### Appendix I: Glossary

**Acculturation**: “…the process of cultural and psychological change that results following meeting between cultures.”¹

**Activities of daily living (ADLs; also see “Instrumental activities of daily living”)**: “…are activities related to personal care. They include bathing or showering, dressing, getting in and out of bed or a chair, walking, using the toilet, and eating.”²

**Advanced practice providers**: Defined in the NCP Guidelines as physician assistants and advanced practice registered nurses utilized to expand the capacity of palliative care interdisciplinary teams to deliver complex care and provide direct care.

**Advance care planning documents**: “…allow individuals to share their treatment preferences in the event they can no longer speak for themselves.” There are two kinds: legal documents and medical orders (eg, legal: living wills, health care surrogate; medical: do not resuscitate (DNR) orders, physician orders for life-sustaining treatment (POLST)).³

**Anticipatory grief**: “…a complex concept that encompasses grief in anticipation of the future loss of a loved one, in addition to previously experienced and current losses as a result of the terminal illness.”⁴

**Autonomy**: “The principle of respect for autonomy is usually associated with allowing or enabling patients to make their own decisions about which health care interventions they will or will not receive.”⁵

**Beneficence**: “The ethical principle of beneficence requires healthcare professionals to treat their patients in a way that provides maximum benefit to that patient.”⁶

**Bereavement**: “The process of grieving and letting go of a loved one who has died.”⁷

**Capacity**: See “Decision-making capacity.”

**Care coordination**: “Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care.”⁸⁹

**Care plan**: In palliative care, the interdisciplinary team develops the care plan, with input from all health and social support providers. The care plan is based on the patient’s goals of care, as well as information gathered via the comprehensive assessments. The services and support needed to achieve those goals and reduce suffering are described, including plans to monitor and adjust the plan based on subsequent patient and family assessments.

**Care transitions**: “The term care transition describes a continuous process in which a patient’s care shifts from being provided in one setting of care to another, such as from a hospital to a patient’s home or to a skilled nursing facility and sometimes back to the hospital.”¹⁰ In addition, care transitions occur when patients change care providers.

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Note: Words bolded in red are defined in this Appendix.
Caregiver assessment: “Caregiver assessment is a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver’s ability to contribute to the needs of the care recipient.”

Clinician: In the context of the NCP Guidelines, clinician refers to any health professional providing direct care to seriously ill persons and their families, whether primary care practitioners, specialist consultants, or specialist-level palliative care teams. While any clinician can apply palliative care principles and practices, specialist palliative care teams are interdisciplinary, and the team members have certification or specialty-level competency to provide specialist palliative care.

Cognitive impairment: “Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may begin to notice changes in cognitive functions, but still be able to do their everyday activities. Severe levels of impairment can lead to losing the ability to understand the meaning or importance of something and the ability to talk or write, resulting in the inability to live independently.”

Communication: In palliative care, “promoting and facilitating open communication to foster patient- and family-centered shared decision-making, and advance care planning is essential. Ethnic and cultural differences should be acknowledged. Family members’ decision-making strategies around options of care, location, and preferences should take into account cultural, ethnic, and religious preferences. The earlier these discussions can occur, the better, so when there are unexpected changes in a patient’s condition, discussions have already happened, and decisions have been made.”

Comprehensive assessment: “Rather than gathering information exclusively from the patient (or caregivers) and medical records, palliative evaluation utilizes a broad range of sources, each contributing to the final assessment. In an interdisciplinary manner, the physician collaborates with nursing staff, chaplains, social workers, therapists, and nutritionists to perform discipline-specific evaluative tasks, together developing the comprehensive palliative assessment. Tasks that are best shared with expert nonphysician team members may include evaluation of existential and spiritual domains, economic needs, and care coordination; however, specific distribution will vary depending on local expertise.”

Continuous quality improvement (CQI): uses an “iterative approach that aims to reduce and eventually eliminate ‘unexplained clinical variation.’ Reducing such variation addresses the root of many of health care’s inefficiencies, excess costs, and poor outcomes. CQI calls for a cultural shift that relies on clinicians constantly asking themselves, ‘How could this process be better?’ and ‘How can I impact this change?’ The underpinnings of this approach view each clinician as an informed agent who can identify bad processes and implement changes. It views medical errors and inefficiencies as results, not of bad people, but of suboptimal processes of care. CQI also recognizes that heterogeneity in patient characteristics, values, and clinical settings dictates that prudent decision-making formulated to reduce unnecessary clinical variation does not mean that 100% of care may meet a quality measure.”

Cultural humility: “In a multicultural world where power imbalances exist, cultural humility is a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals. The results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning.”
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Decision-making capacity: “Medical decision-making capacity refers to the time-sensitive determination of a patient’s ability to make a specific clinical choice.” Thoughtful assessment of capacity is essential for providing care that preserves and respects a patient’s autonomy, while meeting the ethical and legal standards of informed consent.

