

# **Clinical Practice Guidelines for Quality Palliative Care**

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SECOND EDITION

**Clinical  
Practice  
Guidelines  
for Quality  
Palliative  
Care**

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SECOND EDITION

## **Publisher**

National Consensus Project for Quality Palliative Care  
*Clinical Practice Guidelines for Quality Palliative Care, Second Edition*

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**National Consensus Project**  
FOR QUALITY PALLIATIVE CARE

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## Foreword

Palliative care assists increasing numbers of people with chronic, debilitating, and life-limiting illnesses. A growing number of programs provide this care in a variety of settings: hospitals, outpatient settings, community programs within home health organizations, and hospices. Within these settings are dedicated teams of physicians, nurses, social workers, chaplains, counselors, nursing assistants, rehabilitation specialists, speech and language pathologists, and other healthcare professionals. These providers, who are devoted to special populations with palliative-care needs, assess and treat pain along with other symptoms; facilitate patient-centered communication and decision making; and coordinate continuity of care across settings throughout the disease continuum.

The first edition of the *Clinical Practice Guidelines for Quality Palliative Care* was developed by the National Consensus Project (NCP) to describe the core precepts and structures of clinical palliative care programs. Two years later, the National Quality Forum (NQF) adopted the *Clinical Practice Guidelines for Quality Palliative Care* within the document *A National Framework for Palliative and Hospice Care Quality Measurement and Reporting*. This revision continues the consensus process among the four consortium organizations that comprise the NCP.

The *Clinical Practice Guidelines for Quality Palliative Care* have been updated for several reasons. First, as part of its mission, the National Consensus Project for Quality Palliative Care aims to promote consistent and high quality care. Within health care, this is an evolving process, requiring periodic revisions to reflect the growing practice and evidence of palliative care as it continues to move into mainstream health care. This includes an update of the references and definitions used in the *Guidelines*.

Second, when the National Quality Forum released the 38 preferred practices for hospice and palliative care, it was necessary for the *Clinical Practice Guidelines for Quality Palliative Care* to have concordance with those practices. In order to ensure this, it was necessary to review the guidelines to be certain that all the preferred practices were reflected within the domains.

Finally, over the last five years, many organizations have asked how the theory of the *Clinical Guidelines* can be implemented into practice. Consequently, we identified real examples of how various organizations have used the *Guidelines* to operationalize optimal end-of-life care. Some are programs that demonstrate their use in practice. Also included are NCP Leadership Award winners that demonstrated excellence through the use of the *Clinical Practice Guidelines*. Seeing the widespread use of the *Clinical Practice Guidelines for Quality Palliative Care* as the basis of many palliative care programs has, in and of itself, demonstrated another aspect of the mission of the NCP – the widespread dissemination and distribution of the *Guidelines* and the related Preferred Practices from the NQF.

Because the foundational work of the NCP had established the eight domains through a consensus process, they themselves remain the same. In revising the document, clarifications were made to make the document both more inclusive and expansive to all settings that provide palliative care. Additionally, some sections further develop a particular domain. Our goal is for the *Clinical Practice Guidelines for Quality Palliative Care* to continue to serve as the blueprint upon which to build optimal palliative care. We recognize that palliative care will continue to evolve. We welcome your feedback on the *Clinical Practice Guidelines for Quality Palliative Care* and their place in program development.

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In the five years since the National Consensus Project for Quality Palliative Care released the first edition of the *Clinical Practice Guidelines for Quality Palliative Care*, the discipline of palliative care has continued to advance, particularly now that it is recognized as a medical specialty. This revision reflects the continued teamwork in the process. The Steering Committee of the National Consensus Project for Quality Palliative Care extends its thanks to all the healthcare professionals who gave us the benefit of their support, experience, and thoughtful comments as we revised the *Clinical Practice Guidelines for Quality Palliative Care*.

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## Introduction

The mission of the National Consensus Project for Quality Palliative Care is to create clinical practice guidelines to improve the quality of palliative care in the United States. Specifically, the *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 healthcare delivery settings. This is a dynamic process as the field continues to grow. The *Clinical Practice Guidelines for Quality Palliative Care* is intended to strengthen existing programs and foster a solid foundation for newly created programs and those in development.

In 2004, the first edition of the *Clinical Practice Guidelines for Quality Palliative Care* was released. This was an important development in the advancement of palliative care because the document offered a map to the future of palliative care. In the past five years, the growth in hospice and palliative care has been enormous. According to the latest figures from the Center to Advance Palliative Care, there are more than 1240 hospitals with palliative care programs (CAPC release, December 7, 2007). The National Hospice and Palliative Care Organization reports that there are now more than 4500 hospice programs across the country (NHPCO Facts and Figures, November 2007). It is more important than ever to assure consistency and high quality care because there are many new programs developing. In furthering its mission, as well as remaining current with the science and practice of palliative care, the NCP promotes ongoing dissemination of these guidelines. The revision of *Clinical Practice Guidelines for Quality Palliative Care* provides a blueprint for the essential foundation and structure of new and existing programs.

# The National Consensus Project for Quality Palliative Care

## Background

In 2001, palliative care leaders from across the United States met to discuss the standardization of palliative care with the goal of improving the quality of care. To move the discussion to action, the NCP was formed with representation from the five major palliative care membership and leadership organizations: The American Academy of Hospice and Palliative Medicine (AAHPM – the physician membership association), The Center to Advance Palliative Care (CAPC – a palliative care advocacy and information organization), The Hospice and Palliative Nurses Association (HPNA – the nursing membership association), Last Acts Partnership (a consumer organization now part of NHPCO), and the National Hospice and Palliative Care Organization (NHPCO – the hospice membership organization). The NCP goal was simple and straightforward: to build national consensus around the definition, philosophy, and principles of palliative care. The process was more complex: to create voluntary palliative care clinical guidelines through an open and inclusive process that included the many professionals, providers, and consumers involved in and affected by palliative care.

In April 2004, the NCP released the *Clinical Practice Guidelines for Quality Palliative Care*, which described the highest quality of services to patients and families. These guidelines offered a national definition of palliative care while simultaneously encompassing the core essential elements of quality palliative care delineated within eight specific domains. With the overall goal of achieving quality by the systematic evaluation of care, criteria for outcome data, and the development of validated instruments, the *Guidelines* formed a roadmap for the future of palliative care. These included appropriate patient populations, patient- and family-centered care, initiation of palliative care, continuity of care across settings, equitable access to care, comprehensive care, use of an interdisciplinary team, attention to relief of suffering, emphasis on communication, and skill in attending to the dying patient and bereaved survivors, as well as addressing regulatory issues.

The *Guidelines* help clinicians provide key elements of palliative care in the absence of palliative care programs and allow existing and future programs to better define their program organization, resource requirements, and performance measures. A variety of healthcare organizations representing various disciplines and provider groups have endorsed the *Clinical Practice Guidelines for Quality Palliative Care*. These guidelines are intended to serve as a comprehensive description of what constitutes comprehensive high-quality palliative care services, as well as a resource for practitioners addressing the palliative care needs of patients and families in primary treatment settings. Thus, the focus of the NCP *Clinical Practice Guidelines for Quality Palliative Care* is an educational framework and blueprint for the structure and provision of palliative care.

Another goal of the NCP was to promote recognition, stable reimbursement structures, and accreditation initiatives through projects, such as the National Quality Forum (NQF). This important goal was completed in January 2006 when the NQF endorsed and adopted the *Clinical Practice Guidelines for Quality Palliative Care* into their document, *A National Framework for Palliative and Hospice Care Quality Measurement and Reporting*. The NQF also offered 38 Preferred Practices to accompany its document.

Over the past five years, there have been several activities necessitating revision of the *Guidelines*. During the dissemination phase of the first edition of the *Clinical Practice Guidelines for Quality Palliative Care*, the NCP sought the input of various special interest groups to assure the universal applicability among various populations. Their feedback was invaluable, and it alone warranted an update. Additionally, because of the national focus on palliative care, there has been more research and literature that impacts the NCP domains. An extensive review of the literature from 2004 to the present to represent the state of the science of the document was another important reason to revise the document. Finally, in achieving the recognition of the NQF as represented by the Framework documents, there was a need to update the definitions used within the *Guidelines*. Moreover, there was a need to be more inclusive and expand the specificity of operationalizing the domains. Within this revision, the NCP maintains consistency within the two documents, although it retains its consensus definition of palliative care and the consensus-defined philosophy of palliative care.

## The National Quality Forum

The NQF is a private, nonprofit membership organization created to develop and implement a national strategy for healthcare quality improvement. Its mission is to improve American health care through the endorsement of consensus-based national standards for measurement and public reporting of healthcare performance data. This data then provides meaningful information about care delivery, such as the safety, timeliness, benefit, patient-centeredness, equality, and efficiency of health care.

Prior to the publication of the *Clinical Practice Guidelines for Quality Palliative Care*, the NQF had not addressed the topic of hospice and palliative care. The NCP requested NQF to review and possibly endorse the guidelines. Given the consensus-based process of the guideline development, it was consistent with NQF goals. The NQF appointed a Technical Expert Panel to review the guidelines and propose preferred practices. In late 2006, the NQF released: *A Framework for Palliative and Hospice Care Quality Measurement and Reporting*. Within the document, the NQF accepted and adopted the *Clinical Practice Guidelines for Quality Palliative Care*. The eight domains of the *Guidelines* served as the basis of care as well as 38 preferred practices upon which to develop measures for palliative care. Because the NQF is recognized as the national leader in healthcare quality improvement and representative of the broadest possible array of practice areas and topics, it offers palliative care both legitimacy and recognition within a broad healthcare focus, policymakers, and payers. With important recognition of the federal government as the basis for reimbursement, regulation, and accreditation, the significance of this endorsement cannot be overstated.

## The National Consensus Project and the National Quality Forum

Together, the NCP and NQF synergistically advance palliative care by formalizing the concept of palliative care and differentiating it from other types of care. They each espouse eight domains of palliative care:

1. Structure and processes of care
2. Physical aspects of care
3. Psychosocial and psychiatric aspects of care
4. Social aspects of care
5. Spiritual, religious, and existential aspects of care
6. Cultural aspects of care
7. Care of the imminently dying patient
8. Ethical and legal aspects of care

The NCP *Clinical Practice Guidelines for Quality Palliative Care* is a clinical document to promote optimal palliative care. The references offer programs evidence-based practices upon which to build their programs. Within the eight domains, the *Clinical Practice Guidelines for Quality Palliative Care* focus on promoting both the philosophy of palliative care and raising awareness of the necessity of quality palliative care with recommended practices. In essence, it is a practical guide to the provision of palliative care.

