

## **Assessing Adherence to the National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care*<sup>1</sup>**

The National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines) is a terrific compilation of consensus recommendations regarding best practices in palliative care. The NCP framework identifies 8 core domains of care: Domain 1: Structure and Processes of Care, Domain 2: Physical Aspects of Care, Domain 3: Psychological and Psychiatric Aspects, Domain 4: Social Aspects of Care, Domain 5: Spiritual, Religious, and Existential Aspects of Care, Domain 6: Cultural Aspects of Care, Domain 7: Care of the Patient at the End of Life, and Domain 8: Ethical and Legal Aspects of Care. Guidelines and criteria – elements of best practice – are presented for each domain.

It would be useful for the team to get to know the specifics of the NCP guidelines, and to reflect on how your active or proposed palliative care service will address each guideline/set of criteria. This will allow you, right from the beginning, to develop processes that are aligned with national standards, or, where that is not yet possible, to be mindful of how you hope to develop your service over time to become increasingly adherent.

You can demonstrate adherence to guidelines/criteria through structures (staff or resources that you put in place, for example an interdisciplinary team that includes individuals with advanced training in PC) or through processes (the things your staff or systems do). For each area, you might consider if a policy or procedure is needed to support your structures and processes. For example, one of the criteria for Guideline 1.5 is, “Palliative care programs ensure appropriate levels of education for all palliative care professionals.” To demonstrate adherence, you may wish to include in palliative care team job descriptions a requirement addressing training and certification – like requiring that individuals who serve as nurse practitioners on the team have or agree to obtain within one year of hire certification from the Hospice and Palliative Care Nurses Association. Similarly, for processes you might consider if there is a measurement activity that would tell you if your practice matches your policy.

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<sup>1</sup> National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care*, Third Edition (2013). Available at: [http://nationalconsensusproject.org/Guidelines\\_Download2.aspx](http://nationalconsensusproject.org/Guidelines_Download2.aspx)

**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	How will this be addressed by your service?	Policy or metric needed?
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		
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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. 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	How will this be addressed by your service?	Policy or metric needed?
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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. <u>Particular attention is necessary when a patient transfers to a different care setting, with the imperative to communicate with the receiving provider.</u>		
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. <u>Reevaluation of treatment efficacy, patient-family goals, and choices are documented.</u>		
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	How will this be addressed by your service?	Policy or metric needed?
Specialist-level palliative care is delivered by an IDT.		
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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 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	How will this be addressed by your service?	Policy or metric needed?
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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.**

Key principles:

- 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.

Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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 <u>appropriate professional experience in hospice and palliative care or a related health care field</u> . 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	How will this be addressed by your service?	Policy or metric needed?
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.		
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
<p>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:</p> <ul style="list-style-type: none"> <li>• Making care safer by reducing harm caused in the delivery of care.</li> <li>• Ensuring that each person and family is engaged as partners in their care.</li> <li>• Promoting effective communication and coordination of care</li> <li>• Promoting the most effective treatment practices for the leading causes of mortality, starting with cardiovascular disease.</li> <li>• Making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models.</li> </ul>		
<p>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.</p>		
<p>From this QAPI process, the palliative care program establishes quality improvement policies and procedures.</p>		
<p>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.</p>		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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	How will this be addressed by your service?	Policy or metric needed?
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.		

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

Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		
Policies enable timely and effective sharing of information among health care teams while safeguarding privacy.		
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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 pt. & family, to the extent possible.**

Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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## **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.**

**Key principles:**

- 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, 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.

<b>Criteria</b>	<b>How will this be addressed by your service?</b>	<b>Policy or metric needed?</b>
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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	How will this be addressed by your service?	Policy or metric needed?
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.		
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.		

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### **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.**

<b>Criteria</b>	<b>How will this be addressed by your service?</b>	<b>Policy or metric needed?</b>
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 <u>is documented</u> . 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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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, non-pharmacologic, 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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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 PC program is a grief and bereavement program available to patients and families, based on assessment of need.**

Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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Criteria	How will this be addressed by your service?	Policy or metric 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.		
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.		