Developmentally appropriate: Providers of palliative care seek to provide developmentally appropriate care to all people living with a serious illness. Such care “incorporates advanced decision making based on young adult cognitive abilities, acknowledges and treats the high symptom burden, promotes this time of psychological and spiritual growth, and ultimately, empowers and honors this special time of life.”

Doctrine of double effect: “...draws a distinction between impermissible intended consequences and permissible (merely) foreseen consequences.” There are four conditions that are applied: 1) “the action itself (as distinct from its consequences or effects) must not be inherently morally wrong,” 2) “the intention must be to produce the good effect,” 3) “the good effect must not be brought about via the bad effect,” 4) “...there is an appropriate balance (ie, proportionality) between the good and the bad effects, such that the good effect must outweigh the bad.”

Existential: Existential refers to a philosophical approach in which one’s primary task is to find what determines one’s own level of meaning in life. Often this may involve an anguished process where prior beliefs no longer seem valid, and one begins a journey to find one’s own meaning in life. Meaning is often conceived in a way that is personal and acknowledges that others may hold other quite different meanings. At the end of life, terminally ill individuals may expand their curiosity in the hope that this will lead to new self-discovery. This often takes an individual through a process of uncertainty and ambiguity that includes the re-examination of prior understandings to determine what one holds for the self to be true.

Family: The patient defines who constitutes their family and “determine how they will participate in care and decision-making.”

Family caregiver: “A family caregiver is someone who is responsible for attending to the daily needs of another person. Family caregivers are responsible for the physical, emotional and often financial support of another person who is unable to care for him/herself due to illness, injury or disability. The care recipient may be a family member, life partner or friend.”

Gender expression: “The way individuals express or present to others their internal sense of masculinity or femininity.”

Gender identity: “One’s innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One’s gender identity can be the same or different from their sex assigned at birth.”

Grief: “The emotional, cognitive, functional and behavioral responses to the death. Also, grief is often used more broadly to refer to the response to other kinds of loss; people grieve the loss of their youth, of opportunities, and of functional abilities.”

Health care surrogate (health care proxy, health care agent): A health care surrogate is someone appointed to make health care decisions when the patient is unable to make or communicate decisions. The surrogate can be appointed by the patient via an advance directive, or serve as a court-appointed guardian. If the health care providers are unable to locate a decision-maker, a decision-maker may be appointed in accordance with state laws.
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Historical trauma: The “cumulative emotional and psychological wounding across generations, including the lifespan, which emanates from massive group trauma; the historical trauma response is the constellation of features in reaction to this trauma...includes depression self-destructive behavior, suicidal thoughts and gestures, anxiety, low self-esteem, anger, and difficulty recognizing and expressing emotions.”

Hospice: “Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well.”

“Hospice focuses on caring, not curing and in most cases care is provided in the patient’s home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.”

Instrumental activities of daily living (IADLs; see also “Activities of daily living”): “Instrumental Activities of Daily Living (IADLs) are activities related to independent living. They include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.”

Interdisciplinary team: “The interdisciplinary model is based on synergistic and interdependent interaction of team members who each possess particular expertise. Team members work closely together, actively communicating and sharing information. Leadership is often task-dependent, defined by each situation. Collaboration is identified as the process central to the interactions between members.”

Intersections of race (Intersectionality): “A way of understanding and analyzing the complexity in the world, in people, and in human events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are generally shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people’s lives and the organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other.”

Long-term services and supports (LTSS): “…encompasses the broad range of paid and unpaid medical and personal care assistance that people may need – for several weeks, months, or years – when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability.”

Non-beneficial care: “A treatment determined on the basis of current medical knowledge and experience to hold no reasonable promise for contributing to the patient’s well-being or of achieving agreed-on goals of care.”

Nonmaleficence: “Obligation not to inflict harm intentionally.”

Palliative care: Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing seriously ill people relief from the symptoms and stress of an illness. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.
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Palliative care interdisciplinary team (IDT): Specialty palliative care interdisciplinary teams collaborate with other care providers to directly provide and coordinate care. Depending on the care needs of each patient and family, the IDT can expand to include other clinicians and community service providers. All team members are responsible to screen for unmet needs outside of their scope and access team members with expertise for full assessments. (See Domain 1: Structures and Processes for Care for a list of palliative care interdisciplinary team disciplines.)

Palliative care specialists: Palliative care specialists include “physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains.”34

Primary palliative care (also known as generalist): “Palliative care that is delivered by health care professionals who are not palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care.”35

Professional chaplain: The professional chaplain is master’s level prepared and has participated in clinical chaplaincy training. Board Certification in chaplaincy is preferred. Certified chaplains may also specialize in palliative care and have specialized certification. The chaplain is the spiritual care specialist on the interdisciplinary team, and is trained to address spiritual and religious concerns of all patients and caregivers, regardless of their spiritual or religious beliefs and practices. The chaplain is also an emotional care generalist, and interfaces closely with the social worker and other mental health providers to provide psychosocial-spiritual care as a unified domain.

