

NATIONAL CENTER FOR ASSISTED LIVING  
**GUIDING**  
Principles

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*for Dementia Care*

## **INTRODUCTION**

Dementia care is a priority for all long term care providers, including assisted living communities (ALC).<sup>1</sup> According to the National Center for Health Statistics, it is estimated that almost 40% of residents in residential care have Alzheimer's disease or other dementias ([Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013](#)). The Alzheimer's Association estimates that more than 5 million people in the United States are living with Alzheimer's disease. Alzheimer's disease is the sixth leading cause of death in the United States ([Alzheimer's Association, 2014](#)). Creating resources and opportunities for educating staff may increase the level of service and quality of care that ALCs can provide to residents with dementia. This set of *Guiding Principles* was written to improve the assisted living professional and para-professional staff's understanding of the complexities of care needed by residents with dementia. A list of additional resources has been provided at the end of this document.

### *Overview of Dementia*

Dementia is a broad term for a decline in memory or other cognitive abilities that is severe enough to interfere with daily life. Dementia is not a specific disease but describes symptoms caused by a disease or condition. Some of the common types or causes of dementia include: Alzheimer's disease, vascular dementia, dementia with Lewy bodies, Parkinson's disease, and frontotemporal lobar degeneration. The Alzheimer's Association has identified Alzheimer's disease as the most common form of dementia, accounting for up to 80 percent of diagnosed dementia cases.

## **GUIDING PRINCIPLE #1: PERSON-CENTERED CARE**

NCAL is an advocate of person-centered care. Person-centered care focuses on meeting the individual resident's needs. Decision-making is directed by the resident (or with the assistance from family or a designated surrogate decision maker if the resident is unable to fully communicate). Staff assistance is not task-oriented. Person-centered care is relationship-based. The management team and staff know each resident as an individual, his/her life story, strengths, weaknesses, needs, preferences and expectations. The staff members form meaningful relationships with the residents and their family members. Ways to accomplish person-centered care may include:

- Focusing on the resident, a philosophical shift from tasks and care
- Encouraging personal development of residents, on an individual basis
- Maximizing the resident's dignity, autonomy, privacy, socialization, independence, choice, and safety
- Supporting lifestyles that promote health and fitness
- Promoting family and community involvement
- Developing positive relationships among residents, staff, families, and the community
- Ensuring that the dining experience is person-centered.

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<sup>1</sup>Assisted Living Community (ALC) is used in this document as a way to encompass the various terms identifying assisted living.

A person-centered philosophy and approach to care is crucial to meet the needs of persons with dementia.

### *Evaluations*

Evaluations are recommended for any prospective resident entering assisted living. A social assessment is as equally as important as a medical assessment. For residents with dementia who may have difficulty communicating, evaluations are critical. Initial and ongoing evaluations enable the staff to identify the individual's strengths and weaknesses in order to meet the resident's individual needs and preferences. Global elements of evaluations may include:

- Details about the person's medical history
- Current diagnoses, physical abilities and limitations
- Cognitive patterns, mood and behavior
- Barriers to communication or thinking
- Status of personal grooming and ADLs
- Their preferences for social situations, recreational activities, spiritual needs or physical activity.

The Assisted Living Workgroup (ALW) recommended the minimum components of an initial evaluation include a physical history and exam by the current attending medical professional, a mental health evaluation completed by a qualified, licensed, and/or certified professional, an evaluation on the resident's activities of daily living (ADLs), instrumental ADLs, and a review of risk factors, including abuse and exploitation, depression, falls, elopement, self-neglect, and weight loss. The ALW recommended an evaluation of social environment factors such as cultural, spiritual and recreational activities, support resources, and lifestyle preferences. It also recommended that providers obtain documents, such as advance directives. Furthermore, the ALW suggested evaluating a person with dementia's cognitive status as "it relates to the resident's ability to manage his/her own affairs and direct his/her own care."

Initial evaluations are not enough, ongoing evaluations for both physical and mental health are critical. Everyone changes, especially during the initial transition into assisted living. The early days of moving into an assisted living community can be overwhelming, even for the most cognitively intact person. For a person with dementia, this initial period of change may be even more intense. Evaluation of anxiety and interventions to support residents with anxiety, preferably non-pharmacological, are also important factors in helping residents cope with the transition to an assisted living setting.

