

**A highly reliable care system for the usual “cancer” trajectory would accomplish the following:**

- Build advance-care planning into early treatment, adapting the plan as the disease progresses.
- Provide palliation for symptoms and rehabilitation for disabilities throughout the course of illness.
- Provide some costly “aggressive” treatments even very late in the illness, because they still work to enhance lives.
- Smooth the transition across settings—from hospital or office to home care (mostly hospice) as the patient becomes more ill.
- Attend to family needs and spiritual/emotional issues throughout.

The key providers would probably be oncologists, cancer centers, and hospice programs, with additional support from nursing homes, home care providers, and assisted living facilities.

**A highly reliable care system for an advanced chronic organ-system-failure trajectory would include the following:**

- Teach the chronically ill elderly and their families the essentials of disease management, especially how to recognize symptoms and prevent worsening of illness.
- Ensure constant availability of key medications.
- Include planning that provides advance directives for sudden death.
- Provide early intervention for signs of exacerbation, including mobilizing care to the patient’s home.
- Offer in-home adaptations and equipment (e.g., oxygen) to ensure comfort.
- Tailor the care plan to the patient and family.

In good care for advanced organ system failure, prevention and early treatment of exacerbations avoid suffering, reduce costs, and prolong life. The major service providers would be specially trained nurses who are familiar with the medications and physiology and who can call on other professionals from an interdisciplinary team as needed, such as medical specialists, social workers, counselors, and occupational therapists. When the patient wants to forgo or stop aggressive life support, aggressive symptom relief must reliably be available.

**The dementia and frailty trajectory requires further adaptation of services:**

- Provide realistic training, financial support, benefits, and respite for family caregivers.
- Ensure quality care in long-term care facilities.
- Ensure availability of competent home health aides.

For these elderly persons, services need to focus on supporting family caregivers and meeting concrete, everyday needs. Day care centers, home health aides, Meals on Wheels, legal aid, family respite, behavioral management, and nursing homes form the core of the service array. While cancer patients might be very sick for a year, and organ system failure patients sick, off and on, for a few years, dementia and frailty patients can often live for a decade with increasing symptoms and increasing disability. Thus, the care system must be structured to accommodate very long durations of progressive illness and to adapt to changing family situations, slow decline in the patient's capabilities, and either a sudden or lingering death.

**Concluding Thought**

Chronically ill elderly people and families living through the end of life of a family member deserve a better system than the one currently available. They depend on the health care system to serve their needs and certainly not to add to the burden of their or a loved one's final days. Meeting the most important of these patient and family needs will require developing a vision of good care, confronting the barriers to putting the vision in place, and marshalling the political will to change the system. Achieving sustainable reforms quickly will require focused innovation and research. Thus, all Americans are stakeholders in building a system that ensures that each person can count on living comfortably and meaningfully through to the end of life.

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**Clinical  
Practice  
Guidelines  
for Quality  
Palliative  
Care**

**National Consensus Project**  
FOR QUALITY PALLIATIVE CARE

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# Clinical Practice Guidelines for Quality Palliative Care

Palliative care programs are growing in response to patient need. They provide assessment and treatment of pain and other symptoms; help with patient-centered communication and decision-making; and coordination of care across settings and through serious illness. These Guidelines were developed through consensus of *five major United States palliative care organizations* and describe the core precepts and structures of clinical palliative care programs.

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## Foreword

Palliative care and hospice programs have grown rapidly in recent years in response both to growth in the population living with chronic, debilitating and life-threatening illness and to clinician interest in effective approaches to the care of such patients. (1, 2) Palliative care is medical care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, nursing assistants and other health care professions, focused on the relief of suffering and support for the best possible quality of life for patients facing serious life-threatening illness, and their families. It aims to identify and address the physical, psychological, spiritual and practical burdens of illness. (2) This report will provide background on the clinical and educational imperatives that are driving the growth of palliative care and hospice services, review the outcomes of palliative care, describe its clinical components and the range of service models available, and present a professional consensus on the clinical guidelines for quality palliative care services.

