Physicians Urged to Recognize and Support Major Role of Family Caregivers

American College of Physicians position paper endorsed by ten other professional medical societies

Physicians are encouraged to gently guide patients/caregivers when cure is no longer a realistic goal. “Open discussion of the reality of the progressive condition is crucial to earlier access to hospice enrollment, either at home, in the hospital, or in a freestanding facility.”

— ACP Ethics, Professionalism, and Human Rights Committee, Journal of General Internal Medicine

Family caregivers play an integral part in the U.S. health care system, maximizing the health and quality of life for about 90% of dependent, community-dwelling individuals. In 2006, nearly 38 million adult family caregivers helped patients with acute and chronic illness manage their health care needs.

That is according to a recently released position paper from the American College of Physicians (ACP), aimed at providing ethical guidance for physicians on how to maintain patient autonomy and privacy, while expanding the unit of care to support the needs of their collaborators in patient care: the family caregivers.

“The ethical guidance outlined in this paper is intended to heighten physician awareness of the importance and complexity of the patient-physician-caregiver relationship,” states ACP president Joseph Stubbs, MD. “It is essential for physicians to consider quality of life for both patients and caregivers.”

The paper outlines primary ethical principles for physicians on such topics as:

• Respect for the patient
• Physician communication and accessibility
• Drawing boundaries with caregivers who are health care professionals
• Recognition of the value of family caregivers
• Support during the transition to the end stage of illness and continuing after patient death

By far the lengthiest section of the paper is devoted to guidance on supporting caregivers in their crucial role of collaborating in patient care, and on addressing quality-of-life issues for both patients and their caregivers.

**PHYSICIANS ARE URGED TO:**

• Communicate information clearly and consistently.
• Ensure caregiver education regarding medications, symptoms, and signs of advancing disease.
• Assess caregiver well being and concerns.
• Provide timely referrals to appropriate care services, such as hospice and palliative care.

“Early access to the services of a comprehensive palliative care team can significantly reduce the burden of illness and optimize functioning and coping for both patients and caregivers,” the authors point out.

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Higher Feeding Tube Use in Patients with Advanced Dementia Linked to Facility Characteristics

Tube feeding has been shown to have no demonstrable benefit in nursing home patients with advanced cognitive impairment, yet its use among this population is both persistent and uneven, manifesting a striking and unexplained variation in prevalence across and within U.S. states and regions.

Now, two recent studies have found that institutional factors are associated with a higher rate of feeding tube use in this population. The first study analyzed hospital characteristics linked to feeding tube placement among more than one-quarter of a million admissions of nursing home residents with advanced dementia across the country. The second examined organizational characteristics of two similarly-sized nursing homes with two very different rates of feeding tube use, located in the same state.

**LARGER AND FOR-PROFIT HOSPITALS SHOW HIGHER RATES OF FEEDING TUBE INSERTION**

More than one-third of nursing home residents with advanced dementia are tube fed, with nearly 70% of feeding tube insertions among this population occurring during an acute care hospitalization, according to a report published in the *Journal of the American Medical Association*.

Researchers analyzed the rate of feeding tube placement between 2000 and 2007 in 2797 acute care hospitals with 280,869 admissions among 163,022 nursing home residents with advanced cognitive impairment (age, 66 years or older).

The rate of feeding tube insertion varied from 0 to 38.9 per 100 hospitalizations (mean, 6.5) during the 8-year study period. The 12% of hospitals that inserted no feeding tubes tended to be smaller, rural, and less likely to be affiliated with a medical school.

Higher insertion rates were associated with the following hospital factors:
- **For-profit ownership** vs government owned
- **Larger size** vs smaller size (>310 beds vs <101 beds)
- **A more aggressive approach to end-of-life care** (greater use of the intensive care unit in the last 6 months of life)

“Our results suggest that decisions to insert a feeding tube in persons with advanced dementia are more about which hospital you are admitted to than a decision-making process that elicits and supports patient choice,” notes lead author Joan M. Teno, MD, professor of community health and medicine, Warren Alpert School of Medicine, Brown University, Providence, Rhode Island.