The NQF has developed a more formal definition of quality palliative care and established quantitative measures as the basis for developing and testing quality indicators appropriate for palliative care. The NQF has identified each of the NCP domains as a particular problem to be addressed by specific preferred practices. The publication of *A Framework for Palliative and Hospice Care Quality Measurement and Reporting* by the NQF is the first step in the development of rigorous, quantifiable quality indicators.

## The Joint Commission

In the United States, standards of practice for palliative and hospice care have developed over the last 20 years through professional hospice organizations and regulatory bodies. In early 2008, The Joint Commission (TJC), formerly known as the Joint Commission on Accreditation of Healthcare Organizations, drafted voluntary palliative care elements of performance for specialized palliative care programs. A large number of external stakeholders reviewed the document. As of this writing, the final document has yet to be released. Currently, TJC embedded the domains and philosophy of the *NCP Clinical Guidelines for Quality Palliative Care* within the already established performance areas.

One component of TJC standards stresses the nature of care that surrounds both the patients and family. Another key element under program management states that education, experience, and certification are encouraged for all staff. The role of the interdisciplinary team is defined, including medicine, nursing, psychology, social work, spiritual care, rehabilitation services, nutrition, pharmacologists, and child-

life specialists. Moreover, TJC states that practices originating from evidence-based national guidelines or expert consensus are used to deliver care, treatment, and services. Thus, the NCP *Clinical Practice Guidelines for Quality Palliative Care* serves as a basis for care.

Each of the domains is specifically mentioned in various Joint Commission standards of care, including physical and psychological interventions, a focus on imminent death, along with attention to culture, spirituality, grief and loss, care coordination across the healthcare continuum, and a process for solving ethical issues. Certification allows programs to hold a mirror up to reflect if they have indeed implemented all aspects of the *Clinical Practice Guidelines for Quality Palliative Care*.

## **Moving Palliative Care Upstream**

Palliative care and hospice programs will continue to grow in response to growth of the aging patient population living with chronic, debilitating, and life-threatening illness and because of increasing clinician interest in effective approaches to the care of such patients. This includes clinicians in all specialties and disciplines of health care. One of the key elements consistently mentioned during the revision process of this document was the inherent interdisciplinary nature of palliative care. While it is commonly agreed that palliative care is health care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, nutrition, and rehabilitation specialties, this document emphasizes the wide array of rehabilitative specialties, including physical therapy, occupational therapy, speech and language pathology, along with age-specific disciplines, such as child-life and geriatric specialists. These guidelines also apply to disease-specific specialists, such as those within HIV/AIDS, cardiology, neurology, hepatology, endocrinology, and other disciplines that serve as key members of palliative care efforts for patients with diseases other than cancer. Collectively, as suggested in the Foreword, the focus of palliative care is optimal functioning with the relief of suffering for patients facing serious life-threatening or debilitating illness and support for the best possible quality of life for both patients and their families.

As stated in the first edition, palliative care is best achieved through close coordination and partnerships between palliative care and hospice programs from diagnosis to the end stages of an illness across the continuum of care settings and living situations. The fundamental elements of hospice and palliative care maintain the following.

1. Pain and symptom control, psychosocial distress, spiritual issues, and practical needs are systematically addressed with the patient and family throughout the continuum of care. If present, any conditions are treated based upon current evidence and with consideration of cultural aspects of care.
2. Patients and families acquire ongoing information in a culturally sensitive, appropriate, and understandable manner to facilitate the comprehension of the condition and realistic potential of treatment options. In the process, values, preferences, goals, and beliefs 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 and case management.
4. Both patient and family, however defined by the family, are appropriately 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.



### Definition of Palliative Care

In the first edition of the *Clinical Practice Guidelines for Quality Palliative Care* the consensus of the definition of palliative care was achieved and remains unchanged.

“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.

Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient/family needs, preferences, values, beliefs, and culture. 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 to adequately assess and treat the complex needs of seriously ill patients and their families. Leadership, collaboration, coordination, and communication are key elements for effective integration of these disciplines and services (NCP 2004).”

This definition of palliative care is consistent with the definition in use by the NQF and the Centers for Medicare and Medicaid Services (CMS), which follows:

“Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice (Federal Register 2008).”

## **Patient Populations Served**

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 refers to the following:

- Children and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care with support by others with the activities of daily living.
- People 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 and result in poor quality of life.
- People 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).
- People living with chronic and life-limiting injuries from accidents or other forms of trauma.
- Seriously and terminally ill patients (such as people 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 remainder of their lives.

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

Palliative care is both a general approach to patient care that ideally should be routinely integrated with disease-modifying therapies and a growing practice specialty for appropriately trained healthcare professionals 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 his/her family requires the services of palliative care specialists. Specialist palliative care providers are those clinicians who have received formalized specialty training and appropriate credentialing in the field and whose work is largely or entirely involved with palliative care.

It is an expectation, fostered by these clinical guidelines, that palliative care services delivered by all healthcare professionals within the scope of their disciplines and care settings will rise to the level of “best practices” 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 healthcare settings without direct access to palliative care specialty services, resources should be sought through, for example, telemedicine or other forms of remote consultation.

These clinical guidelines do not substitute one set of services (palliative) for another set of services (curative or disease-modifying), but rather 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.

### **World Health Organization Definition of Palliative Care**

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- 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;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO 2008).”

## World Health Organization Definition of Palliative Care for Children

“Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO’s definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders:

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes (WHO 2008).”

The NCP 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.
- **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 goals and preferences of the patient and family, with support and guidance in decision-making from the healthcare team.
- **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.
- **Comprehensive care:** Palliative care employs a multidimensional assessment to identify and relieve suffering through the prevention or alleviation of physical, psychological, social, and spiritual distress. Care providers should regularly assist patients and their families to understand changes in the patient’s 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. 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, speech and language pathologists, 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.
- **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.
- **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.
- **Continuity of care across settings:** Palliative care is integral to all healthcare 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 to ensure coordination, communication, and continuity of palliative care across institutional and homecare settings. Proactive management to prevent crises and unnecessary transfer are important outcomes of palliative care.
- **Equitable access:** Palliative care teams should work toward equitable access to palliative care across all ages and patient populations, all diagnostic categories, all healthcare settings including rural communities, and regardless of race, ethnicity, sexual preference, or ability to pay.
- **Quality assessment and performance improvement:** Palliative care services should be committed to the pursuit of excellence and high quality of care. Determination of quality requires the development, implementation, and maintenance of an effective quality assessment and performance improvement program. This requires regular and systematic assessment and evaluation of the processes of care and measurement of outcomes using validated instruments for data collection. The Institute of Medicine has identified six aims for quality healthcare delivery. They include:
  - 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.
 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. Several activities that have included palliative care outcomes include the Physician Quality Reporting Initiative and the Physician Consortium for Performance Improvement. However, most important is that the NCP endorses the NQF’s 38 Preferred Practices that aim to ensure quality care outlined by domain and corresponding preferred practice (see Appendix 1).

## Models of Palliative Care Delivery

Palliative-care services are appropriate and should be available for all patients from the time of diagnosis with a life-threatening or debilitating condition. To ensure maximal benefit, these services should be integrated into all healthcare settings so that there is a continuum of care from diagnosis of a disease through the terminal phase.

However, there is no model that fits every organization or institution. Thus, palliative care delivery must be individually integrated into specific care settings (e.g., hospital, nursing home, assisted living, home care) with attention to the culture of the organization. Often, this requires training in the fundamentals of palliative care for all providers and establishing access to credentialed palliative care specialists and formal palliative care teams.

Efforts to introduce and sustain palliative care services 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 patient and family, optimal use of institutional and community resources, and ensure close collaboration with other professionals involved with the care of the patient with continuity of care a priority. The palliative care of children differs from palliative care of adults. Therefore, pediatric services 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. Support by academic pediatric settings is encouraged to meet the needs of practitioners in rural areas or for practitioners with little experience in the care of seriously ill children.

There are several clinical models that have demonstrated quality care for patients and families. They include a variety of disciplines that collaborate to provide quality care. These include:

1. **Hospice Care** – a well-established program to provide patients with a prognosis of six months or less. As delineated within the Medicare Hospice Benefit, these services can be provided in the home, nursing home, residential facility, or on an inpatient unit.
2. **Palliative Care Programs** – institutional based programs in the hospital or nursing home to serve patients with life-threatening or life-limiting illnesses. Occur in hospital settings (academic, community, rehabilitation) and skilled nursing facilities. Provide services to patients anywhere along the disease continuum between initial diagnosis and death. Can include a consultation team, a fixed-bed unit, or a swing-bed unit.
3. **Outpatient Palliative Care Programs** – occur in ambulatory care settings to provide continuity of care for patients with serious or life-threatening illnesses.
4. **Community Palliative Care Programs** – occur in communities as consultative teams who collaborate with hospices or home health agencies to support seriously ill patients who have not yet accessed hospice.

The continued success of this project is evidenced by how the *Clinical Practice Guidelines for Quality Palliative Care* encourage new programs. Accomplished either as the expansion of existing palliative and hospice programs to allow greater access to care, *The Clinical Practice Guidelines for Quality Palliative Care* will: continue the development and evaluation of new and existing services, ensure consistent and high quality palliative care as measured by the National Quality Forum Preferred Practices, provide certification initiatives for specialty status in palliative care, and provide recognition of specialty status for certification initiatives in palliative care. Most importantly the *Guidelines* will serve as the basis for all palliative care settings.

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## Baseline Assumptions

The following assumptions are fundamental to the use of the NCP *Clinical Practice Guidelines for Quality Palliative Care*.

- **Goal guidelines:** These palliative care guidelines represent goals that palliative care services should strive to attain, as opposed to minimal or lowest acceptable practices.
- **Healthcare quality standards:** These palliative care guidelines assume that palliative care services will follow established practice standards and requirements for healthcare quality, such as safety, effective leadership, medical recordkeeping, and error reduction.
- **Codes of ethics:** These guidelines assume adherence to established professional and organizational codes of ethics.
- **Ongoing revision:** Palliative care guidelines will continue to evolve as professional practice, the evidence base, and the healthcare system change over time. In the revisions, these guidelines will continue to reflect current evidence-based evaluation and updating.
- **Consensus guidelines:** These clinical practice guidelines have been used as the basis for The National Quality Forum's *A National Framework and Preferred Practices for Palliative and Hospice Care Quality* and The Joint Commission's Voluntary Palliative Care Standards to promote the development of highest-quality clinical palliative care services along the healthcare continuum.
- **Specialty care:** When this document refers to specialty-level palliative care services, it assumes provision of services by palliative care professionals within an interdisciplinary team whose work reflects substantial involvement in the care of patients with life-threatening or debilitating chronic illnesses and their families. Palliative care qualifications are determined by organizations granting professional credentials and programmatic accreditation.
- **Applicability of guidelines:** These guidelines should promote integration and application of the principles, philosophy, and practices of palliative care across the continuum of care by both professional and certified caregivers in these settings.

