

# **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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# Table of Contents

|  |           |
|--|-----------|
| <b>Foreword</b> .....  | <b>1</b>  |
| Definition of Palliative Care .....  | 3         |
| Background.....  | 4         |
| Patient Population Served.....   | 4         |
| Specialty-Level Palliative Care and Palliative Care in Primary Treatment Settings..... | 5         |
| Core Elements of Palliative Care .....   | 5         |
| Models of Palliative Care Delivery .....   | 7         |
| The Need for Further Expansion of Palliative Care Services.....                        | 8         |
| Palliative Care Across the Continuum.....  | 9         |
| The Need for Consensus .....   | 11        |
| Purpose of the Clinical Practice Guidelines for Quality Palliative Care .....          | 11        |
| <b>Clinical Practice Guidelines for Quality Palliative Care</b> .....                  | <b>14</b> |
| Domain 1: Structure and Processes of Care.....   | 16        |
| Domain 2: Physical Aspects of Care.....  | 21        |
| Domain 3: Psychological and Psychiatric Aspects of Care.....                           | 24        |
| Domain 4: Social Aspects of Care .....   | 27        |
| Domain 5: Spiritual, Religious and Existential Aspects of Care.....                    | 29        |
| Domain 6: Cultural Aspects of Care.....  | 31        |
| Domain 7: Care of the Imminently Dying Patient.....                                    | 33        |
| Domain 8: Ethical and Legal Aspects of Care.....                                       | 35        |
| <b>Conclusion</b> .....  | <b>39</b> |
| <b>Notes on References</b> .....   | <b>41</b> |
| <b>References by Section</b> .....   | <b>43</b> |
| <b>Appendix 1</b>  |           |
| Palliative Care and the Hospice Movement in the United States.....                     | 57        |
| Responding to Community Need .....   | 58        |
| History of the National Consensus Project.....   | 61        |
| Organizational Structure of the National Consensus Project.....                        | 62        |
| Process for Developing Consensus.....  | 63        |
| <b>Appendix 2</b>  |           |
| National Consensus Project Advisory Committee .....                                    | 65        |



## 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, addressing regulatory barriers to pain relief 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).

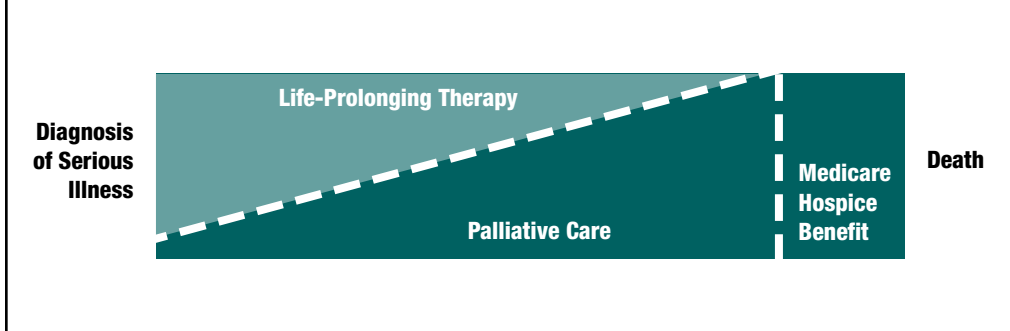
need for palliative care increases, and access to hospice programs must be enhanced to assure comprehensive and high-intensity palliative care during this stage of illness and during family bereavement. Such an approach should provide all patients with an integrated approach to treatment that looks to 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 whom the patient has a significant relationship. The care plan is determined by the

### 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.”

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)

- **Addressing regulatory barriers:** Concerns about drug abuse have led to increased concerns about medically appropriate use of opioid analgesics. While efforts to address abuse are necessary, they should not interfere with medical practice and the care of patients in pain. Palliative care professionals should collaborate with policy-makers, law enforcement and regulators to achieve a balanced and positive regulatory environment for pain management and palliative care. (16a)
- **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)

Further impetus for expansion of palliative care services is the strong correlation between patient/family care preferences and the services provided by palliative care specialists. Studies show that patients' top priorities are to be free of physical and psychological distress; to have some control over decisions about their health care; to avoid death-prolonging treatments; and to improve relationships with and reduce burden on their families. (8) The evidence base of the hospice experience for patients/families during the last few months of a terminal illness, as well as more recent palliative care outcome studies, demonstrate the ability of palliative care to help patients achieve these goals throughout the trajectory of a progressive or life-threatening illness. (22) Other studies have demonstrated financial benefits associated with palliative care programs, including reduction in hospital length of stay, costs and utilization, (23) and increased numbers of referrals to and length of stay in hospice programs. (24)

The need for palliative care in the United States can be met through ongoing health professional education in palliative care principles and practice; increasing access to palliative care specialists in hospital, nursing home and home care settings; promoting timely access to hospice services to all eligible patients; creatively integrating hospice and palliative care programs across treatment settings; and defining appropriate accountability and performance measures for palliative care services.

