


# Clinical Practice Guidelines for Quality Palliative Care

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THIRD EDITION

**National Consensus Project**  
FOR QUALITY PALLIATIVE CARE



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**Publisher**

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

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FOR QUALITY PALLIATIVE CARE

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## Foreword

The number of individuals with a serious or life threatening illness continues to grow as the result of an aging population and advances in technology that allow increased longevity. In order to improve quality of life during serious illness or life threatening illness, an increasing number of palliative care programs have developed. Palliative care is rooted in the interdisciplinary hospice model of care, introduced to the United States over 30 years ago as a grassroots movement. Throughout the country, hospices, with their focus on holistic and team-based care, provide care to patients and their families at the end-of-life. Within their communities, hospices serve as a resource for patients and families facing serious or life threatening illness and also offer grief and bereavement support.

Today, the initiation of palliative care increasingly begins at the diagnosis of a serious or life threatening illness. Contemporary definitions of palliative care reflect the expansion of care throughout the illness trajectory, with a patient and family centered focus. Palliative care is provided across all health settings including: acute care hospitals, rehabilitation hospitals, ambulatory settings, long term care settings, community programs within home health or hospice organizations, and hospices. Palliative care is delivered by interdisciplinary teams consisting of chaplains, nurses (professional registered nurses such as RN, APRNs and LVNs/LPNs as well as other nursing disciplines such as nursing assistants or aides) physicians, and professional social workers. Other disciplines such as licensed massage therapists, art and music therapists, and child life experts often collaborate with the palliative care team. Palliative care is available to all populations across the life span including neonates, children, and older adults in various settings. Palliative care team members manage pain and other symptoms; facilitate person-centered communication, promote decision making; and coordinate care across settings throughout the disease trajectory.

The mission of the National Consensus Project for Quality Palliative Care is to create clinical practice guidelines that improve the quality of palliative care in the United States. Specifically, the *Clinical Practice Guidelines for Quality Palliative Care* promote quality palliative care, foster consistent and high standards in palliative care, and encourage continuity of care across settings. Since there is shared responsibility for palliative care across health care settings, the emphasis is on collaborative partnerships within and between hospitals, community centers, hospices, and home health agencies to ensure quality, continuity, and access to palliative care.

Palliative care is a dynamic field and evolves in response to patient and family needs and the growing evidence base. The development and revision of *Clinical Practice Guidelines for Quality Palliative Care* is accomplished through a consensus process among representatives of the leading hospice and palliative care organizations. The *Clinical Practice Guidelines for Quality Palliative Care* set high expectations for excellence, rather than basic competence for existing programs. They serve as a manual or blueprint to create new programs and guide developing programs. The inaugural version of the *Clinical Practice Guidelines for Quality Palliative Care* by the National Consensus Project (NCP) described the core precepts and structure of clinical care programs. Two years later, the National Quality Forum (NQF), the nation's leading public-private partnership devoted to improving quality of care in the nation's healthcare system, adopted the *Clinical Practice Guidelines for Quality Palliative Care* within the document *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*.

As part of its mission, the NCP stipulated and committed to ongoing revision and dissemination of the Clinical Practice Guidelines. Therefore, in 2009, the NCP revised the guidelines to reflect the tremendous growth and transformation in the field of hospice and palliative care, acknowledging the diverse array of models and approaches to care for this complex population. Now, five years later, the number of hospices continues to grow

and palliative care continues to gain momentum reflected in the establishment of palliative care teams at the majority of U.S. hospitals with an increasing presence in ambulatory care settings, nursing homes, and community home care programs. As in previous versions, the current 2013 edition was produced through a consensus process among the leading professional hospice and palliative care organizations. In this revision, the emphasis is on continuity, consistency, and quality of care.

In keeping with its vision, the NCP has kept the essence of its eight core palliative care domains created in the first edition of *The Clinical Practice Guidelines*. One modification, however, is the wording of Domain 7 – Care of the Imminently Dying Patient which has been changed to Care of the Patient at End of Life to expand the focus of care. Within the guidelines themselves, there have been many revisions. Content has been expanded and various benchmarks, standards, and expectations for quality have been clarified. The result is a broader and more inclusive document, applicable to all health settings. Most important, the revised guidelines reflect changes in practice, policy, and research. In keeping with the Council of Medical Specialty Societies *Principles for the Development of Specialty Society Clinical Guidelines*, all participants on the Task Force have completed Conflict of Interest Forms. We recognize that palliative care will continue to evolve. We welcome your feedback on the *Clinical Practice Guidelines for Quality Palliative Care* and their utility in the development and management of your program.

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In the nine 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, nursing, and social work specialty. This revision reflects the continued consensus process and collaboration of the Task Force of the National Consensus Project for Quality Palliative Care. The task force extends its appreciation to all the health care professionals who offered their support, experience, and thoughtful comments throughout the revision process.

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# 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. The result was the formation of the National Consensus Project for Quality Palliative Care (NCP) with representation from the five major hospice and palliative care organizations at that time: 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 National Consensus Project for Quality Care created the *Clinical Guidelines for Quality Palliative Care* which describe core concepts and structures for quality palliative care, including eight domains of practice.

The 2009 revision of these guidelines reflected the ongoing collaboration of the Hospice and Palliative Care Coalition composed of: the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, and the National Hospice and Palliative Care Organization. The revision further delineated the domains. This 2013 revision continues as a collaborative process of the National Coalition for Hospice and Palliative Care: AAHPM, CAPC, and HPNA; joined by the newest member of the Coalition, the National Palliative Care Research Center (NPCRC). The National Association of Social Workers (NASW) and NHPCO are participants of the National Consensus Project.

## Introduction

In the ten years since the establishment of The National Consensus Project for Quality Palliative Care, the number of hospice programs has increased by 47 percent and non-hospice palliative care programs have increased by 148 percent in hospitals with over 50 beds.<sup>1,2</sup> In 2011, there were approximately 2,513,000 deaths in the United States with 1,059,000 (46%) of those deaths occurring under the care of one of over 5000 hospices.<sup>1</sup> Palliative care services have expanded similarly across hospital and community care settings including: acute care units, emergency and critical care departments, outpatient settings, and within innovative community programs for patients with chronic conditions, such as neurological, cardiac, and pulmonary disease.<sup>3</sup> Research has demonstrated high value care for patients served by palliative care teams in the hospital.<sup>4,5</sup> Research has also found that hospices use reduces Medicare program expenditures. One study revealed costs during the last year of life were decreased by an average of \$2309 per hospice user.<sup>6</sup>

In the years since the 2009 revision of the *Clinical Practice Guidelines for Quality Palliative Care*, several milestones have been achieved in the field of hospice and palliative care. In 2009, the Accreditation Council for Graduate Medical Education recognized hospice and palliative medicine as a subspecialty of eleven different parent boards, thereby providing legitimacy to the field. This paved the way for the development of hospice and palliative medicine graduate medical education fellowships for physicians, now an eligibility requirement for the hospice and palliative medicine board certifying examination. A new examination is in development for hospice medical directors.<sup>7</sup>

In nursing, an increasing number of graduate programs have incorporated palliative nursing into their curricula. Work is in process for advanced practice nurse education for mid-career clinicians to provide primary palliative care, along with the development of a limited number of advanced practice palliative nursing fellowships for

preparation into the specialty. Two new examinations were developed by the National Board of Certification of Hospice and Palliative Nurses: for pediatric hospice and palliative care registered nurses, and hospice palliative care administrators. The development of a new exam for professionals involved in perinatal loss is anticipated in the next year.<sup>8</sup>

In 2008 and 2009, The National Association of Social Workers, in collaboration with the National Hospice and Palliative Care Organization, developed a certification for master's prepared social workers (MSWs)<sup>9,10</sup> and bachelor's prepared social workers (BSW). The Council on Social Work Education's Gero-Ed Center created teaching resources related to hospice, palliative care, loss, and grief, to be incorporated in undergraduate and graduate social work curricula.<sup>11</sup> Work continues in other disciplines to promote education and clinical experience in hospice and palliative care. Finally, The Joint Commission now offers specialty Palliative Care Certification for hospital programs. Criteria for the certification survey are based on these *Clinical Practice Guidelines*.<sup>12</sup>

### Health Care Reform and Palliative Care

Further development of palliative care occurred with the passage of the Patient Protection and Affordable Care Act of 2010 (PPACA).<sup>13</sup> The legislation included a new provision allowing children covered under either Medicaid or the Children's Health Insurance Program (CHIP) to receive simultaneous access to both hospice and curative care.<sup>13</sup> A similar simultaneous care demonstration project was also a provision of PPACA, with the intent of testing, in 15 sites nationwide, the option for concurrently offering hospice and regular Medicare Part A services. Given palliative care's demonstrated quality improvement and impact on health care value, new delivery and payment models rewarding quality over quantity of care create an opportunity for hospice and palliative care programs to participate in novel health delivery paradigms such as accountable care organizations (ACOs), bundled payments, and patient-centered medical homes (PCMHs).<sup>14</sup> There is greater potential to promote introduction of palliative care in all settings.

