



**National Center for Assisted Living**

## **Guiding Principles for Dementia Care in Assisted Living**

Dementia care is a priority for all long term care providers, including assisted living. According to the 2009 Overview of Assisted Living<sup>1</sup>, it is estimated that more than one third of residents residing in assisted living have some form of dementia or Alzheimer's disease. The Alzheimer's Association estimates that more than 5 million people in the United States are living with Alzheimer's disease and that Alzheimer's disease is the seventh leading cause of death<sup>2</sup>. Creating resources and opportunities for educating staff may increase the level of service and quality of care that assisted living communities 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.

Note: NCAL acknowledges that not all states use the title "assisted living" but may use another term to describe these services, such as personal care homes, residential care, housing with services, etc. However, this document is applicable to all residential settings in which similar services are provided.

### **Overview of Dementia**

Dementia is a broad term that defines memory loss caused by various factors. Dementia can be associated not only with Alzheimer's disease but a host of other diagnoses including but not limited to Parkinson's disease, Huntington's disease, mild cognitive impairment and alcoholism. In this document, the word dementia is used to refer to the loss of cognitive, intellectual, psychosocial functioning, general memory loss and confusion that leads to the person's inability to perform normal activities of daily living (ADLs) such as bathing, dressing, eating, toileting, etc. The Alzheimer's Association has identified Alzheimer's disease as the most common form of dementia, accounting for up to 70 percent of diagnosed dementia cases<sup>3</sup>.

### **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

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<sup>1</sup> 2009, Overview of Assisted Living. A collaborative project of AAHSA, ASHA, ALFA, NCAL and NIC

<sup>2</sup> 2009, Alzheimer's Association Web site

<sup>3</sup> 2009, Alzheimer's Association Web site

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 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.

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. 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 such as recreational activities, spiritual needs or physical activity.

In 2001, the Assisted Living Workgroup (ALW) was formed to develop recommendations for assisted living on a national scale<sup>4</sup>. In 2003, the ALW's final report was published with consensus on much of the work completed by the 48 participating organizations. Specifically, the 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 ADLs, instrumental activities of daily living, 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

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<sup>4</sup> 2003, "Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations." A Report to the US Senate Special Committee on Aging by the Assisted Living Workgroup.

documents, such as advance directives<sup>5</sup>. 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 her/her own care."<sup>6</sup>

### Depression

Research has suggested that screenings for depression may be underutilized in long term care<sup>7</sup>. Residents with dementia are more likely to exhibit signs of depression than their peers who are cognitively intact. According to research, depression is most visible in residents with severe cognitive impairment, who suffered from undiagnosed pain as well as those who had behavioral issues<sup>8</sup>.

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 moving into assisted living 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<sup>9</sup>. Staff may assist by providing residents and family with introductions to members of the community and encouraging participation in activities during the transition.

As with all health information, initial and ongoing screenings for depression and mental health issues in general 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. 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 achieve this? 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

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<sup>5</sup> 2003, "Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations." A Report to the US Senate Special Committee on Aging by the Assisted Living Workgroup

<sup>6</sup> 2003, "Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations." A Report to the US Senate Special Committee on Aging by the Assisted Living Workgroup

<sup>7</sup> 2005, "Characteristics Associated with Depression in Long Term Care Residents with Dementia." *The Gerontologist*, 45:50-55.

<sup>8</sup> 2005, "Characteristics Associated with Depression in Long Term Care Residents with Dementia." *The Gerontologist*, 45:50-55

<sup>9</sup> 2006, "Moving Into an Assisted Living Residence: Making a Successful Transition." National Center for Assisted Living.

movement, or withdrawal of extremities during care<sup>10</sup>. For a more in-depth evaluation of pain, there are two types of basic screening instruments, objective and subjective, that staff can use with residents, depending on a resident's ability to communicate. One subjective pain scale type rates the level of pain through a number scale. Zero equals no pain with ten being the worst possible pain<sup>11</sup>. An objective common pain scale type is the "faces" pain scale<sup>12</sup>. This tool may be more useful to use with residents that are more advanced in their dementia and are no longer verbal. The 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. Once pain is determined to be present, the provider 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, their previous reactions to both pharmacological and alternative therapies and to determine the best course of treatment for that individual resident.

Initial evaluations are not enough. Everyone changes-- especially during the initial transition into assisted living. The early days of moving into an assisted living community can be overwhelming for the most cognitively intact person. For a person with dementia, this initial period of change may be even more intense. Ongoing evaluations for health and mental status and successful pain management are critical to form foundational information to compare and contrast with future evaluations.

### 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 his/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

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<sup>10</sup> 2006, "Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes." The Alzheimer's Association.

<sup>11</sup> "Pain Management: Understand Your Aches and Pains. And Take Control." University of Michigan Health System.

<sup>12</sup> "Pain Management: Understand Your Aches and Pains. And Take Control." University of Michigan Health System.

assisted living community 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 that the process of the activity is much more important than the outcome of the activity<sup>13</sup>. That is to say, the experience the residents have with the activity--their level of participation, the level of enjoyment they experience, and their willingness to participate in future activities based on their level of satisfaction is more important than if an object is made or a project is completed.

Many assisted living communities 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 assisted living community.

The ALW also provided a recommendation for activities for special care residents in their 2003 report. It reads: "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"<sup>14</sup>.