## Palliative Care Across the Continuum

The growing need for and interest in palliative care underscores the importance of practice guidelines aimed at promoting palliative care clinical services of a high and consistent quality across all relevant care settings in the United States. Most people receive health care in multiple clinical settings: physicians' offices, hospitals, school-based clinics, nursing homes, emergency facilities and at home. It is well established that communication among these various care settings is extremely difficult, resulting in discontinuities of care. Continuity of care is especially important for patients and families facing life-threatening illness or injury. Toward this end, a core value of palliative care is the promotion and facilitation of continuity of care to avoid needless suffering and errors, eliminate patient and family perceptions of abandonment, and ensure that choices and preferences are respected. (13, 15)

Almost all persons with serious illness spend at least some time in a hospital, usually on multiple occasions, in the course of the disease or condition. More than 50 percent of adult and 85 percent of pediatric deaths occur in hospitals. Similarly, almost half the population age 65 or older will spend some time in a nursing home prior to death, more than half of persons over age 85 die in a nursing home, and 43 percent of persons over age 65 reside in a long-term care facility at some time before they die. (26) Data from numerous studies demonstrate high degrees of symptom distress across all age groups in hospitalized and nursing home patients; high use of burdensome nonbeneficial technologies among the seriously ill; (27) caregiver burden on families; (21) and problems with communication between these patients, their families and their treating physicians about the goals of care and the medical decisions that should follow. (13)

### The Urban Institute reports,

"The nation is about to experience a great demographic shock. Between 2010 and 2030 the over-65 population will rise over 70 percent, while under current law the population paying payroll taxes will rise less than 4 percent." (25) This demographic change, when aligned with progressively higher health care costs, diminishing labor and financial resources, insecurity of federal entitlements and longer life expectancies creates a dramatic projection of future health care needs. Further, the number of children living with life-limiting conditions with significant disability and morbidity continues to increase. (18) These factors help to illustrate the need for more effective application and coordination of chronic disease management services, including the integration of palliative care, in order to more effectively meet the needs of the growing number of persons living with life-threatening and debilitating illnesses.

In addition to serving as a principal location of care, hospitals are the primary training site for the nation's future health care professionals. As a result, hospitals have become a major locus of current efforts to improve access to palliative care. Providers must learn how to respond competently to the various forms of human suffering, know how to work with the medical system on behalf of patients and families, and to regard care of the dying, as well as the care of the chronically and seriously ill, as a core clinical responsibility. They must be taught and mentored at their point of entry into health care and in the environment—the hospital setting—where the majority of people will spend some time during a serious illness. Students of medicine and nursing are acculturated during their training to value what is taught and practiced by their seniors. Palliative care must be taught during clinical rotations in the hospital, in order for it to be viewed as an essential competency for a health professional.

Experiences in nonhospital community settings, including hospice, are also necessary to train future practitioners in both the primary and specialist-level skills required to ensure quality palliative care across all health care settings. As mandated by both the Liaison Council on Medical Education (undergraduate medical education) and the Accreditation Council on Graduate Medical Education (residency and fellowship training), this requires formal educational experiences both within and outside the hospital environment in order to fully understand the importance of continuity of care and the challenges of delivering it. Furthermore, the essential skills of learning to access and utilize community resources, and how to establish practice patterns that will promote palliative care in all settings, can only be gained through educational experiences in the range of settings where patients receive care. (28)

While the practice guidelines for palliative care clinical programs contained in this document are applicable in institutional settings for both pediatric and adult patient populations, focused efforts are required to improve access to quality palliative care in nursing homes, where perceived and actual regulatory barriers, limited resources and staff turnover often make the provision of expert palliative care services difficult. Additional education and training of nursing home professionals and all direct-care staff in the principles and practice of palliative care is a priority of long-term care professional organizations, and many facilities are developing palliative care capabilities on-site or through contractual relationships with palliative care clinicians. Promotion of contractual relationships between nursing homes and hospices is also a prevalent and growing model of palliative care delivery in the nursing home setting. Compared to nursing homes without hospice relationships, homes with hospice relationships show significant reductions in hospitalizations, hospital lengths of stay, restraint use, use of injection analgesics, and insertion of intravenous lines and feeding tubes, as well as a higher likelihood of detection and treatment of pain. (29) Consequently, a nursing home's ability to provide the types of palliative services identified in this document may be achieved through development of on-site capabilities in the delivery of quality palliative care; through seeking one or more contractual relationships with local hospices or palliative care experts; and, as some long-term care facilities have demonstrated, through development of palliative care consultation services in addition to hospice contracts. (30)