### *Depression*

[Gruber-Baldini et al. \(2005\)](#) found that among residents with cognitive impairment, depression was more common in residents with severe dementia, behavioral symptoms, and pain. Transitioning into assisted living may be difficult as it is a major change in environment and way of life. While many make a smooth and successful transition, some residents will find it more challenging based on their current health, cognitive and emotional status and their ability to cope with change. Residents with dementia may have diminished coping skills and may not have the necessary

supportive network of family and friends to prepare and assist in the transition. This can make them more susceptible to depression. Current residents in assisted living suggest one way to combat this tendency for depression is for new residents to engage in formalized programs and interact with other residents. Staff members may assist by providing residents and family with introductions to members of the community and encouraging participation in activities during the transition.

Initial and ongoing screenings for depression and other mental health issues are recommended to best improve the resident's quality of life and better meet their individual needs.

### *Pain Evaluation and Management*

Pain is not normal and may be the cause of behavioral expressions in residents with dementia. It is not a sensation that we expect to feel on a regular basis or during everyday living. Nor should it be for any assisted living residents, especially those with dementia who may not be able to communicate sensations of pain. Like all important health information, pain should be evaluated initially and on an ongoing basis for residents with dementia. How do we evaluate pain in residents with dementia? Observation of the resident for physical signs is the first step. According to the Alzheimer's Association, observation of the resident may show physical signs of pain such as grimacing, sighing, moaning, slow movement, or withdrawal of extremities during care (["Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes," 2006](#)). Once pain is determined to be present, the ALC and primary physician must determine the best solution for relieving the individual's pain. There are pharmacological solutions but also alternative remedies such as exercise, massage, aroma therapy, relaxation therapy, and chiropractic alternatives. The important consideration is to look at the history of the resident, his or her previous reactions to both pharmacological and alternative therapies, and to determine the best course of treatment for that individual resident. (See resources for more information on pain scales.)

### *Social Engagement and Life Enrichment*

As noted under evaluations and person-centered care, it is important to understand the resident's social history, life story (occupations, education, etc.) and identify their strengths, weaknesses, preferences and interests. By knowing this information, the staff can tailor programs to meet the resident's varying needs and interests. For example, if a resident was somewhat introverted for his or her entire life, large group activities would probably be a negative experience. He or she would be better suited to attend a small group activity with close friends or dining partners.

When developing programming for residents with dementia, it is important to note that these programs should be created based on the resident's strengths, ability to participate, and personal interests. Lower-functioning residents should have separate social and recreational activities than residents who function at a higher level. By developing separate activity programs for the varying levels of residents (parallel programming), the ALC will be increasing the opportunity for resident participation and hopefully, the satisfaction of the resident and family.

The Alzheimer's Association notes in their Dementia Care Practice Recommendations (2006) that the process of the activity is much more important than the outcome of the activity. That is to say, the experience the residents have with the activity, including their level of participation and enjoyment, is more important than if an object is made or a project is completed.

Many ALCs develop service plans for residents with components encompassing physical care and social needs and interests. Service plans are individualized plans of services based on needs and preferences for each resident residing in the ALC.

The ALW recommended that, "Assisted living communities that accommodate special care residents shall provide daily interactions and experiences that are meaningful (based upon residents' interests, feelings, and lifestyle), appropriate (for their abilities and functioning levels), and respectful (of their age, beliefs, cultures, values, and life experiences) of residents, as determined by individual assessments and indicated in their service plans."

## **GUIDING PRINCIPLE #2: STAFF EDUCATION**

When initially interviewing a potential staff member, it is critical that the individual understands the specific challenges associated with caring for persons with dementia. Staff should be compassionate, patient, organized, have high self-esteem and flexibility in their expectations. Education of all staff at all levels is critical to the overall success of the ALC. Without the most up-to-date skills and knowledge, the staff is at a disadvantage to meet the residents' individual needs, wants, and desires. Caring for residents with dementia takes different skills and abilities due to the complexity of the illness. An overview of basic disease process should be part of the initial orientation and ongoing educational offerings. Additional topics for educational sessions may include normal changes with aging, addressing unmet needs, communication, and special regulatory requirements specific to dementia.

When it comes to dementia, unmet needs and communication go hand in hand. It is well known that residents with dementia often display behavioral expressions. What is not well recognized is that these behavioral expressions often are nothing more than a mechanism the resident with dementia uses to communicate. If a staff member is unaware that behavioral expressions are a form of communication, then that staff member and resident may have a much more difficult daily routine.