### Quality Measures

Quality is an underlying goal of palliative care. The endorsement of the NCP *Clinical Practice Guidelines* by the National Quality Forum (NQF) in 2006 established initial areas within which to develop outcome measures for palliative care programs.<sup>15</sup> In 2008, the National Priorities Partnership, a consortium of US health care organizations working with NQF, identified palliative care as one of six top priorities for improving the U.S. health system.<sup>16</sup> They developed a National Priority Partners Palliative and End of Life Work Group to consider next steps.

In 2011, as required by the Affordable Care Act, NQF convened the Measure Applications Partnership (MAP), an independent entity that reports directly to the Health and Human Services Secretary and advises on quality measures across all healthcare settings.<sup>17</sup> One of the MAP Work Groups, the Post-Acute/Long Term Care (PAC/LTC) Work Group, is responsible for reviewing and advising on hospice and palliative care measures. The June 2012 MAP Final Report on Performance Measurement Coordination Strategy for Hospice and Palliative Care states that, "while measurement in this area is new, MAP suggests a phased approach that emphasizes clinically-focused measures at first, but quickly expands to more measures that follow the patient and their full set of experiences rather than the setting or fragments of a patient's care (often referred to in this report as 'cross-cutting')." <sup>17</sup> The MAP report also addresses quality reporting in palliative care, by stating "while there is not a formal quality reporting program for palliative care, settings in which palliative care is provided (e.g., hospitals, home health) are required to participate in federal quality initiatives."



In 2010, the PPACA directed the Centers for Medicare and Medicaid Services (CMS) to implement an annual quality reporting program for hospice organizations beginning in 2013 that includes a financial incentive for hospice provider participation. In February 2012, the NQF endorsed 14 quality measures for palliative and hospice care.<sup>16</sup> The goal of these measures is to ensure the provision of high quality palliative care and end of life care. The measures, some of which are applicable to all clinical settings and provider types, will help hospice and palliative care providers to improve quality of care and generate ideas for future research.

## Research

Recently, published studies confirm that palliative care improves quality of life for patients and their families.<sup>18,19</sup> Building the evidence base to support quality requires adequate funding for relevant research and its publication. Private foundations continue to be an important funding source to support palliative care researchers, but increased federal funding is also needed to finance larger investigations. In 2004, the year the first version of the Consensus Guidelines was published, the National Institutes of Health (NIH) supported 162 projects related to palliative care, up from 53 relevant projects in 1995. In 2010, 309 palliative care projects received NIH funding.<sup>20</sup> A search for palliative care clinical trials using PubMed shows similar growth: 180 published trials in 2004 and 252 in 2010. The National Palliative Care Research Center (NPCRC) has been a central organizing force promoting and facilitating the conduct of palliative care research and has supported many of the researchers whose work appears in the Bibliography section of this document. The 2011 National Institute of Nursing Research Summit entitled the *Science of Compassion* reviewed the current research in palliative care, described barriers to research, and suggested strategies for progress and continued research (NINR).<sup>21</sup> Future revisions of the *Clinical Practice Guidelines* will reflect continued growth in the evidence base underlying palliative care practice with more advanced research.

## Populations Served

In an effort to improve access to palliative care within all patient populations in need, NHPCO released three publications in 2009; *Standards of Practice for Pediatric Palliative Care and Hospice* along with the companion publication, *Facts and Figures on Pediatric Palliative and Hospice Care in America*,<sup>22,23</sup> and *Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings*.<sup>24</sup> In 2010, HPNA produced a pediatric resource, *Just in Time Guide: A Primer for Pediatric Palliative Care at Home*.<sup>25</sup> In 2010, NHPCO promoted a campaign for Veterans called, “We Honor Veterans” in collaboration with the Department of Veterans Affairs.<sup>26</sup> The End of Life Nursing Education Consortium (ELNEC) provided specialized education for nurses at Veterans Administration Facilities.<sup>27</sup> CAPC supported pediatric palliative care program development and provided training to all U.S. VA Medical Centers in 2009-2011.

With this background, this current revision of the National Consensus Project Clinical Practice Guidelines provides the following updates. For the purposes of this document, the term *serious or life-threatening illness* is assumed to encompass populations of patients at all ages within the broad range of diagnostic categories, living with a persistent or recurring medical condition that adversely affects their daily functioning or will predictably reduce life expectancy. Correspondingly, populations to be considered for palliative care include:

- Individuals living with chronic and life-threatening injuries from accidents or other forms of trauma
- Neonates, children, adolescents, and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care, supported by others to perform their activities of daily living
- Neonates, children, adolescents, and adults with developmental and intellectual disabilities who develop serious or life threatening illness

- Individuals, of any age, with acute, serious, and life-threatening illnesses (e.g. severe trauma, acute stroke, and leukemia), where cure or reversibility is a realistic goal, but the conditions themselves and/or their treatments pose significant burdens and result in poor quality of life
- People living with progressive chronic conditions (e.g. peripheral vascular disease, malignancies, renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders, and the various forms of dementia)
- Seriously and terminally ill patients (e.g. 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
- Vulnerable, underserved, and under-resourced populations who develop serious or life threatening illness (e.g. homeless individuals, immigrants, individuals with low income, oppressed racial and ethnic groups, veterans, prisoners, older adults, and individuals with mental illness)

## Defining Palliative Care

The definition of palliative care used to characterize palliative care in the United States described by both the US Department of Health and Human Services (HHS) Centers for Medicare & Medicaid Services (CMS) and the National Quality Forum (NQF) states:

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.<sup>15,28</sup>

The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

Prior versions of the NCP specifically describe palliative care delivery as follows, “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.”<sup>29</sup>

## Summary of Revisions in the Domains

In each edition, the Clinical Practice Guidelines are revised to reflect current practice. Except for Domain 7, in which the title has been changed from Care of the Imminently Dying Patient to Care of the Patient at the End of Life, the domains remain consistent with past editions and form the basis of practice. The underlying tenets of palliative care in this document include: patient and family centered palliative care; comprehensive palliative care with continuity across health settings; early introduction of palliative care at diagnosis of a serious disease or life threatening condition; interdisciplinary collaborative palliative care; clinical and communication expertise

within palliative care team members; relief of physical, psychological, emotional, and spiritual suffering and distress of patients and families; a focus on quality; and equitable access to palliative care services. Each domain has been significantly updated as described below.

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

The Structure and Process Domain was enhanced to describe and accentuate the current state of the field with emphasis on interdisciplinary Team (IDT) engagement and collaboration with patients and families. There is emphasis on coordinated assessment and continuity of care across healthcare settings. Clarity and specificity of interdisciplinary team composition, team member qualifications, necessary education, training, and support are described. Finally, the quality assessment process and improvement section incorporates the new mandates for quality under the Patient Protection and Affordable Care Act.

### **Domain 2: Physical Aspects of Care**

The Physical Domain emphasizes the assessment and treatment of physical symptoms with appropriate, validated tools. Management of symptoms is multidimensional with pharmacological, interventional, behavioral, and complementary interventions. The utilization of explicit policies for the treatment of pain and symptom management, as well as safe prescribing of controlled medications is recommended.

### **Domain 3: Psychological and Psychiatric Aspects**

The Psychological and Psychiatric Domain has been significantly revised and expanded to focus on the collaborative assessment process of psychological concerns and psychiatric diagnoses. Essential elements are described and include patient-family communication on assessment, diagnosis, and treatment options for common conditions in context of respect for goals of care of the patient and family. New to the domain are the description and required elements of a bereavement program.

### **Domain 4: Social Aspects of Care**

The Social Domain now has greater emphasis on interdisciplinary engagement and collaboration with patients and families to identify, support, and capitalize on patient and family strengths. Essential elements of a palliative care social assessment are defined. The role of the professional social worker with a bachelor's or master's degree in social work is described.

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

The Spiritual Domain now includes a definition of spirituality, stressing assessment, access, and staff collaboration in attending to spiritual concerns throughout the illness trajectory. Requirements for staff training and education in provision of spiritual care are offered. There is stronger emphasis on the responsibility of the interdisciplinary team, inclusive of an appropriately trained chaplain, to explore, assess, and attend to spiritual issues of the patient and family. The domain promotes spiritual and religious rituals and practices for comfort and relief.

### **Domain 6: Cultural Aspects of Care**

The Cultural Domain defines "culture" and cultural competence for the interdisciplinary team, underscoring culture as a source of resilience and strength for the patient and family. New content accentuates cultural and linguistic competence including plain language, literacy, and linguistically appropriate service delivery.

## Domain 7: Care of the Patient at the End of Life

The Care of the Patient at the End of Life Domain highlights communication and documentation of signs and symptoms of the dying process in the circle of care: the patient, the family, and all other involved health providers. The importance of meticulous assessment and management of pain and other symptoms is underscored. The essential attention to family guidance as to what to expect in the dying process and the post death period is emphasized. Bereavement support beginning with anticipatory grief in the period before the actual death and continues through the actual death is stressed. Social, spiritual, and cultural aspects of care are of utmost concern throughout the process.

