate food and fluid choices can contribute directly to a decline in a resident's health and well-being. Recommendations are based on these goals:

- Provide good screening and preventive systems for nutritional care.
- Assure proper nutrition and hydration, given resident preferences and life circumstances.
- Promote mealtimes as pleasant and enjoyable activities where staff have an opportunity to observe and interact with residents.

Pain Management

Pain is under-recognized and undertreated among people with dementia, primarily because they can have difficulty communicating. Poorly managed pain can result in behavioral symptoms and lead to unnecessary use of psychotropic medications. Our care recommendations are based on the following goals:

- Ease the distress associated with pain and help residents enjoy an improved quality of life.
- Treat pain as the "fifth vital sign" by routinely assessing and treating it in a formal, systematic way, as one would treat blood pressure, pulse, respiration and temperature.
- Tailor pain management techniques to each resident's needs, circumstances, conditions and risks.

Social Engagement

Engagement in meaningful activities is one of the critical elements of good dementia care. Activities help residents maintain their functional abilities and can enhance quality of life. Recommendations are based on these goals:

- Offer many opportunities each day for providing a context with personal meaning, a sense of community, choices and fun.

- Design interactions to do *with* — not *to* or *for* — the resident.
- Respect resident preferences, even if the resident prefers solitude.

When nursing homes and assisted living residences are considering changes to care or to the environment of the residence, they should ensure that these changes comply with relevant state and federal regulations.

Organizations Supporting the Dementia Care Practice Recommendations, Phase 1

AARP

American Assisted Living Nurses Association

American Association of Homes and Services for the Aging

American College of Health Care Administrators

American Dietetic Association

American Health Care Association

American Health Quality Association

American Medical Directors Association

American Occupational Therapy Association

American Physical Therapy Association

American Seniors Housing Association

American Society of Consultant Pharmacists

American Therapeutic Recreation Association

Assisted Living Federation of America

Catholic Health Association

Consumer Consortium on Assisted Living

John A. Hartford Foundation Institute for Geriatric Nursing, New York University College of Nursing

National Association of Activity Professionals

National Association of Directors of Nursing Administration in Long Term Care

National Association of Social Workers

National Center for Assisted Living

National Citizens' Coalition for Nursing Home Reform

National Hospice and Palliative Care Organization

Paralyzed Veterans of America

Service Employees International Union

The American Speech-Language-Hearing Association accepts the recommendations.

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 Quality Care Campaign — to enhance the quality of life of people with dementia by improving the quality of dementia care in assisted living residences and nursing homes.

Commitment to Dementia Care

Fundamentals for Effective Dementia Care

- People with dementia are able to experience joy, comfort, meaning and growth in their lives.
- For people with dementia in assisted living and nursing homes, quality of life depends on the quality of the relationships they have with the direct care staff.
- Optimal care occurs within a social environment that supports the development of healthy relationships between staff, family and residents.
- Good dementia care involves assessment of a resident's abilities; care planning and provision; strategies for addressing behavioral and communication changes; appropriate staffing patterns; and an assisted living or nursing home environment that fosters community.
- Each person with dementia is unique, having a different constellation of abilities and need for support, which change over time as the disease progresses.
- Staff can determine how best to serve each resident by knowing as much as possible about each resident's life story, preferences and abilities.
- Good dementia care involves using information about a resident to develop "person-centered" strategies, which are designed to ensure that services are tailored to each individual's circumstances.

Goals for Effective Dementia Care

- To ensure that staff provide person-centered dementia care based on thorough knowledge of residents and their abilities and needs
- To help staff and available family act as "care partners" with residents, working with residents to achieve optimal resident functioning and a high quality of life

NOTE: "Family members" can include people who are related to a resident or are not related but play a significant role in the resident's life.

- To have staff use a flexible, problem-solving approach to care designed to prevent problems before they occur by shifting care strategies to meet the changing conditions of people with dementia

Recommended Practices for Effective Dementia Care

ASSESSMENT

- A holistic assessment of the resident's abilities and background is necessary to provide care and assistance that is tailored to the resident's needs.
- A holistic assessment includes understanding a resident's:
 - Cognitive health
 - Physical health
 - Physical functioning
 - Behavioral status
 - Sensory capabilities
 - Decision-making capacity
 - Communication abilities
 - Personal background
 - Cultural preferences
 - Spiritual needs and preferences
- Assessments should acknowledge that the resident's functioning might vary across different staff shifts.

EXAMPLE: Residents may become confused, disoriented or more active as evening approaches or during staff changes.



- Thorough assessment includes obtaining verbal information directly from residents and from family when possible.
EXAMPLE: Staff can ask residents about their reactions to care routines, and staff can provide feedback on successful techniques to the entire care team.
EXAMPLE: Family members can help develop a “life story” of the resident, offering detailed background information about a resident’s life experiences, personal preferences and daily routines.
- If obtaining information from a resident or family is difficult, staff can still learn about the resident through other sources, such as medical records, and by observing the resident’s reaction to particular approaches to care.
- Resident behaviors can be seen as a form of communication and an expression of preference.
EXAMPLE: A resident repeatedly refusing a certain food may simply not like that particular food.
EXAMPLE: A resident who consistently resists entering the shower room may need another method of keeping clean.
- Regular formal assessment, as required by federal or state regulation, is key to appropriate management of residents’ care. Equally important is ongoing monitoring and assessment of residents, particularly upon return from the hospital or upon a significant change in their conditions.

- If assessment identifies problems requiring consultation with health or other types of professionals, making the appropriate referrals can help mitigate these problems.

EXAMPLE: Professionals such as physical or occupational therapists can help people with dementia regain physical health and improve their performance of daily activities.

- Obtaining the most current advance directive information (e.g., durable health care power of attorney or living will) as well as information about a resident’s preferences regarding palliative care and funeral arrangements helps ensure that the resident’s wishes will be honored.

NOTE: While residents possess the capacity for decision making, they have the legal right to review and revise their advance directive.

CARE PLANNING AND PROVISION

- Effective care planning includes a resident and family, when appropriate, as well as all staff (including direct care staff) who regularly interact with the resident throughout the process.
EXAMPLE: By asking staff and family members who have the best relationship with the resident to describe how they elicit cooperation regarding necessary care activities, those techniques can become a routine part of care.
- An effective care plan builds on the resident’s abilities and incorporates strategies such as task breakdown, fitness programs and physical or occupational therapy to help residents complete their daily routines and maintain their functional abilities as long as possible.
- When all staff involved in a resident’s care are familiar with the care plan, they will be better equipped to provide appropriate care to the resident.

NOTE: Assessments, care plans and life stories will be most beneficial if they are accessible to all staff.

- Care plans will remain current and most useful if they are regularly updated in conjunction with periodic assessments.
- Care plans need to be flexible enough to adapt to daily changes in a resident's needs and wishes.

BEHAVIOR AND COMMUNICATION

- Residents need opportunities and sufficient time to express themselves.

EXAMPLE: Speaking in simple, direct language to residents, potentially accompanied by gestures, pictures, written words or verbal cues, may help staff communicate with residents when involved in daily activities.

EXAMPLE: Residents may need to work with a speech-language pathologist to maximize their communication skills.

- The behavior and emotional state of people with dementia often are forms of communication because residents may lack the ability to communicate in other ways.
- Staff need initial and ongoing training to identify potential triggers for a resident's behavioral and emotional symptoms, such as agitation and depression.

NOTE: Triggers may include visual or hearing impairments, hunger, thirst, pain, lack of social interaction or inappropriate strategies for care activities by staff.

- When staff recognize these triggers, they can use environmental and behavioral strategies to modify the triggers' impact.
- Staff actions can elicit positive behavioral responses as well.

EXAMPLE: Positive staff actions include providing relaxing physical contact like hand holding, apologizing if a resident complains of pain during a care activity, listening to resident concerns and providing reassurance.

- Information about a resident's life prior to admission, such as his or her culture and role within the family, may provide clues about effective approaches to care.

EXAMPLE: Knowing a resident's morning rituals, such as how they like coffee or tea and what time they prefer to wake up, can provide insight into how to care for a resident.

- If non-pharmacological treatment options fail after they have been applied consistently, then introducing new medications may be appropriate when residents have severe symptoms or have the potential to harm themselves or others.