The initiative to create a consensus on clinical practice guidelines for quality palliative care in the United States has its roots in the recommendations of three Institute of Medicine (IOM) reports, *Approaching Death, When Children Die*, and *Crossing the Quality Chasm*, as well as the American Association of Colleges of Nursing (AACN) report, *Peaceful Death*, and a recent monograph by the National Hospice Work Group (NHWG) and the Hastings Center, in association with the National Hospice and Palliative Care Organization (NHPCO), entitled *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers*. (3, 4) All five reports call for substantive changes to improve access to palliative care across the life span, in all health care settings, during all stages of debilitating chronic or life-threatening illness or injury. These changes include enhancements in the quality of care, restructuring of health care system regulations on service, education of health care professionals and research to support evidence-based palliative care practice.

Broadening medical care to integrate palliative and life-prolonging interventions is a major challenge for health care in the United States. Because palliation is a critical dimension of health care, all patients should have access to primary health care practitioners who are skilled and knowledgeable about basic palliative therapies. All physicians need to know when the services of interdisciplinary specialist-level palliative care clinicians are indicated and how to access them. When a patient moves into the late stages of a life-threatening or debilitating condition, the relative

**Note: Reference numbers in parentheses refer to the grouped references on pages 43 to 55. For complete citations, go to the bibliography at [www.nationalconsensusproject.org/guidelines](http://www.nationalconsensusproject.org/guidelines).**

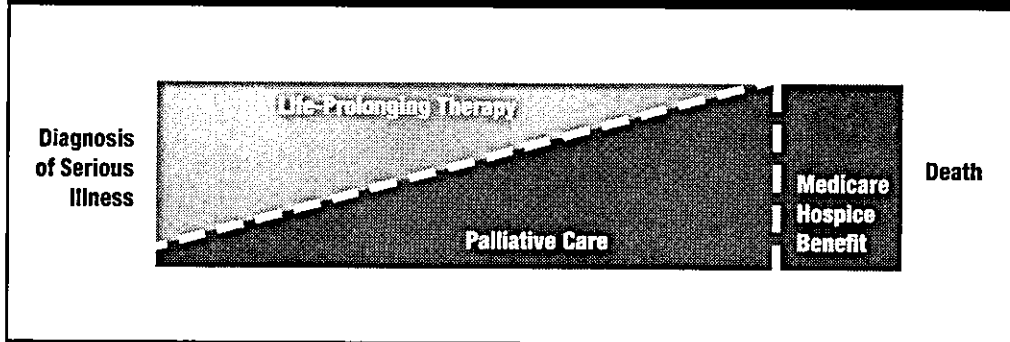
need for palliative care increases, and access to hospice programs must be enhanced to assure comprehensive and high-intensity palliative care during this stage of illness and during family bereavement. Such an approach should provide all patients with an integrated approach to treatment that looks to quality of life as well as quality of care throughout their experience with the health care system. Similarly, the palliative care needs of patients and families across the continuum should be met by a genuine and collaborative partnership between palliative care providers and hospice programs. Close coordination and partnerships between palliative care and hospice programs are critical to achieving continuity of palliative care throughout the full course of an illness and across the continuum of care settings.

The effort to integrate palliative care into all health care for debilitating and life-threatening illnesses should help to ensure that:

1. Pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with patient and family throughout the continuum of care.
2. Patients and families obtain the information they need in an ongoing and understandable manner, in order to grasp their condition and treatment options. Their values and goals are elicited over time; the benefits and burdens of treatment are regularly reassessed; and the decision-making process about the care plan is sensitive to changes in the patient's condition.
3. Genuine coordination of care across settings is ensured through regular and high-quality communication between providers at times of transition or changing needs, and through effective continuity of care that utilizes the techniques of case management.
4. Both patient and family are prepared for the dying process and for death, when it is anticipated. Hospice options are explored, opportunities for personal growth are enhanced and bereavement support is available for the family.