## Domain 8: Ethical and Legal Aspects of Care

The Ethical and Legal Domain is now restructured into three sections: advance care planning, ethics, and the legal aspects of care. Under advance care planning, the responsibility of the palliative care team to promote ongoing discussion about goals of care along with completion and documentation of advance care planning documents is emphasized. Under ethical issues, there is acknowledgement and affirmation of the frequency and complexity of ethical issues in palliative care. Team competencies in the identification and resolution of commonly encountered ethical issues are described, with emphasis on the importance of seeking advice and counsel from ethics committees. Under legal issues, there is acknowledgement of the complex legal and regulatory issues that arise in palliative care that require team members to understand their respective scope of practice within the provision of palliative care. Finally, there is new emphasis on the necessity of and access to expert legal counsel, essential for navigating the intricate and sensitive legal and regulatory issues in palliative care.

## Conclusion

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. As health care evolves, the *Clinical Practice Guidelines* require revision to reflect the continuing maturation of the field, changes in practice, and developments in the palliative care evidence base. Second, seminal events, such as health care reform mandated by the Patient Protection and Affordable Care Act, development of The Joint Commission palliative care advanced certification, and endorsement of new palliative care quality measures by the National Quality Forum, require new perspectives on the role and contribution of palliative care in a changing health system landscape. Finally, publication of significant new palliative care outcomes research findings necessitate that the principles and practices of quality palliative care reflect the highest quality evidence available.

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## Clinical Practice Guidelines for Quality Palliative Care

In 2004, the National Consensus Project identified eight important domains in the creation and maintenance of quality palliative care. They are: Structure and Processes, Physical Aspects of Care, Psychosocial and Psychiatric Aspects of Care, Social Aspects of Care, Spiritual, Religious, and Existential Aspects of Care, Cultural Aspects of Care, Care of the Patient at the End of Life, and Ethical and Legal Aspects of Care. Within each domain, we offer guidelines that delineate optimal practice. The guidelines rest on the principles of assessment, information sharing, decision-making, care planning, and care delivery. Within each guideline, there are corresponding descriptions, clarifying statements, and assessment criteria for meeting the expectation. At the end of the document, there is a selected bibliography with references to support the practices recommended in the guidelines.

### Note on the Bibliography

To support the recommendations and conclusions in this document, select publications are provided. This bibliography is not an exhaustive review of the hospice and palliative care literature. Rather, it is a list of selected citations from a variety of journals from late 2008 to 2012 published since the last edition of the *Clinical Practice Guidelines*. Literature searches from various data bases reflect a sampling of clinical practice, models of care, and the economics of palliative care in the United States. Both qualitative and quantitative studies are included, as well as published consensus statements, expert opinions, and statements from professional organizations.



## DOMAIN 1: STRUCTURE AND PROCESSES OF CARE

**Guideline 1.1 A comprehensive and timely interdisciplinary assessment of the patient and family forms the basis of the plan of care.**

**Criteria:**

- Palliative assessment and documentation are interdisciplinary and coordinated.
- The interdisciplinary team (IDT) completes an initial comprehensive assessment and subsequent reevaluation through patient and family interviews, review of medical and other available records, discussion with other providers, physical examination and assessment, along with relevant laboratory and/or diagnostic tests or procedures.
- An initial evaluation includes: 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: diagnoses and prognosis; comorbid medical and psychiatric disorders; physical and psychological symptoms; functional status; social, cultural, and spiritual strengths, values, practices, concerns, and goals; advance care planning concerns, preferences, and documents; and appropriateness of hospice referral (see 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 7: Care of the Patient at the End of Life, and Domain 8: Ethical and Legal Aspects of Care).
- Assessment of neonates, children, and adolescents must be conducted with consideration of age and stage of neurocognitive development.
- The IDT documents assessment of the patient and family perception and understanding of the serious or life limiting illness including: patient and family expectations of treatment, goals for care, quality of life, as well as preferences for the type and site of care.
- Comprehensive assessment identifies the elements of quality of life. Quality of life is defined by four domains: physical, psychological, social, and spiritual aspects of care.<sup>1</sup> Interventions are focused to alleviate distress in one or any of these domains.
- This comprehensive assessment recurs on a regular basis and in subsequent intervals, or in response to significant changes in the patient's status or the patient and family's goals.

**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 patient-family decision making. *Family* is defined by the patient.**

**Criteria:**

- The care plan is based upon an ongoing assessment and reflects goals set by the patient, family or surrogate in collaboration with the IDT. Such goals reflect the changing benefits and burdens of various care options, at critical decision points during the course of illness.
- In collaboration with the patient, family, and other involved health care professionals, the IDT develops the care plan with the additional input, when indicated, from other community providers such as school professionals, community service providers, and spiritual leaders.
- Changes in the care plan are based on the evolving needs and preferences of the patient and family, with recognition of the complex, competing, and shifting priorities in goals of care. The evolving care plan is documented over time.

- The IDT supports patient-family decision making and then develops, implements, and coordinates the care plan in collaboration with the patient and family. The team promotes patient and family education and assures communication of the care plan to all involved health professionals. Particular attention is necessary when a patient transfers to a different care setting, with the imperative to communicate with the receiving provider.
- Treatment and care setting alternatives are clearly documented and communicated to the patient and family in a manner that promotes informed decision making.
- Treatment decisions are based on goals of care established by the patient, family, and IDT; assessment of risk and benefit; and best evidence. Reevaluation of treatment efficacy, patient-family goals, and choices are documented.
- Complementary and alternative therapies may be included in the plan of care.

**Guideline 1.3 An interdisciplinary team (IDT) provides services to the patient and family consistent with the care plan. In addition to chaplains, nurses, physicians, and social workers, other therapeutic disciplines who provide palliative care services to patients and families may include: child-life specialists, nursing assistants, nutritionists, occupational therapists, recreational therapists, respiratory therapists, pharmacists, physical therapists, massage, art, and music therapists, psychologists, and speech and language pathologists.**

**Criteria:**

- Specialist-level palliative care is delivered by an IDT.
- The team includes palliative care professionals with the appropriate patient population specific education, credentialing, and experience, and the skills to meet the physical, psychological, social, and spiritual needs of both patient and family. Of particular importance is assembling a team which includes chaplains, nurses, pharmacists, physicians, and social workers, appropriately trained and ideally, certified in hospice and palliative care, when such certification is available. The interdisciplinary palliative care team involved in the care of children, whether the child is a patient or a family member of either an adult or pediatric patient, 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 caring for neonates, children, adolescents, or adults with serious or life-threatening illnesses.
- The IDT communicates regularly (at least weekly or more often as required by the clinical situation) to plan, review, evaluate, and update the care plan, with input from both the patient and family.
- The team meets regularly to discuss provision of quality care, including staffing, policies, measurement of quality and quality improvement, and clinical practices.
- Policies are in place for prioritizing and responding to referrals and patient-family crises in a timely manner.

**Guideline 1.4 The palliative care program is encouraged to use appropriately trained and supervised volunteers to the extent feasible.**

**Criteria:**

- For programs utilizing volunteers, policies and procedures are in place to ensure safe, quality volunteer programs including: recruitment, screening (including background checks), training, job descriptions and role clarification, work practices, support, supervision, and performance evaluation.
- A program that uses volunteers has policies and procedures outlining the program's responsibilities to its volunteers.



- An appropriately educated and experienced professional team member screens, educates, coordinates, and supervises volunteers.

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

**Criteria:**

- Education for the IDT includes: the attitudes, knowledge, and skills in the domains of palliative care; pain and symptom assessment and management, communication skills; medical ethics, grief and bereavement; family and community resources; and hospice care including philosophy, eligibility and core features of the Medicare Hospice Benefit.
- Education and training occurs in various venues such as baccalaureate and graduate programs, internships, or fellowships, in compliance with federal and state licensure and credentialing regulations.
- The palliative care program supports each individual team member's professional development through mentorships, preceptorships, and supervision.
- Palliative care staff members participate in necessary continuing palliative care education within the eight domains, and document their participation accordingly. Educational resources, focused on the domains listed in this document, are available and provided to staff.
- Palliative care programs ensure appropriate levels of education for all palliative care professionals. Advanced practice nurses, physicians, and rehabilitation therapists, must have graduate degrees in their respective disciplines, with appropriate professional experience in hospice and palliative care. Chaplains and social workers must have a bachelor's degree and/or graduate degree in their respective disciplines from accredited schools and appropriate professional experience in hospice and palliative care or a related health care field. Specific education requirements do not apply to registered nurses, nursing assistants, personal care attendants, and/or volunteers.
- Palliative care programs encourage discipline-specific certification, or other recognition of competence, as part of the educational support for the interdisciplinary team. Education, resources, and support are provided specifically to enhance IDT communication and collaboration.
- Education is available to support team leadership including effective team management, human resource management, budgets and strategic planning.

**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 commits to the pursuit of excellence and the highest quality of care and support for all patients and their families. The program determines quality by regular and systematic measurement, analysis, review, evaluation, goal setting, and revision of the processes and outcomes of care.
- Quality care follows the national quality strategy set forth by the US Department of Health and Human Services described in the following provisions of the Affordable Care Act. These strategies include:
  - Making care safer by reducing harm caused in the delivery of care.
  - Ensuring that each person and family is engaged as partners in their care.
  - Promoting effective communication and coordination of care.

