

NATIONAL PRIORITY: PALLIATIVE AND END-OF-LIFE CARE

Guarantee appropriate and compassionate care for patients with life-limiting illnesses

OUR VISION: We envision 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.

Why is Palliative and End-of-Life Care a National Priority?

Patients who are diagnosed with life-limiting illnesses and those facing the end of their lives deserve high-quality and compassionate care that addresses all of their needs. During this time, patients need support and assistance to prevent and treat pain, ensure continuity of care, make informed decisions, and meet their own spiritual needs.¹¹⁷ Instead, many patients and families struggle to manage pain and other symptoms, coordinate care among many different healthcare organizations in many different settings, and ensure that treatments reflect the patient's personal preferences. Far too often, patients at the end of their lives spend their final days in hospitals full of unfamiliar faces instead of in their homes surrounded by loved ones. Caregivers and family members face many hardships and need specialized support to overcome emotional and financial challenges.¹¹⁸

Currently, more than 1 million Americans die each year of chronic and debilitating illnesses without receiving hospice services.

Palliative and hospice care programs give patients and family members the opportunity to help develop and guide care programs in a manner that is most comfortable for them and that meets their physical, social, and spiritual needs. Hospital-based palliative care teams can have a major impact on how end-of-life care is managed in hospital systems by clearly identifying transitions

from aggressive and curative plans of care to palliative plans, by clarifying resuscitation status, by discussing benefits and harms of treatment options, and by ensuring that their patients' informed choices are well articulated.¹¹⁹ Multidisciplinary palliative teams in the inpatient setting also frequently recognize problems that otherwise can go unmet by other inpatient staff. Such team consultations have been associated with lower utilization of expensive intensive care units, lower likelihood of dying in an intensive care unit, and overall lower costs of care. Evidence suggests

that patients enrolled in palliative care programs are more satisfied with their care and have fewer emergency room visits, fewer hospital and nursing facility days, and fewer physician visits than those in a comparison group.

Enrolled patients in one study averaged a 45 percent decrease in costs as compared to usual care patients.¹²⁰

Making Palliative and End-of-Life Care a National Priority Will:

REDUCE HARM. Pain is one of the most debilitating and feared symptoms that patients with life-limiting illness face, and many cancer patients have reported under-treatment and inequitable access to pain treatment. Suffering at the end of life can be prevented or alleviated for many patients through palliative care and an emphasis on effective pain management.¹²¹ Other symptoms, such as shortness of breath and

depression, can also be managed through effective clinical support to prevent unnecessary distress. Regular assessment of symptoms combined with skilled clinical care and supportive resources can reduce these types of suffering.

Although the use of hospice and palliative care services has increased in recent years, these services are still underutilized, and many patients who could benefit from these services are never referred at all, or are referred too late for the services to truly help. Currently, more than 1 million Americans die each year of chronic and debilitating illnesses without receiving hospice services.¹²²

REDUCE DISPARITIES. In a 2008 study, less than 50 percent of U.S. hospitals had palliative consultation teams, limiting access to care for many who could greatly benefit.¹²³ In 2000, the vast majority of patients receiving hospice services were white (82 percent), 8 percent were identified as African American, and 8 percent were Hispanic, indicating a clear disparity in the provision of end-of-life care. Cultural, language, and religious differences may present barriers to appropriate referrals to palliative or hospice care, and difficult subjects regarding death and dying may not be adequately discussed.¹²⁴

REDUCE DISEASE BURDEN. On top of the losses experienced by their loved ones facing life-limiting illnesses or death, families and caregivers

are confronted with emotional, physical, and economic challenges and need support to cope with added responsibilities. Caregivers can experience significant physical and psychological stress, contributing to a decline in their own health and in some cases even death. Palliative care, with its holistic focus, has the potential to reduce this burden on family members and caregivers.¹²⁵

REDUCE WASTE. Approximately 25 percent of Medicare's expenses are paid for patients in their last year of life, and these expenses will continue to rise as we face an aging population.¹²⁶ Some of these expenses are for procedures that will ultimately have only marginal if any benefit to the patient in terms of increased quality of life or productivity. These costs have fueled studies to determine how to improve the efficiency and effectiveness of end of life care.

Approximately 25 percent of Medicare's expenses are paid for patients in their last year of life, and these expenses will continue to rise as we face an aging population.