NOTE: Medication and non-pharmacological approaches are not mutually exclusive. At times a combined approach might produce the greatest benefit for the resident.

- When considering new medications, consider the presence of any other potential problems, such as depression.

NOTE: Continued need for pharmacological treatment should be reassessed by a qualified health professional according to the medication regimen or upon a change in a resident's condition.

- Staff communication with a resident's family is critical to helping the family understand the progression of the resident's dementia, particularly as he or she approaches the end of life.

STAFFING

- Staffing patterns should ensure that residents with dementia have sufficient assistance to complete their health and personal care routines and to participate in the daily life of the residence.
- Consistent staff assignments help to promote the quality of the relationships between staff and residents.

- Direct care staff need education, support and supervision that empowers them to tailor their care to the needs of residents.

EXAMPLE: Direct care staff could learn when residents wish to get up and how they wish to be bathed.

EXAMPLE: Provide constructive feedback on staff interactions with residents.

- Staff supervisors may need ongoing coaching to help them empower and support the direct care staff to be decision makers.
NOTE: Facility and staff managers serve an important function as role models in providing good dementia care.
- Administrators have the role of evaluating facility policies and procedures to ensure that they support direct care staff decision making during real-time interactions with residents.
- Staff who understand the prognosis and symptoms of dementia and how this differs from normal aging and reversible forms of dementia are better prepared to care for people with dementia.
- Effective initial and ongoing staff training addresses:
 - Dementia, including the progression of the disease, memory loss, and psychiatric and behavioral symptoms
 - Strategies for providing person-centered care
 - Communication issues
 - A variety of techniques for understanding and approaching behavioral symptoms, including alternatives to restraints
 - An understanding of family dynamics
 - Information on how to address specific aspects of care (e.g., pain, food and fluid, social engagement)

- Staff need (1) recognition for their use of problem-solving approaches to providing care and (2) emotional support as they deal with their own emotional reactions to the decline of residents over time and eventual death.

- Staff should acknowledge and accept a resident's experience and should not ignore a resident's report of an event or his or her feelings and thoughts.

EXAMPLE: When a resident is complaining of pain, staff could tell the resident that they understand it hurts and then report the pain to a staff member who can address the resident's pain experience.

ENVIRONMENT

- The physical environment can encourage and support independence while promoting safety.
EXAMPLE: A positive environment has recognizable dining, activity and toileting areas as well as cues to help residents find their way around the residence.

- The optimal environment feels comfortable and familiar, as a home would, rather than a hospital. The environment should be less about physical structures and more about the feeling inspired by the quality of the place.

EXAMPLE: A home environment provides opportunities for residents to have privacy, sufficient lighting, pleasant music and multiple opportunities to eat and drink, and also minimizes negative stimuli such as loud overhead paging and glare.

EXAMPLE: When appropriate, a home environment might entail a private room and bathroom and the opportunity for residents to have personal furnishings, pictures and other items in their living area.

- Providing easy, safe and secure access to the outdoors while maintaining control over unauthorized exiting enhances the environment.

NOTE: Residents who have elopement behaviors need opportunities for safe wandering.

1

Adequate Food and Fluid Consumption

Dementia Issues

- Insufficient consumption or inappropriate food and fluid choices can contribute directly to a decline in a resident's health and well-being.
- Adequate assistance, preventive screening and intervention for nutritional problems will help to assure the overall health of residents suffering from dementia and will prevent unnecessary complications.
- Dementia may lead to reduced food and fluid intake, due in part to decreased recognition of hunger and thirst, declining perceptions of smell and taste, dysphagia (swallowing difficulty), inability to recognize dining utensils, loss of physical control, such as the ability to feed oneself, apraxia (impairment of ability to move) and depression.
- Residents with dementia may lose the ability to communicate hunger and thirst.
- Residents may refuse to eat because of physiological or behavioral conditions, or they may do so because they are at the end of life.
- Addressing dementia-associated problems and helping to ensure adequate intake of food and fluid requires a concerted staff effort.

Care Goals

- To have good screening and preventive systems for nutritional care to avoid problems such as weight loss, malnutrition, pressure ulcers, infection and poor wound healing
- To assure proper nutrition and hydration so that residents maintain their nutritional health and avoid unnecessary health complications, given resident preferences and life circumstances
- To promote mealtimes as pleasant and enjoyable activities. Mealtime provides an opportunity for staff to observe and interact with residents, helping to ensure health, well-being and quality of life.

Recommended Practices

ASSESSMENT

- Nutrition screening and thorough assessment are the foundation for providing optimal nutrition care.
- Assessments need to address nutritional problems and resident characteristics such as poor dental health, swallowing difficulties or distractibility during meals that may affect food and fluid consumption.

EXAMPLE: Set up referrals to a registered dietitian for residents who are at high risk for nutritional problems, in compliance with regulatory requirements. Registered dietitians can prioritize nutritional problems and interventions by verification, evaluation and interpretation of physical, chemical and behavioral information.

EXAMPLE: Those who have swallowing difficulties may need assessment by a qualified professional familiar with dysphagia.

- Difficulty with eating may also be the result of residents having impairments of balance, coordination, strength or endurance.
- NOTE:** Ensure that seating adequately compensates for these impairments.
- Ongoing monitoring of residents is necessary to discover changes in food and fluid intake, functional ability or behaviors during meals. Any changes should be reported to dietetic staff and care planners.

- Adequate assessment to minimize mealtime difficulties includes observing residents for warning signs such as:
 - Difficulty chewing and swallowing, or changes in swallowing ability
 - Poor utensil use
 - Refusing substitutions
 - Low attentiveness to a meal or wandering away during the meal
 - More than 25 percent of food uneaten during a meal

- Regular monitoring and recording of a resident's weight helps ensure that staff recognize and address the cause of any changes.

STAFF APPROACHES

- Various activities can engage residents in the mealtime experience and stimulate appetite.
EXAMPLE: Create opportunities for residents to help plan the menu and set the table; stimulate olfactory senses by baking bread or a pie prior to the meal.
EXAMPLE: Create a "happy hour" to encourage increased fluid intake.
- When practical, residents can choose the time when the meal is served. Mealtimes may need to be rescheduled for a different time of day if a resident exhibits time- or light-dependent agitation, distraction or disorientation.
- During the meal, residents often require assistance to maximize their own ability to eat and drink. Encouraging residents to function independently whenever possible can help prevent learned dependency.
EXAMPLE: If assessment shows that a resident can eat independently, but does so slowly, the resident can eat at his or her own pace, perhaps with verbal reminders to eat and drink. Mealtimes can be extended for slower-eating residents.
EXAMPLE: Adaptive utensils and lipped plates or finger foods may help individuals maintain their ability to eat.
EXAMPLE: For those residents who manage better if they face fewer choices, serving one food item at a time is preferable.
EXAMPLE: If residents need hand feeding, guide the resident's hand using the "hand-over-hand" technique.
- It is ideal for staff to sit, make eye contact and speak with residents when assisting with meals.
- Fortified foods and supplements may become necessary, but first try other food approaches such as favorite foods and food higher in nutrient density, calories and protein.
- Residents with severe and irreversible dementias may no longer be able to eat at the end of life and may need only comfort care.
NOTE: Residents at the end of life need their mouths moistened and good oral care.
NOTE: When residents are near the end of life, artificial nutrition and hydration may be withheld, in accordance with their wishes.

- Weight loss is often expected at the end of life, but should still be assessed.

NOTE: Residents should not be forced to eat beyond what they desire.

- When considering tube feeding as an option, one should be aware of the potential consequences. Tube feeding could have many serious side effects for residents with dementia, including aspiration, infections and resident removal of tubes.

ENVIRONMENT

- Residents should have a pleasant, familiar dining environment free of distractions to maximize their ability to eat and drink.
EXAMPLE: Distractions during meals should be limited by avoiding mealtime interruptions and by reducing unnecessary noise and the number of items on the table.
EXAMPLE: Serving residents with dementia in smaller dining rooms can minimize distractions.
EXAMPLE: A resident's attention to food can increase through visual cues, such as ensuring visual contrast between plate, food and place setting.
EXAMPLE: Present a variety of foods in attractive ways.
- A positive social environment can promote the ability of residents to eat and drink.
EXAMPLE: Consider where residents are seated to construct the most appropriate arrangements given relative need and personalities.
EXAMPLE: Provide small tables that encourage conversation among tablemates.