The authors call for strategies to improve advance care planning and decision making based on patient preferences rather than place of treatment. “Our research findings call for multifaceted interventions to ensure that the insertion of feeding tubes during acute care hospitalizations is consistent with patient preferences after thorough discussion of the risks and benefits.”

To assist in the development of improvement strategies, the research team has posted a table with feeding tube insertion rates for 2000-2007 and 2006-2007, and national ranking in quintiles for all U.S. hospitals having at least 25 admissions of nursing home residents with advanced dementia at: [http://LTCfocus.org/upload/intubation.pdf](http://LTCfocus.org/upload/intubation.pdf).

“We hope that hospitals will examine these results with attention to how decisions are made for persons with advanced dementia to ensure their informed wishes are respected.”

**‘HOMELIKE’ NURSING HOMES SUPPORT LOW FEEDING TUBE USE**

A focused ethnographic study of two South Carolina nursing homes of comparable size (130-150 beds) located in the same health referral region, but having widely differing feeding-tube rates among patients with advanced dementia (10.7% vs 41.8%) has identified striking contrasts in facility characteristics.

“This study reveals a startling variation in the organizational culture of two nursing homes and its influence on approaches to feeding problems in patients with advanced dementia,” write the authors of a report published in a recent issue of the *Archives of Internal Medicine*.

Using direct observation, semistructured interviews, and publicly available printed and posted material, researchers identified different nursing home factors associated with either low or high use of feeding tubes.

Key features of nursing homes with low use include:
- A homelike environment in which food, mealtimes, and family are central
- Administrative support in solving feeding problems
- Emphasis on the value of and sufficient staff for hand feeding
- Family inclusion in decision making

In contrast, the high-use nursing home had an impersonal, institutional atmosphere with strictly scheduled and poorly staffed mealtimes. Staff attitudes favored tube

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The statement defines family caregivers as “relatives, partners, friends, and neighbors who assist with activities of daily living (ADLs) and complex health care needs that were once the domain of trained hospital personnel.”

In addition to assisting with ADLs, major caregiver contributions include:

- Expediting clinical evaluation
- Helping to prevent medical errors and inefficiencies
- Communicating with multiple health care professionals
- Navigating the health insurance system

While hospice and palliative care have used a family-centered model of approach from their inception, note the authors, views in contemporary bioethics have only recently recognized the need to expand the physician-patient relationship to include the impact of illness on both patients and their families.

Entitled “Family Caregivers, Patients, and Physicians: Ethical Guidance to Optimize Relationships,” the statement has been endorsed by ten other professional medical societies, including the Society of General Internal Medicine, the American Geriatrics Society, the American College of Chest Physicians, the American Medical Directors Association, the Society of Critical Care Medicine, and the American Academy of Hospice and Palliative Medicine.

The full position paper, along with an online list of physician resources for supporting family caregivers, is available on the ACP website at www.acponline.org/clinical_information/guidelines/.


Mitnick S, Leffler C, Hood VL, for the American College of Physicians Ethics, Professionalism, and Human Rights Committee; Philadelphia, Pennsylvania.

Ethical Guidance for Physician Collaboration with Patients and Caregivers

1. Respect for the patient’s dignity, rights, and values should guide all patient-physician-caregiver interactions.
2. Physician accessibility and excellent communication are fundamental to supporting the patient and family caregiver.
3. The physician should recognize the value of family caregivers as a source of continuity regarding the patient’s medical and psychosocial history and facilitate the intellectual and emotional transition to the end stage of serious chronic illness.
4. When the caregiver is a health care professional, the physician should draw appropriate boundaries to ensure that the caregiver is not expected to function in a professional capacity in relation to the patient and that the caregiver receive appropriate support, referrals, and services.