According to the Alzheimer's Association's Dementia Care Practice Recommendations for Nursing Homes and Assisted Living Residences (2006), "Residents with advanced dementia frequently communicate nonverbally through their behaviors, including reactions to care (e.g., facial expressions and body movements). This effective communication involves allowing the resident time to process requests and instructions, 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."

Many states mandate some orientation and yearly in-service training as a basic requirement for all staff members involved in caring for residents with dementia. More states are requiring above and beyond training for assisted living communities that serve residents with dementia, especially if the community has a specified dementia unit. More information about specific regulatory standards in the different states may be found in NCAL's Assisted Living State Regulatory Review, posted at [www.ncal.org](http://www.ncal.org), the Center for Excellence in Assisted Living (CEAL), [www.theceal.org](http://www.theceal.org), and through individual state health care associations.

### **GUIDING PRINCIPLE #3: PHYSICAL ENVIRONMENT**

NCAL revised its *Guiding Principles for Assisted Living* in 2014. That revision addressed physical environment issues in a very broad but important manner. The document states that an ALC should be designed in a way that maximizes the quality of life, independence, autonomy, safety, dignity, socialization, choice, and privacy of residents. Settings should be designed in a manner that encourages family and community involvement.

That being said, not all ALCs were built to serve residents with dementia but have evolved into providing dementia services. It is these communities that face the greatest challenge in meeting residents' changing needs through their physical environment.

Most providers, residents, families and consumers would agree that making an ALC into a home for the resident is a key factor for success. In order to do that, providers need to create an atmosphere and physical environment that matches as closely to one's private home as possible. Communities need to reflect the warmth and sustainability of what we would find in our own homes including but not limited to animals, comfortable seating, fireplaces, pictures of family and friends, and plants. Community rooms such as kitchens and family rooms, elopement safe gardens, and outside decks or areas for gathering help to create a dementia-friendly environment. There is literature available about inside and outside space and design for dementia residents.

Environments should be designed or adapted to maximize the residents' remaining abilities and to create a setting that will compensate for those skills lost. Residents should be encouraged, within reason, to bring personal items from their home. Personalization immediately assists residents with adjustment to their new environment.

#### *Dining*

Meal times have traditionally been the center of activity for residents living in assisted living and long term care. In the case of residents with dementia, the dining environment can be the most important element. In the dining environment, it is important to:

- Serve smaller groups of residents, approximately four to six residents per table
- Divide the spaces into small groupings within larger communities, such as neighborhoods, accommodating no more than eight to twelve residents
- Create a home-like environment
- Provide stable dining chairs with arms (no wheels)
- Provide lighting that offers contrast but no glare

- Choose contrasting colors in general (food against plate, linens against table, etc.)
- Provide adaptive utensils, lipped plates, or finger foods to help maintain independence
- Noise level should be kept to a minimum, and if there is music, it should be soothing in nature.

### *Outdoor Space*

More ALCs are adapting their outdoor space to make it more user-friendly for residents with dementia and to create a sense of independence for each resident. When designing outdoor space for residents with dementia, it is important to have a healthy blend of safety and usability. The Alzheimer's Australia report, *Dementia Care and the Built Environment* (2004), includes recommendations on outdoor spaces be:

- Visible, easily accessible, and user-friendly
- Enticing and interesting
- Safe
- Provided with fixed seating
- Inconspicuously secure
- Designed to facilitate easy return to the indoors
- Large enough to satisfy a need to walk for lengthy periods
- And have an area for watering, gardening, and other untidy activities that should be encouraged.

### *Lighting and Sensory Stimulation*

Much attention has been directed to the affect lighting and environmental stimulation has for residents with dementia. Controlling excess sensory stimuli, including the reduction of noise pollution within the ALC, such as eliminating paging systems, is recommended. Visual examples may include increased recognition triggers for residents so that they are more likely to recognize their individual homes, their communal areas, and the restrooms. Floors and walls can be transformed into tactile environments that are engaging to the residents. Having a hot pot of coffee brewing or a bread maker operating may attract residents to communal areas for simple gatherings or structured activities. These may be recognized as memories of home and entice the resident to be involved in activities taking place. Providers should be aware that glare or inadequate lighting can be an issue for older adults.