FOOD AND FLUID

- Residents need opportunities to drink fluids throughout the day.
EXAMPLE: Incorporate fluids into activities and have popsicles, sherbet, fruit slushes, gelatin desserts or other forms of fluid always available to residents.
- Nutritional requirements need to be met in the context of food and cultural preferences.
- As a resident's functional ability declines, food should be prepared to maximize the food's acceptance.
EXAMPLE: If a resident cannot handle utensils, try modifying the shape of food so it can be picked up with the fingers.

2

Pain Management

Dementia Issues

- Pain is defined as an individual's unpleasant sensory or emotional experience.

NOTE: Acute pain occurs abruptly and escalates quickly, whereas chronic pain is persistent or recurrent.

- Pain is a highly subjective personal experience for which there are no consistent, objective biological markers.

NOTE: Because of a lack of objective markers, pain can be easily under-recognized and undertreated among people with dementia.

- Poorly managed pain can result in behavioral symptoms and lead to unnecessary use of psychotropic medications.
- One of the challenges in managing pain for people with dementia is assessing and communicating with them about their pain experiences and about the side effects of medications.

NOTE: An individual's cognitive functioning, communication abilities, cultural background or emotional status may affect these experiences.

Care Goals

- To ease the distress associated with pain and help a resident enjoy an improved quality of life
- To treat pain as the "fifth vital sign" by routinely assessing and treating it in a formal, systematic way, as one would treat blood pressure, pulse, respiration and temperature
- To tailor pain management techniques to each resident's needs, circumstances, conditions and risks



Recommended Practices

ASSESSMENT

- Pain assessment should occur routinely, including when residents have conditions likely to result in pain and if residents indicate in any manner that they have pain.
- Effective pain assessment addresses:
 - Site of pain
 - Type of pain
 - Effect of pain on the person
 - Pain triggers
 - Whether pain is acute or chronic
 - Positive and negative consequences of treatment
- For those residents who cannot verbally communicate, direct observation by staff consistently working with them can help identify pain and pain behaviors.

EXAMPLE: Observing residents when they move may uncover problems that may not occur when they are at rest. The problems may require referrals to occupational or physical therapists.

EXAMPLE: Observation may uncover behavioral symptoms, such as agitation and mood changes, or verbal and physical expressions of pain, such as sighing, grimacing, moaning, slow movement, rigid posture and withdrawing extremities during care.

- When pain occurs and the cause is not known, conduct a thorough assessment of the resident's condition and contact family, if available, to collect background information on the resident's past pain experiences.
- When residents are in pain, appropriate referrals to a qualified health care professional can lead to effective treatment.

EXAMPLE: Pharmacists could be contacted when there are questions about the positive and negative aspects of employed pharmacological treatments.

- All staff, including direct care staff, should be involved in pain assessment by being trained to record their observations and report signs of pain in residents to licensed nursing staff.

NOTE: Use of assessment tools.

- There are many pain scales and tools available, and staff may want to try various types to determine which ones work most effectively for any given resident with dementia.
- If an appropriate pain scale is determined, staff should be trained to use the same pain scale consistently with a resident.
- Periodic reassessment of a resident's pain experience should use the same assessment tool over time as long as necessary.

STAFF APPROACHES

- Prevention of pain is the first defense against it.

EXAMPLE: Avoid conditions that cause pain, such as infections, fractures, pressure ulcers and skin tears, through use of appropriate caution when caring for residents.

- Pain can be prevented through the regular use of medications. Offering medications PRN, that is, only when the resident reports pain, may not be sufficient treatment for many residents.
- There may occasionally be valid clinical reasons for not wanting to mask acute pain with analgesics until a cause for the pain can be identified or ruled out.

EXAMPLE: It may be necessary to monitor acute abdominal pain to identify a surgical emergency.

- When chronic pain occurs, non-pharmacological approaches are often helpful.

EXAMPLE: Useful strategies to ease pain and promote well-being include relaxation, physical activities, superficial heat and repositioning.

- Analgesics or narcotic pain medications may be necessary if non-pharmacological therapies are not sufficient.

NOTE: Licensed practitioners should determine the type and amount of medication based on the severity of the resident's pain and his or her past experience with analgesics. When deciding on pharmacological treatments, consider all medication side effects, including those affecting dementia and cognitive functioning.

- Residents and their families should receive information about palliative care options, including hospice, when residents appear to have entered the final stages of dementia.
- When appropriate, work with a resident's physician to enroll a resident who is in the final stages of dementia in hospice.

NOTE: Signs that a resident may be in the final stages include a resident's inability to walk without assistance and to sit up without support, inability to smile, unrecognizable speech and swallowing problems.

NOTE: Entry into end-of-life care programs can help promote effective use of pain medication and ease the end of life process.

3

Social Engagement and Involvement in Meaningful Activities

Dementia Issues

- Residents have the opportunity to maintain and enhance their sense of dignity and self-esteem by engaging in meaningful social interactions throughout the day, every day.
- Staff require training and support to understand how to help residents achieve this goal.
- Both formal and informal activities provide the resident and the caregiver a sense of security and enjoyment.

NOTE: Formal activities are those typically found on the community activity calendar (classes, parties, discussions); informal activities are everyday interactions (a chat with a friend, a walk down the hall, a soothing bath).

- Meaningful activities are the foundation of dementia care because they help residents maintain their functional abilities and can enhance quality of life.
 - Every event, encounter or exchange between residents and staff is a potential activity.
- EXAMPLE:** Dining is a meaningful opportunity for socialization, enjoyment, satisfaction and self-fulfillment.
- Access to personal space and opportunities for free time to relax are essential elements for enhancing quality of life.



Care Goals

- To offer many opportunities each day for providing a context with personal meaning, a sense of community, choices and fun
- To design interactions to do *with* — not *to* or *for* — the resident
- To respect resident preferences, even if the resident prefers solitude

Recommended Practices

ASSESSMENT

- A formal initial assessment that involves family, when available, and ongoing interaction with a resident promotes understanding of the activities that would be meaningful to the resident.
- Assessments will help determine various resident characteristics relevant to social engagement and activity participation. To involve residents in the most meaningful activities, assess a resident's:
 - Capacity for physical movement
 - Capacity for mental stimulation
 - Interest in social interaction
 - Desire for spiritual participation and fulfillment
 - Cultural values and appreciation
 - Various specific recreational interests and preferences
- At the time of admission, families and residents should be invited to provide staff with "a life story" that summarizes the resident's past experiences, personal preferences and current capabilities.

STAFF APPROACHES

- Social engagement of residents is not the sole responsibility of the activities staff. Every staff member has the responsibility and the opportunity to interact with each resident in a manner that meets the resident's needs and desires.
- A plan for social engagement and meaningful activity is a critical part of the care plan.

- Staff can achieve both brief and extended interactions with residents throughout the day. Brief but meaningful encounters may greatly enhance a resident's life.
EXAMPLE: It takes very little time to share something personal with a resident, such as family photographs, or to approach a resident in a hallway and compliment her on her dress.
- Lack of verbal communication skills does not prevent residents with dementia from being socially engaged. On the contrary, staff may play an even more important role by initiating an engagement.
EXAMPLE: If a resident's life story indicates that the resident enjoys music, play music or sing a song.
- Activities need to acknowledge that some residents with dementia experience increased confusion, agitation and movement at the end of the day.
- Appropriately trained staff and volunteers can facilitate group activities.

NOTE: Staff training can include methods of adapting activities for the needs of each resident with dementia to maximize participation and engagement.

ENVIRONMENT

- Elements in the structure or layout of assisted living residences or nursing homes can create opportunities for meaningful activity.
EXAMPLE: Develop walking paths that encourage exploration and strolling when the home's facility layout permits.
EXAMPLE: Develop interest points such as a fish tank or a colorful tapestry that encourage visual or tactile stimulation.
- Activity materials can be available at all times for use by non-activity staff and visitors.
NOTE: These materials may include such things as baskets of fabric swatches, greeting cards, calendars with attractive photos and tactile items such as aprons, hats and fishing gear.
- Resident functioning can improve when the environment minimizes distractions that can frighten or confuse residents, while maximizing environmental factors that promote independence.
EXAMPLE: Hold an activity in a quiet room free of distractions or noise.
EXAMPLE: Ensure appropriate lighting, temperature and comfort for residents.