### **Staff Education**

Education of all staff at all levels is critical to the overall success of the assisted living community. Without the most up-to-date skills and knowledge, the staff is at a disadvantage to meet the resident's individual needs, wants, and desires. Research has shown that increased staff satisfaction relates directly to increased resident satisfaction of which quality of care and quality of life are major components<sup>15</sup>. One element of staff satisfaction is the opportunity for continuing education and training to improve their caregiving skills. 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, behavior management, communication, and special regulatory requirements specific to dementia.

When it comes to dementia, behavior management and communication go hand in hand. It is well known that residents with dementia often display challenging behaviors. What is not well recognized is that these behaviors often are nothing more than a mechanism the resident with dementia uses to communicate. If a staff member is unaware that

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<sup>13</sup> 2006, "Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes." The Alzheimer's Association.

<sup>14</sup> 2003. "Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations." A Report to the US Senate Special Committee on Aging by the Assisted Living Workgroup

<sup>15</sup> 2006, "Linking Resident Satisfaction to Staff Perceptions of the Work Environment in Assisted Living: A Multilevel Analysis." *The Gerontologist*, Vol. 46, No. 5, 590—598.

behavior is a form of communication, especially when dealing with dementia residents, 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, "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 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. Examples of states with increased requirements in both hours and topics include New Jersey, Oregon, and Virginia. Examples of these requirements may be found at:

New Jersey: [www.state.nj.us/health](http://www.state.nj.us/health)

Oregon: [www.oregon.gov/DHS/spwpd/index.shtml](http://www.oregon.gov/DHS/spwpd/index.shtml)

Virginia: [www.dss.state.va.us](http://www.dss.state.va.us)

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.

### **Physical Plant Environment**

NCAL revised its Guiding Principles for Assisted Living in 2008. That revision addressed physical plant issues in a very broad but important manner. The document stated "An assisted living residence should be designed, operated, and maintained in a manner that meets the special needs of the population served." It further states "An assisted living setting should be designed in a way that maximizes the quality of life, independence, autonomy, safety, dignity, socialization, choice, and privacy of residents."

That being said, not all assisted living communities 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 plant and environment.

Most providers, residents, families and consumers would agree that making an assisted living community 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- - animals, comfortable seating, fireplaces, pictures of family and friends, plants, etc. Community rooms such as kitchens and family rooms, elopement safe gardens, and outside decks or areas for gathering could be earmarks of a dementia-friendly environment. There is much literature available about inside and outside space and design for dementia residents.

Research has found that residents who reside in environments designed to specifically meet their needs have a much higher chance of retaining their abilities and also experience a higher quality of life<sup>16</sup>. In trying to better meet the needs of residents with diminished skills and abilities, assisted living communities should try either to design or adapt their current environment to maximize the residents' remaining abilities and to create a setting that will compensate for those skills lost. An example of this would be toileting. By making sure the resident's personal toilet and bathroom are clearly visible, identified, and accessible to the resident when in their unit, the chance of the resident using the bathroom is increased. Residents should be encouraged, within their reason, to bring personal items from the resident's home to decorate their new space. 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. Resident satisfaction shows that not only is the menu important, but also the environment. In the case of dementia residents, the environment can be the most important element. Research has shown that dementia residents adjust and do better in dining environments that:

- 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 "domestic character" – home like accoutrements;
- 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)

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### Outdoor Space

More assisted living communities are adapting their outdoor space to make it more user-friendly for residents with dementia and to create a sense of independence for that resident. It is of importance when designing outdoor space for residents with dementia, to have a healthy blend of safety and usability. In the Alzheimer's Australia report on design, they suggest outdoor spaces be:

- "Visible, easily accessible, and user friendly;
- Enticing and interesting;

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<sup>16</sup> June 2004, "Dementia Care and the Built Environment," Position Paper 3. Alzheimer's Australia.

<sup>17</sup> June 2004, "Dementia Care and the Built Environment," Position Paper 3. Alzheimer's Australia

- 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.<sup>18</sup>

### Lighting and Sensory Stimulation

Much attention has been directed to the affect lighting and environmental stimulation has for residents with dementia. Research by Alzheimer's Australia has shown that for an increased level of resident satisfaction and involvement that all five senses should be considered when designing or reinventing an environment serving residents with dementia<sup>19</sup>. Controlling excess sensory stimuli, including the reduction of noise pollution within the assisted living community, 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, the restrooms, etc. 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 is a problem for the elderly. Glare on walkable surfaces increases the chance of falls and injury to residents in general and may cause increased confusion for residents with dementia. An example cited by Alzheimer's Australia is shiny floor coverings can be interpreted by demented residents as a wet floor and then create an avoidance of that area or increased anxiety.<sup>20</sup>

### **Safety**

Safety is certainly one of the most important elements of care when dealing with cognitively impaired residents. One of the biggest challenges for assisted living staff is balancing safety with quality of life. Elopement (exit-seeking) is also a concern. 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 created guidelines for wandering for assisted living and skilled nursing communities 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 incorporate features of home and not institutional life.<sup>21</sup> All of the clinical guidelines for safety developed for assisted living by the Alzheimer's Association may be found at [www.alz.org](http://www.alz.org).

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<sup>18</sup> June 2004, "Dementia Care and the Built Environment," Position Paper 3. Alzheimer's Australia

<sup>19</sup> June 2004, "Dementia Care and the Built Environment," Position Paper 3. Alzheimer's Australia

<sup>20</sup> June 2004, "Dementia Care and the Built Environment," Position Paper 3. Alzheimer's Australia

<sup>21</sup> 2006, "Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes." Alzheimer's Association.

**Conclusion**

Caring for elders 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 are provided as a framework to help promote a general understanding of dementia care in assisted living. The guiding principles and content in this document are not "standards of care."