— ACP Ethics, Professionalism, and Human Rights Committee, Journal of General Internal Medicine

Higher Feeding Tube Use in Patients with Advanced Dementia Linked to Facility Characteristics

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feeding, and although the decision-making process was not clear, it emphatically did not include the family.

“The contrasting ‘culture’ in our two participant nursing homes was manifested in differences in physical environment, care processes for feeding, decision-making processes, and values,” note the authors. “Our results corroborate previous observations describing a link between physical environment and quality of nursing home end-of-life care.”

Source: “Hospital Characteristics Associated with Feeding Tube Placement in Nursing Home Residents with Advanced Cognitive Impairment,” Journal of the American Medical Association; February 10, 2010; 303(6):544-550. Teno JM, Mitchell SL, Gozalo PL, Dosa D, Hsu A, et al; Center for Gerontology and Health Care Research, Warren Alpert School of Medicine, Brown University, Providence, Rhode Island; Institute for Aging Research, Hebrew SeniorLife, Harvard Medical School, Boston; Providence Veterans Affairs Medical Center, Providence. “The Influence of Nursing Home Culture on the Use of Feeding Tubes,” Archives of Internal Medicine; January 11, 2010; 170(1):83-88. Lopez RP, Amella EJ, Strumpf NE, Teno JM, Mitchell SL; Institute of Health Professions School of Nursing, Boston; College of Nursing, Medical University of South Carolina, Charleston; University of Pennsylvania School of Nursing, Philadelphia; Warren Alpert School of Medicine, Brown University, Providence, Rhode Island; Division of Gerontology, Beth Israel Deaconess Medical Center, and Institute for Aging Research, Hebrew SeniorLife, Harvard Medical School, Boston.
Racial and ethnic differences in hospice use among patients with cancer have been well documented. A recent study of more than 98,000 Medicare patients with heart failure has found similar results: black and Hispanic patients are up to 50% less likely than their white counterparts to be enrolled in hospice.

“In our sample, blacks had 41% lower odds of hospice use and Hispanics, 51% lower odds of receiving hospice care than whites,” write investigators, whose findings based on their national study were published in the Archives of Internal Medicine.

Heart failure currently affects nearly five million Americans and is the leading cause of hospitalization among Medicare beneficiaries, the authors point out. “Despite progress in treatment, patients with advanced heart failure have a one-year mortality of 50% to 70%, and hospice care is increasingly recommended in guidelines for such patients.”

The researchers analyzed hospice use among a national sample of 98,258 Medicare beneficiaries with diagnosis of heart failure in 2001, representing about 2.7 million beneficiaries. Subjects were aged 66 years and older, with at least one physician or hospital encounter and no hospice use in the previous year.

Overall, 18.2% of beneficiaries enrolling in hospice did so with a diagnosis of heart failure, with 18.5% of whites entering hospice care with heart failure. Researchers made adjustments for factors previously associated with hospice entry, such as: income, urbanicity, illness severity, comorbidity, and local density of hospice use.

The following groups were less likely to use hospice than were whites:

• Blacks (14.1%; adjusted odds ratio [aOR] = 0.59; 95% confidence interval [CI], 0.47-0.73)
• Hispanics (13.2%; aOR = 0.49; 95% CI, 0.37-0.66)
• Other (15.8%; aOR = 0.64; 95% CI, 0.52-0.80)

“Our findings document significant racial differences in hospice use and show that overall increases in the availability of hospice services in the 1990s have not erased racial differences in hospice utilization,” says lead author Jane L. Givens, MD, of the Hebrew SeniorLife Institute for Aging Research, an affiliate of Harvard Medical School, Boston.

“To our knowledge, our study is the largest longitudinal cohort study examining factors associated with hospice entry for a noncancer diagnosis,” note the authors. They recommend further studies on noncancer patients to examine such possible underlying causes for differences in hospice use as patient preference and physician referral behavior.

