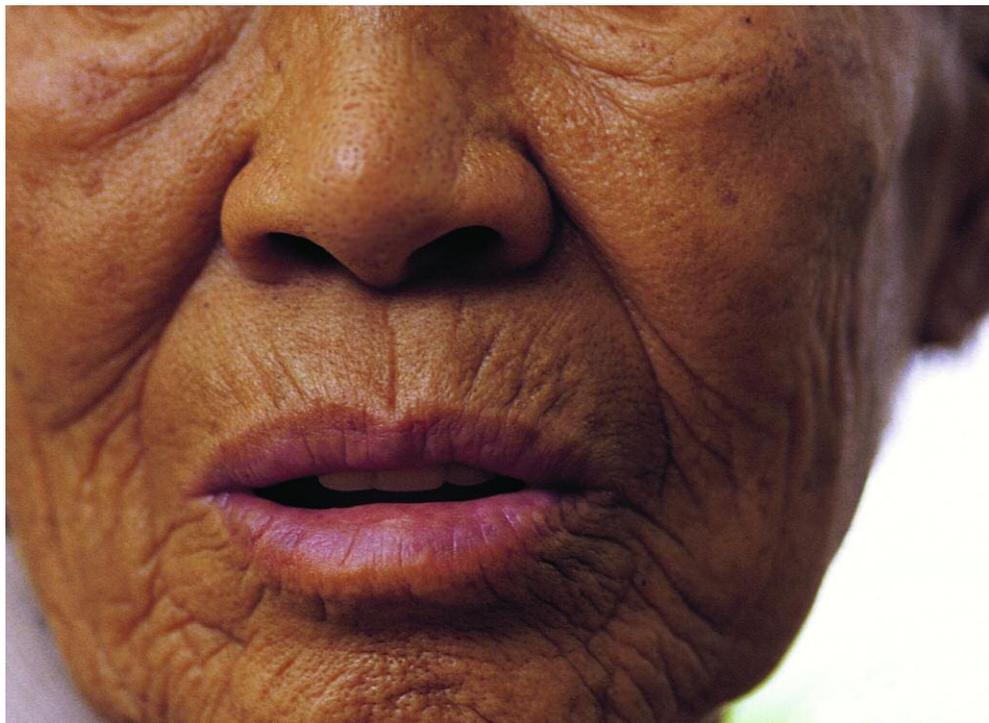

End-of-Life Care: Are We Meeting the Need?

Janet Lieto, DO, CMD and Stephen Goldfine, MD, DABHPM

Assisted living (AL) residences are designed to care for the elderly while they “age in place.” Different facilities may offer various added programs or services as residents’ needs increase and change. These programs are designed to provide residents with help in managing their activities of daily living (ADLs) so that the residents may remain safely in an assisted living environment. However, is there enough support available to allow residents to actually die in place in their assisted living apartment, while providing quality care, symptom management, and support to the residents, their families, and the AL staff?

When residents medically and functionally decline to a point that a facility struggles to keep them safe, there are several available options. One option is to transfer the resident to a nursing home or hospital. According to a National Center for Assisted Living (NCAL) 2000 survey, 33% of AL residents who left their assisted living apartment were sent to a nursing facility. This meant a loss of continuity of care for the residents, and the residents were not allowed to live out the rest of their life in a place they considered home.¹ This raises the question, “Does a patient’s independence and autonomy in making care decisions become void when there is a problem with safety?” Continued-stay criteria for AL residences have attempted to address this issue, but have not explored how the criteria may change if the resident’s



goals are palliative care, symptom management, or a “good death.”²

A second option is to optimize the added services that a resident may receive from their AL facility. If the resident is still deemed unsafe, a risk management agreement or contract may be signed by both parties. In addition, families may increase the amount of supervision or care provided to the resident by hiring “outside staff” to help meet the residents’ needs. There are families who have the resources to provide companions 24 hours a day, 7 days a week to ensure that their loved one is safe. This is a costly option to the family and relies on help outside the regular AL staff.

A third option occurring more

frequently in AL is to face the medical decline head-on by redefining the goal of care for the resident, thus allowing him or her to die in place.” According to the NCAL 2000 Survey of Assisted Living Facilities, 28% of residents who no longer lived at an AL facility died.¹ These residents should have the option to die at their AL facility and not be transferred to a nursing home or hospital. Educated residents and families realize that at some point, chronic medical conditions, dementias, or newly diagnosed diseases are not going to be cured. In these situations, residents and families may change the goal of care from curative with aggressive medical interventions, to palliative with

symptom management interventions, so as to preserve independence, quality of life, and dignity.

