Foreword

Individuals who are seriously ill need care that is seamless across settings, can rapidly respond to needs and changes in health status, and is aligned with patient-family preferences and goals. Patients of all ages, living in all areas of the country, have unmet care needs that cause a burden on families and the US health care system.

Providing “crisis-care” to individuals with a serious illness whose ongoing care needs are poorly managed has resulted in increased health care spending that does not necessarily improve quality of life. Care of individuals with serious illness is often “marked by inadequate symptom control and low patient and family perceptions of the quality of care; and potentially discordant with personal goals and preferences.”1 Patients with serious illness and their family caregivers are seldom able to have their care needs reliably met, leading to symptom exacerbation crises and emergency department visits and/or repeated hospitalizations.2

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 people living with serious illness relief from the symptoms and stress of an illness. Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and the family.

Palliative care is:

- Appropriate at any stage in a serious illness, and it is beneficial when provided along with treatments of curative or life-prolonging intent.
- Provided over time to patients based on their needs and not their prognosis.
- Offered in all care settings and by various organizations, such as physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices, and long-term care providers.
- Focused on what is most important to the patient, family, and caregiver(s), assessing their goals and preferences and determining how best to achieve them.
- Interdisciplinary to attend to the holistic care needs of the patient and their identified family and caregivers.

Palliative care principles and practices can be delivered by any clinician caring for the seriously ill, and in any setting. All clinicians are encouraged to acquire core skills and knowledge regarding palliative care and refer to palliative care specialists as needed. Analogous to the management of hypertension and heart disease by primary clinicians who may turn to cardiology specialists and clinical practice guidelines for consultation or management of more complex cases, specialist level palliative care is necessary to attend to the complex needs of individuals with serious illness.
Foreword

care is available for consultation, teaching, research, and care of the most complex patients living with a serious illness. Specialist level palliative care is delivered through an interdisciplinary team with the professional qualifications, training, and support needed to deliver optimal patient- and family-centered care.

Recognizing the changes to the practice of palliative care in all care settings, the National Consensus Project for Quality Palliative Care defines palliative care as follows:

Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

In addition, specific definitions of palliative care are applicable depending on the audience and context within which the definition is used:

The 2015 Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life report defines palliative care as, “Care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics.” The report explicitly states that care outcomes are optimized when palliative care begins early after the diagnosis of a serious illness, is delivered at the same time as curative or disease-modifying treatments, and is available in all settings where patients and families need care.

The Centers for Medicare and Medicaid Services defines palliative care as, “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.”

The Center to Advance Palliative Care and the American Cancer Society developed a definition of palliative care (based on public opinion research), “Palliative care is specialized medical care for people with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

The Institute of Medicine (IOM) offers the following definitions (2015):

Specialty palliative care: “Palliative care that is delivered by health care professionals who are palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains.”

Primary palliative care (also known as generalist palliative care): “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.”
Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.6

**Specialist palliative care** provides an added layer of support towards maximizing patient and family quality of life during serious illness. Palliative care knowledge and skills, however, should be core competencies for all health professionals serving seriously ill patients and their families and caregivers.

**Hospice**

Hospice is a specific type of palliative care provided to individuals with a life expectancy measured in months, not years. Hospice teams provide patients and families with expert medical care, emotional, and spiritual support, focusing on improving patient and family quality of life.

To be eligible to receive hospice under the Medicare or Medicaid hospice benefit, adult patients must have a defined, time-limited prognosis (certified by two physicians as six months or less if the disease follows its usual course) and desire care focused on comfort, foregoing insurance coverage for further terminal disease-directed curative treatment efforts. The Patient Protection and Affordable Care Act of 2010 contained provisions allowing pediatric patients to receive disease-modifying treatment while also receiving hospice services.

Nearly 50% of Medicare decedents received hospice in 2016,7 most of which was provided in community settings, primarily the patient’s chosen residence, which includes home, nursing homes and other residential facilities, as well as skilled nursing facilities.8 Hospice is also available to Medicaid recipients in most states and is covered as part of many commercial health plans.

**History of the National Consensus Project’s Guidelines**

Seventeen years ago, leaders from across the country gathered to discuss the development of consensus guidelines for quality palliative care so that patients with serious illness who were not hospice-eligible could access palliative care. Representatives of hospice and palliative care organizations collaborated in the development of the first edition of the National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care (NCP Guidelines), which described core concepts and structures and processes necessary for quality palliative care, including eight domains of practice.