Psychological/psychiatric: “The psychosocial implications of disease progression result in a range of challenges for both the patient and the caregiver. The consequences of advanced disease can comprise emotional states such as anxiety, distress and depressive episodes, fear of being a burden to others, loss of control, anger, loss of sense of dignity, uncertainty, and changes in close relationships and social roles. Adjustment disorder, anxiety disorder, depressive disorder, and the demoralization syndrome represent common disorders and phenomena among patients with advanced cancer. Moreover, uncontrollable pain and high unrelied physical symptom burden, depression, feelings of helplessness and hopelessness, delirium, and low family support are major factors in the desire for thoughts of suicide and the desire for hastened death. Caregivers play an important and challenging role, providing emotional and social support for the patient, helping with medical needs, and meeting increasingly complex instrumental needs such as running the household and work.”36

The psychiatric syndromes that may manifest for a patient and/or family member during a serious or life-threatening illness include depression, anxiety, and delirium. Patients and family members may already be diagnosed with a mental health disorder, which could include any listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). Psychiatric conditions can be challenging for palliative care staff to differentiate from the serious illness because symptoms may intersect with those of the medical conditions. Psychiatry can assist in these situations, as well in the use of psychotropic medications.37

Religion: “…involves beliefs, practices, and rituals related to the sacred. Religion may also involve beliefs about spirits, both good (angels) and bad (demons). Religion may be organized and practiced within a community, or it may be practiced alone and in private. In either case, religion originates in an established tradition that arises out of a community with common beliefs and practices.”38
**Serious illness:** Serious illness is defined as a “health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains their caregiver.”

**Shared decision-making:** “At its core, shared decision making is an interpersonal, interdependent process in which the health care provider and the patient relate to and influence each other as they collaborate in making decisions about the patient’s health care.”

“Three essential elements must be present for shared decision making to occur. First, both the health care provider and the patient must recognize and acknowledge that a decision is, in fact, required. Second, they must both know and understand the best available evidence concerning the risks and benefits of each option. Third, decisions must take into account both the provider’s guidance and the patient’s values and preferences.”

**Social determinants of health:** “The social determinants of health are the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.”

**Specialist palliative care:** Specialist palliative care is the active, total care of patients with serious illness and their families. Care is provided by an interdisciplinary team whose members have undergone recognized specialist palliative care training.

**Spirituality:** Spirituality is recognized as a fundamental aspect of compassionate, patient and family-centered care. “Spirituality is 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 to the significant or sacred.”

**Spiritual assessment:** “Formal spiritual assessment refers to a more extensive process of active listening to a patient’s story conducted by a board-certified chaplain that summarizes the needs and resources that emerge in that process. The chaplain’s summary should include a spiritual care plan with expected outcomes that is then communicated to the rest of the treatment team. Unlike history taking, the major models for spiritual assessment are not built on a set of questions that can be used in an interview. Rather, the models are interpretive frameworks that are based on listening to the patient’s story as it unfolds. Because of the complex nature of these assessments and the special clinical training necessary to engage in them, this assessment should be done only by a board-certified chaplain or an equivalently prepared spiritual care provider.”

**Spiritual distress:** “…a state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world or a Superior Being. This definition contains the attributes of spiritual distress: suffering, impaired spirituality, contrary to spiritual well-being, and related to meaning in life.”
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**Spiritual history:** “…history-taking uses a broader set of questions to capture salient information about needs, hopes, and resources. The history questions are asked in the context of a comprehensive examination by the clinician who is responsible for providing direct care or referrals to specialists. The information from the history permits the clinician to understand how spiritual concerns could either complement or complicate the patient’s overall care. It also allows the clinician to incorporate spiritual care into the patient’s overall care plan. Unlike spiritual screening, which requires only brief training, those doing a spiritual history should have some education in and comfort with issues that may emerge and knowledge of how to engage patients comfortably in this discussion.”

**Spiritual screening:** “Spiritual screening or triage is a quick determination of whether a person is experiencing a serious spiritual crisis and therefore needs an immediate referral to a board-certified chaplain. Spiritual screening helps identify which patients may benefit from an in-depth spiritual assessment. Good models of spiritual screening use a few simple questions that can be asked in the course of an overall patient and family screening. Examples of such questions include, ‘Are spirituality or religion important in your life?’ and ‘How well are those resources working for you at this time?’”

**Substituted judgement:** Substituted judgement refers to the ethical duty of guardians and surrogate decision-makers to make an effort to understand the patient’s beliefs and values prior to making decisions on the patient’s behalf.

**Total pain:** A holistic experience that extends beyond the physiological domain and was first introduced by Dame Cicely Saunders in the 1960s. Total pain recognizes the holistic nature of pain and the interplay of psychological and social well-being, spirituality, and culture. Symptoms rarely occur in isolation; rather, they cluster with other symptoms and are influenced by the psychological, social, and cultural characteristics of the individual.

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**Endnotes**


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