## Domains of Quality Palliative Care

**Domain 1: Structure and Processes of Care**

**Domain 2: Physical Aspects of Care**

**Domain 3: Psychological and Psychiatric Aspects of Care**

**Domain 4: Social Aspects of Care**

**Domain 5: Spiritual, Religious and Existential Aspects of Care**

**Domain 6: Cultural Aspects of Care**

**Domain 7: Care of the Imminently Dying Patient**

**Domain 8: Ethical and Legal Aspects of Care**

# Clinical Practice Guidelines for Quality Palliative Care

Excellence in specialist-level palliative care requires expertise in the clinical management of problems in multiple domains, supported by a programmatic infrastructure that furthers the goals of care and supports practitioners. In 2004, The National Consensus Project identified eight domains as the framework for these guidelines: Structure and Processes; Physical Aspects of Care; Psychological and Psychiatric Aspects of Care; Social Aspects of Care; Spiritual, Religious, and Existential Aspects of Care; Cultural Aspects of Care; Care of the Imminently Dying Patient; and Ethical and Legal Aspects of Care.

The guidelines rest on fundamental processes that cross all domains and encompass assessment, information sharing, decision making, care planning, and care delivery. Each domain is followed by specific clinical practice guidelines regarding professional behavior and service delivery. These are followed by justifications, supporting and clarifying statements, and suggested criteria for assessing whether or not the identified expectation has been met. References to the literature supporting these recommendations are included in the guidelines. In addition, there are case examples to illustrate the operationalization of the domains into practice.

## Notes on Bibliographies

We have again included select citations that provide the evidence base for each domain of the *NCP Guidelines for Quality Palliative Care, Second Edition*. The citations reflect work published in the interim period since the first edition. They focus on well-designed, useful studies, both observational and experimental, as well as published consensus statements and expert opinions. All NCP task force members were invited to suggest key references. We also conducted a variety of literature searches in Medline and the Cochrane Collaboration and reviewed many articles. Where experimental evidence of good quality care exists, it is cited. Other citations reflect the expert opinion of consensus efforts, professional organizations, and experts in the field. This document does not represent an exhaustive review of the literature relevant to hospice and palliative care.

## Notes on Exemplars

Since the release of the first edition, at presentations, meetings, and conferences, many people have asked how to use the *Clinical Practice Guidelines for Quality Palliative Care*. The National Consensus Project Committee has offered many ideas in these discussions. However, in this second edition, we offer specific exemplars of how to implement and operationalize the *Clinical Practice Guidelines for Quality Palliative Care*. These exemplars were gleaned from various sources, including best practices demonstrated by the American Hospital Association Circle of Life Award Winners and programs that highlighted best practices in posters and conferences. We also are proud to include the National Consensus Project Leadership Award winners, who demonstrated innovation and commitment to excellence in care delivery. Supported by the Mayday Fund, these awards recognize organizations that have enhanced their palliative care services by implementing the eight domains of the *Clinical Practice Guidelines for Quality Palliative Care* and the 38 preferred palliative care practices defined in *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*.

## DOMAIN 1: Structure and Processes of Care

### **Guideline 1.1 The timely plan of care is based on a comprehensive interdisciplinary assessment of the patient and family.**

Criteria:

- Assessment and its documentation are interdisciplinary and coordinated.
- Initial and subsequent comprehensive assessments are carried out through patient and family interviews, review of medical records, discussion with other providers, physical examination and assessment, and relevant laboratory and/or diagnostic tests or procedures. The consultative evaluation should include the patient's current medical status, adequacy of diagnosis and treatment consistent with review of past history, diagnosis and treatment, and responses to past treatments.
- Assessment includes documentation of disease status, including diagnoses and prognosis; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; social, cultural, spiritual, and advance care planning concerns and preferences, including appropriateness of referral to hospice. Assessment of children must be conducted with consideration of age and stage of neurocognitive development.
- Patient and family expectations, goals for care and for living, understanding of the disease and prognosis, as well as preferences for the type and site of care, are assessed and documented.
- The assessment is reviewed on a regular basis.

### **Guideline 1.2 The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for decision making.**

Criteria:

- The care plan is based upon an ongoing assessment determined by goals set with patient and family and with consideration and discussion of the changing potential benefits and burdens of care along with assessment at critical decision points during the course of illness. Family is defined by the patient and may include relatives or friends.
- The care plan is developed with the input of patient, family, caregivers, involved healthcare providers, and the palliative care team with the additional input, when indicated, of other specialists and caregivers, such as school professionals, clergy, friends, etc.
- Care plan changes are based on the evolving needs and preferences of the patient and family over time and recognize the complex, competing, and shifting priorities in goals of care.
- The interdisciplinary team coordinates and shares the information, provides support for decision making, develops and carries out the care plan, and communicates the palliative care plan to patient and family, to all involved health professionals, and to the responsible providers when patients transfer to different care settings.
- Treatment and care setting alternatives are clearly documented and communicated and permit the patient and family to make informed choices.
- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence, and patient/family preferences. Reevaluation of treatment efficacy and patient-family preferences is documented.
- It is essential that the evolving care plan is documented over time.

**Guideline 1.3 An interdisciplinary team provides services to the patient and family consistent with the care plan. In addition to nursing, medicine, and social work, other therapeutic disciplines with important assessment of patients and families include physical therapists, occupational therapists, speech and language pathologists, nutritionists, psychologists, chaplains, and nursing assistants. For pediatrics, this should include child-life specialists. Complementary and alternative therapies may be included.**

Criteria:

- Specialist-level palliative care is delivered by an interdisciplinary team.
- The team includes palliative care professionals with the appropriate patient-population-specific education, credentialing, and experience and the ability to meet the physical, psychological, social, and spiritual needs of both patient and family. Of particular importance is hiring physicians, nurses, and social workers “appropriately trained” and ultimately certified in hospice and palliative care. Education should include a fundamental understanding of the domains of palliative care and the goals of the Medicare Hospice Benefit, in addition to pain, symptoms, grief, bereavement, and communication. Ideally this occurs in preceptorships, fellowships, or in baccalaureate and graduate specific programs. Continuing education is an essential for professionals currently in practice.
- The interdisciplinary palliative care team involved in the care of children, either as patients or as the children of adult patients, has expertise in the delivery of services for such children.
- The patient and family have access to palliative care expertise and staff 24 hours a day, seven days a week. Respite services are available for the families and caregivers of children or adults with life-threatening illnesses.
- The interdisciplinary team communicates regularly (at least weekly or more often as required by the clinical situation) to plan, review, and evaluate the care plan, with input from both the patient and family.
- The team meets regularly to discuss provision of quality care, including staffing, policies, and clinical practices.
- Team leadership has appropriate training, qualifications, and experience.
- Policies for prioritizing and responding to referrals in a timely manner are documented.

**Guideline 1.4 The use of appropriately trained and supervised volunteers within the interdisciplinary team is strongly encouraged.**

Criteria:

- If volunteers participate, policies and procedures are in place to ensure the necessary education of volunteers and to guide recruitment, screening (including background checks), training, work practices, support, supervision, and performance evaluation and to clarify the responsibilities of the program to its volunteers.
- Volunteers are screened, educated, coordinated, and supervised by an appropriately educated and experienced professional team member.

**Guideline 1.5 Support for education and training is available to the interdisciplinary team.**

Criteria:

- Educational resources and continuing professional education focused on the domains of palliative care contained in this document are regularly provided to staff, and participation is documented.

- This education also should comply with federal and state licensure and credentialing regulations.

**Guideline 1.6 In its commitment to quality assessment and performance improvement, the palliative care program develops, implements, and maintains an ongoing data driven process that reflects the complexity of the organization and focuses on palliative care outcomes.**

Criteria:

- The palliative care program must be committed to the pursuit of excellence and the highest quality of care and support for all patients and their families. Determining quality requires regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of care provided by the program.
- Quality care must incorporate attention at all times to:
  - Safety and the systems of care that reduce error.
  - Timeliness – care delivered to the right patient at the right time.
  - Patient-centered care, based on the goals and preferences of the patient and the family and also be inclusive of the principles of family-centered care.
  - Beneficial and/or effective care, demonstrably influencing important patient outcomes or processes of care linked to desirable outcomes.
  - Equitable care that is available to all in need and all who could benefit.
  - Efficient care designed to meet the actual needs of the patient so that it does not waste resources.
- A quality assessment and performance review is done across all the domains including organizational structure, education, team utilization, assessment and effectiveness of physical, psychological, psychiatric, social, spiritual, cultural, and ethical assessment and interventions. From this, the palliative care program establishes quality improvement policies and procedures.
- Quality improvement activities are routine, regular, reported, and are shown to influence clinical practice. While the palliative care organization leadership is responsible for such programs, there are designated individuals who operate the quality assessment and performance improvement program.
- The clinical practices of palliative care programs reflect the integration and dissemination of research and evidence of quality process.
- Quality improvement activities for clinical services are collaborative, interdisciplinary, and focused on meeting the identified needs of patients and their families.
- Patients, families, health professionals, and the community may provide input for evaluation of the program.

**Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families.**

Criteria:

- Emotional support is available to staff and volunteers as appropriate.
- Policies guide the support of staff and volunteers, including regular meetings for review and discussion of the impact and processes of providing palliative care.

**Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources to ensure continuity of the highest-quality palliative care across the illness trajectory.**

Criteria:

- Palliative care programs must support and promote continuity of care across settings and throughout the trajectory of illness.
- As appropriate, patients and families are routinely informed about and offered referral to hospice and other community-based healthcare resources.
- Referring physicians and healthcare providers are routinely informed about the availability and benefits of hospice and other community resources for care for their patients and families as appropriate and indicated. Policies for formal written and verbal communication about all domains in the plan of care are established between the palliative care program, hospice programs, and other major community providers involved in the patients' care.
- Policies enable timely and effective sharing of information among teams while safeguarding privacy.
- Where possible, hospice and palliative care program staff routinely participate in each other's team meetings to promote regular professional communication, collaboration, and an integrated plan of care on behalf of patients and families.
- Palliative and hospice care programs, as well as other major community providers, routinely seek opportunities to collaborate and work in partnership to promote increased access to quality palliative care across the continuum.