- Promoting the most effective treatment practices for the leading causes of mortality, starting with cardiovascular disease.
- Making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models.<sup>13</sup>
- Care is coordinated and consistently focused on the illness trajectory, which offers the right care at the right time, in the course of an individual's disease or condition.
- A quality assessment and performance improvement (QAPI) review is conducted across all the domains, including organizational structure, education, team utilization, and assessment. This review includes effectiveness of physical, psychological, psychiatric, social, spiritual, cultural, and ethical assessment and interventions to manage these aspects of care.
- From this QAPI process, the palliative care program establishes quality improvement policies and procedures.
- A documented process for quality improvement leads to change in clinical practice. Quality improvement projects might include the development and testing of screening, history, and assessment tools, and appropriate protocols for diagnoses, interventions and outcomes. Some examples may include:
  - Structure and Processes – development of outcomes for program development, education, and training; development of quality measures, and cost analysis
  - Physical Aspects of Care – education and training; development and testing of evidence based therapies
  - Psychological and Psychiatric Aspects of Care – education and training; development and testing of bereavement and grief screening; assessment tools of various types of grief; and development and testing of evidence based therapies
  - Social Aspects of Care – education and training; development and testing of social screening, assessment and intervention tools; and identification and enhancement of the evidence base within the social domain
  - Spiritual, Religious, and Existential Aspects of Care – education and training; development and testing of spiritual screening, history and assessment tools; and appropriate protocols for spiritual diagnoses, interventions and outcomes
  - Cultural Aspects of Care – education and training; development and testing of cultural assessment tools and culturally appropriate interventions; and evaluation of outcomes within and across cultural and linguistic communities
  - Care of the Patient at the End of Life – education and training; and appropriate protocols for the patient at the end of life
  - Ethical and Legal Aspects of Care – education and training; appropriate protocols for ethical and legal occurrences; and best practices for advance care planning
- Quality improvement activities are routine, regular, reported, and demonstrate influence upon clinical practice. Designated staff, with experience in QAPI planning, direct the QAPI process in collaboration with leaders of the palliative care program.
- The clinical practice of palliative care reflects the integration and dissemination of current evidence and is based on QAPI.
- Quality improvement activities for clinical services are collaborative, interdisciplinary, and focused on meeting the identified needs and goals of patients and their families.
- Patients, families, health professionals, and the community participate in evaluation of the palliative care program.

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

**Criteria:**

- The program provides emotional support to their administrative staff, IDT, and volunteers in coping with the stress of caring for individuals and families affected by serious or life-threatening illness.
- Support structure for staff and volunteers includes regular meetings during which the impact and processes of the provision of palliative care are discussed.
- The program and IDT implements interventions to promote staff support and sustainability.

**Guideline 1.8 Community resources ensure continuity of the highest quality palliative care across the care continuum.**

**Criteria:**

- Palliative care programs support and promote continuity of care throughout the illness trajectory across all settings.
- Non-hospice palliative care programs have a relationship with one or more hospices and other community resources to ensure continuity of the highest-quality palliative care across the care continuum.
- Non-hospice palliative care programs routinely inform patients and families about hospice and other community based healthcare resources, when such resources are consistent with the patient's and family's values, beliefs, preferences, and goals of care. Referrals are made only with patient and family consent.
- Referring clinicians (advanced practice registered nurses, physicians, and physician assistants) as defined by The Centers for Medicare & Medicaid Services and primary physicians are routinely informed about the availability and benefits of hospice, as well as other appropriate community resources for their patients and families. Early discussion of hospice and palliative services and early referral to such programs is facilitated by hospices and community resources.
- Hospice programs, non-hospice palliative care programs, and other major community service providers involved in the patient's care, establish policies for formal written and verbal communication among and between clinicians involved in the patient and family's care.
- Policies enable timely and effective sharing of information among health care teams while safeguarding privacy.
- When possible, hospice and palliative care program staff 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.
- Hospice and palliative programs, as well as other major community providers, routinely seek opportunities to collaborate and partner to increase access to quality palliative care across the continuum.

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

**Criteria:**

- When feasible, care occurs in the setting preferred by the patient and his or her family.

- When care is provided outside the patient's or family's home, the IDT collaborates with residential service providers to maximize the patient's safety and sense of control. Flexible visiting hours, as appropriate, occur to promote patient social interaction. A space is arranged for families to visit, rest, prepare or eat meals, along with other needs identified by the family. The environment also provides privacy to meet with palliative care providers and other professionals.
- Providers, in all settings, address the unique care needs of neonates, children, and adolescents whether they are patients, family members, or visitors.

## References

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## Clinical Implications

Palliative care occurs across the health spectrum. It necessitates the involvement of an interdisciplinary team that is trained and supported to do the work. Care focuses on promoting the physical, psychological, social and spiritual domains of quality of life. It is delivered in a safe environment with respect for the patient's and family's values, preferences, and wishes. The palliative care program strives for best practices inclusive of quality assessment and performance improvement.

## DOMAIN 2: PHYSICAL ASPECTS OF CARE

### **Guideline 2.1 The interdisciplinary team assesses and manages pain and/or other physical symptoms and their subsequent effects based upon the best available evidence.**

#### **Criteria:**

- The goal of pain and symptom management is the safe and timely reduction of a physical symptom to a level acceptable to the patient, or to the surrogate, if the patient is unable to report distress.
- Symptom assessment and treatment requires an IDT (see Domain 1: Structure and Processes of Care, Guideline 1.3) including professionals with specialist-level skill in symptom control for all types of serious or life-threatening illnesses. Symptoms include, but are not limited to: pain, shortness of breath, nausea, fatigue, anorexia, insomnia, restlessness, confusion, and constipation.
- It is essential that health care organizations develop and utilize symptom assessment tools, treatment policies, standards, and guidelines appropriate to the care of patients with serious or life-threatening illnesses that conform to best palliative care practices.
- The palliative care team regularly documents ongoing assessment of pain, other physical symptoms, and functional capacity. Validated symptom assessment instruments are utilized when available. Symptom assessment of adults with cognitive impairment and of neonates, children, or adolescents is performed by appropriately trained professionals using available validated instruments.
- Treatment of distressing symptoms and side effects includes the entire spectrum of pharmacological, interventional, behavioral, and complementary therapies/interventions, supported by efficacy research, with referral to appropriate specialists.
- Symptom assessment, treatment, side effects, and treatment outcome information is recorded in the medical record and transmitted across health care settings during transitions.
- Barriers related to the use of opioid analgesics are assessed and addressed with attention to misconceptions of side effect risks, the potential for addiction, respiratory depression, and hastening of death.
- Opioid prescribers develop an opioid analgesic risk assessment and management plan consistent with state and federal regulations for use with patients requiring long term opioid therapy for chronic pain syndromes. Patients, families, and/or other involved health providers are instructed about safe usage of opioids including: driving, operation of machinery, appropriate and safe storage, inventory and appropriate opioid disposal.

### **Guideline 2.2 The assessment and management of symptoms and side effects are contextualized to the disease status.**

#### **Criteria:**

- Treatment plans for physical symptoms are developed in the context of the disease, prognosis, and patient functional limitations. The patient, family or surrogate's understanding of the illness is assessed in relation to patient-centered goals of care.
- Patient understanding of disease and its consequences, symptoms, side effects of treatments, functional impairment, and potentially useful treatments is assessed with consideration of culture, cognitive function, and developmental stage.
- Family or surrogate understanding of the disease and its consequences, symptoms, side effects, functional impairment, and treatments is assessed (See Domain 1: Structure and Processes of Care, Guideline 1.2).

- Family and other health care providers are educated and supported to provide safe and appropriate care to the patient. The family is provided with resources for response to urgent needs (See Domain 1: Structure and Processes of Care, Guideline 1.3).

### **Clinical Implications**

Physical comfort represents a core feature of compassionate care. Expert pain and symptom management sets the foundation of palliative care and promotes psychological, social, and spiritual quality of life.