The purpose of the National Consensus Project for Quality Palliative Care is to establish Clinical Practice Guidelines that promote care of consistent and high quality and that guide the development and structure of new and existing palliative care services. These guidelines are applicable to specialist-level palliative care delivered in a range of treatment settings, as well as to the work of providers in primary treatment settings where palliative approaches to care are integrated into daily clinical practice.

## Palliative Care's Place in the Course of Illness



### Definition of Palliative Care (5)

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care. (6)

Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s). Evaluation and treatment should be comprehensive and patient-centered, with a focus on the central role of the family unit in decision-making. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death. Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals during whatever time they have remaining. Comprehensive palliative care services often require the expertise of various providers in order to adequately assess and treat the complex needs of seriously ill patients and their families. Members of a palliative care team may include professionals from medicine, nursing, social work, chaplaincy, nutrition, rehabilitation, pharmacy and other professional disciplines. Leadership, collaboration, coordination and communication are key elements for effective integration of these disciplines and services.

## **Background**

The hospice and pain management movements have demonstrated the efficacy of the patient-centered model of interdisciplinary team care and provided the impetus to formalize and promote a broader application of palliative care in the United States. In recent years, palliative care services outside hospice have increased rapidly in response to the growth in the population living with debilitating and life-limiting illnesses. The increase in demand for these services reflects the need to integrate and extend the well-established philosophy and practice of hospice care in this country to all stages of illness and to every care setting, including attention to symptom distress, patient and family support, and care coordination across settings. While there are aspects of contemporary palliative care that require specialized training for expert levels of knowledge and skill, the need for attention to palliative care issues is pervasive in the health care system. Palliative care, as an emerging health care specialty, is an important part of the response to these needs, serving both as a resource and a model for improved care throughout the trajectory of serious and life-threatening illness.

### **Patient Populations Served (7)**

For the purposes of this document, the term *life-threatening or debilitating illness* is assumed to encompass the population of patients of all ages and a broad range of diagnostic categories, who are living with a persistent or recurring condition that adversely affects their daily functioning or will predictably reduce life expectancy.

Based on this definition, the patient population referred to includes:

- Children and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care by others for support of the activities of daily living.
- Persons of any age with acute, serious and life-threatening illnesses (such as severe trauma, leukemia or acute stroke), where cure or reversibility is a realistic goal, but the conditions themselves and their treatments pose significant burdens.
- Persons living with progressive chronic conditions (such as peripheral vascular disease, malignancies, chronic renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders and dementia).
- Persons living with chronic and life-limiting injuries from accidents or other forms of trauma.
- Seriously and terminally ill patients (such as persons living with end-stage dementia, terminal cancer or severe disabling stroke), who are unlikely to recover or stabilize, and for whom intensive palliative care is the predominant focus and goal of care for the time remaining.



## Specialty-Level Palliative Care and Palliative Care in Primary Treatment Settings

Palliative care is both a general approach to patient care that should be routinely integrated with disease-modifying therapies and a growing practice specialty for appropriately trained physicians, nurses, social workers, chaplains and others whose expertise is required to optimize quality of life for those with life-threatening or debilitating chronic illness. Primary practitioners, in the routine course of providing health care, are expected to provide basic elements of palliative care (e.g., pain and symptom assessment and management, advance care planning). In other cases, complexity may determine that the patient or their family requires the services of palliative care specialists. Specialist palliative care providers are professionals whose work is largely or entirely involved with palliative care and who have received appropriate training and credentialing in the field. It is an expectation, fostered by these clinical guidelines, that palliative care services delivered by all health care professionals within the scope of their disciplines and care settings will rise to the level of “best practices” in order to meet the needs of their patients. The specialty of palliative care (programs and professionals committed largely or entirely to the delivery of palliative care), like other medical specialties, requires defined areas of expertise, skill and self-regulation. In health care settings without direct access to palliative care specialty services, resources should be sought through, for example, telemedicine or other forms of remote consultation.