Source: “Racial and Ethnic Differences in Hospice Use among Patients with Heart Failure,” Archives of Internal Medicine; March 8, 2010; 170(5):427-432. Givens JL, Tjia J, Zhou C, Emanuel E, Ash AS; Hebrew SeniorLife Institute for Aging Research; Department of Medicine, Division of Gerontology, Beth Israel Deaconess Medical Center; and Health Care Research Unit, Boston University School of Medicine; Division of Geriatric Medicine, University of Massachusetts Medical School, Worcester; Department of Bioethics, Clinical Center, National Institutes of Health, Bethesda, Maryland.


Despite the prevailing ethical principle of autonomy, which implies that patients should always be fully informed, clinicians routinely make judgments on whether to delay or withhold information. These decisions must be made so as to maximize benefit and minimize burden, says a team of experts in an article published in The New England Journal of Medicine.

“[M]ore information is not always better. Dumping all available information on patients can be overwhelming and may paradoxically undermine their ability to choose wisely.”

Clinical information benefits patients when it: helps in decision making; provides meaningful options; helps the patient to make sense of and cope with illness; and builds trust. However, write the authors, imparting too much information can reduce patient autonomy when it: impairs understanding and decision making; sidetracks exploration of a serious illness’ complexities and relevant treatment options; results in unnecessary distress; or distracts from practical discussions.

“In our view, clinicians should withhold information that is likely to over-
Management of Dyspnea in Patients with Advanced Heart or Lung Disease: An Ethical Obligation

As with pain, assessment of dyspnea begins with asking the patient

The need for improved treatment of a highly prevalent symptom among patients with advanced lung or heart disease has prompted the American College of Chest Physicians (ACCP) to issue a consensus statement on the management of dyspnea.

“Although assessment of a patient’s intensity of pain is a requirement, it is not standard practice for health care providers to ask patients to provide a rating of dyspnea,” writes an expert panel of pulmonologists, cardiologists, nurses, and palliative care specialists reporting in *Chest*, the official journal of the ACCP.

Over 90% of patients with advanced chronic obstructive pulmonary disease and more than 60% of those with advanced heart disease report problems with breathlessness, the panel found in its systematic review of the topic in the literature from 1966 to 2008. Further, about 94% of patients with chronic lung disease experience dyspnea in the last year of life.

The topic condition was defined as “dyspnea that persists at rest or with minimal activity and is distressful despite optimal therapy of advanced lung or heart disease.” The stated aim of the paper is to influence clinical practice in the “care of the patient in whom medical therapy has been optimized, and the focus of treatment is on symptom management, relief of suffering, and maintenance of quality of life.”

“Many patients with advanced lung or heart disease have a tremendous concern about the experience of dying, and a large component of this anxiety is focused on their breathing difficulty and ‘suffocating,’” the panel writes. They strongly emphasize the importance of physician communication in reassuring patients that their needs will be met.

However, they point out, “patients with advanced lung or heart disease receive poor quality palliative and end-of-life care” compared with cancer patients. One reason the panel found is that “patient-physician communication about end-of-life care is unlikely to occur.”

Consensus Statement Key Points Include:

- Health care professionals are ethically obligated to treat dyspnea, and patients and their families should be reassured that they will be provided the means to effectively treat this symptom.
- Patients should be asked to routinely and regularly rate the intensity of their breathlessness as part of a comprehensive care plan, and such ratings should be routinely documented.
- Concerns about contributing to addiction and/or physical dependence should never limit effective treatment or palliation of dyspnea.
- It is important for clinicians to communicate about palliative and end-of-life care with their patients.

“More Information Is Not Always Better”

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whelm and distress patients if their having the information would provide no obvious benefit and they don’t ask for it,” write the authors.

“Information overload — especially if the information is not clinically relevant — may render more important discussions impossible.”