## DOMAIN 3: PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE

**Guideline 3.1 The interdisciplinary team assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.**

**Criteria:**

- The IDT includes professionals with skills and training in the potential psychological and psychiatric impact of serious or life threatening illness, on both the patient and family including depression, anxiety, delirium, and cognitive impairment
- Based on patient and family goals of care, interventions include assessing psychological needs, treating psychiatric diagnoses, and promoting adjustment to the physical condition or illness. The IDT supports opportunities for emotional growth, psychological healing, cognitive reframing, completion of unfinished business from diagnosis of a serious and life threatening illness through the bereavement period.
- Regular, ongoing assessment of psychological reactions related to the illness (including but not limited to stress, coping strategies, and anticipatory grieving), and psychiatric conditions is documented. Whenever possible and appropriate, a validated and context-specific assessment tool is used.
- Psychological assessment and treatment includes patient and family education about the disease or condition, symptoms, side effects, and treatments, as well as caregiving needs, decision making capacity, and coping strategies.
- The IDT effectively treats psychiatric diagnoses, such as depression, suicidal ideation, anxiety, delirium, whether a consequence of the illness or among patients with comorbid psychiatric illness accompanying their serious or life-threatening illness.
- Family education includes the provision of safe and appropriate psychological measures supportive to the patient.
- The IDT skillfully communicates and documents discussions concerning treatment alternatives, promoting informed patient and family decision making.
- The palliative care team response to psychological distress and psychiatric syndromes is prompt, effective, and reflects patient/family choice. Interventions are based on IDT assessment and informed by evidence based practice and may include pharmacologic, nonpharmacologic, and complementary therapies.
- Regular reassessment of treatment efficacy, response to treatment, and patient-family preferences is performed and consistently documented.
- Referrals to appropriate healthcare professionals with specialized skills in age-appropriate psychological and psychiatric treatment are available (e.g. psychiatrists, psychologists, and social workers). Identified psychiatric comorbidities present in family members are appropriately referred for treatment.
- The team performs a developmentally appropriate assessment and supports pediatric patients and children of family members of pediatric or adult patients.
- Patient and professional communication occurs using verbal, nonverbal, and/or symbolic means appropriate to the patient, with particular attention to patients with cognitive impairment and the developmental stage and cognitive capacity of neonates, children, and adolescents.
- Staff education includes recognition and treatment of common psychological and psychiatric syndromes (e.g. anxiety, depression, delirium, hopelessness, suicidal ideation, and substance withdrawal symptoms) as well as professional coping strategies to manage anticipatory grief and loss.

**Guideline 3.2 A core component of the palliative care program is a grief and bereavement program available to patients and families, based on assessment of need.**

**Criteria:**

- The IDT includes professionals with patient population appropriate education and skill in the care of patients, families, and staff experiencing loss, grief, and bereavement.
- The identification and recognition of loss and grief in patients and families living with serious or life-threatening illness begins at diagnosis. Ongoing assessment and reassessment occurs throughout the illness trajectory.
- Staff and volunteers, including those who provide bereavement services, receive ongoing education, supervision, support in coping with their own grief, and guidelines to effectively respond to patients' and families' grief.
- At time of admission to hospice or a palliative care program, an initial, developmentally appropriate, professional assessment is completed to identify patients and families at risk for complicated grief, bereavement, and comorbid complications, particularly among older adults.
- Identified patients and families at risk for complicated grief and bereavement receive intensive psychosocial support, and prompt referral to appropriate professionals as needed.
- Bereavement services and follow-up are available to the family for a minimum of 12 months, after the death of the patient.
- Culturally and linguistically appropriate information on loss, grief, and the availability of bereavement services is routinely communicated to the family before and after the death of the patient. Such community services include support groups, counselors and collaborative partnerships with hospice (see Domain 6: Cultural Aspects of Care).
- The IDT provides grief support and promotes interventions which are in accordance with developmental, cultural, and spiritual needs and the expectations and preferences of the family, with attention to children who are family members of any patient.

**Clinical Implications**

Psychological and psychiatric assessment and services occur systematically using evidence-informed screening, assessment tools, and interventions. Education for the patient, family, and staff is an essential element of management. Grief and bereavement services are fundamental aspects of palliative care for support staff, patients, and family. Services are appropriate to patients' and families' needs, goals, ages, culture, and level of development to reflect a multidimensional intervention strategy.



## DOMAIN 4: SOCIAL ASPECTS OF CARE

**Guideline 4.1 The interdisciplinary team assesses and addresses the social aspects of care to meet patient-family needs, promote patient-family goals, and maximize patient-family strengths and well-being.**

**Criteria:**

- The IDT facilitates and enhances:
  - patient-family understanding of, and coping with, illness and grief;
  - support for patient-family decision making;
  - discussion of the patient's and family's goals for care;
  - provision of emotional and social support;
  - communication within the family and between patient-family and the IDT.
- The IDT includes a social worker with patient population specific skills in assessment and interventions in order to address social needs during a life-threatening or serious illness (see Domain 1: Structure and Process of Care, Guideline 1.5).
- Health professionals with expertise in the developmental needs and capacities of neonates, children, and adolescents assess and intervene in the care of pediatric patients and child family members of pediatric or adult patients.

**Guideline 4.2 A comprehensive, person-centered interdisciplinary assessment (as described in Domain 1, Guideline 1.1) identifies the social strengths, needs, and goals of each patient and family.**

**Criteria:**

- The IDT assesses and documents the elements of a social assessment that includes:
  - Family structure and function: roles, communication and decision making patterns
  - Strengths and vulnerabilities: resiliency; social and cultural support networks; effect of illness or injury on intimacy and sexual expression; prior experiences with illness, disability, and loss; risk of abuse, neglect, or exploitation
  - Changes in family members' schooling, employment or vocational roles, recreational activities, and economic security
  - Geographic location, living arrangements, and perceived suitability of the living environment
  - Patient's and family's perceptions about caregiving needs, availability, and capacity
  - Needs for adaptive equipment, home modifications, transportation
  - Access to medications (prescription and over-the-counter) and nutritional products
  - Need for and access to community resources, financial support, and respite
  - Advance care planning and legal concerns (see Domain 8: Ethical and Legal Aspects of Care, Guideline 8.1)
- The social care plan reflects the patient's and family's culture, values, strengths, goals, and preferences, which may change over time.
- The IDT implements interventions to maximize the social well-being and coping skills of both the patient and family, including education and family meetings.
- The IDT refers the patient and family to appropriate resources and services that both address the patient's and family's identified social needs and goals, and maximize patient-family strengths.

## **Clinical Implications**

Each patient and family has a unique social structure. Understanding the social fabric of the patient and family promotes coping. Interventions support the social structure including culture, values, strengths, goals, and preferences. The assessment of social aspects of care is the responsibility of the interdisciplinary team, which includes specialists in social aspects of care and pediatric populations.

## DOMAIN 5: SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE

### **Guideline 5.1 The interdisciplinary team assesses and addresses spiritual, religious, and existential dimensions of care.**

#### **Criteria**

Spirituality is recognized as a fundamental aspect of compassionate, patient and family centered care that honors the dignity of all persons.

- Spirituality is defined as, “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and/or to the significant or sacred.”<sup>1</sup> It is the responsibility of all IDT members to recognize spiritual distress and attend to the patient’s and the family’s spiritual needs, within their scope of practice.<sup>2</sup>
- The interdisciplinary palliative care team, in all settings, includes spiritual care professionals; ideally a board certified professional chaplain, with skill and expertise to assess and address spiritual and existential issues frequently confronted by pediatric and adult patients with life-threatening or serious illnesses and their families.
- Communication with the patient and family is respectful of their religious and spiritual beliefs, rituals, and practices. Palliative care team members do not impose their individual spiritual, religious, existential beliefs or practices on patients, families, or colleagues.

### **Guideline 5.2 A spiritual assessment process, including a spiritual screening, history questions, and a full spiritual assessment as indicated, is performed. This assessment identifies religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family; as well as symptoms, such as spiritual distress and/or pain, guilt, resentment, despair, and hopelessness.**

#### **Criteria**

- The IDT regularly explores spiritual and existential concerns and documents these spiritual themes in order to communicate them to the team. This exploration includes, but is not limited to: life review, assessment of hopes, values, and fears, meaning, purpose, beliefs about afterlife, spiritual or religious practices, cultural norms, beliefs that influence understanding of illness, coping, guilt, forgiveness, and life completion tasks. Whenever possible, a standardized instrument is used.
- The IDT periodically reevaluates the impact of spiritual/existential interventions and documents patient and family preferences.
- The patient’s spiritual resources of strength are supported and documented in the patient record.
- Spiritual/existential care needs, goals, and concerns identified by patients, family members, the palliative care team, or spiritual care professionals are addressed according to established protocols and documented in the interdisciplinary care plan, and emphasized during transitions of care, and/or in discharge plans. Support is offered for issues of life closure, as well as other spiritual issues, in a manner consistent with the patient’s and the family’s cultural, spiritual, and religious values.
- Referral to an appropriate community-based professional with specialized knowledge or skills in spiritual and existential issues (e.g. to a pastoral counselor or spiritual director) is made when desired by the patient and/or family. Spiritual care professionals are recognized as specialists who provide spiritual counseling.

### **Guideline 5.3 The palliative care service facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.**

#### **Criteria**

- Professional and institutional use of religious/spiritual symbols and language are sensitive to cultural and religious diversity.
- The patient and family are supported in their desires to display and use their own religious/spiritual and/or cultural symbols.
- Chaplaincy and other palliative care professionals facilitate contact with spiritual/religious communities, groups or individuals, as desired by the patient and/or family. Palliative care programs create procedures to facilitate patients' access to clergy, religious, spiritual and culturally-based leaders, and/or healers in their own religious, spiritual, or cultural traditions.
- Palliative professionals acknowledge their own spirituality as part of their professional role. Opportunities are provided to engage staff in self-care and self-reflection of their beliefs and values as they work with seriously ill and dying patients. Core expectations of the team include respect of spirituality and beliefs of all colleagues and the creation of a healing environment in the workplace.
- Non-chaplain palliative care providers obtain training in basic spiritual screening and spiritual care skills.
- The palliative care team ensures postdeath follow up after the patient's death (e.g. phone calls, attendance at wake or funeral, or scheduled visit) to offer support, identify any additional needs that require community referral, and help the family during bereavement (see Domain 3: Psychological and Psychiatric Aspects of Care, Guideline 3.2).