**Guideline 1.9 The physical environment in which care is provided should meet the preferences, needs, and circumstances of the patient and family to the extent possible.**

Criteria:

- When feasible, care is provided in the setting preferred by the patient and his or her family.
- When care is provided away from the patient's home, the care setting addresses safety and, as appropriate and feasible, flexible or open visiting hours, space for families to visit, rest, eat, or prepare meals and to meet with the palliative care team and other professionals, as well as privacy and other needs identified by the family.
- The setting should address the unique care needs of children as patients, family members, or visitors.

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## EXEMPLAR DOMAIN 1, Guideline 1.1: Documentation

### Midwest Palliative and Hospice Care Center Uses NCP Domains of Care as Framework for Thorough Interdisciplinary Assessment

At Midwest Palliative and Hospice, the interdisciplinary assessment is critical to providing care. To do a thorough evaluation, team members have included all of the National Consensus Project Domains into their consultation notes. Thus, the evaluation includes the pertinent documentation necessary for Medicare, such as history of present illness, past medical history, allergies, medications, family history, social history (which includes cultural and spiritual domains of care), a symptom review, prognosis, and physical examination. However, there is also a review of the domains, including processes of care, in terms of the patient's goal for care, a review of the areas in the physical domain, a review of psychologic and psychiatric issues, social issues, spiritual issues, care for the imminently dying, and ethical and legal issues in terms of decision making. Then they make their recommendations. Thus the notes are very comprehensive and serve as a tool for the interdisciplinary team and as a teaching tool for clinicians outside palliative care.

#### Palliative Care Consultative Report

Asked to see \_\_\_\_\_ by Dr. \_\_\_\_\_ for issues related to:

Impression:

#### Recommendations:

##### Process of Care

- Goals of Care
- Prognosis
- Disposition
- Safety

##### Physical Aspects of Care

##### Psychological Aspects of Care

##### Social Aspects of Care

##### Cultural Aspects of Care

##### Spiritual Aspects of Care

##### Ethical/Legal Aspects of Care

F/U in: \_\_\_\_\_

Note: Sample section of *Palliative Care Consultative Report* form reprinted with permission from Martha L. Twaddle, MD, FACP, FAAHPM, Chief Medical Officer, Midwest Palliative & Hospice CareCenter, 2050 Claire Court, Glenview, IL 60025

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## EXEMPLAR DOMAIN 1, Guideline 1.3: Education

### Massachusetts General Hospital's RN Residency Program Based on NCP Domains

Massachusetts General Hospital (MGH) is a 900-bed teaching hospital with a well-established palliative care service, as well as a clinical and professional development center for patient-care services. MGH was awarded a grant funded by the Health Resources and Services Administration (HRSA) to fund a nine-month nurse residency program titled, "RN Residency: Transitioning to Geriatrics and Palliative Care". The program includes classroom and mentored clinical experience and is designed as a broad survey of geropalliative care nursing to address several challenges. First, geriatrics, described as the core business of hospitals, places compelling demands on nurses, most of whom have never received formal education in the field. Second, nurses find themselves in distressing moral situations whereby they are providing aggressive care of elders with unclear goals of treatment. Third, nearly 50% of deaths occur in the hospital setting; yet research findings consistently report poor control of pain and symptoms.

The program uses the eight National Consensus Project Domains to frame the palliative care structure content and focus. With permission from the City of Hope, each of the domains has been aligned with the ELNEC curriculum, along with other materials and current research. Thus, using the state of the knowledge of geropalliative care, nurses can improve quality of care to elders and their families.

### MGH RN Residency Program Curriculum

NCP Domains	Course Materials
1. Structure and Processes	ELNEC Module – Overview of Palliative Care Module – Achieving Quality Care Module - Communication OTHER – NQF
2. Physical Aspects	ELNEC Module – Pain Management Module – Symptom Management OTHER ICU Pain Review
3. Psychological and Psychiatric	ELNEC Module – Loss and Grief OTHER Psychology Review
4. Social	OTHER Social work discussion on family systems
5. Spiritual, Religious, and Existential	OTHER Chaplaincy and Spiritual Assessment ELNEC
6. Cultural Aspects of Care	ELNEC Module – Culture
7. Care of Imminently Dying	ELNEC Module - Final Hours
8. Ethics and Legal Aspects of Care	ELNEC Module – Ethics OTHER Respecting Choices

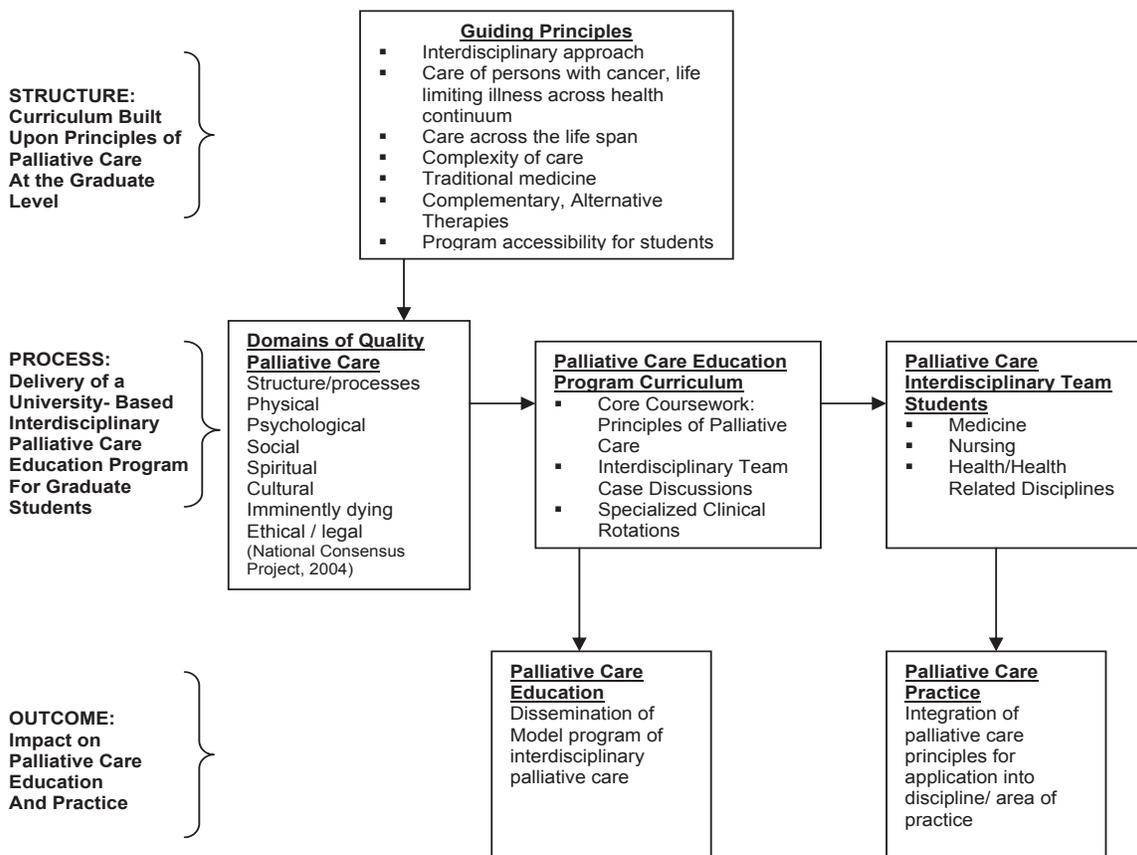
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## EXEMPLAR DOMAIN 1, Guideline 1.3: Education

### Rush University Medical Center Incorporates Eight NCP Domains into Graduate Course

Rush University Medical Center is an academic medical center in Chicago, IL. Rush has incorporated the eight NCP Domains into a National Institutes of Health-National Cancer Institute funded graduate level course called “Interdisciplinary Studies in Palliative Care”. The 8 Domains have been an instrumental guide during many phases of the organization’s work in palliative care education. They are a key element of the organizing, ‘structures-processes-outcomes’ framework used in developing the university’s education program and are important content in the palliative care course itself. The course, developed in 2006, is online with associated activities, and is offered quarterly. It has been completed by more than 390 students from the university’s graduate nursing, medicine, and allied health professions programs.

### Interdisciplinary Palliative Care Education Framework



Note: From: Breakwell, S. (2004). “Interdisciplinary Palliative Care Education Framework” in *Developing a university based palliative care education program*, p.36. Unpublished nursing practice doctoral project, RUSH University College of Nursing, Chicago and Grant funded “Interdisciplinary Palliative Care Education Program”, M. Faut-Callahan, PI (2005 – 2010), National Cancer Institute #R25CA114084-01. Used with permission.

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## **EXEMPLAR DOMAIN 1, Guideline 1.6: Quality Assessment and Performance Improvement**

### **Palliative Medicine Program at Our Lady of Lourdes Memorial Hospital in Binghamton, NY, Provides Evidence-Based Care along the Continuum**

The Palliative Medicine Program at Our Lady of Lourdes Memorial Hospital in Binghamton, NY, is dedicated to effective care for patients along the continuum. The program has used many aspects of the NCP Structure and Processes of Care to develop a solid program. They use evidenced-based practice in daily documentation of pain, dyspnea, and gastrointestinal symptoms. The assessment tool, The Edmonton Scale, is well-known and well-documented as being valid and reliable. It is used as part of an ongoing quality assessment and improvement process to look at this data monthly to see how successful they are. Additionally, members of the palliative medicine team work to role-model collaborative practice and ensure a team approach. A patient/family meeting is arranged within 24 hours of admission to the program, with the goal of including as many interdisciplinary members as possible.