## The Need for Consensus

Professional consensus on what constitutes high-quality palliative care is prerequisite to the effective delivery of such services across the continuum of care. This consensus process provides credible common ground to begin systematic improvements in palliative care delivery. In addition, the consensus process fosters the development of a broad-based and enduring palliative care constituency through the dissemination of these guidelines throughout the many sectors of the U.S. health care system and to policy-makers, regulators and the media.

## Purpose of the Clinical Practice Guidelines for Quality Palliative Care

The mission of the National Consensus Project for Quality Palliative Care is to create a set of clinical practice guidelines to improve the quality of palliative care in the United States. Specifically, these Clinical Practice Guidelines for Quality Palliative Care aim to promote quality and reduce variation in new and existing programs, develop and encourage continuity of care across settings, and facilitate collaborative partnerships among palliative care programs, community hospices and a wide range of other health care delivery settings.

While the focus of this document is on the specialist component of palliative care (programs and professionals whose work is primarily focused on palliative care), most palliative care needs to be delivered in primary treatment settings in the course of routine care. This requires guidance for health care professionals who lack specialist training in palliative care. Thus, these guidelines are intended to serve as a comprehensive description of what constitutes a high-quality palliative care clinical service, as well as a resource for practitioners addressing the palliative care needs of patients and families in primary treatment settings.

In the United States, practice standards for palliative care during the last phase of life have developed over the last 20 years through hospice professional organizations and regulatory bodies. These standards and precepts, along with published palliative care service guidelines from Australia, New Zealand and Canada, served as the basis for the development of these clinical practice guidelines. (31)

The success of this project will be determined by the degree to which the Clinical Practice Guidelines for Quality Palliative Care are used to: 1) foster the integration of the principles, philosophy and practices of palliative care across care settings; 2) stimulate and guide the development and evaluation of new and existing services within and across care settings; 3) ensure that palliative care services deliver care of consistent and measurably high quality; 4) promote formal recognition of specialty status for certification initiatives in palliative care; and 5) support the expansion of efforts by hospices and other palliative care programs to coordinate care services across the continuum.

### The purposes of these Clinical Practice Guidelines for Quality Palliative Care are to:

1. Facilitate the development and continuing improvement of clinical palliative care programs providing care to patients and families with life-threatening or debilitating illness.
2. Establish uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency and reliability of these services.
3. Establish national goals for access to quality palliative care.
4. Foster performance measurement and quality improvement initiatives in palliative care services.
5. Foster continuity of palliative care across settings (home, residential care, hospital, hospice).