How does AL meet the new needs of these residents? Frequently, AL residences are turning to hospice organizations to help support residents in the decision to remain in their assisted living apartment and provide the resources to assure the resident is safe and will not suffer. In addition, hospice organizations will support the families with spiritual, psychosocial, and bereavement services to help them through the end of their loved one's life.

End-of-Life Care for Elderly in Assisted Living

Most people want to die at home, in their sleep, surrounded by loved ones. Studies have demonstrated that residents want aggressive symptom management to control pain and shortness of breath, and do not want to be a burden to their families or caregivers.³

How do health care workers help residents and families transition from aggressive to palliative care in AL? Clinicians need to be proactive in discussing residents' needs and conditions. In order to be proactive, clinicians, whether physicians, hospice workers, or facility staff, must themselves be educated in end-of-life care, understand the options and services available, and be able to present them to the residents and their families. Table 1 demonstrates six key areas that health care workers must address with residents and families to achieve a successful end-of-life experience.⁴

The first step toward a successful end-of-life experience in AL is the discussion of the goal of care with the resident and the family, if indicated.⁴ Residents and families are constantly processing their experiences with interventions and illness, whether health care workers discuss them or not. Sometimes it is harder for a health care worker

Table 1.
Issues that Need to Be Addressed in End-of-Life Care in the Elderly⁴

- Goals of care
- Communication with residents and families
- Coordination of services
- Symptom management including:
 - Physical symptoms
 - Psychosocial issues
 - Spiritual symptoms
- The active dying process
- Grief and bereavement

than the resident or family to open the line of communication about end-of-life issues. Frequently, residents and families are more ready than expected to have an initial end-of-life discussion. Repetitive hospitalizations and functional decline do not go unnoticed by residents and families! Health care workers should be ready to have this discussion no matter who initiates the conversation. When discussing the option of transitioning from curative to palliative care with a resident or family, never expect them to make an immediate deci-

sion. Before a decision can be reached, the resident and their family need to process information and discuss it with other loved ones.

Good communication with residents and families is essential when dealing with end-of-life issues.⁴ Table 2 represents a stepwise protocol to help health care workers when addressing end-of-life goals with residents and families.⁴ Keep in mind that end-of-life discussions may result in an action plan that is a compromise of what the resident, family, and health care provider think is appropriate. The key is to continue to readdress issues as the resident's disease progresses or situation changes.⁴ Residents and families continually need to process situations, and health care workers need to allow ongoing discussions to help them process these changes. A resident or family may need "one more hospitalization" or "one more round of antibiotics." Often this will help them process a situation or illness where, regardless of the intervention, the result will remain the same and their quality of life will not change. When a resident is ready to make the transition to palliative care with the goal of care being symptom management, facilities should respond to make the transition successful. Facilities hold the key to recognizing and accessing

Table 2.
Stepwise Protocol for Successful Communication with Patients and Families⁴

- The right setting is important for the discussion
- Determine the patient and family's understanding of the situation
- Ask what *their* understanding is and what *they* want to discuss
- Determine what their expectations or hopes are
- Discuss realistic goals
- Be empathetic with your responses
- Decide on a plan and follow through
- Understand that plans may constantly change

hospice services that can best help meet the resident's needs.

Hospice and the Medicare Hospice Benefit

Hospice is a Medicare program paid for by the federal government under Medicare Part A. The program benefits individuals who decide they no longer want aggressive interventions to cure a disease or disorder. It supports those beneficiaries who want to receive services that will enhance the quality of their life through palliative or symptom management of their disease.

To enroll in a Medicare hospice benefit, the resident must be eligible for Medicare Part A, receive care from a Medicare-approved hospice organization, and sign a statement choosing hospice over other Medicare-covered benefits to treat their disease. In addition, the resident's attending physician must certify that the resident is terminal, which is defined as having a prognosis of 6 months or less.^{5,6}

Hospice services may be provided in a variety of settings, including the home, AL residences, nursing homes, and inpatient hospice units. These services are provided by an interdisciplinary team, which consists of a physician, a nurse, a home health aide, a social worker, and a chaplain or other spiritual support staff. Residents receive regular nursing visits to assess and make recommendations for end-of-life symptom management. A home health aide may provide up to 2 hours a day for 5 days a week of one-on-one care.⁷ Social worker and spiritual support are available both to residents and their families. In addition, hospices will provide bereavement care for families, as well as AL staff who are regarded as a resident's extended family. Some hospices even provide alternative or complementary services, including but not limited to, massage therapy, music and art therapy, and pet therapy.

