
Caring for Those with Dementia in Assisted Living

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At the most recent annual meeting of the Assisted Living Federation of America (ALFA), the presenter at one program asked the audience, most of whom were executives and leaders in the senior housing field, to raise their hands if they felt they had residents with Alzheimer's and other dementias living in their facilities. Every hand in the room went up. Then the presenter asked them to keep their hands raised if they felt that approximately 30% of their residents had some form of dementia. All of the hands remained raised. How many people felt that 40% of their residents have some form of dementia? Most hands remained raised. It was not until the presenter asked if over 50% of residents in AL have at least mild dementia that the majority of hands were lowered.

The next question to the audience was about staff training with regard to caring for dementia. Only about 25% of participants raised their hands when asked if they offered specialized training or certification to their staff to help prepare them to care for demented residents.

Challenges of Dementia in AL: Real and Growing

Most of us are familiar with the statistics regarding the aging of our national population. According to the U.S. Census Bureau, in 2002 there were slightly more than 4 million people who were 85 years or



older living in the U.S. By the year 2040, there will be 9 million. This number will increase to 15 million in 2040, and 20 million in 2050.

As the population ages and the need for supportive living environments increases, the percent of

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residents with dementia residing in ALFs will soar. And dementia is just one of the chronic health conditions that people bring to this care setting. Heart failure, Parkinson's disease, diabetes, emphysema, and arthritis are some of the common geriatric syndromes. Most of these people are choosing not to move into skilled nursing facilities if they can avoid it. Increasingly, assisted living is seen as an alternative for the frail elderly. Many see it as their last address; they don't even want to move to acute or skilled nursing settings when their frailty increases.

The average age of AL residents is 82 years, and Alzheimer's disease (AD) is a common condition of people in this age range. As individuals age, the incidence of Alzheimer's disease rapidly increases until at age 85, there is almost a 50% occurrence of AD. Combined with other forms of dementia, such as Lewy Body, Parkinson's, and vascular dementias, there will be an increased need for the AL industry to have well-trained staff who can help maintain safety as well as a good quality of life for residents with dementia.

Challenges of Quality Dementia Care

People with dementia are often given a low priority for quality care. These individuals are usually elderly, confused, inarticulate, unable to advocate for themselves, and may have associated challenges such as incontinence, poor hygiene, and difficult behavior. Even experienced leaders and caregivers may find it an arduous task to provide quality care for these residents.

The national dialogue already has started about what is considered "quality care" for AL residents with dementia. The Alzheimer's Association and other professional organizations and individuals in the field of dementia are developing recommen-

dations for standards of care; and the models of care for dementia residents are evolving and changing. Simply keeping dementia residents safe and clean is no longer accepted as an adequate standard of care.

Consumers (often the baby-boomer children of dementia residents) are educating themselves about new tools described in professional literature such as programs of cognitive stimulation, engagement, and redirection, as well as new medications for dementia. As these individuals become more informed and sophisticated in their knowledge and expectations, families increasingly will

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be looking for an environment that is "life enhancing" for their loved ones. To meet these demands and to effectively care for residents, all ALFs may be expected in the future to provide more cutting-edge types of programs and medical supervision for residents with dementia. (The book *Alive with Alzheimer's* documents the life enhancing environment of one ALF that specializes in dementia care.)

Defining Quality of Life

How is "quality of life" defined for a person with dementia? William Webster defines *quality* as "the degree of excellence of a thing."

This author defines "quality of life" as "those things that *matter*—that give meaning to *life*." AL residential environments that furnish good quality of life for their dementia residents enable them to:

- be comfortable
- have dignity
- be valued
- have choices
- experience vigor and zest for life.

These are somewhat nebulous social values. How do these translate into practical standards of care for the AL industry?

Comfort

Comfort for a person with dementia often means that those in the caregiving role will take the time to notice if basic needs are being met, such as adequate nutrition and hydration. Even some persons with mild cognitive impairment (MCI) may skip meals or forget to drink enough fluids. Slow but steady weight loss may result, contributing to further debilitation. Poor fluid intake can cause frequent urinary infections that may become very serious in the elderly.

Another area of comfort is freedom from pain. Staff may not be aware that a resident suffers pain because persons with dementia may not be able to articulate their pain. A change in behavior or social withdrawal may be subtle signs of chronic pain. Training for AL staff on how to assess a dementia resident for pain can improve his or her quality of life.

Skin problems, such as small skin tears on the forearms or shins, may result from minor bumps or falls. Caregivers require training on the delicate condition of elderly persons' skin and the need to be cautious and vigilant for changes in skin condition when bathing or assisting in activities of daily living (ADLs). A dementia resident who is sedated or not encouraged to walk and participate in activities can develop pressure ulcers from sitting or lying too long in one position.

The ability to walk and move about one's environment is another comfort factor. Difficult behaviors often are a result of boredom or confinement. ALFs that allow residents with dementia to have free access and flow throughout a large area help maintain residents' physical conditioning and also provide improved cognitive stimulation. It is important to note that banging on doors, frequently asking to leave, and acting out toward other residents or staff are not natural consequences of the dementia but expressions of unmet needs. The need to be able to roam and explore the environment is strong for many residents with dementia. Confinement may lead to the expression of difficult behaviors.