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#### **Clinical Implications**

Spiritual, religious, and existential issues are a fundamental aspect of quality of life for patients with serious or life-threatening illness and their families. All team members are accountable for attending to spiritual care in a respectful fashion. In order to provide an optimal and inclusive healing environment, each palliative care team member needs to be aware of his or her own spirituality and how it may differ from fellow team members and those of the patients and families they serve.

## DOMAIN 6: CULTURAL ASPECTS OF CARE

### Guideline 6.1 The palliative care program serves each patient, family, and community in a culturally and linguistically appropriate manner.

#### Criteria:

- Culture is multidimensional. “The word ‘culture’ implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group.”<sup>1 p iv</sup>
- Culture is far reaching. “Cultural identification may include, but is not limited to, race, ethnicity, and national origin; migration background, degree of acculturation, and documentation status; socioeconomic class; age; gender, gender identity, and gender expression; sexual orientation; family status; spiritual, religious, and political belief or affiliation; physical, psychiatric, and cognitive ability; and literacy, including health and financial literacy.”<sup>2 p 15-16</sup>
- During the assessment process, the IDT elicits and documents the cultural identifications, strengths, concerns, and needs of the patient and family, with recognition that cultural identity and expression vary within families and communities.
- The plan of care addresses the patient’s and family’s cultural concerns and needs, recognizing and maximizing their cultural strengths (see Domain 1: Structure and Processes of Care, Guideline 1.2).
- All palliative care staff consistently convey respect for the patient’s and family’s cultural perceptions, preferences, and practices regarding illness, disability, treatment, help seeking, disclosure, decision making, grief, death, dying, and family composition.
- Palliative care program staff communicate in a language and manner that the patient and family understand.
  - Personnel tailor their communication to the patient’s and family’s level of literacy, health literacy, financial literacy, and numeracy.
  - When patients and families do not speak or understand English, or feel more comfortable communicating in a language other than English, the palliative care program makes all reasonable efforts to use professional interpreter services, accessed either in person and/or by phone.
  - When professional interpreter services are unavailable, other health care providers, preferably those trained in palliative care, may interpret for patients and families. Family members are not placed in the role of interpreter. However, in the absence of all other alternatives, family members may interpret in an emergency situation, if the patient and family agree to this arrangement.
  - In addition to interpreter services, the palliative care program endeavors to provide written materials in each patient’s and family’s preferred language. When translated written materials are unavailable, the program utilizes professional interpreter services, as described above, to facilitate patient and family understanding of information provided by the program.
- Palliative care staff respect and accommodate dietary and ritual practices of patients and their families.
- Palliative care staff members identify community resources that serve various cultural groups and refer patients and families to such services, as appropriate.

## **Guideline 6.2 The palliative care program strives to enhance its cultural and linguistic competence.**

### **Criteria:**

- “*Cultural competence*” refers to the process by which individuals and systems respond respectfully and effectively to people of all cultures and languages in a manner that recognizes, affirms, and values the worth of individuals, families, and communities.”<sup>3 p12-13</sup>
- The palliative care program values diversity, demonstrated by creating and sustaining a work environment that affirms multiculturalism. The recruitment, hiring, retention, and promotion practices of the palliative care program reflect the cultural and linguistic diversity of the community it serves.
- Palliative care staff members cultivate cultural self-awareness and recognize how their own cultural values, beliefs, biases, and practices inform their perceptions of patients, families, and colleagues. Staff members strive to prevent value conflicts from undermining their interactions with patients, families, and colleagues.
- To reduce health disparities within and among the communities it serves, the palliative care program provides education to help staff members increase their cross-cultural knowledge and skills.
- The palliative care program regularly evaluates and, if needed, modifies its services, policies, and procedures to maximize its cultural and linguistic accessibility and responsiveness to a multicultural population. Input from patients, families, and community stakeholders is elicited and integrated into this process (see Domain 1: Structure and Processes of Care, Guideline 1.6).

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## **Clinical Implications**

Culture is a source of resilience for patients and families and plays an important role in the provision of palliative care. It is the responsibility of all members of the palliative care program to strive for cultural and linguistic competence to ensure that appropriate and relevant services are provided to patients and families.

## **DOMAIN 7: CARE OF THE PATIENT AT THE END OF LIFE**

**Guideline 7.1 The interdisciplinary team identifies, communicates, and manages the signs and symptoms of patients at the end of life to meet the physical, psychosocial, spiritual, social, and cultural needs of patients and families.**

**Criteria:**

- Care of the patient at the end of life is time and detail intensive, requiring expert clinical, social, and spiritual attention to the process as it evolves. Care of the patient is divided into three phases; predeath, perideath, and postdeath.
- The IDT recognizes the need for high acuity and high intensity care during the dying process.
- The IDT routinely elicits and honestly addresses concerns, hopes, fears, and expectations about the dying process in a developmentally appropriate manner, with respect for the social and cultural context of the family (See Domain 6: Cultural Aspects of Care).
- In collaboration with the patient and family, the IDT provides care with respect for patient and family values, preferences, beliefs, culture, and religion.
- The IDT acknowledges the patient's needs at the end of life and educates the family and other care providers about what to expect in terms of the death. As death approaches, they communicate signs and symptoms of imminent death, in culturally and developmentally appropriate language, with attention to population specific issues and age appropriateness.

**Guideline 7.2 The interdisciplinary team assesses and, in collaboration with the patient and family, develops, documents, and implements a care plan to address preventative and immediate treatment of actual or potential symptoms, patient and family preferences for site of care, attendance of family and/or community members at the bedside, and desire for other treatments and procedures.**

**Criteria:**

- The IDT assesses the patient for symptoms and proactively prepares family and other caregivers on the recognition and management of potential symptoms and concerns.
- With the patient and family, a plan is developed to meet their unique needs during the dying process as well as the needs of family immediately following the patient's death. Reassessment and revision of the plan occurs in a timely basis.
- Any inability to honor the patient's and family's expressed wishes for care immediately leading up to and following the patient's death is documented and communicated in the medical record that is accessible to other health care providers.
- For patients who have not accessed hospice services, care planning at this stage may include the introduction or reintroduction of a hospice referral, if such an option is congruent with the patient's and family's goals and preferences.
- Before the patient's death, sensitive communication occurs, as appropriate, about autopsy, organ and tissue donation, and anatomical gifts, adhering to institutional and regional policies.

**Guideline 7.3 Respectful postdeath care is delivered in a respectful manner that honors the patient and family culture and religious practices.**

**Criteria:**

- In post death, the focus of care includes respectful care of the body and support of the family.

- The interdisciplinary team assesses and documents cultural and religious practices particular to the postdeath period, and delivers care honoring those practices, in accordance with both institutional practice, local laws, and state regulations (see Domain 5: Spiritual, Religious, and Existential Aspects of Care and Domain 6: Cultural Aspects of Care).

#### **Guideline 7.4 An immediate bereavement plan is activated postdeath.**

##### **Criteria:**

- As described in Domain 3 Guideline 3.2, the IDT formulates and activates a postdeath bereavement plan based on a social, cultural, and spiritual grief assessment.
- A health care team member is assigned to support the family in the postdeath period and assist with religious practices, funeral arrangements, and burial planning.

#### **Clinical Implications**

It is essential that the interdisciplinary team attends to the patient's and family's values, preferences, beliefs, culture, and religion to promote a peaceful, dignified and respectful death.



## DOMAIN 8: ETHICAL AND LEGAL ASPECTS OF CARE

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

**Criteria:**

- The IDT includes professionals with knowledge and skill in ethical, legal, and regulatory aspects of medical decision-making.
- To assist in understanding patient and family decision-making, the patient or surrogate's expressed values, care preferences, religious beliefs, and cultural considerations are sensitively elicited, in collaboration with the family. Confirmation of these values, preferences, and considerations, with particular attention to change in health care status or transitions of care, is routinely reviewed and documented.
- The IDT discusses achievable goals for care in the context of patient values and preferences and educates the patient and family about advance care planning documents to promote communication and understanding of the patient's preferences for care across the care continuum. These documents may include, but are not limited to, designation of a surrogate health care decision maker (except for minors), inpatient and out of hospital do-not-resuscitate orders, and advance directives or living wills.
- Palliative care team members assist in the completion of these documents.
- All expressed wishes, preferences, values, goals, plan of care, surrogate decision makers and advance care plans are routinely documented, including the completion of clinical orders such as inpatient resuscitation status, out of hospital do not resuscitate orders, and health care surrogate declaration documents for adult patients. These care plans are accurately communicated when patients transition from one care setting to another.
- Failure to honor the patient's or surrogate's preferences is documented and addressed by the team, and accessible to other health care providers
- To determine decision making capacity, the ability of the patient and family to secure and accept needed care and to cope with the illness and its consequences is assessed. The adult patient with decisional capacity determines the level of involvement of the family in decision making and communication about the care plan. Patients with disabilities are assumed to have decision making capacity unless determined otherwise.
- In the care of pediatric patients with serious or life threatening illness, the child's views and preferences for medical care, including assent for treatment (when developmentally appropriate), is 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 as well as the family.
- The team advocates for the observance of previously expressed wishes of the patient or surrogate in clinical situations. For patients who are unable to communicate and have not previously expressed their values, preferences, or beliefs, the palliative care team members seek to determine the presence of advance directives, evidence of previously expressed wishes, values and preferences, and designated surrogate decision makers.
- Assistance and guidance is provided to surrogate decision makers about the legal and ethical basis for surrogate decision making, including honoring the patient's known preferences, substituted judgment, and best-interest criteria.