Ethicists and clinicians generally agree, note the authors, that withholding information is appropriate when: a patient lacks the cognitive capacity to understand (in which case, a surrogate should be told); if urgent intervention is needed; or if the patient explicitly or implicitly chooses not to receive it (then a proxy should be kept informed).

“[S]ince information can sometimes increase patients’ cognitive and emotional burden and lead to greater confusion rather than clarity, the right to autonomy must be balanced with the ethical obligations to do good for patients (beneficence) and not to harm them (nonmaleficence).”

Source: “Withholding Information from Patients — When Less Is More,” The New England Journal of Medicine; February 4, 2010; 362(5):380-381. Epstein RM, Korones DN, Quill TE; Departments of Family Medicine, Pediatrics, Internal Medicine, Psychiatry, and Oncology, the Rochester Center to Improve Communication in Health Care, and the Center for Ethics, Humanities, and Palliative Care, University of Rochester Medical Center, Rochester, New York.
Helping Patients Determine Whether and When Hospice Fits Their Needs

The importance of eliciting patients’ individual goals regarding how they hope to live the end of their lives is emphasized in a review of hospice care published in the *Journal of the American Medical Association*. The discussion is based on the case report of an 86-year-old woman with progressive congestive heart failure and multiple chronic conditions.

While still enjoying certain aspects of her life, the patient dreads becoming more incapacitated and fears losing control over the circumstances of the end of her life. Although her life expectancy is uncertain, she wonders if hospice can help her.

“[This patient] is not thinking just about hospice. She is also considering how she envisions the end of her life,” writes Jean S. Kutner, MD, MSPH, professor of medicine and head of the Division of General Internal Medicine, University of Colorado Denver School of Medicine, Aurora.

In the context of this case discussion, notes Kutner, “I consider the ‘end of life’ to begin with the onset of advanced illness that is beyond cure, rather than limiting it to the time of imminent death.”

There is significant agreement among the many studies that have explored the meaning of a “good death,” in that it includes such components beyond pain and symptom management as: spending time with family and friends; not being a burden; maintaining dignity and self-respect; avoiding prolongation of dying; and achieving a sense of control.

“However,” states Kutner, “the process of dying and death remains highly individualized, making it essential that clinicians both ask questions and listen to their patients to ascertain their priorities and facilitate achievement of their stated goals.”

### An Approach to Presenting the Hospice Option to a Patient with Uncertain Prognosis

- Understand what is known about the patient’s current status, treatment options, and prognosis.
- Ascertained the patient’s understanding of her prognosis.
- Learn about her goals, asking “What do you hope for most in the next few months?” and “What are you afraid of?”
- Identify her symptoms and psychosocial support needs, and the needs of her family.
- Introduce hospice as a service that might help meet her needs, explaining both what it can and cannot offer her at the present time.
- Understand her desired place of death and how she envisions it.
- Remind her and her family that a decision to enter hospice is not permanent.
- Provide additional resources to help her understand her options.

— Adapted from Kutner, *Journal of the American Medical Association*

### HOSPICE WORKS TO ACHIEVE PATIENT GOALS

“Hospice would work with [the patient] to help her determine the story of the end of her life — how she lives her last months, weeks, days, and hours,” states Kutner. In fact, she adds, hospice “excels” at working with patients to achieve their goals.

The Medicare Hospice Benefit defines hospice not simply as a service for patients who have decided to stop curative treatment, but also as “a health care delivery system focused on caring for the patient and family after treatment efforts aimed at changing the course of the terminal illness substantially are no longer effective.”

Although the Medicare hospice requirement for 6-month life expectancy may be difficult to meet in a heart failure patient, notes Kutner, patients remain eligible for as long as this criterion is met. Further, patients can choose to disenroll from hospice at any time, retaining the option of enrolling again as their goals or health conditions change.

