ASSISTED LIVING PROVIDER RESOURCE

GUIDING PRINCIPLES

DEMENTIA CARE

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INTRODUCTION

According to the National Center for Health Statistics' 2020 National Survey of Residential Care Facilities, over 800,000 people live in assisted living communities (ALCs)[1] across the nation. Assisted living embraces a philosophy of person-centered care while supporting physical activities and health-related needs. Assisted living communities strive to meet the social, emotional, cultural, intellectual, nutritional, and spiritual needs of its residents.

The National Center for Assisted Living (NCAL) developed these Guiding Principles as an informational resource to generally describe what assisted living is and highlight how the profession is striving to continually develop and improve services. The contents of ***Guiding Principles for Assisted Living*** may represent some preferred practices but do not represent minimum standards, "standards of care," or profession-wide norms for assisted living communities.

Dementia care is a priority for all long term care providers, including assisted living communities (ALC). According to the National Center for Health Statistics, it is estimated that over 42 percent of residents in residential care have Alzheimer's disease or other dementias (National Post-acute and Long-term Care Survey, 2020). The Alzheimer's Association estimates that more than 6 million people in the United States are living with Alzheimer's disease, the seventh leading cause of death in the United States (Alzheimer's Association, 2024). Creating resources and opportunities for educating and training 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 developed 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 (e.g., disorientation, language impairment, disorganization, etc.) that is severe enough to interfere with daily life functioning. Dementia is not a specific disease, but it 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 60-80 percent of diagnosed dementia cases.

1 Assisted Living Community (ALC) is used in this document as a way to encompass the various terms identifying assisted living. The assisted living model is built on the concept of delivering person-centered services (e.g., personal care) and supports (e.g., housing) that meet each resident's specific needs and preferences. In addition to supporting residents in completing activities of daily living (e.g., bathing, dressing, managing medications), assisted living provides a variety of specialized services, including social work, mental health or counseling, or therapies.

Person-Centered Care

NCAL is an advocate of person-centered care, focusing 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, their life story, strengths, weaknesses, goals, identity of purpose, 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 holistic shift from tasks and care;
- Promoting and supporting each resident's sense of purpose;
- Encouraging personal development of residents, on an individual basis;
- Maximizing the resident's dignity, respect, autonomy, privacy, socialization, independence, preferences, choice, and safety;
- Supporting lifestyles that promote, empower, and enable mental and physical health and fitness;
- Promoting family and community involvement;
- Developing positive and meaningful relationships among residents, staff, families, and the community; and,
- Ensuring the dining experience is person-centered.

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 equally as important as a clinical 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 opportunities 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;
- Cultural patterns in the individual's life;
- History of trauma;
- Barriers to communication (verbal and non-verbal) or thinking;
- Status of personal grooming, bathing/showering and time of day, and activities of daily living (ADLs); and,
- Their preferences for social situations such as recreational activities, spiritual needs, or physical activity.

The Assisted Living Workgroup (ALW, 2003) recommended the minimum components of an initial evaluation include:

- A physical history and exam by the current attending medical professional;
- Assessment of cognitive abilities and behavioral issues unless included in the resident's medical history – Note: When indicated, a structured evaluation should be conducted, such as a mini-mental health exam; and
- An evaluation on the resident's ADLs, instrumental ADLs, and a review of risk factors, including abuse and exploitation, depression, falls, elopement, self-neglect, safety awareness, and weight loss.

The ALW also recommended an evaluation of social environmental factors such as cultural, spiritual and recreational activities, support resources, and lifestyle preferences. Additionally, it 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 their own affairs and direct their own care."

Initial evaluations are not enough. Ongoing evaluations for both physical psychosocial well-being and mental health are critical. Everyone changes, especially during the initial transition into assisted living. The early days of moving into an ALC can be overwhelming for the most cognitively intact person. For a person with dementia, this initial period of change may be even more intense. Utilization of non-pharmacological interventions to support a safe and secure environment may assist the resident with dementia or cognitive impairments in transitioning to a new setting. It is imperative to identify that behaviors are due to unmet needs. You must identify what that need is in order to address behaviors.

Depression

According to Harris-Kojetin et al. (2019), the most prevalent mental health concern among resident care/ALCs is depression, with 10-30 percent of residents evidencing a formal depression diagnosis. Transitioning into assisted living may be difficult, as it is a major change in the 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 may assist by providing residents and family with introductions to members of the ALC and encourage participation in activities during the transition.

Initial and ongoing screenings for depression and other mental health conditions are recommended to best improve the resident's quality of life and better meet their individual needs. Inclusion of a mental health care provider is recommended, when possible, to offer additional support.

Pain Evaluation and Management

Pain is not normal and may be the cause of behavioral expressions. 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 resident, 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. Observation of the resident for physical signs of pain is the first step in the initial and ongoing evaluation.

