



## **LCAO Advanced Care, Hospice, and End-of-Life Principles**

Older adults living with advanced illness or nearing the end-of-life need and deserve person and family-centered care that is well coordinated and honors their dignity, values, and health care choices at each stage of their illness. Older adults must have access to the full range of high-quality medical care and treatment, including curative care, palliative care, and hospice care.

### **Definitions**

*Advanced Illness* occurs when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact. This is a process that continues to the end-of-life.<sup>1</sup>

*Hospice care* is end-of-life care. The goal of the care is to help people who are dying have peace, comfort, and dignity.<sup>2</sup>

*Palliative care* is treatment of the discomfort, symptoms, and stress of serious illness.<sup>3</sup>

### **Person and Family-Centered Care**

- **Comprehensive, integrated care** – Promote coordinated, person- and family-centered, assessment-based care. Use an interdisciplinary approach to address older adults' and families' medical, psychosocial, and spiritual needs and goals.
- **Individualized planning and support for self-determination** – Provide counseling, education, and psychosocial support to promote discussion of values, preferences, care options, and choices. Facilitate participation in the advance care planning process, including discussions about pain relief, advance directives, programs based on the National POLST (Physician Orders for Life-Sustaining Treatment) Paradigm, and other tools to communicate a person's wishes and values. Develop written care plans in collaboration with each older adult and family (as appropriate), revising those care plans as the individual's (and family caregivers', as appropriate) goals and needs change.
- **Consumer collaboration and education** – Encourage communication among individuals, families, health care agents, and health care practitioners to ensure each older adult's goals and wishes are understood and followed, including for those persons with related dementias, including Alzheimer's disease. Ensure that health care teams fully inform older adults and families (as appropriate) regarding what to expect as illness progresses. Create and promote public resources to help older adults and families navigate the health care and social service systems.

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<sup>1</sup> <http://advancedcarecoalition.org/what-is-advanced-illness/>

<sup>2</sup> <http://www.nlm.nih.gov/medlineplus/hospicecare.html>

<sup>3</sup> <http://www.nlm.nih.gov/medlineplus/palliativecare.html>

- **Consumer rights** – Provide, in both oral and written formats, clear, culturally and linguistically appropriate information about consumer rights to older adults and families at the time of admission to or enrollment in a health care plan, program, or organization. Such information includes grievance procedures, the right to an expedited appeal of care plan decisions (such as whether the provider will furnish a service, medication, or medical equipment) and the right to appeal discharges. Ensure accessible, efficient appeals processes, in which older adults are protected from interruptions in care pending the outcome of appeals.
- **Support for family caregivers** – Support the central role families may play in planning for and providing care during advanced illness and at the end-of-life. Assess the needs of family caregivers and provide information, training, counseling, respite, and other supports to address those needs.
- **Community engagement** – Support older adults with advanced illness in continuing to participate in their communities and activities to the maximum extent they wish.

#### Access

- **Continuum of services** – Ensure access to a comprehensive range of needed services, including home and community-based long-term services and supports, to enable people with advanced illness to live in a setting of their choice through the end-of-life.
- **Interdisciplinary team** – Ensure access to care by an interdisciplinary team (including nurses, physicians, social workers, direct care workers, and spiritual care professionals) with the individual and family at the center of the care team.
- **Hospice and palliative care** – Increase access to hospice and palliative care across settings to relieve pain, suffering, and other medical symptoms, and to address older adults' and families' psychosocial and spiritual needs. Provide palliative care throughout the continuum of illness.
- **Pain management** – Provide pain assessment reflecting biological, psychological, and social factors for the individual and provide effective medications and other treatments to prevent and control pain.

#### Quality of care

- **Program integrity** – Ensure transparency and appropriate oversight of practitioners, programs, and organizations supporting older adults and families affected by advanced illness and at the end-of-life. Such oversight includes compliance with state and federal operating guidelines and statutes that promote trust and confidence in providers.
- **Service utilization** – Respect the care and treatment preferences and wishes of individuals to avoid the inappropriate overuse, underuse, and misuse of health care services.

- **Chemical restraints** – End the inappropriate use of antipsychotic medications for older adults with advanced illness, including those with related dementias, including Alzheimer’s disease, while recognizing that antipsychotic medications may be appropriate in treating physiological symptoms in certain end-of-life situations.
- **Quality assurance** – Address the special needs of individuals with related dementias, including Alzheimer’s disease, and their family caregivers to understand and improve their experiences with the health care system.
- **Continuity of care** – Minimize unnecessary transitions between practitioners and settings. When care transitions are necessary, promote continuous and coordinated care with access to current practitioners, services, treatments, and medications.
- **Cultural and linguistic competence** – Promote education, training, and policies to ensure health care practitioners and other staff provide culturally and linguistically appropriate services to older adults and families affected by advanced illness and at the end-of-life.
- **Systems Change** – Require Medicare advanced care programs and demonstrations to meet rigorous standards for consumer rights as discussed above.

### **Financing and Hospice**

- **Innovative payment mechanisms** – Modify existing payment models and incentives to expand options for advance care planning, care coordination, care transitions, and care management services. Align reimbursement with each individual’s needs.
- **Medicare hospice administration, funding, and benefit integrity** – Ensure fair, efficient program operations, with adequate funding for program administration, beneficiary education, and outreach. Protect the Medicare Hospice Benefit from reductions, revisions, and cost-sharing that would hinder appropriate beneficiary access to hospice services.
- **Alternate models of care** – Support the concurrent care model for hospice programs and other models that encourage broader use of palliative care and end-of-life care.
- **Research** – Fund further research and data on the quality and effectiveness of hospice and other advanced illness care models.

### Workforce

- **Practitioner education and training** – Support the use and development of protocols, training programs, and retraining support systems to promote a health care workforce with the knowledge, skills, and competencies to care for people with advanced illness and to support family caregivers. This includes training professionals and paraprofessionals to work as interdisciplinary teams, integrating the physical, psychosocial, and spiritual aspects of care; training in the biological, psychological and social aspects of pain management; training specific to the care of people affected by related dementias, including Alzheimer’s disease; training addressing the appropriate and inappropriate use of antipsychotics in end-of-life care; and expanding practitioners’ capacity to meet the needs of family caregivers.
- **Practitioner recruitment, retention, and efficacy** – Support strategies to bolster the professional and paraprofessional workforce providing hospice, palliative care, and advanced care services. Such strategies may include recruitment, loan forgiveness, grants, competitive compensation, data collection, and credentialing.

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