ACTIVITIES

- Residents should be encouraged to use their remaining skills in their daily activities. Use techniques that encourage residents to be as independent as possible.
- Frequent, meaningful activities are preferable to a few, isolated programs.
- Activities should proactively engage residents.
EXAMPLE: Having residents watch staff make decorations for a party is not as meaningful as asking residents to help make the decorations.
- The outcome of an activity or social interaction is not as important as the process of engaging the residents.
EXAMPLE: A gardening activity can be pleasant whether or not a plant grows.
- Offering activities that accommodate the resident's level of functioning can promote participation in them.
EXAMPLE: Word games may be highly successful for residents at one cognitive level and highly frustrating for residents at another.
- When an activity includes multiple participants, consider the group dynamic and the overall mood of the group, and be flexible in adapting the focus and purpose of the activity.
- Opportunities for involvement in the community are important for the sake of feeling part of the greater society.
EXAMPLE: Consider attending a concert at a local theater, participating in a community service project or playing with local children through an intergenerational program.
- Staff can offer opportunities for families to be involved in activities.
- Group sizes and lengths of time for the activity need to be tailored to the functional level of residents.
EXAMPLE: Ideal group sizes range from four to 10, depending on the activity and abilities of the residents.
EXAMPLE: Thirty minutes or less of one specific activity or task is appropriate for most individuals with dementia before transitioning to another task.
EXAMPLE: Residents who are not ambulatory can be meaningfully engaged and stimulated by such activities as massages, music and storytelling.

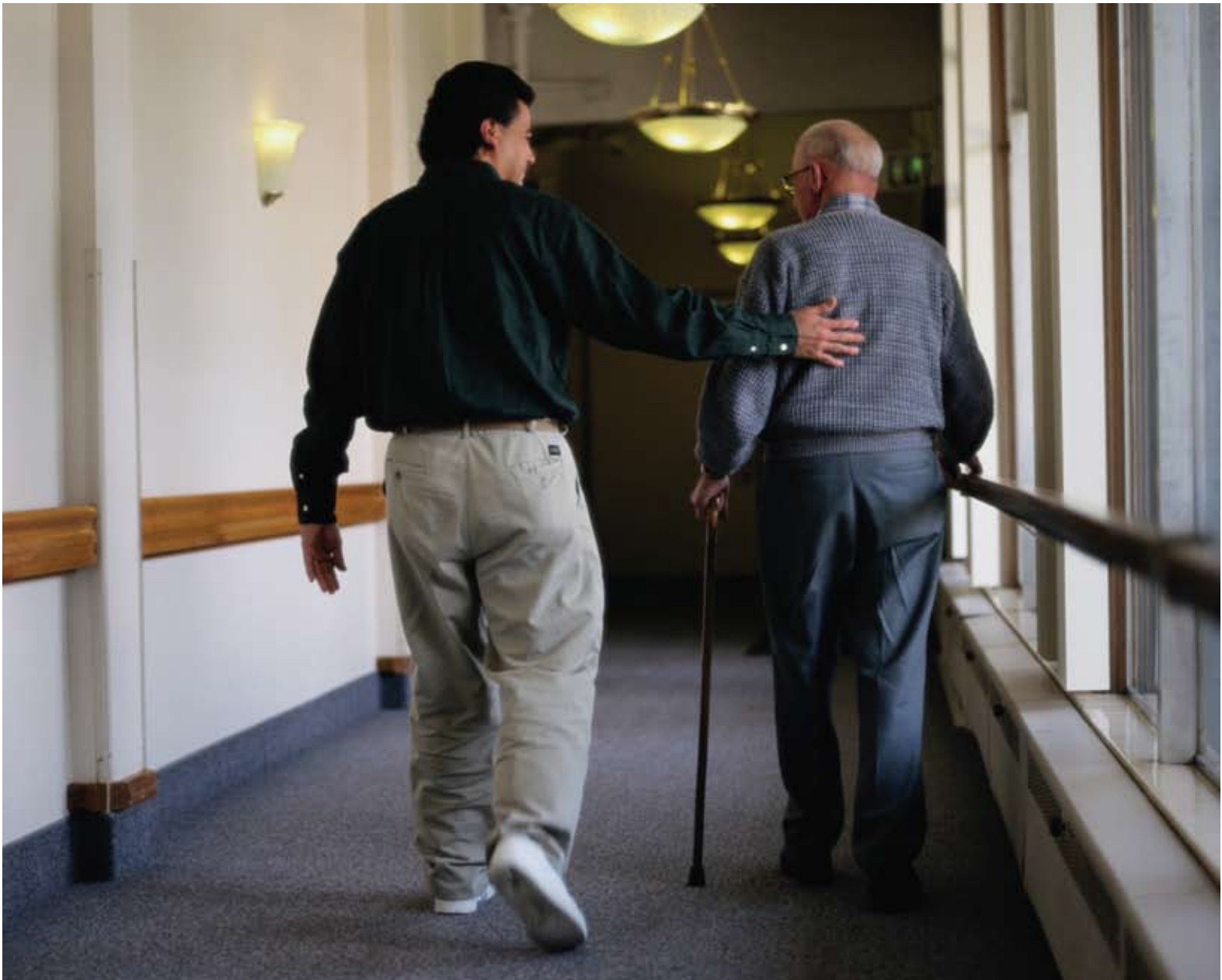
Phase 2

Introduction

Resident Wandering

Resident Falls

Physical Restraint-Free Care



Introduction to the Dementia Care Practice Recommendations

Phase 2

The second phase of the Dementia Care Practice Recommendations are again based on the latest evidence in dementia care research and the experience of care experts. In addition to the evidence used to inform Phase 1, The Association conducted a comprehensive literature review, *Falls, Wandering and Physical Restraints: Interventions for Residents with Dementia in Assisted Living and Nursing Homes*, which critiques evidence on interventions designed to improve dementia care. Dementia care experts and professional staff from the entire Alzheimer's Association used this evidence and a consensus-building process to translate the research into specific recommendations for dementia care practices.

Underlying the practice recommendations are person-centered approaches to dementia care, which involve tailoring care to the abilities and changing needs of each resident. Recommended practices for care include comprehensive assessment and care planning as well as understanding behavior and effective communication. Strategies for implementing person-centered services rely on having effective staff approaches and an environment conducive to carrying out recommended care practices.

The recommendations emphasize the importance of consistency in 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 appropriately trained staff.

For the second year of the Quality Care Campaign, the Alzheimer's Association chose three priority care areas where we believe intervention can make a significant difference in an individual's quality of life — wandering, falls and use of physical restraints. The dementia care recommendations define goals for each care area and present strategies for achieving them.

Resident Wandering

Wandering may be a behavioral expression of a basic human need such as the need for social contact, or a response to environmental irritants, physical discomforts or psychological distress. Recommendations are based on these goals:

- Encourage, support, and maintain a resident's mobility and choice, enabling him or her to move about safely and independently.
- Ensure that causes of wandering are assessed and addressed, with particular attention to unmet needs.
- Prevent unsafe wandering and successful exit seeking.

Resident Falls

People with dementia are at risk of falls because of their neurological impairments. The environment may also contribute to risk conditions. Recommendations are based on these goals:

- Promote safety and preserve mobility by reducing risk of falls and fall-related injuries.
- Minimize injuries by avoiding physical restraints.

Physical Restraint-Free Care

Physical restraints may be used in the mistaken belief that they help ensure safety, but they generally harm residents. Recommendations are based on these goals:

- Foster a restraint-free community in the nursing home or assisted living residence.
- Identify the underlying problems or needs that prompt the use of restraints, and address them using restraint-free methods.
- Provide staff with techniques they can use to prevent, reduce and eliminate use of restraints.

When nursing homes and assisted living residences are considering changes to care or to the environment of the residence, they should ensure that these changes comply with relevant state and federal regulations.