Coordination of Care: AL and Hospice Organizations

Successful end-of-life care in AL requires the coordination of care and services with hospice organizations.⁴ End-of-life care research in AL has demonstrated the importance of coordination of care for dying residents. Families recognize and value their loved one's requests to die "in their home" in AL.⁸ Residents consider AL staff as their extended family. However, facilities vary in their ability to provide hospice services for successful end-of-life care. As the needs of the dying resident increase, facilities do not have the training in



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end-of-life care or staff ratios to accommodate these needs. The same research showed that even when hospices provided services, AL and hospice staffs were unsuccessful in communicating and coordinating their respective services.⁸ It is not enough just to provide hospice services in AL. To be successful, both AL and hospice organizations need to maintain efficient and effective communication with each other to keep everyone aware of residents' and families' needs. The dying resident needs an interdisciplinary team that includes the AL and hospice organization staffs, but with a sin-

gle, well-defined action plan to meet the ultimate goal of care.

Obstacles for End-of-Life Care in Assisted Living

Even when the coordination of services between hospice organizations and AL residences exists successfully, there are many obstacles to be dealt with.

Regulatory Obstacles

In a study that examined AL regulations and surveyed AL administrators, state regulators, nursing boards, and professional nursing and palliative care associations about aging in place and end-of-life care in AL, many obstacles were found.⁹ These obstacles included inconsistent regulations from state to state regarding residents who needed skilled nursing care. Essentially, all dying residents are going to need a higher level of care to treat symptoms that naturally coincide with the dying process. Residents who sign service contracts upon admission to an AL residence may be asked to leave the facility when they require too many hospice services because facilities fear they may be held liable if they continue to allow the resident to remain in their apartment. The study reported that some facilities routinely transferred residents to a nursing home or hospital unless they were receiving the Medicare hospice benefit to avoid being legally liable for the death of the resident.⁹

Facility Obstacles

Staffing in AL is set up to care for a resident's needs on a 24-hour basis. However, a resident's needs increase when they are dying and symptom management is required. Staff may not feel comfortable with caring for residents who are dying. Nursing staff is not typically available on site 24-hours a day, 7 days a week. Because an RN is needed to assess symptoms and administer medications that are ordered on an as-needed basis, it becomes

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country are recognizing the benefits of a total wellness approach for dementia residents. For example, Lakeside Village, an Immanuel Senior Living community in Omaha, NE, features a wellness center, which focuses on body, mind, and spirit, geared toward older adults in their senior living community as well as in the city, according to Assisted Living Director, Debra Welk, RN.

Immanuel Senior Living is comprised of 5 assisted living and independent living communities in eastern Nebraska. Lakeside Village is building a memory support center that is expected to open in the fall of 2007 where 12 residents will live. The Lincoln site already has such a center. Nonmedical caregivers currently help assisted living residents who have Alzheimer's disease and dementia with certain rituals, such as visiting the wellness center, going for coffee, walking,

reading the Bible, and praying.

According to Welk, "A caregiver can offer consistency for those residents who are losing their memories. They can't always remember people, but they often appreciate being involved in activities they previously enjoyed. A caregiver provides variation in their day and helps fulfill their lives. We provide 3 meals a day, but in addition, the caregiver can help to remind dementia residents to keep up their hydration and eat small snacks. The caregiver gets to know the resident and what they like to do. They're so patient, many times helping the resident complete a task over and over again like it's a new thing every day."

That kind of dedication builds loyalty among residents and their families, who come to appreciate the respite that a nonmedical caregiver can provide. An example from Welk's own family is a

perfect illustration.

"My husband has an aunt with dementia and an uncle who is the primary caregiver. A nonmedical caregiver has been with them for 4 to 5 years, providing care for his aunt and assistance to his uncle. This caregiver returned to her home in Jamaica to be married. The uncle hired another caregiver to care for his wife, and he traveled to Jamaica as an honored guest at the wedding. I think when a trust level is built and people get to know their caregiver, they mean so much to you, they almost become family." ALC

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virtually impossible to control acute symptoms unless they occur during the time the RN is in the facility.⁹ If residents develop symptoms in facilities where hospice services are in place, residents, families, and staff should be educated and encouraged to call the hospice nurse to make an acute visit or provide advice on symptom management with medications that are available. If the resident is able to self-medicate, he or she may utilize the hospice comfort pack, which typically holds medications such as acetaminophen, morphine, and lorazepam to manage symptoms. However, some facilities do not have storage options for comfort packs.⁹

Looking to the Future

Residents want to be able to age and die in place at AL that have become their homes. Health care

workers need to be ready to discuss palliative goals of care with residents who request symptom management of their disease. To meet the resident's goals and manage their symptoms, the AL staff and the hospice organization need to understand the obstacles to care and collaborate with each other to overcome them. The provision of quality end-of-life care in AL will entail future changes of policies and regulations and enhanced communication between AL and hospice organizations. ALC

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