Hospice and Assisted Living: Improving Care at the End of Life

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Seniors have embraced the concept of "aging in place." The challenge that inevitably occurs is the concept of "dying in place." Seniors do not want to go through another change in living arrangements and do not want to become a burden on their families at the end of their life.

Is it realistic to think that an elderly resident may be able to die in an assisted living (AL) residence? Depending upon what state you live in, it may or may not be possible. Some states have very strict move-in and discharge requirements that prohibit a dying resident from staying in their AL residence because they become bedbound, have a foley catheter, or require oxygen. Such requirements are usually in response to concerns for life and safety in the event that a building needs to be evacuated quickly or that the resident has complex needs that cannot be met by the AL staff. Other states waive these rules for residents who elect to receive care from hospice.

The Medicare Hospice Benefit

The Medicare Hospice Benefit is available to Medicare and Medicaid beneficiaries in all states, except Oklahoma, New Hampshire, and Connecticut. To qualify, the resident must have a prognosis of 6 months or less if the illness runs its normal course and elects to receive palliative/comfort care instead of curative care. The AL residence is considered to be the resident's home, where the following services can be provided:

- Services by an interdisciplinary health care team comprised of physicians, nurses, home health aides, social workers, chaplains, and volunteers.
- Medications, durable medical equipment, and medical supplies related to the terminal illness.
- On-call services, 24 hours a day.
- Bereavement care to the family/loved ones following the death of the resident.

The goal of care is to control the resident's pain and other uncomfortable symptoms through the dying process. Once their symptoms are controlled, support is provided in addressing spiritual/psychosocial

issues if the resident so desires. Hospice providers, for short crisis periods, will be able to offer care in their hospice inpatient unit or through contracts with hospitals and skilled nursing facilities. Some hospices may be able to offer continuous care at the bedside when the resident does not want to be hospitalized. If the resident's needs cannot be met through these means, alternative placement will need to be considered to ensure that he or she receives the care that is needed.

AL Expectations of Hospice

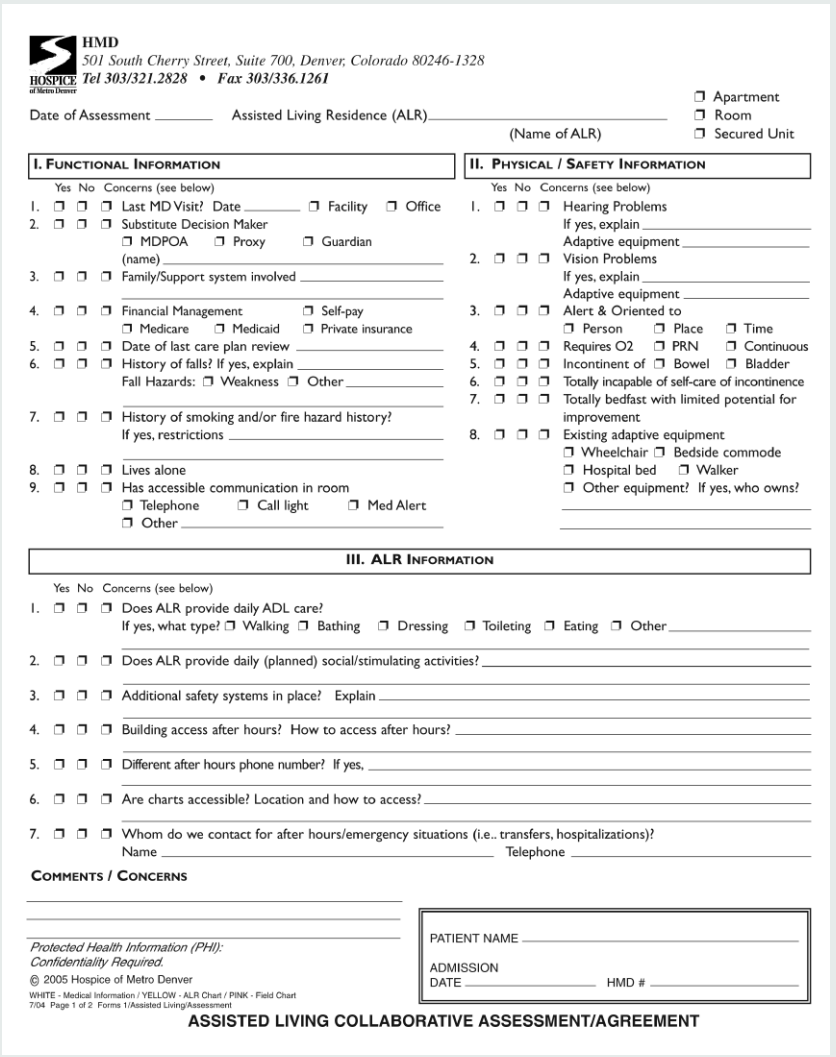
Beyond the basic services that are offered under the Medicare Hospice Benefit, the services provided are dependent upon the staffing and policy/procedures of the hospice. In most states, although a contractual arrangement between the hospice and the AL residence is not required, it is important for these facilities to have a discussion to clarify expectations and outline how their relationship will work. An AL collaborative assessment/agreement form can form the basis of a productive discussion on this matter (Figure 1). For example, what in-service training does the hospice offer the AL staff so that they will be comfortable with dying residents? How quickly does the hospice assess a resident who has been referred? Does the hospice provide consistent staff to make visits? Do the nurses communicate and coordinate the resident's care in an effective manner? Does the hospice staff respond promptly when called? Does the hospice staff make visits in the off hours? Is the hospice staff able to assist the resident or family in making treatment decisions and completing advance directives? Can the hospice provide continuous care in the AL residence when the resident does not want to be hospitalized? Does the hospice provide bereavement support for other residents and AL staff who are grieving over the loss of the resident?