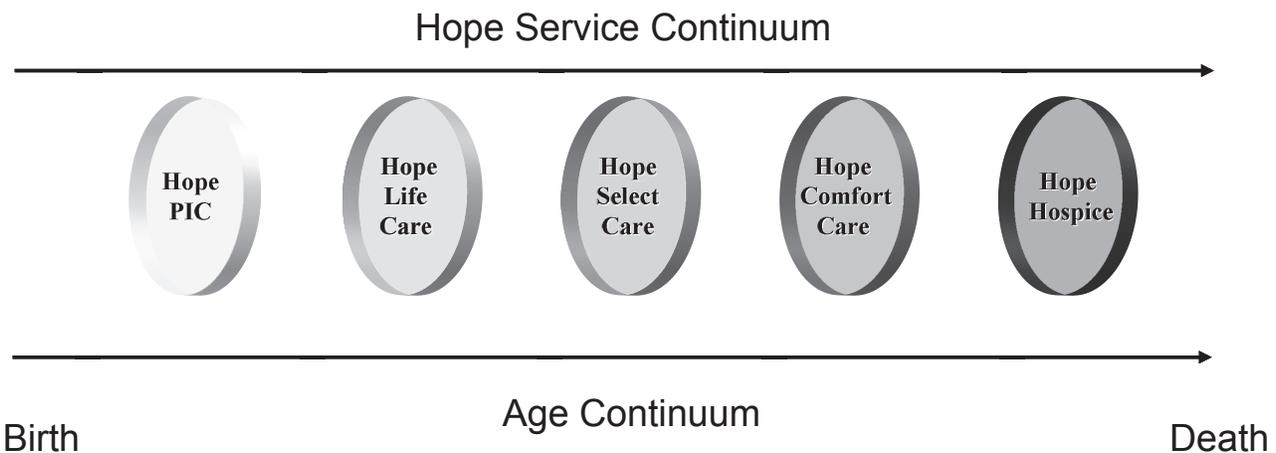


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## EXEMPLAR DOMAIN 1, Guideline 1.8: Hospice and Palliative Care Resources Along the Illness Trajectory

### Hope Hospice and Community Services Tailors Care to Five Patient Populations

In Fort Myers, FL, Hope Hospice and Community Services demonstrates a unique continuum of palliative care at the time of diagnosis to five specific populations. First, there is Hope, a program for neonates and children with life-limiting illnesses. Second, there is Hope Life Care, a Medicaid Diversion Program to help patients stay in the setting they call home. Third, there is Hope Select Care, which is a Program for All-Inclusive Care for the Elderly (PACE) that offers medical care to older adults with chronic needs within their own specialized care communities. Fourth, there is Hope Comfort Care, which is a symptom management team. Finally there is Hope Hospice. The focus is on care across the continuum and moving palliative care upstream.



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## DOMAIN 2: Physical Aspects of Care

**Guideline 2.1 Pain, other symptoms, and side effects are managed based upon the best available evidence, with attention to disease-specific pain and symptoms, which is skillfully and systematically applied.**

Criteria:

- The interdisciplinary team includes professionals with specialist-level skill in symptom control for all types of life-threatening illnesses, including physicians, nurses, social workers, rehabilitation specialists, physical therapists, occupational therapists, speech and language pathologists, psychologists, child-life specialists (and other appropriate therapists for children), and chaplains (see Domain 1: Structure and Processes of Care, 1.3).
- Regular, ongoing assessment of pain, nonpain symptoms (including but not limited to shortness of breath, nausea, fatigue and weakness, anorexia, insomnia, anxiety, depression, confusion, and constipation), treatment side effects, and functional capacities are documented through a systematic process. Validated instruments, where available, should be utilized. Symptom assessment in children and cognitively impaired patients should be performed by appropriately trained professionals with appropriate tools.
- The outcome of pain and symptom management is the safe and timely reduction of pain and symptom levels, for as long as the symptom persists, to a level that is acceptable to the patient or the family if the patient is unable to report distress.
- The response to symptom distress is prompt and tracked through documentation in the medical record.
- Barriers to effective pain management should be recognized and addressed, including inappropriate fears of the risks of side effects, addiction, respiratory depression, and hastening of death in association with opioid analgesics.
- A risk management plan should be implemented when controlled substances are prescribed for long-term symptom management.
- Patient understanding of disease and its consequences, symptoms, side effects of treatments, functional impairment, and potentially useful treatments is assessed with consideration of culture and development. The capacity of the patient to secure and accept needed care and to cope with the illness and its consequences is assessed (see Domain 3: Psychological and Domain 8: Ethics).
- Family understanding of the disease and its consequences, symptoms, side effects, functional impairment, and treatments is assessed. The capacity of the family to secure and provide needed care and to cope with the illness and its consequences is assessed with consideration of culture and development.
- Treatment of distressing symptoms and side effects incorporates pharmacological, nonpharmacological, and complementary/supportive therapies. Approach to the relief of suffering is comprehensive, addressing physical, psychological, social, and spiritual aspects (see Domain 3: Psychological and Domain 4: Social Support).
- Referrals to healthcare professionals with specialized skills in symptom management are made available when appropriate (e.g., radiation therapists, anesthesia pain management specialists, orthopedists, physical and occupational therapists, speech and language pathologists, child life specialists).
- Family is educated and supported to provide safe and appropriate comfort measures to the patient. Family is provided with backup resources for response to urgent needs (see Domain 3: Psychological and Domain 4: Social Support).

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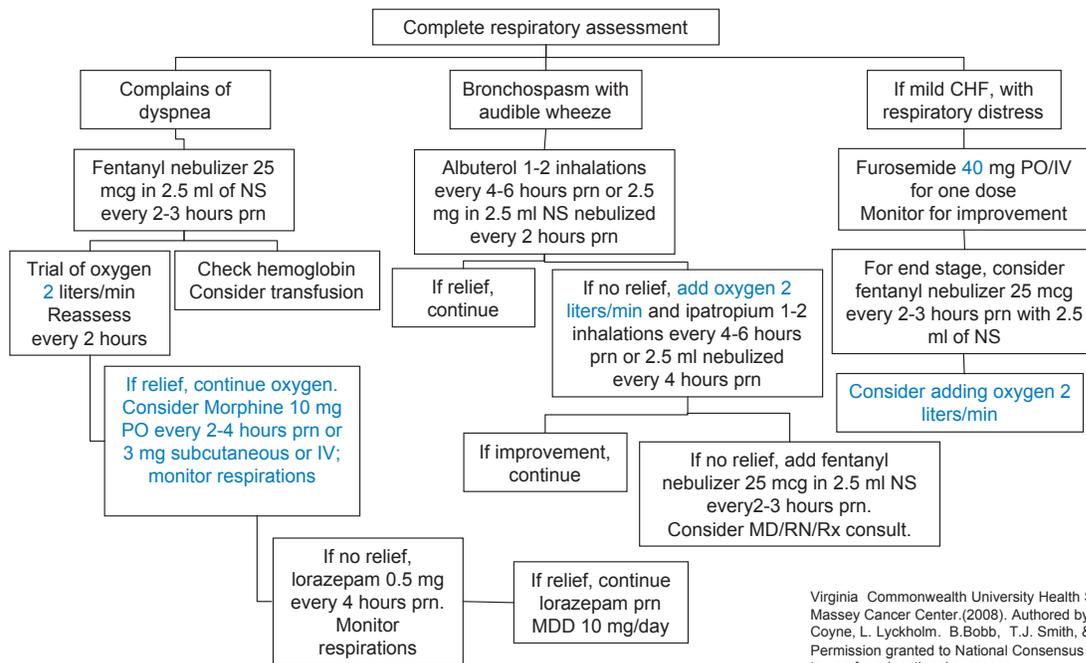
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## EXEMPLAR DOMAIN 2: Evidenced-Based Pain and Symptom Assessment and Management

### VCU Bases Systematic Approach to Pain and Symptom Management on NCP Domain 2

The Thomas Palliative Care Program of Virginia Commonwealth University/ Massey Cancer Center is a tertiary academic hospital in Richmond, VA. It has a well-established palliative care service with both an inpatient unit, a consult service seeing more than 1,600 new patients annually, as well as an outpatient clinic. It has used the National Consensus Project Domains to guide its expert care delivery. In particular, pain and symptom management is provided using a systematic approach as delineated by Domain 2, Physical Aspects of Care. Staff has a common assessment tool for evaluation and consistent management with use of evidenced-based practice to guide treatment while evaluating outcomes. This has helped not only the program's care but care provided by the entire healthcare system.

# Dyspnea



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## DOMAIN 3: Psychological and Psychiatric Aspects of Care

**Guideline 3.1 Psychological status is assessed and managed based upon the best available evidence, which is skillfully and systematically applied. When necessary, psychiatric issues are addressed and treated.**

Criteria:

- The interdisciplinary team includes professionals with patient-specific skills and training in the psychological consequences and psychiatric comorbidities of serious illness for both patient and family, including depression, anxiety, delirium, and cognitive impairment. (see Domain 2: Physical Aspects of Care).
- Regular, ongoing assessment of psychological reactions related to the illness (including but not limited to stress, anticipatory grieving, and coping strategies) and psychiatric conditions occurs and is documented. Whenever possible, a validated and context-specific assessment tool should be used.
- Psychological assessment includes patient understanding of disease, symptoms, side effects, and their treatments, as well as assessment of caregiving needs, capacity, and coping strategies.
- Psychological assessment includes family understanding of the illness and its consequences for the patient, as well as the family; assessment of family caregiving capacities, needs, and coping strategies.
- Psychiatric illnesses, such as severe depression, suicide ideation, anxiety, delirium, or patients with comorbid psychiatric illness accompanying their life-threatening illness should be treated by a psychiatrist.
- Family is educated and supported to provide safe and appropriate psychological support measures to the patient.
- Pharmacologic, nonpharmacologic and complementary therapies are employed in the treatment of psychological distress or psychiatric syndromes, as appropriate.
- Treatment alternatives are clearly documented and communicated and permit the patient and family to make informed choices.
- Response to symptom distress is prompt and tracked through documentation in the medical record. Regular reevaluation of treatment efficacy and patient-family preferences is documented.
- Referrals to healthcare professionals with specialized skills in age-appropriate psychological and psychiatric management are made available when appropriate (e.g., psychiatrists, psychologists, and social workers). Identified psychiatric comorbidities in family or caregivers are referred for treatment.
- Developmentally appropriate assessment and support are provided to pediatric patients, their siblings, and the children or grandchildren of adult patients.
- Communication with children and cognitively impaired individuals occurs using verbal, nonverbal, and/or symbolic means appropriate to developmental stage and cognitive capacity.
- Treatment decisions are based on goals of care, assessment of risk and benefit, best evidence and patient/family preferences. The goal is to address psychological needs, treat psychiatric disorders, promote adjustment, and support opportunities for emotional growth, healing, reframing, completion of unfinished business, and support through the bereavement period.

**Guideline 3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services.**

Criteria:

- The interdisciplinary team includes professionals with patient-population-appropriate education and skill in the care of patients, families and care staff experiencing loss, grief and bereavement.