Organizations Supporting the Dementia Care Practice Recommendations, Phase 2

AARP

American Assisted Living Nurses Association
American Association of Homes and Services
for the Aging

American College of Health Care Administrators

American Health Care Association

American Health Quality Association

American Medical Directors Association

American Occupational Therapy Association

American Physical Therapy Association

American Seniors Housing Association

American Society of Consultant Pharmacists

American Therapeutic Recreation Association

Assisted Living Federation of America

Catholic Health Association

Consumer Consortium on Assisted Living

John A. Hartford Foundation Institute for
Geriatric Nursing, New York University
College of Nursing

National Association of Activity Professionals

National Association of Directors of Nursing

Administration in Long Term Care

National Association of Social Workers

National Center for Assisted Living

National Citizens' Coalition for Nursing

Home Reform

National Hospice and Palliative Care Organization

Paralyzed Veterans of America

Service Employees International Union

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 Quality Care Campaign — to enhance the quality of life of people with dementia by improving the quality of dementia care in assisted living residences and nursing homes.

4

Resident Wandering

Dementia Issues

- Wandering is a term many use to describe the behavior of people with dementia who move about in ways that may appear aimless, but which are often purposeful. Wandering, like all behavioral symptoms of dementia, occurs for understandable reasons. It may be a behavioral expression of a basic human need, or a response to environmental irritants, physical discomforts or psychological distress (see examples below).
- To many people, use of the term “wandering” suggests that the activity should be stopped when, in fact, it is often better to support a resident’s movement. Without agreement about an acceptable replacement, these recommendations use the term wandering, while also emphasizing the potential beneficial effects of moving about and exploring.
- Wandering is helpful when it provides stimulation or social contact, or helps maintain mobility. The beneficial effects of this activity can include resident conditioning and strength preservation, prevention of skin breakdown and constipation, and enhancement of mood.
- Wandering may be detrimental when it results in a resident leaving the premises, or entering unsafe areas or another resident’s space. Physical problems can occur, such as injuries, dehydration, weight loss, excessive fatigue or agitation, or death.
- Wandering may serve as a form of communication occurring in response to many factors or situations, including:
 - Physical or psychological needs
 - EXAMPLE:** A need for food, fluids, toileting or exercise
 - EXAMPLE:** A need for security or companionship
 - Environmental irritants
 - EXAMPLE:** Excessive sound, confusing visual stimuli or unfamiliar surroundings
 - EXAMPLE:** Changes in routines or caregivers
 - Distressing medical or emotional conditions
 - EXAMPLE:** Pain, urinary urgency, constipation, infection or medication effects
 - EXAMPLE:** Depression, anxiety, delusions or hallucinations, boredom or isolation
 - Desire for more physical stimulation
 - EXAMPLE:** Desire for fresh air, to see and touch plants, to feel sunlight or simply the desire to move
- *Exit seeking* is a form of wandering in which a resident attempts to leave the premises. It can result from the resident’s desire to return to a secure, familiar home or former workplace. The resident may be trying to reconnect with family members or may be following old habits, such as leaving for work in the afternoon. The resident may be drawn outside by a sunny day or have a desire for fresh air or a daily walk.
 - NOTE:** Some residents may not actually be trying to leave, but may simply see a door and decide to go through it, thus, they exit their residence unintentionally.
- A resident may wander when in a new environment. The unfamiliarity of the new environment may make persons with dementia more confused and increase their risk for wandering.
- *Successful exiting* (commonly referred to as elopement in the clinical setting) occurs when a resident who needs supervision leaves the residence without staff awareness or supervision.
 - NOTE:** People who wander persistently are the source of 80 percent of successful exiting. About 45 percent of these incidents occur within the first 48 hours of admission to a new residence.
- Potential consequences of successful exiting include injury and death.
 - NOTE:** Physical restraints have not been demonstrated to reduce the incidence of successful exit seeking or to enhance safety in residents who wander. Rather, restraint use is associated with an increased risk of injury.

Care Goals

- To encourage, support, and maintain a resident's mobility and choice, enabling him or her to move about safely and independently
- To ensure that causes of wandering are assessed and addressed, with particular attention to unmet needs
- To prevent unsafe wandering or successful exit seeking

Recommended Practices

ASSESSMENT

- Before admission, collect information from family, friends or the transferring facility about the resident's history and patterns of wandering and strategies the family used to prevent unsafe wandering or successful exiting.
- Assess each resident's desire and ability to move about, and associated risks, such as becoming lost, entering unsafe areas or intruding on another resident's private space. While evaluating the triggers of wandering and a resident's wandering patterns, it is essential to determine:
 - Whether wandering is a new occurrence
 - Wandering patterns
 - Medical conditions that may contribute to wandering, such as urinary tract infections, pain and constipation
 - Cognitive functioning, especially safety awareness and being impulsive
 - Vision and hearing
 - Functional mobility status: balance, gait and transfer abilities
 - Sleep patterns
 - Resident life history, including past occupation, daily routines and leisure interests
 - The resident's own toileting routines
 - Emotional or psychological conditions that may be related to wandering, such as depression and anxiety or need for companionship
 - Social considerations, such as interest in involvement with others
 - Environmental hazards (e.g., poor lighting and uneven floors)

- History of recent falls or near falls
- The resident's footwear and clothing
- The resident's access and response to safeguards (e.g., video monitors, sensors, door alarms, access to handrails and places to rest)
- Determine if unsupervised wandering presents a risk or benefit to the resident and others in the residence.
- Assess the residence to determine if it can meet the needs of a resident who wanders. An adequate environment involves:
 - Physical and social environments that provide activities appropriate for a resident's cognitive functioning and interests, as well as opportunities for walking, exploring and social interaction
 - Communication and search plans in the event of successful exiting

STAFF APPROACHES

- Develop a care plan, based on resident assessment, which promotes resident choice, mobility and safety. Update the plan as the resident's wandering patterns change with the progression of dementia. Involving family or other caregivers in planning will help them understand the resident's condition as it changes.
- Assign staff to work with residents in ways that support consistent relationships so that each resident develops a sense of safety and familiarity with staff.
- Ensure that staff understand whether a resident has a propensity to wander and the conditions under which this occurs.
- Staff need to understand and recognize the consequences of limited mobility.
- Ensure that residents are able to move about freely, are monitored and remain safe.
- Residents who have just moved into a new area or home may need additional staff assistance until they are comfortable in their new environment.

EXAMPLE: Have specific welcome activities for new residents to help them feel comfortable and part of the community. These activities should avoid overwhelming the residents with new situations and people. Involve family members or previous caregivers to ease the transition.

- Communicate regularly with families of residents who wander regarding their need for movement. Describe resident behaviors and discuss measures to support their continued mobility, while protecting them and other residents with whom they may have contact.
- Help residents who do not have cognitive impairment understand wandering as a symptom of dementia.
- Ensure that residents who wander have adequate nutrition and hydration, which may include offering food and drinks while they are “on the go.”

NOTE: This is particularly important for residents who are unable to remain seated during mealtime.

- Staff may use various approaches to minimize unsafe wandering. These approaches include:
 - Identifying resident needs and wishes, and then offering to help the resident engage in related, suitable activities
 - Using a preventive approach to unsafe wandering

EXAMPLE: For those who wander when needing to use the toilet, schedule toileting according to the resident’s patterns and use cues to help the resident find the bathroom quickly.

EXAMPLE: Engage the wandering resident with food, drink or activities that promote social engagement and purposeful tasks, such as sorting, building or folding.

EXAMPLE: Provide regular exercise and stimulation for residents through programs tailored to a resident’s level of cognitive and physical functioning. Balance physical activities with regular quiet time to allow for rest. Consider involving family or friends in these activities on a voluntary basis.

EXAMPLE: Take residents outside regularly, preferably daily except during adverse weather.

EXAMPLE: For residents who are awake during the night, make activities available with an adequate level of staffing to provide encouragement and supervision.

- Accompany wandering residents on their journeys when supervision is required to ensure safety or encourage a meaningful alternate activity. Companionship is an added benefit.

RESIDENT EXAMPLE: A resident heads for an exit door at 3:00 p.m. when she sees nursing staff leaving the facility. She states that she must get home to meet her daughter after school.

DO: Begin by *offering to help* the resident.

Ask about her daughter, or ask what kind of snack she would like to prepare and offer to help her with the preparation. The goal is for the resident to perceive the staff person as a friend and advocate.

DON’T: Begin by *telling her that she can’t go out* or that her daughter is now grown up. The goal is to avoid having the resident perceive staff as an adversary.