The National Hospice and Palliative Care Organization (NHPCO) has recently made available a toolkit entitled, *Operational Guidance: Hospice and Assisted Living* (Figure 2). The toolkit offers valuable information that may assist hospice providers in developing successful collaborative arrangements with AL staff and includes guidelines on:

- State licensing regulations
- Assisted living residences
- Assessment of the resident

The toolkit can be purchased at a nominal fee by visiting: www.nhpco.org.

Figure 1.



HMD
501 South Cherry Street, Suite 700, Denver, Colorado 80246-1328
HOSPICE of Metro Denver
Tel 303/321.2828 • Fax 303/336.1261

Date of Assessment _____ Assisted Living Residence (ALR) _____ (Name of ALR)
❒ Apartment ❒ Room ❒ Secured Unit

I. Functional Information

Yes No Concerns (see below)
1. ❒ ❒ ❒ Last MD Visit? Date _____ ❒ Facility ❒ Office
2. ❒ ❒ ❒ Substitute Decision Maker ❒ MDPOA ❒ Proxy ❒ Guardian (name) _____
3. ❒ ❒ ❒ Family/Support system involved _____
4. ❒ ❒ ❒ Financial Management ❒ Self-pay ❒ Medicare ❒ Medicaid ❒ Private insurance
5. ❒ ❒ ❒ Date of last care plan review _____
6. ❒ ❒ ❒ History of falls? If yes, explain _____ Fall Hazards: ❒ Weakness ❒ Other _____
7. ❒ ❒ ❒ History of smoking and/or fire hazard history? If yes, restrictions _____
8. ❒ ❒ ❒ Lives alone
9. ❒ ❒ ❒ Has accessible communication in room ❒ Telephone ❒ Call light ❒ Med Alert ❒ Other _____

II. Physical / Safety Information

Yes No Concerns (see below)
1. ❒ ❒ ❒ Hearing Problems If yes, explain _____ Adaptive equipment _____
2. ❒ ❒ ❒ Vision Problems If yes, explain _____ Adaptive equipment _____
3. ❒ ❒ ❒ Alert & Oriented to ❒ Person ❒ Place ❒ Time
4. ❒ ❒ ❒ Requires O2 ❒ PRN ❒ Continuous
5. ❒ ❒ ❒ Incontinent of ❒ Bowel ❒ Bladder
6. ❒ ❒ ❒ Totally incapable of self-care of incontinence
7. ❒ ❒ ❒ Totally bedfast with limited potential for improvement
8. ❒ ❒ ❒ Existing adaptive equipment ❒ Wheelchair ❒ Bedside commode ❒ Hospital bed ❒ Walker ❒ Other equipment? If yes, who owns? _____

III. ALR Information

Yes No Concerns (see below)
1. ❒ ❒ ❒ Does ALR provide daily ADL care? If yes, what type? ❒ Walking ❒ Bathing ❒ Dressing ❒ Toileting ❒ Eating ❒ Other _____
2. ❒ ❒ ❒ Does ALR provide daily (planned) social/stimulating activities? _____
3. ❒ ❒ ❒ Additional safety systems in place? Explain _____
4. ❒ ❒ ❒ Building access after hours? How to access after hours? _____
5. ❒ ❒ ❒ Different after hours phone number? If yes, _____
6. ❒ ❒ ❒ Are charts accessible? Location and how to access? _____
7. ❒ ❒ ❒ Whom do we contact for after hours/emergency situations (i.e.. transfers, hospitalizations)? Name _____ Telephone _____

Comments / Concerns

_____
_____
_____

Protected Health Information (PHI): Confidentiality Required.