- Bereavement services are recognized as a core component of the palliative care program.
- Bereavement services and follow-up are made available to the family for at least 12 months, or as long as is needed, after the death of the patient.
- Grief and bereavement risk assessment is routine, developmentally appropriate, and ongoing for the patient and family throughout the illness trajectory, recognizing issues of loss and grief in living with a life-threatening illness.
- Clinical assessment is used to identify people at risk of complicated grief and bereavement and its association with depression and comorbid complications, particularly among the elderly.
- Information on loss and grief and the availability of bereavement support services, including those available through hospice and other community programs, is made routinely available to families before and after the death of the patient, as culturally appropriate and desired.
- Support and grief interventions are provided in accordance with developmental, cultural and spiritual needs and the expectations and preferences of the family, including attention to the needs of siblings of pediatric patients and children of adult patients.
- Staff and volunteers who provide bereavement services receive ongoing education, supervision, and support.
- Referrals to healthcare professionals with specialized skills are made when clinically indicated.

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## EXEMPLAR DOMAIN 3: Evidenced-Based Psychological Assessment and Management

### PedsCare – A Pediatric Hospice and Palliative Care Program with a Focus on Patient and Family Psychological Needs

Community PedsCare is a comprehensive in-home pediatric palliative and hospice program for children with life-limiting and life-threatening conditions. The program was established in 2000 by Community Hospice of Northeast Florida in collaboration with Wolfson Children’s Hospital, Nemours Children’s Clinic, and the University of Florida. PedsCare focuses on a wide spectrum of patients and families, including the perinatal care of an unborn child with a fatal condition to young adults with congenital conditions. Their services include hospital consultation and home care to allow children and their families the most respectful death possible within the setting where they are most comfortable.

Caring for dying children requires great attention to psychological and psychiatric aspects of care. When the death of the child draws near, one way the program promotes better grieving is the use of Bereavement Baskets. The baskets contain a small handmade blanket, a journal, modeling clay to make prints of the child’s fingers, hands, or foot, a small container to hold a locket of hair, a disposable camera for pictures, a small metal token with the imprint of an angel, and brochures with information on funeral planning and grief. But the staff does not just leave a basket with the family. Team members guide the family in performing whatever of the rituals family members find therapeutic. This allows for catharsis and promotes healthy grieving.



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## Domain 4: Social Aspects of Care

### **Guideline 4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed to respond to these needs as effectively as possible.**

Criteria:

- The interdisciplinary team includes professionals with patient-population-specific skills in the assessment and management of social and practical needs during a life-threatening or chronic debilitating illness (see Domain 1: Structure and Processes of Care, Guideline 1.5).
- It is essential that practitioners skilled in the assessment and management of the developmental needs of children are available for pediatric patients and the children of adult patients, as appropriate.
- A comprehensive interdisciplinary social assessment is completed and documented to include: family structure and geographic location; relationships; lines of communication; existing social and cultural networks; perceived social support; medical decision-making; work and school settings; finances; sexuality; intimacy; living arrangements; caregiver availability; access to transportation; access to prescription and over-the-counter medicines and nutritional products; access to needed equipment; community resources, including school and work settings; and legal issues (see Domain 6).
- Routine patient and family meetings are conducted with appropriate members of the interdisciplinary team to assess understanding and address questions; provide information and help with decision making, discuss goals of care and advance care planning; determine wishes, preferences, hopes and fears; provide emotional and social support; and enhance communication.
- The social care plan is formulated from a comprehensive social and cultural assessment and reassessment and reflects and documents values, goals, and preferences as set by the patient and family over time. Interventions are planned to minimize the adverse impact of caregiving on the family and to promote caregiver and family goals and well-being.
- Referrals to appropriate services are made that meet identified social needs and promote access to care, help in the home, school or work, transportation, rehabilitation, medications, counseling, community resources, and equipment.

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## EXEMPLAR DOMAIN 4: Skilled Social Assessment from Expert Team Member

### St. Rose Dominican Hospitals Develop Innovative Social Worker Palliative Pathway Competency Matrix



**St. Rose Dominican Hospitals**

A member of CHW

St. Rose Dominican, located in Henderson, NV, is part of the Catholic Healthcare West system. Its consultative palliative care team comprises nurses, a chaplain, and a social worker. NCP Domain 4: Social Aspects of Care is a fundamental part of this program. Families are encouraged to ask for and participate in family conferences. Families are given information about such conferences in terms of who attends, meeting goals and expectations, and meeting outcomes.

Moreover, to support expertise in palliative care, there is an innovative Social Worker Palliative Pathway Competency Matrix to ensure that social workers are aware of the physical and psychological aspects of care while being able to communicate with and support patients and families.

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## DOMAIN 5: Spiritual, Religious and Existential Aspects of Care

### **Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied.**

Criteria:

- The interdisciplinary team includes professionals with skill in assessment of and response to the spiritual and existential issues common to both pediatric and adult patients with life-threatening illnesses and conditions and their families. These professionals should have education and appropriate training in pastoral care and the spiritual issues evoked by patients and families faced with life-threatening illness.
- The regular assessment of spiritual and existential concerns is documented. This includes, but is not limited to, life review, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, and life completion tasks.
- Whenever possible a standardized instrument should be used to assess and identify religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family.
- Periodic reevaluation of the impact of spiritual/existential interventions and patient-family preferences should occur with regularity and be documented. Spiritual/existential care needs, goals, and concerns are addressed and documented, and support is offered for issues of life completion in a manner consistent with the individual's and family's cultural and religious values.
- Pastoral care and other palliative-care professionals facilitate contacts with spiritual/religious communities, groups, or individuals, as desired by the patient and/or family. Of primary importance is that patients have access to clergy in their own religious traditions.
- Professional and institutional use of religious symbols is sensitive to cultural and religious diversity.
- The patient and family are encouraged to display their own religious/spiritual symbols.
- The palliative-care service facilitates and advocates for the religious or spiritual rituals as desired by patient and family, especially at the time of death.
- Referrals to professionals with specialized knowledge or skills in spiritual and existential issues are made available when appropriate.

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## EXEMPLAR DOMAIN 5: Skilled Spiritual Assessment with Sensitivity to Diversity

### MPTF Palliative Care Service Helps Those in the Entertainment Industry to “Forget the Tigers for the Moment to Taste the Sweetness of Life”

The Motion Picture and Television Fund Palliative Care Service is an innovative organization that delivers health and human services to the large numbers of people involved in the entertainment industry community in Southern California. It has an assisted living facility and a nursing home, as well as a health center and wellness center. This newly developed program used the NCP domains to frame its care.

Within their Palliative Care Program, spirituality is recognized as a significant factor that contributes to patients’ health and well-being and that facilitates transcendent meaning, purpose, and value. In the Jewish model, it is called *hitlavut ruchanit* or spiritual accompanying—walking with the patient. In the Christian model, it is called pastoring, or acting as Jesus the Shepherd. Their spiritual care is best summed up by the following parable of Buddha:

“One day a man was being chased by a vicious tiger. Coming to a precipice, with no place to go, he grabbed hold of a wild vine growing over the edge and began to climb down. The tiger sniffed at him from above. Trembling, the man looked down to where, far below, another tiger was waiting to eat him.

Only the vine sustained him but he felt that slipping. Two mice, one white and one black, little by little started to gnaw away at the vine. The man saw a luscious strawberry near him. Grasping the vine with one hand, he picked the strawberry with the other. And the parable ends: How sweet it tasted!”

If illness, disease, suffering, and pain are like the tigers that stand above and below announcing to us the futility of our lives, their care allows the patient to taste the strawberry and forget the tigers for that moment.



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## DOMAIN 6: Cultural Aspects of Care

### Guideline 6.1 The palliative care program assesses and attempts to meet the needs of the patient, family, and community in a culturally sensitive manner.

Criteria:

- The cultural background, concerns, and needs of the patient and his or her family are elicited and documented.
- Cultural needs identified by the team and family are addressed in the interdisciplinary team care plan as outlined in Domain 1.
- Communication, in all forms, with patient and family is respectful of their cultural preferences regarding disclosure, truth telling, and decision making.
- The program aims to respect and accommodate the range of language, dietary, and ritual practices of patients and their families.
- Communication should occur in a language and manner that the patient and family understand. For the patient and family who do not speak or understand English, the palliative care program should make all reasonable efforts to use appropriate interpreter services. Interpreters can be accessed both by person and phone. When professional interpreters are unavailable, other healthcare providers may be used to provide translation. In the absence of all other alternatives, family members may be used in an emergency situation and if the patient is in agreement.
- Recruitment and hiring practices strive to reflect the cultural diversity of the community.

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## EXEMPLAR DOMAIN 6: Culturally Sensitive Communication and Explanation

### UMMC Develops Terminology Tool to Aid in End-of-life Discussions

The University of Minnesota Medical Center (UMMC), Fairview, cares for a diverse immigration population. To meet the communication needs of this population, the Palliative Consult Service has worked with translation and interpreter services to develop a tool to describe common medical terms used in end-of-life discussions. This tool includes 13 terms, such as CPR, hospice, and dialysis with translations to Hmong, Russian, Somali, and Spanish. Following is an example of the cross-translation of chemotherapy.

English	Hmong	Russian	Somali	Spanish
<p><b>Chemotherapy:</b> A way to treat cancer that uses medicines to kill cancer cells. These medicines may be given by mouth or through a blood vein.</p>	<p><b>Chemotherapy:</b> Yog ib txoj kev kho mob Cancer. Cov tshuaj no siv tua kab mob cancer Cov tshuaj no noj los tau los yog tso raws dej mus hauj hlab ntsa.</p>	<p><b>Химиотерапия:</b> Способ лечения рака с использованием лекарств, чтобы убить раковые клетки. Эти лекарства могут быть в виде таблеток или даваться внутривенно.</p>	<p><b>Dawada kansarka:</b> waa hab lagu daweeyo kansarka oo la isticmaalo dawooyin si loo dilo unugyada kansarka. Daawooyinkan waxa laga siin karaa afka amma xidid dhiig.</p>	<p><b>Quimioterapia:</b> Tipo de tratamiento para el cáncer que mata las células del cáncer con medicamentos. Estos medicamentos se pueden dar por vía intravenosa o en pastillas.</p>

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## EXEMPLAR DOMAIN 6: Culturally Sensitive Communication and Explanation

### Breaking Down Barriers: Ocala, FL, Hospice Produces all Patient Literature in English and Spanish; Most Staff Members Bilingual

The Center for Comprehensive Palliative Care is a consultative service in Ocala, FL, that works in collaboration with its parent company Hospice of Marion County, Inc. It serves patients throughout the county, as well as those who seek care at Monroe Regional Medical Center. There is a growing Latino culture in the area. To work fully with this immigrant population, the staff has made all of its literature available in both Spanish and English. Moreover, most of the staff is bilingual which has decreased communication barriers.