For patients with heart failure and most other noncancer diseases characterized by a prolonged state of poor health with spikes of intermittent exacerbations, no definitive threshold marks the time when decisions about changing treatment modes should be made. A health crisis can occur with no contingency plan outlined. “Thus,” Kutner asserts, “the patient’s individual end-of-life goals are critical.”


Source: “An 86-Year-Old Woman with Cardiac Cachexia Contemplating the End of Her Life: Review of Hospice Care,” *Journal of the American Medical Association*; January 27, 2010; 303(4):349-356. Kutner JS; Division of General Internal Medicine, Department of Medicine, University of Colorado Denver School of Medicine, Aurora, Colorado.
The National Institute of Nursing Research (NINR) of the federal National Institutes of Health has produced a 14-page brochure highlighting the benefits of palliative care, and directing patients and caregivers on how and when to request it.

“Our goal is to increase the number of provider-patient conversations about palliative care resources, so that fewer patients suffer needlessly from pain and distressing symptoms,” says NINR director Patricia A. Grady, PhD, RN.

The brochure explains how to decide if palliative care is needed, how it differs from hospice care, how it is paid for, which specialists participate on a care team, and how to ask a physician for a referral.

The team approach to patient-centered care is presented as providing:

- Coordination of care with the primary care physician and all other health care providers
- Open discussion about treatment choices
- Expert treatment of pain and other symptoms
- Emotional support

Palliative care “not only relieves pain and suffering, but also provides critical emotional support to family members who are faced with difficult end-of-life decisions while grappling with the impending loss of a loved one,” Grady points out. But palliative care should not be seen as restricted to those in the last months of life, she notes. “[P]alliative care provides relief to patients dealing with chronic illnesses as well, including AIDS, cystic fibrosis, and diseases of the heart, lungs, and kidneys.”

One section of the brochure encourages patients to start palliative care as soon as needed: “There is no reason to wait. Serious illnesses and their treatments can cause exhaustion, anxiety, and depression. Palliative care teams understand that pain and other symptoms affect your quality of life and can leave you lacking the energy or motivation to pursue the things you enjoy. They also know that the stress of what you’re going through can have a big impact on your family. And they can assist you and your loved ones as you cope with the difficult experience.”

Entitled “Palliative Care: The Relief You Need When You’re Experiencing the Symptoms of Serious Illness,” the brochure is available for free downloading and reproduction from the NINH website, or small quantities can be ordered free of charge in print form. A state-by-state list of palliative care programs from the online Palliative Care Provider Directory of Hospitals is available at www.getpalliativecare.org.

To access the brochure, visit www.ninr.nih.gov/newsandinformation/ninpublications.
When faced with an illness such as my husband Paul’s, some seek to travel to far away places to fulfill personal dreams. Paul had traveled and experienced many wonderful adventures in his 44 years. In the end with the love, compassion, and guidance from our Hospice of the Valley “family,” we as a family met our goal and were exactly where we needed and wanted to be... at home.

— Mary S.

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When your patients are coping with serious illness, they require expert care, compassion and personal attention. Whether it is spending time with loved ones, fulfilling dreams, or simply remaining comfortable and independent for as long as possible, Hospice of the Valley guides patients and their families to meet their goals.

• The hallmark of hospice care is that it serves patients wherever they live—be it in their home, nursing home, hospital or assisted-living facility

• Our interdisciplinary team members consist of physicians, nurses, social workers, chaplains, hospice aides, volunteers, and grief counselors who are experts in palliative and hospice care and who are here to assist you in the management of your patient’s end-of-life care needs

• For those dealing with grief and loss, our Community Grief and Counseling Center provides families and individuals with one-on-one counseling and loss-specific support groups to adults, teens and children

• Since 1979, Hospice of the Valley’s legacy of compassionate care, community education, advocacy and outreach has set the standard for quality hospice care state wide and nationally, and we are a locally-based, operated, and supported non-profit organization

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