WHITE - Medical Information / YELLOW - ALR Chart / PINK - Field Chart
7/04 Page 1 of 2 Forms 1/Assisted Living/Assessment

PATIENT NAME _____
ADMISSION DATE _____ HMD # _____

ASSISTED LIVING COLLABORATIVE ASSESSMENT/AGREEMENT

Sample assisted living collaborative assessment/agreement form that can be used to clarify expectations and outline how the relationship between hospice and AL providers will work. Form provided by Hospice of Metro Denver.

Hospice Expectations of AL Residences

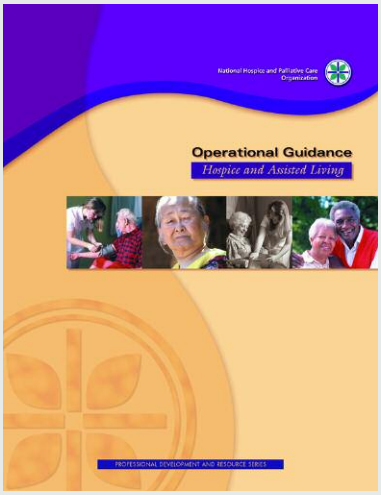
Likewise, the hospice has expectations about the care provided by the AL residence. Since hospice provides the services of the interdisciplinary health care team on an intermittent basis, someone will need to provide the primary care services in assisting with activities of daily living. This role can be assumed by the AL staff, family, friends, or sitters employed by the resident.

Hospice is most effective when the resident is referred to the hospice

earlier in their disease process as opposed to when he or she is in the actively dying phase. Earlier referral allows time to prepare the resident, family, and friends as to what can be anticipated and attains earlier control of symptoms. Everyone benefits.

Some information that is helpful in determining hospice expectations of an AL residence and developing a collaborative relationship includes an assessment of what services the AL facility can provide and what level of care the resident needs.

Figure 2.



Developed by the National Hospice and Palliative Care Organization (NHPCO), *Operational Guidance: Hospice and Assisted Living*, is a toolkit for hospice and AL providers to assist them in developing successful collaborative arrangements. The toolkit is available at: www.nhpco.org.

Again, an AL collaborative assessment/agreement form is useful in gaining this information (Figure 1). What services are offered to all residents? Has the hospice resident purchased any additional services from the AL facility? What services and when are they provided by the AL facility? What is the AL facility policy on the handling of narcotics? Does there need to be a physician-specific order for the administration of the medication or can it be ordered on an as-needed basis PRN? Does the AL staff have a current medication list? Who is responsible for the administration of medications? Is there any special packaging required for the medications? Is trained staff available to administer medications or treatments during the middle of the night? Which physician is going to be responsible for writing orders? Who is on staff during the night in the residence? Who should the hospice staff contact if there is a medical emergency?

Coordination and Communication

Extensive coordination and communication are required from providers, the resident, and his or her family to ensure that there are no gaps in care. Some states require AL providers to inform the regulatory agency when an individual requires hospice services. This requirement is being met through applications for waivers or filing an agreement for care that has been developed by the hospice and AL providers. The intent is to ensure that the needs of the resident have been assessed and that a plan designates responsible parties to ensure that appropriate care is provided. These arrangements are means by which the state agency holds providers accountable for the outcomes of care.

Working together, hospice and AL providers have the opportunity of affording quality end-of-life care to residents who would otherwise be required to seek alternative placement. This opportunity is accompanied by a great responsibility. At this time, AL providers have not been burdened with the regulatory oversight that skilled nursing facility providers have been subjected to. However, if there are significant service failures, more intense state regulations and potential federal regulations may be enacted. Regulations have the potential of eroding the philosophy of AL service delivery, which is designed to maximize individual choice, dignity, autonomy, independence, and quality of life. It will take mutual collaboration and work from all parties to make these goals possible. ALC

Cherry Meier is the Senior Director of Public Affairs of VITAS Innovative Hospice Care®, the nation's largest and leading provider of end-of-life care, and the Nationanl Hospice and Palliative Care Organization (NHPCO) Long-term Care Manager.

Hospice Care Facts and Figures

3,650
hospice programs nationwide in 2004

3,100
hospice programs nationwide in 2000

1,060,000
patients sought hospice care in 2004

700,000
patients sought hospice care in 2000

63%
of hospice programs in 2004 were non-profit, down from 67% in 2003

6%
of hospice programs in 2004 were government-run, up from 4% in 2003

33.3%
of hospice patients are 85 years of age or older

35.3%
of hospice patients are under the age of 75

Source: National Hospice and Palliative Care Organization's 2004 Facts and Figures.