DO: Develop a longer-term approach to avoiding exit-seeking behavior. For example, involve the resident in a 2:30 p.m. activity in a location where she doesn’t see the staff preparing to leave when shifts change.

- If an alarm system is used to alert the staff when a wandering resident is attempting to leave the facility, choose the system that is least intrusive and burdensome.

NOTE: For some residents, chair and personal alarm systems are a burden (as evidenced by the resident’s protests or attempts at removal) and in some cases may lead to an increase in agitated behavior.

NOTE: Chair, bed, and personal alarms that are audible to the resident may discourage all movement, not just unsafe attempts to stand or walk unassisted.

- Train all staff on the consequences of unsafe wandering, the protocols to follow to minimize successful exiting and the procedures to follow when a resident is lost.
- Promote identification of residents who are at risk of successful exiting:
 - Keep photographs of residents who wander in a central, secure location and ensure that receptionists, security staff and others in a position to help can prevent successful exiting by recognizing these residents.

NOTE: Care should be taken to ensure confidentiality and compliance with any relevant federal and state requirements.

- Provide opportunities for everyone to get to know these residents.
- Have a “lost person” plan to:
 - Account for each resident on a regular basis, such as during mealtimes, and when shifts change.
 - Establish a sign-in and sign-out policy for families and visitors when taking residents out of the residence.

- Have recent photographs of residents and former addresses on file to provide to law enforcement personnel in case of successful exiting.

NOTE: Care should be taken to ensure confidentiality and compliance with any relevant federal and state requirements.

- Notify management, family, law enforcement personnel, and state and local agencies as required immediately when a resident is missing and ensure that personnel receive information such as the resident's photo, home address, description of clothing worn and other relevant information.
- Carry out an organized search plan of the facility and its immediate vicinity and understand that a person with dementia may not respond when his or her name is called.
- Maintain local telephone numbers of nearby bus terminals, train stations or taxi services in case the search expands beyond the residence.
- Prepare a report that describes the resident's successful exit so the residence can learn from the experience as part of a quality improvement program.
- Organize routine practice searches.
- Enroll residents in the Alzheimer's Association Safe Return® program, which the Association operates with funding from the U.S. Department of Justice. Safe Return is a nationwide program that helps identify, locate and return people with dementia to their homes.

ENVIRONMENT

- Work to eliminate non-emergency paging-system announcements and other institutional features that make the residence feel foreign or different from one's home.
- When possible, create indoor and outdoor pathways which are free of obstructions and have interesting, safe places to explore and comfortable places to rest along the way. Pathways need to be well-lit without shadows or pools of bright light. Install window coverings to eliminate glare in key rooms and passageways. Ensure that transitions from pathways onto grass and other areas are smooth with no uneven surfaces.
- Create activity zones with recreational opportunities, such as multi-sensory theme boxes, that residents can explore with staff encouragement.

- Create a low-stimulus setting for periodic rest breaks, perhaps playing music or nature sounds that have been observed to calm the person who wanders.

- Provide substitute physical activities, such as dance, exercise or rocking.

EXAMPLE: Encourage use of safe gliding chairs that have a wide base and do not tip over easily.

- Provide cues to help residents who wander orient themselves to the residence. Cues can include memory boxes by a resident's door, personal furnishings that residents will recognize or large visual signs or pictures for bathrooms.
- Consider the following approaches to minimize the risk of successful exit seeking. Before implementing them, check with fire marshals and other relevant officials regarding safety regulations, which vary by state.
 - Make exits less obvious to reduce visual cues for exiting so the resident who wanders does not realize exiting is possible.

EXAMPLE: When designing a new residence or unit, place doors parallel to the walking path with no windows in or beside the doors.

- Install non-intrusive alarm systems that alert staff to resident exiting.
- Post signs at exterior doors to alert visitors that people with dementia might try to leave when they do.

Learning From an Individual With Dementia

An 83-year-old man repeatedly entered the rooms of other residents, removing magazines and papers from their nightstands and tray tables. After consulting with the family, care planning staff determined that this man had been a letter carrier for the postal service for more than 40 years and suggested that staff give him a canvas shoulder bag. Staff asked families to bring in old magazines and empty envelopes and strategically placed them around the nurses' station and commons areas where he would see them. He quickly became preoccupied with collecting and hoarding the materials they "planted" and the intervention effectively reduced the frequency of wandering into the rooms of other residents.

5

Resident Falls

Dementia Issues

- Falling is defined as accidentally coming into contact with the ground or other surfaces. Falls may occur with or without injury and often result from a loss of balance.
- People with dementia are at increased risk of falls due to such conditions as neurological impairments in perception or cognition and changes in motor function, stance or gait, which can lead to progressive loss of physical functioning.
- Falls are associated with a variety of contributing factors, some of which are characteristics of the individual resident, and some of which are characteristics of the environment.
- Individual risk factors include depression, fatigue, history of falls, postural hypotension, incontinence and prolonged immobility.
- Environmental risk conditions include such things as:
 - Confusing environment and clutter
 - Inadequate cueing, such as posting unclear or confusing directional signs
 - Improper footwear
 - Unsafe equipment
 - Lack of stable furniture or handrails to steady oneself
 - Floors or ground that are uneven, slippery or have glare
 - Inadequate lighting
 - Weather conditions that may result in such problems as slippery surfaces, perceptual difficulties or heat exhaustion
- Use of certain medications may increase risk of falls by contributing to such conditions as fatigue or confusion, perceptual disturbances, dizziness and altered muscle tone. Caution should be used when considering new medications or changes in medication.

NOTE: Sleep medications, tranquilizers, anti-anxiety medications, narcotics and certain anti-hypertensives are among the drug classes most commonly associated with increased risk of falls.

- The consequences of falls include broken bones and bruises, concussions and fear of falling that can limit a resident's willingness and ability to stay mobile.

Care Goals

- To promote safety and preserve mobility by reducing risk of falls and fall-related injuries
- To minimize fall-related injuries by avoiding physical restraints

Recommended Practices

ASSESSMENT

- Before admission, collect information from family, friends or the transferring facility about the resident's history and patterns of falling and strategies the family used to prevent falls.
 - Initial resident assessment is critical in the first few weeks after entering a residence because of a resident's potential confusion due to relocation. After a reasonable adjustment period, ongoing assessment addresses the changing risk of falls as dementia progresses.
- EXAMPLE:** Newly admitted residents with dementia require close monitoring. The first 24-48 hours after an admission to a new setting are critically important because staff and surroundings are unfamiliar to the resident.
- A comprehensive assessment includes both identification of resident risk factors and evaluation of environmental conditions related to falls. It also includes collecting information from a resident as well as his or her family or caregivers about the history of falling and any other factors that may contribute to falls.



- Effective resident assessment includes:
 - History and patterns of near-falls, recent falls and fall-related injury
 - Cognitive impairment and capacity for safe and proper use of adaptive equipment and mobility aids, such as walkers
 - Functional status and factors that affect mobility, including muscle tone and strength, transfer ability, balance, stance, gait and ambulatory ability
 - Sensory function, including vision, ability to sense position of limbs and joints, and tactile senses

NOTE: Visual impairment may be related to contrast sensitivity, field loss, and use of glasses with incorrect prescriptions. A new prescription for corrective lenses may cause falls. Residents with cognitive impairment may be unable to use bifocals or trifocals properly.

 - Medical conditions that may contribute to falls, such as pain, infections, cardiovascular disease, osteoporosis, deconditioning, and nighttime urinary frequency and urgency
 - Hallucinations and delirium
 - Presence of restraints
 - Nutritional status and recent weight loss
 - Current medication regimen and use or recent change in medications
 - History or presence of substance abuse or withdrawal symptoms
 - Psychological conditions such as depression and anxiety

- Aspects of a resident's life history, professional and personal occupations, and daily routines could lead a resident to attempt activities that might result in falls

EXAMPLE: A resident previously in the furniture business might try to move heavy furniture, thus increasing the risk of falling.

- Environmental assessment includes:
 - Environmental layout (shape of space and ease of getting around)
 - Lighting and glare
 - Presence of obstructions in both resident rooms and common areas
 - Accessibility, visibility and safety of bathroom and dining room
 - Sturdiness and visibility of handrails and furniture
 - Contrast of the toilet and sink from the wall and the floor
 - Safety and working condition of equipment and fixtures (e.g., bedside commodes, shower chairs, adequacy of brakes on wheel chairs)
 - Appropriate use of personal safety devices, such as canes, walkers or wheelchairs
 - Bathing facilities with non-slip surfaces
 - Floor surfaces, textures and patterns

EXAMPLE: A blue-and-black border may look like a river or a hole.