Palliative care consultation teams have been associated with significant hospital savings. Patients receiving palliative care in the hospital who were discharged alive saw a net savings of nearly \$1,700 in direct costs per admission and nearly \$300 in direct costs per day. They also

recognized significant reductions in laboratory and intensive care costs compared with patients receiving usual care. When palliative care patients die in the hospital, the savings are nearly \$5,000 in direct costs per admission, and nearly \$400 in direct costs per day including significant reductions in pharmacy, laboratory, and intensive care unit costs.¹²⁷

Palliative and End-of-Life Care: Examples of Actions

The American Board of Internal Medicine recently launched a certification program in Hospice and Palliative Medicine through collaboration with 10 specialty areas and is incorporating palliative care into core competencies for Maintenance of Certification for specialists. Core competencies include issues such as clinical care, interpersonal and communication skills, and practice-based learning.¹²⁸ The American College of Physicians has developed guidelines specifically aimed at improving care at the end of life, which include regular assessment of and the use of proven therapies to manage pain, shortness of breath, and depression. These actions will supply an increased number of healthcare professionals trained and qualified to provide hospice and palliative care services to patients.¹²⁹

After realizing that 50 percent of Kaiser Permanente TriCentral patients with heart failure, chronic obstructive pulmonary disease, and cancer were dying in hospital care units, Kaiser created a palliative care program to address the needs of those patients and to facilitate the patient's choice to die at home instead of in an inpatient setting. The program emphasizes evidence-based medicine and has developed protocols and guidelines to ensure consistent care for all of their patients, including home visits by all team members, ongoing care management, telephone support, and advance care planning that empowers patients and their families to make informed decisions. Their model has been shared with more than 200 healthcare teams and agencies throughout the United States.¹³⁰

The National Hospice and Palliative Care Organization has created a consumer-focused website—*Caring Connections*—that offers extensive resources for patients and caregivers coping with end-of-life issues. Resources include free information on healthcare decisionmaking, living with an illness, caring for the caregiver, finding local services, and more.¹³¹

Delaware Hospice's nationally recognized *New Hope* program provides counselors to assist children and adolescents in coping with the emotions associated with the loss of a loved one. Counselors listen, empathize, acknowledge feelings, and provide comforting support through one-on-one counseling, group support, workshops, therapeutic activities, ongoing communications, and a four-day summer camp where the children get to know peers who are facing similar hardships. *Camp New Hope* was created to provide an environment for children and adolescents to come together with others who have experienced a similar loss so that they know they are not alone.¹³²

The American Association of Colleges of Nursing, the national voice for America's baccalaureate- and higher-degree nursing education programs, administers an end-of-life care educational project in concert with the City of Hope, Los Angeles, California. The End-of-Life Nursing Education Consortium project provides undergraduate and graduate nursing faculty, continuing education providers, staff development educators, specialty nurses in pediatrics, oncology, critical care, and geriatrics, and other nurses with training in end-of-life care so they can teach this essential information to nursing students and practicing nurses.¹³³

PALLIATIVE AND END-OF-LIFE CARE

HOW WILL WE GET THERE?

The Partners will work together to ensure that:

Goal: All patients with life-limiting illnesses will have access to effective treatment for relief of suffering from symptoms such as pain, shortness of breath, weight loss, weakness, nausea, serious bowel problems, delirium, and depression.

To get there, we will need a workforce with the skills, knowledge, and demonstrated performance to provide palliative care and hospice expertise across a broad range of specialties of medicine and other healthcare disciplines, especially nursing, social work, and chaplaincy. Specialty board certification beginning in 2008 will allow the recognition of medical experts in hospice and palliative care for 10 different physician specialties. Funding support will be needed for fellowship training in these areas, as well as for comparable programs in other disciplines. Adequate funding for clinical services will be needed to attract trainees to this discipline.

Goal: All patients with life-limiting illnesses and their families will have access to help with psychological, social, and spiritual needs.

To get there, we will need healthcare professionals able to recognize and respond to the psychological and spiritual needs of patients. We will provide ways to make accurate information available to patients and families and ways to enlist community support around families in need. Payment will need to be available beyond the current Medicare Hospice Benefit for patients who need this broader range of care, especially at home, but who do not qualify for the Medicare Benefit because of the stage of their illness, the unpredictability of their clinical trajectory, or the requirement for the use of selected treatment modalities not accepted in the Medicare Hospice Benefit.

Goal: All patients with life-limiting illnesses will receive effective communication from healthcare professionals about their options for treatment; realistic information about their prognosis; timely, clear, and honest answers to their questions; advance directives; and a commitment not to abandon them regardless of their choices over the course of their illness.

To get there, healthcare professionals will need to have the communication skills to elicit values and advance directives. Information will need to be meaningfully recorded and accessible to and respected by every clinical contact the patient might make (including emergency medical teams and emergency departments). Communities and healthcare organizations and their staff will need to be accepting of different cultural and religious choices.

Goal: All patients with life-limiting illnesses will receive high-quality palliative care and hospice services.

To get there, all communities and/or institutions will ensure that high-quality palliative and/or hospice care programs are available and that all patients eligible for such care and with access to such services will receive a timely referral. All healthcare professionals will need to understand the value of palliative and hospice care and the advantages of such care throughout many stages of illness, and communities will need to have an adequate number of certified hospice and palliative care specialists available.