The goal of these clinical guidelines is not to substitute one set of services (palliative) for another set of services (curative or disease-modifying), but rather to create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered. Only then can a reasonable determination be made of what mix of services is required to meet the physical, psychological, social, practical and spiritual needs of patients and their families. Good health care requires continual reappraisal of the benefits and burdens of therapies, and a proactive engagement with the philosophy of palliative care supports this fundamental tenet of the practice of medicine.

### Core Elements of Palliative Care

The World Health Organization (WHO) definition of palliative care provides a foundation and context for palliative care in all settings. The National Consensus Project agreed on the following key elements of palliative care:

- **Patient population:** The population served includes patients of all ages experiencing a debilitating chronic or life-threatening illness, condition or injury. (7)
- **Patient- and family-centered care:** The uniqueness of each patient and family is respected, and the patient and family constitute the unit of care. The family is defined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. In this context, family members may be related or unrelated to the patient; they are individuals who provide support and with

### The World Health Organization defines palliative care as (5)

“An approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.

#### Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a part of the life cycle;
- Intends neither to hasten nor postpone death;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement, including the needs of children;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance the quality of life, and may also positively influence the course of a patient's illness.”

whom the patient has a significant relationship. The care plan is determined by the goals and preferences of the patient and family, (8) with support and guidance in decision-making from the health care team. (9)

- **Timing of palliative care:** Palliative care ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues through cure, or until death, and into the family's bereavement period. (2)
- **Comprehensive care:** Palliative care employs multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social and spiritual distress. (10) Care providers should regularly assist patients and their families to understand changes in condition and the implications of these changes as they relate to ongoing and future care and goals of treatment. Palliative care requires the regular and formal clinical process of patient-appropriate assessment, diagnosis, planning, interventions, monitoring and follow-up.
- **Interdisciplinary team:** Palliative care presupposes indications for, and provision of, interdisciplinary team evaluation and treatment in selected cases. (11) The palliative care team must be skilled in care of the patient population to be served. Palliative care teams may be expanded to include a range of professionals, based on the services needed. They include a core group of professionals from medicine, nursing and social work, and may include some combination of volunteer coordinators, bereavement coordinators, chaplains, psychologists, pharmacists, nursing assistants and home attendants, dietitians, physical-, occupational-, art-, play-, music-, and child-life-therapists, case managers and trained volunteers.
- **Attention to relief of suffering:** The primary goal of palliative care is to prevent and relieve the many and various burdens imposed by diseases and their treatments, and consequent suffering, including pain and other symptom distress. (12)
- **Communication skills:** Effective communication skills are requisite in palliative care. These include developmentally appropriate and effective sharing of information, active listening, determination of goals and preferences, assistance with medical decision-making, and effective communication with all individuals involved in the care of patients and their families. (13)
- **Skill in care of the dying and the bereaved:** Palliative care specialist teams must be knowledgeable about prognostication, signs and symptoms of imminent death, and the associated care and support needs of patients and their families before and after the death, including age-specific physical and psychological syndromes, opportunities for growth, normal and aberrant grief, and bereavement processes. (14)
- **Continuity of care across settings:** Palliative care is integral to all health care delivery system settings (hospital, emergency department, nursing home, home care, assisted living facilities, outpatient and nontraditional environments such as schools). The palliative care team collaborates with professional and informal caregivers in each of these settings, in order to ensure coordination, communication and continuity of palliative care across institutional and home care settings. Prevention of crises and unnecessary transfers are important outcomes of palliative care. (15)

- **Equitable access:** Palliative care teams should work toward equitable access to palliative care across all ages and patient populations, all diagnostic categories, all health care settings including rural communities, and regardless of race, ethnicity, sexual preference or ability to pay. (16)
- **Quality improvement:** Palliative care services should be committed to the pursuit of excellence and high quality of care. Determination of quality requires regular and systematic evaluation of the processes of care and measurement of outcomes data using validated instruments. (17) These aims are built around the core need for palliative care to incorporate attention at all times to safety and the systems of care that reduce error, and to be:
  - Timely—delivered to the right patient at the right time.
  - Patient-centered—based on the goals and preferences of the patient and the family.
  - Beneficial and/or effective—demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes.
  - Accessible and equitable—available to all who are in need and who could benefit.
  - Knowledge- and evidence-based.
  - Efficient and designed to meet the actual needs of the patient and not wasteful of resources.