 - Fit and use of resident footwear

EXAMPLE: Examine shoes and slippers regularly for potential poor traction.

 - Use of housekeeping equipment

EXAMPLE: Ensure that machines like floor buffers are run when residents are not likely to be moving about. However, they should not be used at night when residents are sleeping.
- Use documentation and a tracking tool to identify falls, fall patterns and patterns of risky movement. Follow up with a family care plan meeting to evaluate options, such as use of an individual caregiver or presence of family and friends to help during peak activity times.

- If necessary, refer the resident to a qualified professional for evaluation using a more in-depth assessment of the resident's functional mobility, and ability to use safety awareness and compensatory strategies. Upon admission to the residence, refer residents to appropriate professionals if they have any of the following:
 - History of recent falls
 - Existing or new gait disorder or other condition that may be related to falls
 - Need for restorative activity to support mobility by strengthening muscles, improving balance, stabilizing gait and increasing physical endurance
- NOTE:** Professionals can help identify creative, individual solutions to minimize the number of falls and injuries.

STAFF APPROACHES

- Based on the resident assessment, develop a care plan that promotes resident mobility and safety while preventing or minimizing injuries. Update the plan as the resident's falling patterns change with the progression of dementia. Involve family or other caregivers in planning to help them understand the resident's condition as it changes.
- Dementia care training is the first step to ensuring effective staff approaches to reducing risks and managing falls. Effective staff training on fall prevention addresses:
 - Resident risk assessment
 - Identifying and monitoring resident needs that may increase risk of falls or fall-related injuries
 - Identifying and monitoring behaviors that increase fall risk, such as wandering patterns
 - Understanding risks and benefits of potential interventions to prevent falls
 - Understanding the benefits of exercise for improving a resident's strength and endurance

- Proper use of safety equipment and personal safety devices
 - Safe techniques for lifting and transferring residents
- Some key points related to falls that staff need to understand include the following:
 - Because maintaining mobility is important, resident movement should be encouraged. The more a resident is immobile, the more he or she is at risk for injurious falls.

EXAMPLE: Exercise that promotes sit-to-stand activities and walking as part of the daily routine can help preserve a resident's mobility.
 - It is necessary to follow existing organizational policies and procedures relating to fall management and response.

EXAMPLE: Perform fall event assessments at the time of the fall to identify and address the specific cause for a fall, such as water on the floor or resident dizziness after standing up.

- A range of interventions are available to individually tailor preventive strategies for residents at risk of falling.

NOTE: Strategies informed by thorough resident assessments have the highest likelihood of reducing falls.

EXAMPLE: To reduce falls associated with urgent trips to the bathroom, consider using an individual toileting schedule or a bedside commode. Consider clothing that is easy for residents to remove when they have to go to the bathroom.

- Ensure staff are available to help those residents who need assistance with ambulation, dressing, toileting and transferring. Consistent staff assignment increases staff familiarity with individual residents.
- Eliminate physical restraints, unless needed for medical treatment in an emergency.
- Promote consistent and appropriate use of assistive devices, such as a walker.

NOTE: Some residents may always need staff to walk with them to prevent falls.

- Promote a regular sleep-wake cycle by keeping bedding dry and ensuring residents are exposed to sufficient daylight, identifying a resident's regular bedtime routine, and matching the sleep-wake cycle to lifelong sleep habits.
EXAMPLE: Ensure a comfortable sleeping environment with a good quality mattress, optimal temperature and minimal noise.
EXAMPLE: Ensure that residents who like to bathe or read before bed can do so.
EXAMPLE: Help a resident choose between extended-wear absorbent incontinence products to promote uninterrupted sleep or an individual toileting schedule.
- Have a scheduled and structured exercise or walking program for those residents who can safely participate in order to maintain or improve function, posture and balance.
EXAMPLE: Develop walking programs around a resident's need to get someplace, such as walking to and from the dining room, instead of using a wheelchair.

ENVIRONMENT

There are various ways to modify the environment to help prevent falls.

- Adjust bed, wheelchair, other chairs and toilet heights when indicated to help prevent falls.
NOTE: Existing safety guidelines recommend that toilet height be at about knee height.
- Understand that a person with loss of balance will grab onto anything within reach. Ensure that stable handholds are available by providing such items as grab bars and railings.
- Make sure furniture is sturdy and in good condition and adjust furniture location to match as closely as possible the resident's previous bedroom-to-bathroom path.
- Create and maintain a clear path to the bathroom.
- Whenever possible, provide non-slip floor treatments throughout the residence, especially in bathrooms and next to beds.

- Encourage use of footwear that is non-skid and provides a wide base of support.
- Ensure good lighting.
EXAMPLE: Increase resident ability to turn on lights by installing motion-activated lighting or sensor lights.
EXAMPLE: Install nightlights between a resident's bed and bathroom.
- Use silent alarms to alert staff when a resident at risk of falling attempts to leave a bed or chair.
CAUTION: Alarm systems can inadvertently restrict a resident's movement, in which case the systems function as restraints. For example, some residents may become afraid to move for fear of setting off an alarm. Staff need to respond to alarms by providing the assistance needed to help the resident to move.

Learning From an Individual With Dementia

A resident who had a pattern of falls in her room was often found in the closet area with her pants down. The care planning team determined that a possible cause of falls was the resident trying to independently use the toilet, but confusing the closet with the bathroom. Falls ceased after the staff set up a preventive toileting schedule and placed a sign on the door that helped the resident understand that the space behind the door was a closet.

6

Physical Restraint-Free Care

Dementia Issues

- Physical restraints include any method or device which restricts a resident's freedom of movement or access to his or her body and which the individual cannot remove easily. It is the effect of the method or device on the person that results in it being considered a restraint.
- Although psychoactive medications are sometimes used inappropriately to restrain residents, the topic is outside the scope of this set of practice recommendations.
- Examples of methods or devices considered physical restraints include:
 - Side rails on beds.

NOTE: Sometimes residents use "quarter or half rails" to reposition themselves in bed.
 - Limb and waist restraints
 - Hand mitts
 - Geri-chairs
 - Over-the-bed tables and trays that cannot be removed without assistance
 - Chairs or recliners from which a resident is unable to get up on his or her own
 - Involuntary confinement to a room, except when isolation is medically necessary to protect residents from a contagious disease.

NOTE: A device that a person cannot remove at will is considered a restraint. Exceptions may include items that are used in the provision of medical care, such as casts, braces and bandages.
- One of the primary predictors of using physical restraints is cognitive impairment.

NOTE: In many cases, restraints are used because of the mistaken belief that they are necessary to ensure resident safety, prevent agitation, physically support residents or prevent falls.
- Physical restraints are generally harmful to residents because of negative effects on multiple body systems and interference with normal functioning, including a resident's capacity to walk, get food, get fluids, change position, toilet and socialize.

- Physical consequences of using restraints may include death, injuries, falls, physical de-conditioning, incontinence, malnutrition, dehydration, bone demineralization, muscle atrophy, skin tears and pressure ulcers, contractures, cardiac rhythm disturbances and infection.
- Emotional consequences of restraints include distress and worsening agitation. Individuals with dementia may exhibit marked behavioral disturbances in response to being restrained. People with and without dementia experience emotions ranging from frustration and anxiety to anger and terror when restrained and typically view restraints as barriers to be overcome.

Care Goals

- To foster a restraint-free community in the nursing home or assisted living residence

NOTE: Restraints may be temporarily necessary when a medical professional determines they are required for the safe and effective management of a medical emergency. For example, a person experiencing delirium may require physical containment to permit medical assessment and to enable staff to safely deliver essential care.
- To identify the underlying problems or needs that prompt the use of restraints and to address them using restraint-free methods
- To provide staff with techniques they can use to prevent, reduce and eliminate use of restraints

Recommended Practices

ASSESSMENT

- Using assessment to find out each resident's life history, habits and preferences is critical to restraint-free care.
- Ongoing assessment is an essential strategy for identifying use of restraints and alternatives to their use, as well as to support restraint-free care.
- Residents need regular, comprehensive assessment so that their individual care plans address needs and prevent use of restraints for conditions



such as frequent falls, behavioral symptoms or wandering.