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," 2018). 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 non-pharmacological interventions, such as exercise, massage, aroma therapy, music therapy, pet therapy, compassionate touch, relaxation therapy, and chiropractic alternatives. The important consideration is to review the resident's history, assess their potential of having unmet needs, their previous reactions to both pharmacological and non-pharmacological interventions, 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, hobbies, etc.) and identify their strengths, challenges, preferences, cultural mores, history of trauma, and interests. By knowing this information, staff can tailor programs to meet the resident's varying needs and interests. For example, if a resident was somewhat introverted their entire life, large group activities may be a negative experience. The resident may 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 engage, and personal interests. Resident cognitive abilities vary based on the disease and its progression. Activities should be designed to meet the residents where they are in the disease process. By developing separate activity programs for the varying levels of residents (parallel programming), the ALC will be increasing the opportunity for resident participation and identifying activities that bring a sense of purpose and promote dignity and autonomy to the resident increases the satisfaction of the resident, family, and staff.

The Alzheimer's Association notes in its Dementia Care Practice Recommendations (2018) 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.

ALCs develop person-centered service plans for residents with components encompassing physical, mental, and psychosocial needs and interests. Person-centered service plans are individualized plans of services based on needs and preferences for each resident residing in the assisted living community.

Staff Education and Training

It is important upon initial interview of a potential staff member that the individual understands the specific challenges and opportunities associated in caring for persons with dementia. Staff should be empathetic, compassionate, patient, organized, and flexible in their expectations. Education and training of all staff at all levels are critical to the overall success of the ALC. Without the most up-to-date skills and knowledge, the staff are at a disadvantage to meet the resident's individual needs, preferences, choices, wants, and desires. Caring for residents with dementia requires different skills and abilities due to the complexity of the diagnosis. 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; challenging behaviors; diversity, equity, and inclusion; and special regulatory requirements specific to dementia. Providers should check, and know, their regulatory requirements for staff education and training.

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 a form of communication expressed by residents with dementia. If a staff member is unaware that behavioral expressions are a form of communication, then that staff member and resident may have a more difficult daily routine, and importantly, building trust and relationships.

According to the Alzheimer's Association's Dementia Care Practice Recommendations for Nursing Homes and Assisted Living Residences (2018), "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 area. More information about specific regulatory standards in the different states may be found in NCAL's Assisted Living State Regulatory Review, the Center for Excellence in Assisted Living (CEAL), and through individual state health care associations.

Physical Environment

Dementia often affects an individual's safety awareness, judgement, and problem solving ability, so the environment should be designed to ensure, the safety and comfort of the individuals to the best extent possible. The Guiding Principles for Assisted Living provides information about how an ALC may be designed to maximize the quality of life, independence, autonomy, safety, dignity, socialization, choice, privacy, and safety of residents while encouraging family and community involvement. However, not all ALs were originally built to serve residents with dementia but have evolved into providing dementia care services.

Most providers, residents, families, and consumers would agree that making an ALC into a home for the resident is a key factor for success. To accomplish this, providers need to create an atmosphere and physical environment that matches as closely to one's private home as possible. Communities need to reflect a home-like environment. 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.

Environments should be designed or adapted to maximize the residents' remaining abilities and to create a setting that will compensate for those skills lost. Modifying the external environment may help to support resident independence and quality of life in everyday activities (Woodbridge et al., 2018). Visual cues or cognitive ramps are examples of things that can be implemented to help promote resident independence. Residents should be encouraged, within their reason, to bring personal items from their home. Personalization assists residents with adjustment to their new environment.

Dining

Eating is not only essential to physical survival but is also important for the emotional and social needs of human life. The dining experience may symbolize comfort, care, and social relationships. The rituals and activities surrounding food eating and the dining experience can also provide a link to personal identity (Hung & Chaudhury, 2011). Mealtimes 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 environment can be one of the most important elements.

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, if possible;
- 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;
- Keep noise level to a minimum, and if there is music, it should be soothing in nature;
- Provide flexible dining times to allow the individual to eat at times that are normal to the individual rather than strict dining schedules;
- Eliminate "clinical tasks" in the dining area (i.e., taking vital signs, administering medications including insulin, etc.);
- Provide a selective menu based on the individual's food and cultural preferences;
- Provide visual representation of available options to promote informed choice; and
- Allow for individual requests whenever possible.

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 that resident (Marcus, 2007). It is of importance when designing outdoor space for residents with dementia, to have a healthy blend of safety and usability. The Alzheimer's Australia report, *Dementia Care and the Built Environment* (2022), 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, Sensory Stimulation, and Indoor Space

Much attention has been directed to the affect lighting, environmental stimulation, and indoor sensory centers (i.e., nursery, gardening, and occupational sensory centers) have for residents with dementia. Controlling excess sensory stimuli, including the reduction of noise pollution within the memory care community, such as eliminating paging systems, and eliminating or minimizing audible alarms 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 cookies baking 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.