Currently, some ALFs provide dementia care in small confined areas, separate from the larger physical structure. This not only increases the safety and security of the residents with dementia but it also increases the safety and comfort of non-demented residents.

Dignity

This is a sense of "personal dignity" or "personal worth" that comes from *within* the person. It is wonderful to watch a woman with advanced dementia who may not be able to verbalize or articulate her desires respond to positive attention.

On Mother's Day, one ALF provides a free hairdresser, makeup artist, and photographer to take photographs of all the female residents for their families. When she is pampered and made up, it is not unusual to see the woman with dementia come alive, hold her head high, flash a smile, and have a sparkle in her eye. Likewise, it is satisfying to see the gentleman, who every day of his life dressed in a suit, perk up and become more alert when the caregivers have properly bathed, shaved, and dressed him.

It is important for caregivers to remember that residents with

dementia still have pride and walk with dignity throughout their environment. Staff should be trained to assist these residents to groom themselves to the extent that they are capable so that they are indistinguishable visually from other residents or visitors.

Being Valued

This comes from the *external* environment. Do the caregivers acknowledge and respond to demented residents with the same respect as non-demented residents? How do the staff members greet the resident?



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Is there eye contact? Does the staff know the resident's name? Do they know each resident's preferences and dislikes? Does the staff take the time to listen to the resident with dementia? While it may be difficult to comprehend initially what is said, many dementia residents are able to express their desires if enough time is taken in communication.

Are activities in the ALF age-appropriate? It is not uncommon for residents with dementia to be treated as children and placed in organized activities with children's toys, such as blocks, plastic tools, or crayons. Residents with dementia just as easily can be engaged in age-appropriate activities that don't infantilize them.

These include flower arranging, assisting with cooking projects, lawn bowling, musical activities, art projects, and even folding laundry. Progressive dementia units train staff to engage residents in the same type of activities that age-matched individuals without dementia would enjoy.

Choice

Choice is probably the most essential aspect of a good quality of life. The ability to make choices is what society takes away from those people it wants to punish. Dementia units often justify suspension of choice as necessary to keep residents "safe."

To this end, residents may be kept in a small confined area and even encouraged to spend much of the day in bed or sitting in the same chair. Despite the fact that falls are always a risk, there is also an important degree of dignity associated with letting residents make choices and maximize their freedom. Maintaining ambulatory skills also helps preserve bone and muscle strength, decreasing the risk for falls and subsequent injury.

It is encouraging to see that more and more dementia units in ALFs do not use any physical restraints. Staff can be trained to pay special attention to residents who are at an increased risk for falls.

Choices also can be offered for meal times and locations, food preferences, clothing, and activities. This takes extra staff training, but the rewards are evident in the smiles and involvement of the residents. Residents with dementia may not always be able to express their preferences verbally, but they usually know what they like; and alert caregivers watch for signs of pleasure or distaste.

Staff should be encouraged to discover resident preferences. One caregiver excitedly told a change-of-shift meeting she had found out that a resident, Mrs. S., used to have a beautiful garden. When the caregiver sat and shared photos in a gardening magazine with the elderly woman, Mrs. S. could name all

the flowers in the photos and talked at length about her garden. Until that time, the staff thought that she could hardly speak.

Vigor and Zest for Life

Residents with Alzheimer's disease may not be able to remember yesterday clearly or plan for tomorrow, but that doesn't mean they can't enjoy today or this moment. Many ALFs have observed the fun their residents with dementia will have during a party or special event. Dancing, laughing, singing, and hugging are abundant. There is no doubt that these residents are enjoying the moment every bit as much as the staff and visitors.

If staff is trained to show the residents with dementia the possibilities and joy of the day and the moment, residents will thrive. A dementia unit can be chaotic and lively, but residents are busy enjoying their lives. A dementia unit that is too quiet or

subdued may be an indication that the residents are depressed or lack meaningful stimulation. The staff can be taught skills to engage those residents socially who are always quiet and unresponsive. Many residents will respond positively to a concerned staff member's efforts to involve them in social activities.

If senior housing leaders agree with the concept that residents with dementia can fully enjoy the "moment," they will design environments and programs that will bring enjoyment and pleasure to these residents. A resident with Alzheimer's disease may not be able to remember certain parts of their past or be able to prepare effectively for the future, but—given the opportunity and the means—they absolutely can enjoy the moment.

Dementia in AL

The senior housing industry is looking carefully at national demo-

graphics and designing their future environments to meet the upcoming needs of the residents will live in this setting. The demand for safe AL residences that maximize autonomy and independence, as well as the quality of life experience for those residents with dementia, will increase. The small, secluded unit may have been a viable solution in the past, but it may not be acceptable as consumers and their families expand their expectations of what is beneficial or possible for people with dementia.

AL leaders are encouraged to partner with experts in dementia care, such as the Alzheimer's Association, to help develop innovative and life-enhancing environments that will allow residents with dementia to thrive in assisted living. ALC

Reference

1. Greenblat, CS. *Alive with Alzheimer's*. Chicago: University of Chicago Press 2004.

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