In its recently revised Ethical Policy Statement “Decisions Near the End of Life,” the American College of Healthcare Executives (ACHE) urges healthcare leaders to address the ethical dilemmas and care issues surrounding death and dying and to promote public dialogue that will lead to awareness and understanding of end-of-life issues.

The National Priorities Partnership, convened by the National Quality Forum, estimates that more than 1 million people in the United States die each year without important palliative care services, and many patients and families endure prolonged and needless suffering and costly or ineffective treatments. The alternative, according to the Partnership, is “healthcare capable of promising dignity, comfort, companionship, and spiritual support to patients and families facing advanced illness or dying, fully in synchrony with all of the resources that community, friends, and family can bring to bear at the end of life.”

Healthcare executives play a crucial role in making this vision increasingly a reality for more patients.

We offer six specific recommendations to help executives more effectively honor the preferences of patients with advanced illness and their families. These recommendations are built on ACHE’s Ethical Policy Statement and equally draw from the work of the Institute for Healthcare Improvement and the findings of the Expert Panel on End-of-Life Care in the Commonwealth of Massachusetts.

Understanding the realities of current practice in your organization concerning advanced illness is essential to charting a course forward.

Action 1: Know Your Organization’s Current Performance
Understanding the realities of current practice in your organization concerning advanced illness is essential to charting a course forward. In our experience, staff, patients and family members all welcome respectful inquiry. Some questions leaders might ask include: In what ways and how often do staff members inform patients with advanced illness and their family members of the full range of options for care, including the availability of palliative care? Do staff reliably elicit and respect patient preferences?

These questions can be incorporated in Patient Safety Leadership WalkRounds, surveys of patients’ families after hospitalization, meetings with palliative care and chaplaincy staff, interviews with administrators of nursing homes that transfer a high number of patients to the hospital, and interviews with clergy and funeral directors in the community. Interviews should focus on what happens 24 hours a day, seven days a week—not just during certain time periods.

Also, make sense of data you are already collecting and generate some facts about in-hospital deaths and the percentage of patients in your organization who are receiving palliative care referrals. What percentage of your patients die at home? How has the number of such patients changed over time? What percentage of patients have an advance directive? What does your data show about pain management?

In addition, know how your organization, your community and your state rank in the management of patients who are chronically ill. These data are supplied by the Dartmouth Atlas of Health Care, the Center to Advance Palliative Care’s (CAPC’s) State-by-State Report Card.
Leaders need to position their staffs (including all physicians) to be knowledgeable, competent and compassionate about the preferences of patients with advanced illness.

Action 2: Set Bold and Measurable Aims
Governance and executive leadership should set a bold aim to always honor a patient’s preferences at the end of life, providing no more care than desired and no less. Communicate this aim clearly to all staff members and explain why it is important, not only for patients and families but also for the organization. Each year AHA’s Circle of Life Award honors exemplary organizations and communities in this area.

Aims for the community matter, too. Across the nation, states and communities are implementing advance-care-planning campaigns and programs for patients with advanced illness, such as the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm program at Oregon Health and Science University. These efforts are engaging everyone—from the patient and family caregiver to the ambulance driver, primary care physician, nurse practitioner and ICU staff—in a systematic approach to ensure the patient’s preferences at the
end of life are honored. The National Business Group on Health is working with hospitals and communities using the Employer’s Toolkit on Palliative and End-of-Life Care. Which initiative is your organization a part of?

**Action 3: Prepare People for Success**
With the expectation set, leaders need to position their staffs (including all physicians) to be knowledgeable, competent and compassionate about the preferences of patients with advanced illness. Palliative care education should be tailored to match the different needs of various types of practitioners (e.g., primary care staff, oncology staff, ICU staff, etc.). The international EPEC (Education in Palliative and End-of-Life Care) Project serves as one example of many, offering guidelines for this type of training.

Patients, family members and the public also need education and information regarding ways to become engaged with the issues surrounding end-of-life care. National Healthcare Decisions Day, the Five Wishes program by the nonprofit organization Aging with Dignity, the National Hospice and Palliative Care Organization’s Caring Connections program and many other programs offer ways to engage with the local community to bolster your organization’s efforts.

**Action 4: Establish Systems to Support Effective Care Delivery**
Training, while important, is insufficient to support respectful practices 100 percent of the time. Patients, families and staff need a system they can rely on to reinforce what has been learned.

Across the United States, only 53 percent of hospitals with 50 or more beds reported they have a hospital palliative care program, according to the latest public data available from CAPC. This has to improve. Strikingly successful programs that have proven to reduce unwanted hospital care and increase satisfaction at the end of life include Aetna’s Compassionate Care Program and the U.S. Department of Veterans Affairs’ VA Care program. These programs have a care management system that uses clinical indicators to trigger the discussion about initiating palliative care with patients, family members and staff across the care continuum. Strong clinical ethics consult services and teams can also make significant contributions to supporting end-of-life decision making.

**Action 5: Create Measures and Accountability**
Establish specific measures for palliative care programs, and have your organization’s leadership team and the board review the data for these measures periodically. While structure and process measures, such as “access to a palliative care program,” “percentage of patients dying at home or in hospice” or “number of palliative care consults,” are all important, leaders should also track and report patient and family experience outcome measures, including the number of times a patient’s stated preferences for end-of-life care are known and carried out correctly.

**Action 6: Remove External Barriers**
Barriers to effective, respectful care for patients with advanced illness include reimbursement systems that don’t cover hospice or palliative care and the absence of systems that enable clinicians to seamlessly address the palliative care needs of patients also receiving curative therapy. As healthcare executives experiment with accountable care organizations, medical homes, episode- or global-based payments, and other care and payment reforms, they should seek to identify mechanisms that support advanced illness planning and care delivery. Efforts to improve care transitions and continuity of care across settings can have a huge impact as long as the associated financial requirements are met and incentives are aligned.

Care at the end of life has become a topic of national and international discussion and debate, driven by strong advocacy, concerns about significant costs (including unwanted and unneeded care) and fears that what patients truly want and need won’t be heard or respected. Unlike many other challenges in healthcare, we know how to improve care for patients with advanced illness and palliative care. We have endless examples of how to do it well, and leaders can play a big part in harnessing and implementing this knowledge to make it part of everyday practice in their organizations.

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**Editor’s note:** Read the ACHE Ethical Policy Statement “Decisions Near the End of Life” in the Policy Statements area of ache.org.