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. Understanding the nature of wandering behavior helps staff, family, and caregivers better understand the need to wander and appropriately intervene. Structured wandering opportunities (i.e., enclosed wandering paths or wandering paths in secure outside spaces) may decrease the desire to leave communities unsupervised. The Alzheimer's Association (2018) 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 person-centered 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, local and regional disaster planning managers, 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.

Antipsychotic Medications

The use of antipsychotic medication to treat behavior associated with dementia is not supported clinically and is considered off-label by the FDA, which issued a "black box" warning for the elderly with dementia due to an increased risk of death (Rubino et al., 2020). 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, focusing on individualized, non-pharmacological strategies for responding to challenging behavioral expressions in residents with dementia before considering medications. Behaviors result from unmet needs. Identify what that need is in order to address behaviors.

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 and training, 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. Collaborating with home care and therapy can further increase and maintain independence and engagement. This additional strategy can be used for risk management and resident safety.

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."

Resources

National Center for Assisted Living
Resources on person-centered care and dementia care. Link to LTC Trend Tracker which includes web-based tool to track off-label antipsychotic rates, hospitalizations and re-hospitalizations, occupancy rates, and falls and falls with injury. Link to quality improvement efforts including the AHCA/NCAL National Quality Awards program based on the nationally recognized Baldridge Criteria for Performance Excellence.
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® Online Dementia Care Training and the Alzheimer's Association essentiALZ® certification program.
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

Alzheimer's Society
Alzheimer's Society provides information on improving the eating and dining experience. The mealtime experience can positively impact the person's wellbeing and health.
https://www.alzheimers.org.uk/

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

Center for Excellence in Assisted Living
Numerous resources on providing quality care in assisted living.
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

Additional Information

- Alzheimer's and Related Dementia Resources for Professionals (NIA)
- Cognitive Care Kit (American Academy of Family Physicians)
- Disclosing an Alzheimer's Diagnosis (video from Actionalz)
- Management & Patient Care (Alzheimer's Association)
- Physicians Guide to Assessing and Counseling Older Drivers (American Geriatrics Society and National Highway Traffic Safety Administration)
- Next Steps After an Alzheimer's Diagnosis
- Caring for a Person with Alzheimer's Disease
- Tips for Managing Agitation, Aggression, and Sundowning
- Alzheimers.gov

References

Alzheimer's Association. (2023). 2023 Alzheimer's disease facts and figures. ***Alzheimer's & Dementia***, 10(2), e47-e92. https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf

Alzheimer's Association. (2018). Dementia care practice recommendations for assisted living residences and nursing homes. https://www.alz.org/media/documents/dementia-care-practice-recommend-assist-living-1-2-b.pdf

Assisted Living Workgroup. (2003). Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulations, and Operations. A report to the U.S. Senate Special Committee on Aging. https://www.huduser.gov/portal/sites/default/files/pdf/Assuring-Quality-in-Assisted-Living-Guidelines.pdf

Dementia Care and the Built Environment. (2022): Alzheimer's Australia. https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-Environment03_HowToDesign_english.pdf

Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes. (2018): Alzheimer's Association. https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf

Gruber-Baldini, A. L., Zimmerman, S., Boustani, M., Watson, L. C., Williams, C. S., & Reed, P. S. (2005). Characteristics Associated With Depression in Long-Term Care Residents With Dementia. ***The Gerontologist***, 45(suppl 1), 50-55. doi: 10.1093/geront/45.suppl_1.50

Harris-Kojetin, L., Sengupta, M., Lendon, J. P., Rome, V., Valverde, R., & Caffrey, C. (2019). ***Long-term care providers and services users in the United States***, 2015–2016. National Center for Health Statistics. https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf

Hung, L., & Chaudhury, H. (2011). Exploring personhood in dining experiences of residents with dementia in long-term care facilities. In ***Journal of Aging Studies***, 25(1), 1-12.

Marcus, C. C. (2007). Alzheimer's garden audit tool. ***Journal of Housing for the Elderly***, 21(1/2), 179-191.

Off-label use of atypical antipsychotics: An update. (2011) ***Comparative Effectiveness Review: Agency for Healthcare Reseach and Quality.***

Rubino, A., Sanon, M., Ganz, M., Simpson, A., Fenton, M., Verma, S., Hartry, A., Baker, R., Duffy, R., Gwin, K., & Fillit, H. (2020). Association of the US Food and Drug Administration antipsychotic drug boxed warning with medication use and health outcomes in elderly patients with dementia. ***JAMA Network Open***, 3(4), e203630.

Woodbridge, R., Sullivan, M. P., Harding, E., Crutch, S., Gilhooly, K. J., Gilhooly, M. L. M., McIntyre, A., & Wilson, L. (2018). Use of the physical environment to support everyday activities for people with dementia: A systematic review. ***Dementia***, 17(5), 533-572.