### **GUIDING PRINCIPLE #4: SAFETY**

Safety is certainly one of the most important elements of resident care. One of the biggest challenges for assisted living staff is balancing safety with quality of life. Elopement or exit-seeking is a concern for residents with dementia. Structured wandering (e.g., enclosed wandering paths or wandering paths in secure outside spaces) opportunities may decrease the desire to leave communities unsupervised. The Alzheimer's Association (2006) created guidelines for wandering for assisted living communities and skilled nursing care centers to better serve this daily challenge. These

guidelines recommend an evaluation for exit seeking behavior prior to moving in and the development of a service plan that promotes resident choice, mobility, and safety as mechanisms to manage elopement behavior as well as creating an environment that incorporates features of home and not institutional life.

ALCs should have an emergency preparedness plan that takes into consideration the special needs of residents with dementia. It is important to work with local law enforcement, first responders, and the hospital to prepare for emergencies so they are aware of the ALCs residents' needs. Being prepared for possible loss of power is vital as safety precautions the community has implemented, such as delayed egress, may be compromised.

The use of antipsychotic medication to treat behavior associated with dementia is not supported clinically and the U.S. Food and Drug Administration ("FDA") considers such use to be off-label. The FDA has also issued a "black box" warning as applied to antipsychotic use in the elderly with dementia due to an increased risk of death. Antipsychotics increase the risk of falls with fractures, hospitalizations and other complications resulting in poor health and high costs ("[Off-label use of atypical antipsychotics: An update," 2011](#)"). ALCs should work to safely reduce the off-label use of antipsychotics by finding alternative strategies for responding to challenging behavioral expressions in residents with dementia before considering medications.

## **CONCLUSION**

Caring for persons with dementia is a privilege. Providing a safe home with opportunities for engagement and successful living should be the top priority for all caregivers in the assisted living setting. Utilizing such tools as initial and ongoing evaluations, new and increased staff education, person-centered care approaches, life enrichment programming and environmental design will increase the quality of life for residents with dementia and improve their level of satisfaction and well-being.

**Note:** The assisted living profession continues to grow and evolve as does NCAL's perspectives on our changing profession. The concepts and terms used in this document may vary from state to state and time to time and are provided as a framework to help promote a general understanding of assisted living. The contents of this document may represent some preferred practices, but do not represent minimum standards, "standards of care," or industry-wide norms for ALCs. As always, an ALC is responsible for making clinical decisions and providing care and services that are best for each individual person. In addition, the contents of this document are for general informational purposes only and may not be substituted for legal advice.

*As approved by NCAL's Board of Directors on October 20, 2014.*



## **RESOURCES**

### *National Center for Assisted Living*

Resources on person-centered care and dementia care including the NCAL Quality Initiative that includes resources focused on safely reducing the off-label use of antipsychotics.

[www.ncal.org](http://www.ncal.org)

### *Alzheimer's Association*

Includes many free resources including *Dementia Care Practice Recommendations in Long Term Care*. There are also links to the CARES<sup>®</sup> Online Dementia Care Training and the Alzheimer's Association essentiALZ<sup>®</sup> certification program.

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

### *IA-ADAPT (Improving Antipsychotic Appropriateness in Dementia Patients)*

A free online resource center for clinicians, providers, and consumers understand how to provide care for persons with dementia using evidence-based approaches.

[www.healthcare.uiowa.edu](http://www.healthcare.uiowa.edu)

### *Dining with Friends<sup>™</sup>*

A free online video from the Alzheimer's Resource Center of Connecticut which provides assistance with making a dining experience for resident with dementia, person-centered. This includes addressing hydration, nutrition, and socialization.

### *Toolkit for Person-Centeredness in Assisted Living (PC-PAL)*

PC-PAL is a free toolkit that includes questionnaires to be completed by residents and staff to measure person-centered practices in the assisted living. The toolkit includes instructions for scoring and interpreting the results.

[www.shepscenter.unc.edu](http://www.shepscenter.unc.edu) or [www.theceal.org](http://www.theceal.org)

### *Center for Excellence in Assisted Living*

Numerous resources on providing quality care in assisted living.

[www.theceal.org](http://www.theceal.org)

### *Pain Evaluation*

For a more in-depth evaluation of pain, there are two types of basic screening instruments, depending on a resident's ability to communicate. These tools are more appropriate for residents in early stages of dementia. One pain scale type rates the level of pain through a number scale. Zero equals no pain with ten being the worst possible pain. Another common pain scale type is the "faces" pain scale. This scale

identifies different faces to measure the level of pain the resident is experiencing. A “happy face” indicates that there is no pain. A “sad face with tears” defines the most hurtful pain. Whichever tool is selected, it is important to use the same tool in future evaluations to benchmark either improvement or decline in the resident’s situation.

[www.painedu.org](http://www.painedu.org)

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