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Número local: (352) 291-5881. Nuestro doctor y enfermera habla español.



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## **DOMAIN 7: Care of the Imminently Dying Patient**

**Guideline 7.1 Signs and symptoms of impending death are recognized and communicated in developmentally appropriate language for children and patients with cognitive disabilities with respect to family preferences. Care appropriate for this phase of illness is provided to patient and family.**

Criteria:

- The patient's and family's transition to the actively dying phase is recognized when possible and is documented and communicated appropriately, with attention to population-specific issues and age appropriateness, to patient, family, and staff.
- End-of-life concerns, hopes, fears, and expectations are addressed openly and honestly in the context of social and cultural customs and within a developmentally appropriate manner.
- Symptoms at the end of life are assessed and documented on a timely basis and are treated based on patient-family preferences.
- The care plan is revised to meet the unique needs of the patient and family at this phase of the illness. The need for higher intensity and acuity of care during the active dying phase is met by the interdisciplinary team and documented.
- Patient and family wishes regarding care setting for the death are documented. Any inability to meet these needs and preferences is reviewed and addressed by the palliative care team.
- As patients decline, the hospice referral option will be introduced (or reintroduced) for those who have not accessed hospice services as appropriate.
- The family is educated regarding the signs and symptoms of approaching death in a developmentally, culturally, and age-appropriate manner.
- Ideally, sensitive communication is done around autopsy and organ donation decision making before the time of death as appropriate.

**Guideline 7.2 Postdeath care is delivered in a respectful manner. Cultural and religious practices particular to the postdeath period are assessed and documented. Care of the body postdeath is delivered with respect to these practices, as well as in accordance to both organizational practice and local law.**

**Guideline 7.3 A postdeath bereavement plan is activated. An interdisciplinary team member is assigned to the family in the postdeath period to help with religious practices, funeral arrangements, and burial planning.**

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## EXEMPLAR DOMAIN 7: Care of Imminently Dying and Preference to Site of Death

### Palliative Care Program at Western Reserve Offers Transition to Hospice at Any Stage

The Palliative Care Program at Hospice of the Western Reserve (HWR) serves many people for whom hospice is not yet appropriate. Because of its established expertise in hospice care, the program has a wide variety of available services. This is particularly evident within Domain 7: Care of the Imminently Dying Patient. The Western Reserve program is able to offer a transition to hospice at any phase and at various sites, including at home or at their inpatient hospice facility.

Staff is attuned to ascertaining patient and family preferences for site of death. Team members assure the patient's comfort while dying and support the families in this process. They are able to facilitate effective grieving by implementing bereavement care plans that every family receives in a bereavement packet. One of the tools used as death becomes imminent is a booklet titled "The Journey's Path," which was written by HWR staff and describes the final stages of life's journey. The booklet provides information on deep sadness, grief, uneasy feelings, nearing death awareness, and the physical signs and symptoms of imminent death. "Journey's Path" assists families in understanding a patient's journey inward and offers families suggestions on how to say good-bye.



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## DOMAIN 8: Ethical and Legal Aspects of Care

### **Guideline 8.1 The patient's goals, preferences and choices are respected within the limits of applicable state and federal law, within current accepted standards of medical care, and form the basis for the plan of care.**

Criteria:

- The interdisciplinary team includes professionals with knowledge and skill in ethical, legal, and regulatory aspects of medical decision-making.
- The patient or surrogate's expressed wishes, in collaboration with the family and the interdisciplinary team, form the basis for the care plan.
- The adult patient with decisional capacity determines the level of involvement of the family in decision making and communication about the care plan.
- Evidence of patient preferences for care is routinely sought and documented in the medical record. Failure to honor these preferences is documented and addressed by the team.
- Among minors with decision-making capacity, the child's views and preferences for medical care, including assent for treatment, should be documented and given appropriate weight in decision-making. When the child's wishes differ from those of the adult decision maker, appropriate professional staff members are available to assist the child.
- The palliative care program promotes advance care planning to understand and communicate the patient's or an appropriate surrogate's preferences for care across the healthcare continuum.
- When patients are unable to communicate, the palliative care program seeks to identify advance care directives, evidence of previously expressed wishes, values and preferences, and the appropriate surrogate decision makers. The team must advocate the observance of previously expressed wishes of the patient or surrogate when necessary.
- Assistance is provided to surrogate decision makers on the legal and ethical bases for surrogate decision making, including honoring the patient's known preferences, substituted judgment, and best-interest criteria.

### **Guideline 8.2 The palliative care program is aware of and addresses the complex ethical issues arising in the care of people with life-threatening debilitating illness.**

Criteria:

- Ethical concerns commonly encountered in palliative care are recognized and addressed, using ethical principles to prevent or resolve ethical dilemmas, including: beneficence, respect for people and self-determination, and associated regulatory requirements for truth telling, capacity assessment, confidentiality, assent and permission for people not of legal age to consent, and informed consent; attention to justice and nonmaleficence and associated avoidance of conflicts of interest. The team recognizes the role of cultural variation in the application of professional obligations, including truth telling, disclosure, decisional authority, and decisions to forgo therapy (see Domain 6: Cultural Considerations). Attention must be paid to the role of children and adolescents in decision making.
- Care is consistent with the professional codes of ethics, and the scope, standards, and code of ethics of palliative care practice are modeled on existing professional codes of ethics for all relevant disciplines.
- The palliative care team aims to prevent, identify, and resolve ethical dilemmas related to specific interventions, such as withholding or withdrawing treatments (including nutrition and hydration), instituting DNR orders, and the use of sedation in palliative care.

- Ethical issues are documented; referrals are made to ethics consultants or a committee, as appropriate including case consultation, conflict resolution, policy development, and staff education.

**Guideline 8.3 The palliative care program is knowledgeable about legal and regulatory aspects of palliative care.**

Criteria:

- Palliative care practitioners are knowledgeable about legal and regulatory issues, including federal and state statutes and regulations regarding medical decision making, advance care planning and directives; the roles and responsibilities of surrogate decision-makers; appropriate prescribing of opioids and other controlled substances; pronouncing death; request for autopsy and organ transplant; and associated documentation in the medical record.
- Patients and families are routinely advised of the need to seek professional advice on creating or updating property wills and guardianship agreements.

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## EXEMPLAR DOMAIN 8, Guideline 8.1: Advance Care Planning

### California Coalition for Compassionate Care Strives to Establish POLST as the Accepted Tool for End-of-Life Care

The California Coalition for Compassionate Care (CCCC) is working with key stakeholders in California to establish the Physician Orders for Life-Sustaining Treatment (POLST) paradigm as the recognized and widely used tool in California to help ensure that patients' treatment wishes at the end of life are honored. POLST was developed at Oregon Health Science University in Portland Oregon in the early 1990s. Since then, it has been adapted and adopted in 14 states and in counties of five other states. The hallmarks of this order sheet are many: the orders are immediately recognized interventions signed by a clinician; the orders address a range of life-sustaining interventions and indicate the patient's preferences for palliative care; they are usually on brightly colored paper so that they are easily and clearly identifiable; and, finally, the orders can be honored across all care settings. The CCCC is working with various groups to individualize the form for California regulations, work in communities to establish pilot programs to help with dissemination, and to reach key groups, such as the Alliance of Catholic Health Care and the Emergency Physicians group, to ensure support for the project.



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## EXEMPLAR DOMAIN 8, Guideline 8.1: Documentation of Code Status

### Stony Brooke SOS Team Focuses on Patient Preferences for End-of-Life Decision Making

The Survivorship and Supportive Care Service was recently established at Stony Brooke Medical Center in 2007. The team, known as the SOS team, provides specialist support using a consultative approach to patients throughout the system. Serving the community on the eastern section of Long Island, NY, the hospital serves a diverse population. To ensure respect for patients' preferences, values, and beliefs, the service has a strong focus in advance care planning. This includes a very comprehensive "Do-Not-Resuscitate Progress Note" with a guide to Capacity Evaluation. This tool has facilitated conversations with patients to discuss decision making for care at the end of life.

#### Sample DNR Progress Note

DATE: _____ Time _____ To be used when a Do Not Resuscitate, (DNR) order is written after <i>oral</i> consent from: 1) Adult patient with capacity, or 2) Health care agent, or 3) Court appointed guardian, or 4) Surrogate decision maker** 5) Close friend, (requires affidavit)
<b>Note: If the patient is from a correctional facility or has mental retardation, or under the jurisdiction of the Office of Mental Retardation and Developmental Disabilities, (even if a legal guardian has been appointed), Do Not Proceed until Risk Management has been notified. Telephone: 4 2823 or via pager.</b>
The decision regarding DNR has been made by the <input type="checkbox"/> patient, <input type="checkbox"/> guardian, <input type="checkbox"/> health care agent or <input type="checkbox"/> surrogate Name _____ Relationship to patient _____
<b>Note:</b> (See Decision to Forego Life Sustaining Treatment Admin. P&P capacity guideline attachment).
<b>A second physician must concur if patient lacks capacity.</b> See Concurring Physician Determination section on reverse side. (Check one) 1. <input type="checkbox"/> Patient has capacity; Go to Section 3. <input type="checkbox"/> <b>Attending Physician determination that patient lacks capacity</b> "I have examined the patient and his /her medical record and have determined that the patient lacks the ability to understand and appreciate the nature and consequences of a DNR order, including benefits and burdens of such an order and to reach an informed decision regarding the order." <i>Describe the cause, nature and extent of the lack of capacity:</i> _____ _____ _____
<i>Probable duration:</i> _____

Note: The Progress Note is based on Public Health Law (article 29-B) by the NY State Assembly 1/7/1987. It is modeled after the NY State MOLST form issued 10/2003 by the Rochester Health Commission. It was approved for use at Stony Brook University Medical Center in 3/2008. It is part of their policy on Foregoing Life-Sustaining Treatment. Reprinted with permission from Stony Brook University Medical Center.