## **Models of Palliative Care Delivery**

Palliative care is appropriate for all patients from the time of diagnosis with a life-threatening or debilitating condition, and service delivery should be structured accordingly. Palliative care services are most effective when integrated into specific care settings (e.g., hospital, nursing home, assisted living, home care, etc.). This requires training in the fundamentals of palliative care for practitioners in a range of primary treatment settings, as well as establishing referral patterns and access to credentialed palliative care specialists and formal palliative care teams.

Efforts to introduce and sustain palliative care delivery must be tailored to the needs of the patient population, providers, institution, specific care setting and local community. Palliative care services must organize and maintain an interdisciplinary team that can provide sufficient services including support for the family, continuity of care, optimal use of institutional and community resources, and close collaboration with other professionals involved with the care of the patient. Models of adult palliative care delivery may not be well suited to the needs of children. Where possible, pediatric palliative care should be delivered by professionals with skill and training in the care of children across a range of care settings, developmental stages and diagnostic categories. (18)

The established and proven model of palliative care at the end of life is hospice care. This form of care has been normalized in the United States through the provision of a Medicare Part A entitlement, the Medicare Hospice Benefit. (See Appendix 1 for a discussion of hospice care in the United States.) For individuals whose condition

warrants the use of similar comprehensive services at an earlier period in life, there is a broad array of emerging palliative care programs situated in acute hospital, hospice, home care, nursing home and community settings. Common organizational delivery models for palliative care programs inclusive of hospice programs include: (19)

- Consultation service team (usually in a hospital, office practice setting, nursing home or home setting), consisting of physician, nurse and/or social work evaluations.
- Dedicated inpatient unit (acute and rehabilitation hospital, nursing home) or combined with freestanding inpatient hospice.
- Combined consultative service team and inpatient unit (hospital and nursing home).
- Combined hospice program and palliative care program (hospital, nursing home and some freestanding hospice inpatient facilities).
- Hospital- or private-practice-based outpatient palliative care practice or clinic.
- Hospice-based palliative care at home.
- Hospice-based consultation in outpatient settings.

### **The Need for Further Expansion of Palliative Care Services**

Repeated surveys of patient preferences and current care outcomes strongly support the need for expanded access to palliative care services. There continues to be a high prevalence of undertreated pain and other distressing symptoms in hospital, office practice, home care and nursing home settings among seriously ill patients of all ages and in all stages of illness. In addition, multiple studies document poor communication about the goals of care among health care practitioners, patients and families. (13) Despite the fact that more than 90 percent of Americans say they would rather be cared for at home, more than three-quarters of all deaths in the U.S. occur in hospitals (about 50 percent) or nursing homes (about 25 percent). (20) Recent research demonstrates high family caregiver burden, as well as increased morbidity and mortality for the family members of patients with chronic and life-threatening illness. (21)

Infant and child mortality rates associated with once-fatal illnesses and conditions are decreasing and more children now survive with severe or life-threatening disabilities. Palliative care for children is influenced by developmental considerations affecting diagnostic, treatment and communication approaches, as well as options for care. Physical, emotional and spiritual suffering in both pediatric patients and their families is clearly documented in recent studies. Serious illness in children is associated with high levels of uncertainty about prognosis and optimum management strategies, as well as great difficulty in accepting the possibility of death. Advance directives are not recognized for children, although the role of children in shared medical decision-making about their own care is critical. In contrast to older adults, nearly all of whom have Medicare coverage, about 15 percent of American children have no health insurance at all, and those with coverage have widely variable access to palliative care services. Nearly 85 percent of pediatric deaths currently occur in hospitals where pediatric palliative care services are largely unavailable or inadequate. (18)