- Residences need to assess their own capacity to provide a restraint-free environment. Self-assessment includes:
 - Extent to which restraint-free policies exist and are implemented
 - Level of staff training and understanding of restraint-free care
 - Circumstances under which restraints are used inappropriately
 - Identification of residents with restraints
 - Identification of conditions that might trigger use of restraints

EXAMPLE: Review medications because some can cause dizziness, loss of balance or delirium; others can reduce psychotic symptoms and the perceived need for physical restraints.

STAFF APPROACHES

- The key to eliminating use of restraints is individualized care, which depends on staff knowing the resident as a person. Consistent assignment of staff to residents promotes individualized care.
- Effective care planning involves knowing a

resident's remaining abilities and understanding how to make use of them to avoid conditions such as wandering and falls that can lead to inappropriate use of restraints. Care planning staff are responsible for trying and documenting various options to avoid use of restraints.

- Staff at all levels need to understand the hazards of using restraints and the process of individualized assessment and care planning to meet each resident's unique needs.
- Effective staff education about restraints includes:
 - Definition of restraints
 - Restraint-free care and reasons why restraints are unacceptable
 - Myths and misconceptions about restraints, including, for example, the misconception that restraints are an effective and acceptable approach to ensuring resident safety
 - Negative impact of physical restraints on residents and staff
 - Restraint-related assessment strategies
 - Appropriate care for residents with behavioral symptoms
 - Residents' rights and legal aspects of restraint use
 - Residence restraint policy and protocol for use in emergency situations
- Families need education about restraints to develop an understanding of:
 - The harmful consequences of restraints
 - Why restraints are unacceptable
 - Legal aspects of restraint use
 - Support of resident autonomy and freedom of movement
- EXAMPLE:** Provide written educational information regarding restraint use to families upon resident admission.
- Staff, sometimes with the assistance of consul-

tants, can implement creative solutions for identifying and meeting individualized care needs regarding safety, behaviors and postural support.

Examples:

- Respond promptly to resident calls and minimize their waiting times.
- When residents repeatedly slide out of their wheelchairs in an attempt to self-propel, place them in lower height wheelchairs without footrests or with footrests in the closed position that allow their feet to touch the floor.
- Assign staff to identify and help fatigued residents go to bed when they need rest so they won't attempt to get into bed unassisted.
- Use individualized day and nighttime activities to increase resident contentment and decrease behavioral symptoms.
- Seek assistance from a professional to help reduce use of restraints through evaluation and treatment of physical, cognitive or sensory impairments.
- Camouflage and protect areas of active wound care so the resident will not disturb dressings or the healing process.
- Encourage family members and friends to sit with the resident and provide support or reassurance.
- When using restraints during a medical emergency, staff need to obtain orders from the resident's physician and notify the designated family member or surrogate decision-maker as soon as possible. Staff should begin medical evaluation and appropriate treatment as ordered, call emergency services or transfer the resident to an appropriate health care facility.
- If the residence uses restraints, senior staff need to establish an interdisciplinary team to develop and implement a plan for reducing use of restraints and working toward eliminating restraints.
NOTE: Nursing homes must have an interdisciplinary team for assessment and care planning. Designing alternatives to using restraints is an integral part of these processes.
- Make the restraint-reduction plan part of the resi-

dence's quality improvement program and include baseline collection of data, measures of progress and rewards for progress.

NOTE: Elimination of restraints requires that staff are adequately trained, alternative programs are in place, and adequate resources are available to implement individualized care plans.

ENVIRONMENT

- The environment can be modified to move toward a restraint-free environment. Examples of such modifications include:
 - Using chairs that are at the right height, depth and level of backing for each resident to have comfortable and safe seating; individualize the time a resident spends sitting up in a chair.
 - Individualizing each chair a resident uses in his or her room, public place or dining room.
 - Using a wheelchair only when needed for transportation.
 - Providing visual cues that are meaningful to a resident to deter him or her from entering the rooms of other residents.
- NOTE:** Please see the recommendations concerning the basics of dementia care, wandering and falls for additional examples of helpful environmental modifications to enhance safety and avoid use of physical restraints.

Learning From an Individual With Dementia

An 87-year-old woman moved into an assisted living residence with her own furniture. Staff noticed that she experienced significant distress when trying to leave her recliner. An assessment revealed that she had difficulty maneuvering the chair's handle and, in fact, the recliner was becoming a restraint due to her inability to remember how to operate it. Staff consulted with the resident and her family about the situation and asked if she had another chair that might be an acceptable substitute for the recliner. The family found one that pleased the resident and her distress decreased markedly.

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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

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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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The Alzheimer's Association offers quality care education programs for direct care workers and other residential care staff. For more information, call 1.866.727.1890 or visit www.alz.org/qualitycare.

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.

August 2007

Organizations Supporting the Dementia Care Practice Recommendations, Phase 3

AARP

American Academy of Hospice and Palliative Medicine

American Assisted Living Nurses Association

American Association for Geriatric Psychiatry

American Association of Homes and Services for the Aging

American Association of Nurse Assessment Coordinators

American College of Health Care Administrators

American Dietetic Association

American Health Care Association

American Medical Directors Association

American Occupational Therapy Association

American Pain Foundation

American Physical Therapy Association

American Seniors Housing Association

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

National Association of Social Workers

National Center for Assisted Living

National Citizens' Coalition for Nursing Home Reform

National Conference of Gerontological Nurse Practitioners

National Gerontological Nursing Association

National Hospice and Palliative Care Organization

Paralyzed Veterans of America

Service Employees International Union

Supportive Care Coalition

The American Speech Language Hearing Association accepts the recommendations.

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.

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

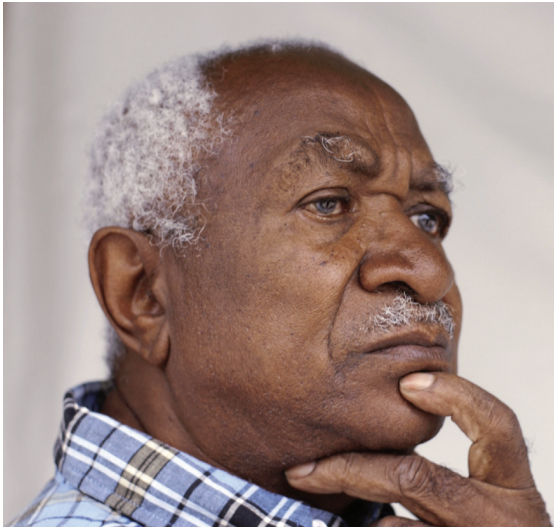
On receiving a diagnosis of dementia, many issues must be considered, including the resident's preferences regarding end-of-life care. Discussion with a resident about his or her preferences across many areas should begin as soon as possible after the dementia diagnosis is known. This is particularly 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.

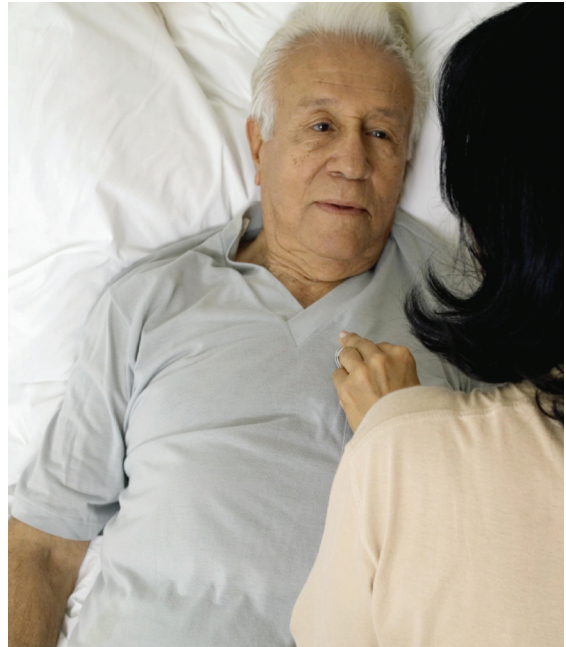
EXAMPLE: Oxygen or an oscillating fan set on low and aimed toward the resident can produce enough moving air to make breathing easier.

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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