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## CONCLUSION

Palliative care is a dynamic process of supporting patients with debilitating and life-threatening illness and their families. Regardless of the duration of such an illness, palliative care serves patients of any age from diagnosis of a disease until cure or until death and then supports families through the bereavement period. The goal is to assist with the care needs of patients and their families to achieve the best possible quality of life in accordance with their values, preferences, and beliefs. Palliative care is delivered through skilled and interdisciplinary attention to pain and other distressing symptoms; emotional, spiritual and practical support; assistance with complex medical decision-making; and coordination across the continuum of care settings.

Clinical practice guidelines are the accepted means of promoting quality, consistency, and comprehensiveness across the many domains of health care. The adoption of these guidelines in the United States has established palliative care as an integral component of the health care of persons living with life-threatening and debilitating chronic illness. Palliative care programs understand the key elements of providing palliative care including organizational structure, resource requirements, and performance measures. As the growth of palliative care continues, it is hoped that these *Clinical Practice Guidelines for Palliative Care, Second Edition*, will provide a blueprint to strengthen existing programs and foster a solid foundation for newly created or developing programs.

Finally, these guidelines for quality palliative care programs represent a consensus opinion of the major palliative care organizations and leaders in the United States and are based both on the available scientific evidence and expert professional opinion. With the systematic evaluation of care and used in tandem with the National Quality Forum Preferred Practices, the *Clinical Practice Guidelines for Palliative Care, Second Edition*, provide a roadmap to ensure the future of palliative care. Moreover, it assures access to palliative care to all patients and families with consistent services that can be expected and relied upon.

# Appendix 1: National Consensus Project Domains and Corresponding National Quality Forum Preferred Practices

<p><b>DOMAIN 1: PROCESSES AND STRUCTURE OF CARE</b></p>	<p><b>PREFERRED PRACTICE 1</b> Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).</p> <p><b>PREFERRED PRACTICE 2</b> Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.</p> <p><b>PREFERRED PRACTICE 3</b> Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.</p> <p><b>PREFERRED PRACTICE 4</b> Provide adequate training and clinical support to assure that professional staff is confident in their ability to provide palliative care for patients.</p> <p><b>PREFERRED PRACTICE 5</b> Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.</p> <p><b>PREFERRED PRACTICE 6</b> Formulate, utilize and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient’s care.</p> <p><b>PREFERRED PRACTICE 7</b> Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient’s goals, preferences, values and clinical information so that continuity of care and seamless follow-up are assured.</p>
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	<p><b>PREFERRED PRACTICE 8</b> Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.</p> <p><b>PREFERRED PRACTICE 9</b> Patients and caregivers should be asked by palliative and hospice care programs to assess physicians’/healthcare professionals’ ability to discuss hospice as an option.</p> <p><b>PREFERRED PRACTICE 10</b> Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.</p> <p><b>PREFERRED PRACTICE 11</b> Provide education and support to families and unlicensed caregivers based on the patient’s individualized care plan to assure safe and appropriate care for the patients.</p>
<p><b>DOMAIN 2: PHYSICAL ASPECTS OF CARE</b></p>	<p><b>PREFERRED PRACTICE 12</b> Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.</p> <p><b>PREFERRED PRACTICE 13</b> Assess and manage symptoms and side effects in a timely, safe and effective manner to a level acceptable to the patient and family.</p>
<p><b>DOMAIN 3: PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE</b></p>	<p><b>PREFERRED PRACTICE 14</b> Measure and document anxiety, depression, delirium, behavioral disturbances and other common psychological symptoms using available standardized scales.</p> <p><b>PREFERRED PRACTICE 15</b> Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.</p> <p><b>PREFERRED PRACTICE 16</b> Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.</p> <p><b>PREFERRED PRACTICE 17</b> Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after the death of the patient.</p>

<p><b>DOMAIN 4: SOCIAL ASPECTS OF CARE</b></p>	<p><b>PREFERRED PRACTICE 18</b>  Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis, and advance care planning, and to offer support.</p> <p><b>PREFERRED PRACTICE 19</b>  Develop and implement a comprehensive social care plan that addresses the social, practical, and legal needs of the patients and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.</p>
<p><b>DOMAIN 5: SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE</b></p>	<p><b>PREFERRED PRACTICE 20</b>  Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.</p> <p><b>PREFERRED PRACTICE 21</b>  Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual care counseling or through the patient’s own clergy relationships.</p> <p><b>PREFERRED PRACTICE 22</b>  Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.</p> <p><b>PREFERRED PRACTICE 23</b>  Specialized palliative and hospice spiritual care professional should build partnerships with community clergy and provide education and counseling related to end-of-life care.</p>

<p><b>DOMAIN 6: CULTURAL ASPECTS OF CARE</b></p>	<p><b>PREFERRED PRACTICE 24</b>          Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communicate, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving, and funeral/ burial rights.</p> <p><b>PREFERRED PRACTICE 25</b>          Provide professional interpreter services and culturally sensitive materials in the patient’s and family’s preferred language.</p>
<p><b>DOMAIN 7: CARE OF THE IMMINENTLY DYING PATIENT</b></p>	<p><b>PREFERRED PRACTICE 26</b>          Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.</p> <p><b>PREFERRED PRACTICE 27</b>          Educate the family on a timely basis regarding signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.</p> <p><b>PREFERRED PRACTICE 28</b>          As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death and fulfill patient and family preferences when possible.</p> <p><b>PREFERRED PRACTICE 29</b>          Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about using narcotics and of analgesics hastening death.</p> <p><b>PREFERRED PRACTICE 30</b>          Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.</p> <p><b>PREFERRED PRACTICE 31</b>          Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient’s death, when the family remains the focus of care.</p>

**DOMAIN 8: ETHICAL AND LEGAL ASPECTS OF CARE**

**PREFERRED PRACTICE 32**

Document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.

**PREFERRED PRACTICE 33**

Document the patient/surrogate preferences for goals of care, treatment options, and settings of care at first assessment and at frequent intervals as conditions change.

**PREFERRED PRACTICE 34**

Convert the patient treatment goals into medical orders, and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care through a program such as the Physician Orders for Life-Sustaining Treatments (POLST) Program.

**PREFERRED PRACTICE 35**

Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to Health Insurance Portability and Accountability Act (HIPPA) regulations (for example, using Internet-based registries or electronic personal health records).

**PREFERRED PRACTICE 36**

Develop healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals (for example, the Respecting Choices and Community Conversations on Compassionate Care programs)

**PREFERRED PRACTICE 37**

Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.

**PREFERRED PRACTICE 38**

For minors with decision making capacity, document the child's views and preferences for medical care, including assent for treatment, and give appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision maker.

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## **Appendix 3: Organizations Endorsing the 2004 NCP Clinical Practice Guidelines for Quality Palliative Care**

*“We have endorsed the Clinical Practice Guidelines for Quality Palliative Care developed by the National Consensus Project for Quality Palliative Care. These guidelines are for all health care professionals to help address the growing population of patients with advanced illness.”*

### **Center to Advance Palliative Care**

**National Hospice and Palliative Care Coalition comprising: the American Academy of Hospice and Palliative Medicine, the Hospice and Palliative Nurses Association, and the National Hospice and Palliative Care Organization**

**Academy of Medical-Surgical Nurses**

**American Academy of Ambulatory Care Nursing**

**American Academy of Pediatrics**

**American Alliance of Cancer Pain Initiatives**

**American Association of Colleges of Nursing**

**American Association of Critical Care Nurses**

**American Association of Neonatal Nurses**

**American Association of Spinal Cord Injury Nurses**

**American Board of Hospice and Palliative Medicine**

**American College of Nurse Practitioners**

**American College of Surgeons**

**American Geriatrics Society**

**American Medical Directors Association**

**American Nephrology Nurses Association**

**American Pain Foundation**

**American Pain Society**

**American Society for Bioethics and Humanities**

**American Society for Pain Management Nursing**

**American Society of Law, Medicine, and Ethics**

**American Society of Pediatric Hematology/Oncology**

**American Society of Plastic Surgical Nurses**

**Association of Nurses in AIDS Care**

**Association of Pediatric Oncology Nurses**

**Dermatological Nurses Association**

**Emergency Nurses Association**

**Hospital Corporation of America**

**International Association for Hospice and Palliative Care**

**National Association of Directors of Nursing Administration for Long-Term Care**

**National Association of Social Workers**

**National Association of Clinical Nurse Specialists**

**Oncology Nursing Society**

**Sigma Theta Tau (Honorary Nursing Society)**

**Society of Critical Care Medicine**

**Society of Hospital Medicine**

**Society of Internal General Medicine**

**Society of Pediatric Nurses**

**Supportive Care Coalition: Pursuing Excellence in Palliative Care**

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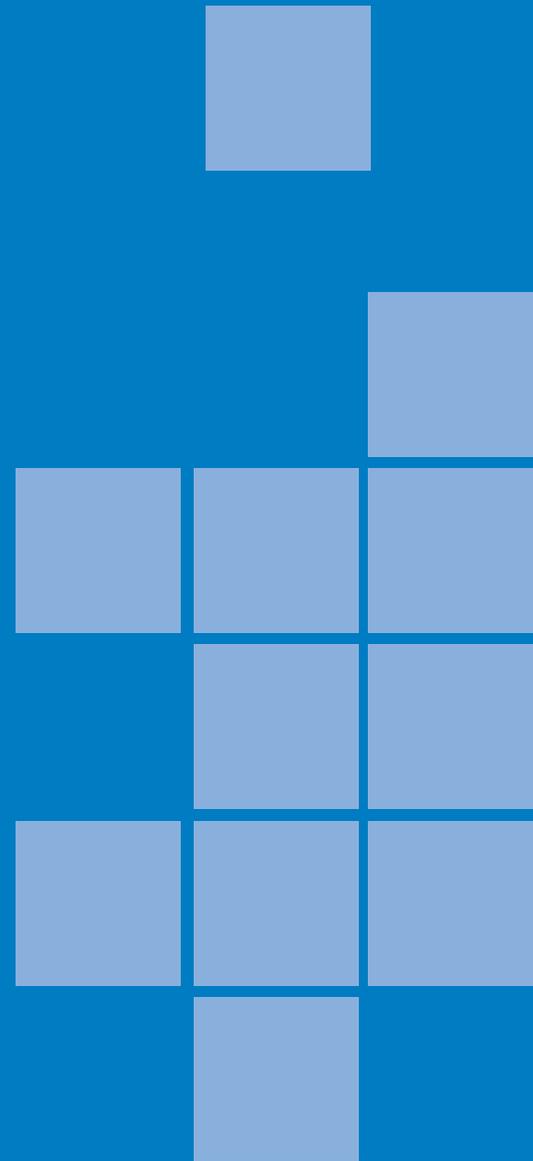
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