- Patients and families are routinely encouraged to seek professional advice on creating or updating legal and financial documents such as property wills, guardianship agreements, and custody documents.

**Guideline 8.2 The palliative care program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.**

**Criteria:**

- The palliative care team aims to prevent, identify, and resolve ethical dilemmas common to the provision of palliative care such as withholding or withdrawing treatments, instituting Do Not Resuscitate (DNR) orders, and the use of sedation in palliative care.
- All interdisciplinary team members have education in the fundamental ethical principles guiding the provision of palliative care.
- Ethical concerns commonly encountered in palliative care are identified, recognized, and addressed to prevent or resolve these concerns, using the ethical principles of beneficence, respect for individuals and self-determination, justice and nonmaleficence, with attention to avoidance of conflicts of interest.
- Ethical clinical issues are documented and appropriate referrals are made to ethics consultants or a committee for case consultation and assistance in conflict resolution.
- Ethics committees are consulted in the appropriate manner to guide policy development, assist in clinical care, and provide staff education in common palliative care situations including, but not limited to: a patient's right to decline treatments of any kind; use of high dose medications; withdrawal of technology (e.g. ventilators, dialysis, antibiotics); palliative sedation, futile care, and cessation of hydration and artificial and oral nutrition.

**Guideline 8.3 The provision of palliative care occurs in accordance with professional, state and federal laws, regulations and current accepted standards of care.**

**Criteria:**

- The palliative care program is knowledgeable about legal and regulatory aspects of palliative care. Access to legal and regulatory experts is imperative to provide care in accordance with legal and regulatory aspects of palliative care.
- Palliative care practice is modeled on and consistent with existing professional codes of ethics, scopes of practice, and standards of care for all relevant disciplines.
- Palliative care providers are knowledgeable about federal and state statutes, regulations, and laws regarding: disclosure of medical records and health information; medical decision making; advance care planning and directives; the roles and responsibilities of surrogate decision-makers; appropriate prescribing of controlled substances; death pronouncement and certification processes; autopsy requests, organ and anatomical donation; and health care documentation.
- Adherence to legal and regulatory requirements is expected for disclosure, decision making capacity assessment, confidentiality, informed consent, as well as assent and permission for people not of legal age to consent.
- The palliative care program establishes and implements policies outlining staff responsibility in regards to state and federal legal and regulatory requirements regarding patient and family care issues such as abuse, neglect, suicidal ideation, and potential harm to others.
- The palliative care staff recognizes the role of cultural variation in the application of professional obligations, including information on diagnosis, disclosure, decisional authority, care, acceptance of and decisions to forgo treatments (see Domain 6: Cultural Considerations). Attention is paid to the rights of children and adolescents in decision making.

- Legal counsel is accessible to palliative care providers particularly in common palliative care situations including but not limited to: determination of decision-making capacity, use of high dose analgesic or anxiolytic medications, withdrawal of technology (e.g. ventilators, dialysis), palliative sedation, use of “futile” care, and cessation of artificial and oral nutrition and hydration.

## **Clinical Implications**

Ethical and legal principles are inherent to the provision of palliative care to patients with serious or life threatening illness. Interdisciplinary team members must have an understanding of the central ethical principles underlying healthcare delivery in the context of their own professional practice setting and discipline. Palliative care teams must have access to legal and ethics expertise to support palliative care practice.

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## **DOMAIN 2 Physical Aspects of Care**

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## Appendix 1 - The 2013 National Consensus Project Domains and the Corresponding 2006 National Quality Forum Preferred Practices

NCP DOMAINS	NQF PREFERRED PRACTICES
DOMAIN 1.1. GENERAL STRUCTURE OF CARE	<p><b>PREFERRED PRACTICE 1</b></p> <ul style="list-style-type: none"> <li>■ 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).</li> </ul> <p><b>PREFERRED PRACTICE 2</b></p> <ul style="list-style-type: none"> <li>■ Provide access to palliative and hospice care that is responsive to the patient and family <u>24 hours a day, 7 days a week</u>.</li> </ul>
DOMAIN 1.1. GENERAL STRUCTURE OF CARE	<p><b>PREFERRED PRACTICE 3</b></p> <ul style="list-style-type: none"> <li>■ Provide <u>continuing education</u> to all healthcare professionals on the domains of palliative care and hospice care.</li> </ul> <p><b>PREFERRED PRACTICE 4</b></p> <ul style="list-style-type: none"> <li>■ Provide <u>adequate training and clinical support</u> to assure that professional staff are confident in their ability to provide palliative care for patients.</li> </ul>
DOMAIN 1.1. GENERAL STRUCTURE OF CARE	<p><b>PREFERRED PRACTICE 5</b></p> <ul style="list-style-type: none"> <li>■ Hospice care and specialized palliative care professionals should be <u>appropriately trained, credentialed, and/or certified</u> in their area of expertise.</li> </ul>
DOMAIN 1.2. GENERAL PROCESSES OF CARE	<p><b>PREFERRED PRACTICE 6</b></p> <ul style="list-style-type: none"> <li>■ Formulate, utilize and regularly review a <u>timely care plan</u> 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.</li> </ul> <p><b>PREFERRED PRACTICE 7</b></p> <ul style="list-style-type: none"> <li>■ Ensure that on <u>transfer between healthcare settings</u>, there is <u>timely and thorough communication</u> of the patient's goals, preferences, values and clinical information so that continuity of care and seamless follow-up are assured.</li> </ul>
DOMAIN 1.2. GENERAL PROCESSES OF CARE	<p><b>PREFERRED PRACTICE 8</b></p> <ul style="list-style-type: none"> <li>■ Healthcare professionals should <u>present hospice as an option to all patients</u> and families when death within a year would not be surprising, and reintroduce the hospice option as the patient declines.</li> </ul> <p><b>PREFERRED PRACTICE 9</b></p> <ul style="list-style-type: none"> <li>■ Patients and caregivers should be asked by palliative and hospice care programs to <u>assess physicians'/healthcare professionals' ability</u> to discuss hospice as an option.</li> </ul>
DOMAIN 1.2. GENERAL PROCESSES OF CARE	<p><b>PREFERRED PRACTICE 10</b></p> <ul style="list-style-type: none"> <li>■ Enable patients to make <u>informed decisions</u> about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.</li> </ul> <p><b>PREFERRED PRACTICE 11</b></p> <ul style="list-style-type: none"> <li>■ Provide <u>education and support to families</u> and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.</li> </ul>



<b>DOMAIN 2. PHYSICAL ASPECTS OF CARE</b>	<p><b>PREFERRED PRACTICE 12</b></p> <ul style="list-style-type: none"> <li>■ <u>Measure and document</u> pain, dyspnea, constipation, and other symptoms using available standardized scales.</li> </ul> <p><b>PREFERRED PRACTICE 13</b></p> <ul style="list-style-type: none"> <li>■ <u>Assess and manage symptoms</u> and side effects in a timely, safe, and effective manner to a level acceptable to the patient and family.</li> </ul>
<b>DOMAIN 3. PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE</b>	<p><b>PREFERRED PRACTICE 14</b></p> <ul style="list-style-type: none"> <li>■ <u>Measure and document</u> anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.</li> </ul> <p><b>PREFERRED PRACTICE 15</b></p> <ul style="list-style-type: none"> <li>■ <u>Manage</u> anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a <u>timely, safe, and effective</u> manner to a level acceptable to the patient and family</li> </ul> <p><b>PREFERRED PRACTICE 16</b></p> <ul style="list-style-type: none"> <li>■ <u>Assess and manage psychological reactions</u> of patients and families to address emotional and functional impairment and loss, (including stress, anticipatory grief and coping), in a regular ongoing fashion.</li> </ul> <p><b>PREFERRED PRACTICE 17</b></p> <ul style="list-style-type: none"> <li>■ <u>Develop and offer a grief and bereavement care plan</u> to provide services to patients and families prior to and for at least 13 months after the death of the patient.</li> </ul>
<b>DOMAIN 4. SOCIAL ASPECTS OF CARE</b>	<p><b>PREFERRED PRACTICE 18</b></p> <ul style="list-style-type: none"> <li>■ Conduct <u>regular patient and family care conferences</u> with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis, and advanced care planning, and offer support.</li> </ul> <p><b>PREFERRED PRACTICE 19</b></p> <ul style="list-style-type: none"> <li>■ <u>Develop and implement a comprehensive social care plan</u> which addresses the social, practical and legal needs of the patient and caregivers, including but not limited to: relationships, communication, existing social and cultural networks, decisionmaking, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.</li> </ul>
<b>DOMAIN 5. SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE</b>	<p><b>PREFERRED PRACTICE 20</b></p> <ul style="list-style-type: none"> <li>■ Develop and document a plan based on <u>assessment of religious, spiritual, and existential concerns</u> using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.</li> </ul> <p><b>PREFERRED PRACTICE 21</b></p> <ul style="list-style-type: none"> <li>■ Provide information about the availability of spiritual care services and make <u>spiritual care available</u> either through organizational spiritual counseling or through the patient's own clergy relationships.</li> </ul> <p><b>PREFERRED PRACTICE 22</b></p> <ul style="list-style-type: none"> <li>■ Specialized palliative and hospice care teams should include <u>spiritual care professionals appropriately trained and certified</u> in palliative care.</li> </ul> <p><b>PREFERRED PRACTICE 23</b></p>