#### **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	How will this be addressed by your service?	Policy or metric needed?
<p>The IDT facilitates and enhances:</p> <ul style="list-style-type: none"> <li>• Patient-family understanding of, and coping with, illness and grief;</li> <li>• Support for patient-family decision making;</li> <li>• Discussion of the patient's and family's goals for care;</li> <li>• Provision of emotional and social support;</li> <li>• Communication within the family and between patient-family and the IDT.</li> </ul>		
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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 identifies the social strengths, needs, and goals of each patient and family.**

Criteria	How will this be addressed by your service?	Policy or metric needed?
<p>The IDT assesses and documents the elements of a social assessment that includes:</p> <ul style="list-style-type: none"> <li>• Family structure and function: roles, communication and decision making patterns</li> <li>• 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</li> <li>• Changes in family members' schooling, employment or vocational roles, recreational activities, and economic security</li> <li>• Geographic location, living arrangements, and perceived suitability of the living environment</li> <li>• Patient's and family's perceptions about caregiving needs, availability, and capacity</li> <li>• Needs for adaptive equipment, home modifications, transportation</li> <li>• Access to medications (prescription and over-the-counter) and nutritional products</li> <li>• Need for and access to community resources, financial support, and respite</li> <li>• Advance care planning and legal concerns</li> </ul>		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

## **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.**

#### Key principles:

- 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." 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 practice.
- 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.

Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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**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	How will this be addressed by your service?	Policy or metric needed?
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 after-life, 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.		

Guidelines and criteria from National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care*, Third Edition (2013). Available at: [http://nationalconsensusproject.org/Guidelines\\_Download2.aspx](http://nationalconsensusproject.org/Guidelines_Download2.aspx)

**Guideline 5.3 The PC service facilitates religious, spiritual, and cultural rituals or practices as desired by pt. & family, especially at and after the time of death.**

Key Principle:

- Palliative professionals acknowledge their own spirituality as part of their professional role.

Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		
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 post-death 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.		

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## **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.**

#### Key principles:

- 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."
- 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.

<b>Criteria</b>	<b>How will this be addressed by your service?</b>	<b>Policy or metric needed?</b>
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.		
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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

- 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.”

Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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## **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.**

**Key Principles:**

- 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; pre-death, peri-death, and post-death.
- The IDT recognizes the need for high acuity and high intensity care during the dying process.

<b>Criteria</b>	<b>How will this be addressed by your service?</b>	<b>Policy or metric needed?</b>
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.**

<b>Criteria</b>	<b>How will this be addressed by your service?</b>	<b>Policy or metric needed?</b>
The IDT assesses the patient for symptoms and proactively prepares family and other caregivers on the recognition and management of potential symptoms and concerns.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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 post-death care is delivered in a respectful manner that honors the patient and family culture and religious practices.**

Key principle:

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

Criteria	How will this be addressed by your service?	Policy or metric needed?
The interdisciplinary team <u>assesses and documents</u> cultural and religious practices particular to the post-death period, and delivers care honoring those practices, in accordance with institutional practice, local laws, and state regulations.		

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**Guideline 7.4 An immediate bereavement plan is activated post-death.**

Criteria	How will this be addressed by your service?	Policy or metric needed?
The IDT formulates and activates a post-death bereavement plan based on a social, cultural, and spiritual grief assessment.		
A health care team member is assigned to support the family in the post-death period and assist with religious practices, funeral arrangements, and burial planning.		

**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	How will this be addressed by your service?	Policy or metric needed?
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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
<p>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.</p>		
<p>Palliative care team members assist in the completion of these documents.</p>		
<p>All expressed wishes, preferences, values, goals, plan of care, surrogate decision makers and advance care <u>plans are routinely documented</u>, 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.</p>		
<p>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.</p>		
<p>Failure to honor the patient's or surrogate's preferences is documented and addressed by the team, and accessible to other health care providers</p>		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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

Criteria	How will this be addressed by your service?	Policy or metric needed?
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 non-maleficence, 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.		

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

Key principle:

- Access to legal and regulatory experts is imperative to provide care in accordance with legal and regulatory aspects of palliative care.

Criteria	How will this be addressed by your service?	Policy or metric needed?
The palliative care program is knowledgeable about 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.		

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Criteria	How will this be addressed by your service?	Policy or metric needed?
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.		

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