

Building consensus  
on quality care for  
people with dementia

Alzheimer's Association  
Campaign for Quality Residential Care

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



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

For 25 years, the Alzheimer's Association has been committed to advancing Alzheimer research and enhancing care, education and support for individuals affected by the disease. This year, recognizing that more than one million residents in assisted living residences and nursing homes have some form of dementia or cognitive impairment, and that number is increasing every day, we join with other leaders in dementia care by announcing our new multiyear initiative, the **Alzheimer's Association Campaign for Quality Residential Care**. The campaign, which will be launched in July at our Dementia Care Conference, is designed to improve the quality of care for residents with dementia.

The foundation of our Quality Residential Care is a set of evidence-based *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*. The campaign, which builds

on our tradition of concern for the quality of life for people with dementia, is an outgrowth of multiple activities: our involvement in the United States Senate Special Committee on Aging Assisted Living Workgroup and The Center on Excellence in Assisted Living; advocacy efforts for improved quality assurance in nursing homes and assisted living residences; innovative training programs for long-term care staff, offered through our chapters; and the popular publications *Guidelines for Dignity, Key Elements of Dementia Care* and *Family Guide for Alzheimer's Care*.

To date, 24 leading organizations have expressed their support or acceptance of the dementia care practice recommendations. We are grateful to these organizations for their counsel and cooperation during development of the recommendations.

### Organizations Supporting the Dementia Care Practice Recommendations

AARP

American Association of Assisted Living Nurses

American Association of Homes and Services for the Aging

American College of Health Care Administrators

American Dietetic Association

American Health Care 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

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.

To help us reach our goal — to improve the quality of dementia care in assisted living residences and nursing homes — the Alzheimer's Association is enlisting the support of these and other organizations, as well as consumers and policy-makers.

## INTRODUCTION TO THE DEMENTIA CARE PRACTICE RECOMMENDATIONS

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.

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.

During the next few years, we will add dementia care practice recommendations related to care areas such as use of restraints or end-of-life care and will update recommendations as new evidence on effective care interventions becomes available.

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.

During the coming year, we will begin to implement strategies for our overall Quality Care Campaign:

To encourage adoption of our recommended practices in assisted living residences and nursing homes, we will advocate with dementia care providers.

To ensure incorporation of the practice recommendations into quality assurance systems for nursing homes and assisted living residences, we will work with federal and state policy-makers.

To encourage quality care among providers, we will offer training and education programs to all levels of care staff in assisted living residences and nursing homes.

To empower people with dementia and their family caregivers to make informed decisions, we will educate them about how to select an assisted living residence or nursing home and how to advocate for quality within a residence.

# Dementia Care Practice Recommendations for 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.*



the compassion to care, the leadership to conquer

**Alzheimer's Association**

**1.800.272.3900**

**[www.alz.org](http://www.alz.org)**

The Alzheimer's Association, the world leader in Alzheimer research and support, is the largest voluntary health organization dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer's. For 25 years, the donor-supported, not-for-profit Alzheimer's Association has provided reliable information and care consultation; created supportive services for families; increased funding for dementia research; and influenced public policy changes.

Our vision is a world without Alzheimer's disease.

© 2005 Alzheimer's Association. All rights reserved.

For more information, visit [www.alz.org](http://www.alz.org) or contact:

Peter Reed, Ph.D.  
National Office  
Alzheimer's Association  
225 N. Michigan Ave., Fl. 17  
Chicago, IL 60601-7633  
phone: 312.335.5178  
[peter.reed@alz.org](mailto:peter.reed@alz.org)

Jane Tilly, Dr.P.H.  
Public Policy Office  
Alzheimer's Association  
1319 F Street N.W., Suite 710  
Washington, D.C. 20004-1106  
phone: 202.393.7737, ext. 224  
[jane.tilly@alz.org](mailto:jane.tilly@alz.org)