	<ul style="list-style-type: none"> <li>Specialized palliative and hospice spiritual care professionals should build <u>partnerships</u> with community clergy, and provide education and counseling related to end-of-life care.</li> </ul>
<b>DOMAIN 6. CULTURAL ASPECTS OF CARE</b>	<p><b>PREFERRED PRACTICE 24</b></p> <ul style="list-style-type: none"> <li>Incorporate <u>cultural assessment</u> as a component of comprehensive palliative and hospice care assessment, including, but not limited to: locus of decisionmaking, preferences regarding disclosure of information, truth telling and decisionmaking, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving, and funeral/burial rituals.</li> </ul> <p><b>PREFERRED PRACTICE 25</b></p> <ul style="list-style-type: none"> <li>Provide professional interpreter services and culturally sensitive materials in the <u>patient's and family's preferred language</u>.</li> </ul>
<b>DOMAIN 7. CARE OF PATIENT AT END OF LIFE</b>	<p><b>PREFERRED PRACTICE 26</b></p> <ul style="list-style-type: none"> <li><u>Recognize and document the transition to the active dying phase and communicate</u> to the patient, family, and staff the expectation of imminent death.</li> </ul> <p><b>PREFERRED PRACTICE 27</b></p> <ul style="list-style-type: none"> <li>The family is <u>educated</u> on a timely basis regarding signs and symptoms of imminent death in a developmentally, age-, and culturally appropriate manner.</li> </ul> <p><b>PREFERRED PRACTICE 28</b></p> <ul style="list-style-type: none"> <li>As part of the ongoing care planning process, routinely ascertain and <u>document patient and family wishes</u> about the care setting for site of death, and fulfill patient and family preferences when possible.</li> </ul> <p><b>PREFERRED PRACTICE 29</b></p> <ul style="list-style-type: none"> <li>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.</li> </ul> <p><b>PREFERRED PRACTICE 30</b></p> <ul style="list-style-type: none"> <li><u>Treat the body post-death with respect</u> according to the cultural and religious practices of the family and in accordance with local law.</li> </ul> <p><b>PREFERRED PRACTICE 31</b></p> <ul style="list-style-type: none"> <li><u>Facilitate effective grieving</u> by implementing in a timely manner a bereavement care plan after the patient's death when the family remains the focus of care.</li> </ul>
<b>DOMAIN 8. ETHICAL AND LEGAL ASPECTS OF CARE</b>	<p><b>PREFERRED PRACTICE 32</b></p> <ul style="list-style-type: none"> <li><u>Document the designated surrogate/decisionmaker</u> in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.</li> </ul> <p><b>PREFERRED PRACTICE 33</b></p> <ul style="list-style-type: none"> <li><u>Document the patient/surrogate preferences</u> for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.</li> </ul> <p><b>PREFERRED PRACTICE 34</b></p> <ul style="list-style-type: none"> <li>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 hospitals, such as the Physician Orders for Life-Sustaining Treatments (<u>POLST</u>) Program.</li> </ul> <p><b>PREFERRED PRACTICE 35</b></p> <ul style="list-style-type: none"> <li>Make advance directives and surrogacy designations available across care settings, while</li> </ul>

	<p>protecting patient privacy and adherence to Health Insurance Portability and Accountability Act (HIPAA) regulations, e.g., by Internet-based registries or electronic personal health records.</p> <p><b>PREFERRED PRACTICE 36</b></p> <ul style="list-style-type: none"> <li>■ <u>Develop healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals, e.g., Respecting Choices, Community Conversations on Compassionate Care.</u></li> </ul> <p><b>PREFERRED PRACTICE 37</b></p> <ul style="list-style-type: none"> <li>■ <u>Establish or have access to ethics committees</u> or ethics consultation across care settings to address ethical conflicts at the end of life.</li> </ul> <p><b>PREFERRED PRACTICE 38</b></p> <ul style="list-style-type: none"> <li>■ <u>For minors with decisionmaking capacity, document the child's views and preferences for medical care,</u> including assent for treatment, and give appropriate weight in decisionmaking. Make appropriate professional staff members available to both the child and the adult decisionmaker for consultation and intervention when the child's wishes differ from those of the adult decisionmaker.</li> </ul>
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Adapted from The National Consensus Project for Palliative Care 2013 *Clinical Practice Guidelines for Palliative Care* and the National Quality Forum 2006 *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*.

## Appendix 2 - 2013 Clinical Practice Guidelines for Quality Palliative Care Endorsing Organizations

AARP	Friends of Cancer Research
Aetna	The Gerontological Society of America
American Academy of Board of Directors	The Grant Group, LLC
American Academy of Hospice and Palliative Medicine	HealthCare Chaplaincy
American Academy of Nursing	Hospice and Palliative Nurses Association
American Academy of Pediatrics	The Institute for Healthcare Improvement
American Association of Colleges of Nursing	LeadingAge
American Association of Colleges of Pharmacy	National Association of Catholic Chaplains
American Association of Neuroscience Nurses	National Association of Directors of Nursing Administration in Long-Term Care
American Association for Respiratory Care	National Association of Jewish Chaplains
American Cancer Society	National Association of Neonatal Nurses
American Case Management Association	National Association of Professional Geriatric Care Managers
American College of Chest Physicians	National Association of Social Workers
American College of Surgeons	National Business Group on Health
American Geriatrics Society	The National Consumer Voice for Quality Long-Term Care
American Osteopathic Association	National Hospice and Palliative Care Organization
American Society for Pain Management Nursing	National Hospice Work Group
Assisted Living Federation of America	National PACE Association
Association for Clinical Pastoral Education	National Palliative Care Research Center
Association of Oncology Social Work	National Partnership for Women and Families
Association of Professional Chaplains	Oncology Nursing Society
CCAL – Advancing Person-Centered Living	Planetree
Center to Advance Palliative Care	Sigma Theta Tau International
Center for Practical Bioethics	Social Work Hospice and Palliative Network
Council on Social Work Education	The Society for Social Work Leadership in Health Care
Dartmouth Institute of Health Policy at the Geisel School of Medicine	Supportive Care Coalition
End of Life Nursing Education Consortium	The UPMC Palliative and Supportive Institute

### **Appendix 3 - 2013 *Clinical Practice Guidelines for Quality Palliative Care* Supporting Organizations**

American Academy of Ambulatory Care Nurses

Association of Community Cancer Centers

C-Change Together

Cancer Support Community

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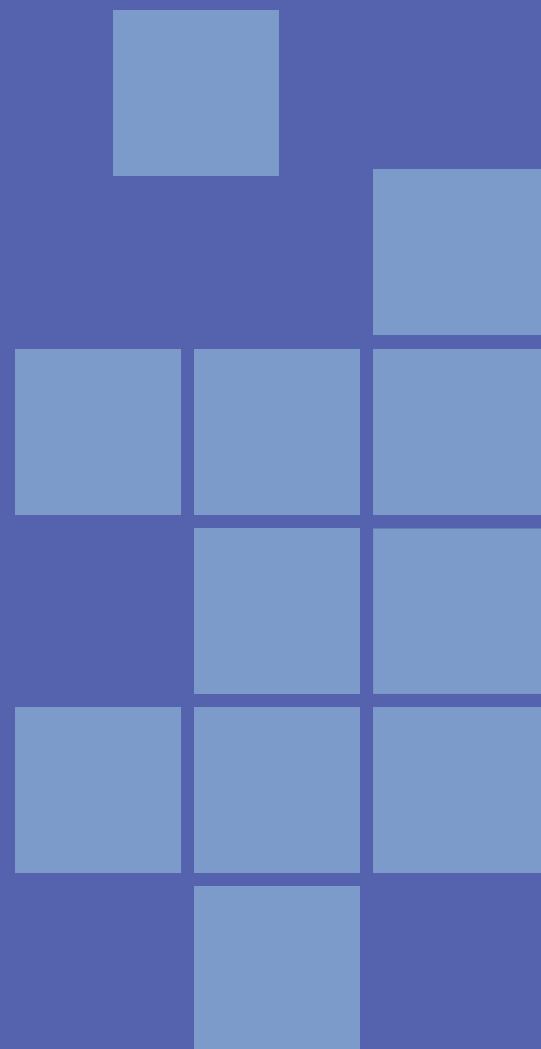
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