## Selected References for Foreword

- American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care (2000). Palliative Care for Children. *Pediatrics* 106(2 Pt 1): 351–357.
- American Association of Colleges of Nursing (2002). *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*. Washington: American Association of Colleges of Nursing; available at [www.aacn.nche.edu/Publications/deathfin.htm](http://www.aacn.nche.edu/Publications/deathfin.htm).
- American Board of Internal Medicine, Committee on Evaluation of Clinical Competence (1998). *Caring for the Dying: Identification and Promotion of Physician Competency*. Philadelphia: American Board of Internal Medicine.
- American College of Surgeons (2002). The American College of Surgeons: Statement on Principles Guiding Care at the End of Life. *Journal of the American College of Surgeons* 194(5): 664.
- American Geriatrics Society Ethics Committee (1994). The Care of Dying Patients: A Position Statement from the American Geriatrics Society. *Journal of the American Geriatrics Society* 43(5): 577–578; available at [www.americangeriatrics.org/products/positionpapers/careofd.shtml](http://www.americangeriatrics.org/products/positionpapers/careofd.shtml).
- American Society of Clinical Oncology End of Life Care Task Force (1998). Cancer Care During the Last Phase of Life. *Journal of Clinical Oncology* 16: 1986–1996.
- Association for Palliative Medicine of Great Britain and Ireland; available at [www.palliative-medicine.org/](http://www.palliative-medicine.org/).
- Children’s International Project on Palliative/Hospice Services (ChIPPS) Administrative/Policy Workgroup, National Hospice and Palliative Care Organization (2001). *A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions*. Alexandria, Va.: National Hospice and Palliative Care Organization. White paper; available at [www.nhpco.org/files/public/ChIPPSCallforChange.pdf](http://www.nhpco.org/files/public/ChIPPSCallforChange.pdf).
- Drug Enforcement Administration, Last Acts, Pain & Policy Studies Group, et al. (2001). *Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act*. Washington: Lasts Acts; available at [www.medsch.wisc.edu/painpolicy/dea01.htm](http://www.medsch.wisc.edu/painpolicy/dea01.htm).
- Ferris FD, Balfour HM, et al. (2002). *A Model Guide to Hospice Palliative Care*. Ottawa: Canadian Hospice Palliative Care Association.
- Field MJ and Cassel CK, eds., et al. (1997). *Approaching Death: Improving Care at the End of Life*. Washington: Institute of Medicine, National Academy Press.
- Field MJ, Behrman DE, eds., et al. (2003). *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington: Institute of Medicine, National Academy Press.
- Hospice and Palliative Nurses Association, American Nurses Association (2002). *Scope and Standards of Hospice and Palliative Nursing Practice*. Washington: American Nurses Publishing.
- Institute of Medicine (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington: Institute of Medicine, National Academy Press.
- Jennings B, Ryndes T, et al. (2003). Access to Hospice Care: Expanding Boundaries, Overcoming Barriers. *Hastings Center Report*, Supplement 33(2): S1–59.
- Last Acts (2002). *Means to a Better End: A Report on Dying in America Today*. Washington: Last Acts; available at [www.lastacts.org](http://www.lastacts.org).

National Hospice and Palliative Care Organization (2000). *Standards of Practice for Hospice Programs*. Alexandria, Va.: National Hospice and Palliative Care Organization.

National Hospice and Palliative Care Organization (2003). *NHPCO Facts and Figures*. Alexandria, Va.: National Hospice and Palliative Care Organization; available at [www.nhpco.org/files/ublic/facts\\_and\\_figures\\_0703.pdf](http://www.nhpco.org/files/ublic/facts_and_figures_0703.pdf)

Palliative Care Australia (1999). *Standards for Palliative Care Provision* (third ed.); available at [www.pallcare.org.au/publications/Standards\\_99.pdf](http://www.pallcare.org.au/publications/Standards_99.pdf).

Schapiro R and Byock I (2003). *Living and Dying Well with Cancer: Successfully Integrating Palliative Care and Cancer Treatment*. Princeton, NJ: Promoting Excellence in End-of- Life Care, Robert Wood Johnson Foundation.

Teno J (2000). *TIME: Toolkit of Instruments to Measure End-of-Life Care*; available at [www.cher.brown.edu/pcocl/toolkit.htm](http://www.cher.brown.edu/pcocl/toolkit.htm).

NOTE: An easy reference to the various sections of the NHPCO Standards of Practice for Hospice Programs (2000) is provided in brackets at the end of each domain.

NHPCO Standards: {ARE 3, 3.1-3.3, 3.5, 3.6, 8, 14, 14.1, 14.2; CCS 3.1-3.4, 6, 10, 10.1-10.3, 11, 11.1, 11.3, 13, 13.1, 13.2, 14, 14.1, 14.2; HIF CCS 3; HIF SIC 1,1.1-1.7, 5; HRCF SIC 1, 1.1-1.9, 2, 2.1-2.6, 3, 3.1, 5, 7, 7.1-7.4; HR 1, 1.3, 4, 4.1, 4.2, 4.4, 7.2; IDT 1.1, 4.1, 5.1; PI 1.1, 2, 2.1-2.3, 3.2, 4, 4.1, 4.3, 4.4, 5.2, 5.3, 6, 6.1,6.2}<sup>1</sup>

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<sup>1</sup> References from sections of the National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs (2002) are cited in brackets, using their abbreviations as follows:

|     |                                     |      |  |
|-----|-------------------------------------|------|--|
| ARE | Access, Rights, Ethics              | MI   | Management of Information                        |
| BCS | Bereavement Care and Services       | PI   | Performance Improvement and Outcomes Measurement |
| CC  | Coordination and Continuity of Care | SIC  | Safety and Infection Control                     |
| CCS | Clinical Care and Services          | HIF  | Hospice Inpatient Facility                       |
| HR  | Human Resources                     | NF   | Nursing Facility Hospice Care                    |
| IDT | Interdisciplinary Team              | HRCF | Hospice Residential Care Facility                |
| LG  | Leadership and Governance           |      |  |