The first edition of the NCP Guidelines, published in 2004, presented a blueprint for excellence in the delivery of palliative care. For the first time outside of hospice, teams had a framework to guide the development of quality palliative care services. Since that time, palliative care has continued to grow and evolve, necessitating updated NCP Guidelines in 2009 and 2013. The second edition of the NCP Guidelines, published in 2009, reflected 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. The third edition of the NCP Guidelines, published in 2013, emphasized continuity, consistency, and quality of care.
The NCP Guidelines, 4th edition, are organized into 8 domains:

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

The composition of an interdisciplinary team is outlined, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Domain 1 also defines the elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care.

**Domain 2: Physical Aspects of Care**

The palliative care assessment, care planning, and treatment of physical symptoms are described, emphasizing patient- and family-directed holistic care.

**Domain 3: Psychological and Psychiatric Aspects**

The domain focuses on the processes for systematically assessing and addressing the psychological and psychiatric aspects of care in the context of serious illness.

**Domain 4: Social Aspects of Care**

Domain 4 outlines the palliative care approach to assessing and addressing patient and family social support needs.

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

The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs.

**Domain 6: Cultural Aspects of Care**

The domain outlines the ways in which culture influences both palliative care delivery and the experience of that care by the patient and family, from the time of diagnosis through death and bereavement.

**Domain 7: Care of the Patient Nearing the End of Life**

This domain focuses on the symptoms and situations that are common in the final days and weeks of life.

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

Content includes advance care planning, surrogate decision-making, regulatory and legal considerations, and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy.
NCP Guidelines, 4th edition

The goal of the 4th edition of the National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care (NCP Guidelines) is to improve access to quality palliative care for all people with serious illness regardless of setting, diagnosis, prognosis, or age. The NCP Guidelines are intended to encourage and guide health care organizations and clinicians (including non-palliative care specialists) across the care continuum to integrate palliative care principles and best practices into their routine assessment and care of all seriously ill patients. Also, the NCP Guidelines formalize and delineate available evidence-based processes and practices as well as consensus recommendations for the provision of safe and reliable high-quality palliative care for adults, children, and families with serious illness in all care settings.

Specifically, the purpose of the NCP Guidelines, 4th edition, is to promote access to quality palliative care, foster consistent standards and criteria, and encourage continuity of palliative care across settings. Because there is shared responsibility for delivery and quality of palliative care across health care settings and over time, the emphasis is on collaborative partnerships within and between all care providers to ensure access, quality, and continuity of palliative care.

The NCP Guidelines set expectations for excellence among clinicians treating patients with serious illness, rather than basic competence levels for professionals, teams, and organizations.

Audience

This revision addresses best practices for both palliative care specialists, as well as all clinicians who care for people with serious illness. The expectation is that other clinicians caring for seriously ill patients will integrate palliative care competencies (such as safe and effective pain and symptom management, and expert communication skills) in their practice and palliative care specialists will provide expertise for those with the most complex needs.

The audience for the 4th edition of the NCP Guidelines includes specialty hospice and palliative care practitioners and teams, as well as health systems, primary care and specialist physician practices, cancer centers, dialysis units, long-term care facilities, assisted living facilities, Veterans Health Administration providers, home health and hospice agencies, prisons, and other care providers. The NCP Guidelines are also applicable to social service agencies, homeless shelters, and any other community organizations serving seriously ill individuals.

Most importantly, the goal of the NCP Guidelines is to improve the care that patients and families receive by defining and supporting access to high-quality palliative care in all care settings. All practitioners are encouraged to use the NCP Guidelines to strengthen knowledge and skills to better meet the needs of people living with serious illness. It is our hope that the care children and adults with serious illness, and their families, receive will meet or exceed the criteria in these guidelines.

Settings of Care

Since palliative care is not setting-specific, palliative care principles and practices are applicable throughout the course of a serious illness. Palliative care is available across and between care settings, thereby
improving continuity and coordination of care and, as a consequence, decreasing expenses related to
duplicative or non-beneficial interventions or waste.

While hospital-based palliative care and hospice are widely available in the United States, access to
palliative care in other settings is often unavailable. Reliable access to palliative care in community-based
settings is essential to the delivery of expert care and symptom management, as well as psychological,
practical, and social support, helping patients and families remain safely in their care setting of choice.

New community-based palliative care models are meeting the needs of those with a serious illness who
are neither hospitalized nor hospice-eligible, through provision of care in patient homes, physician offices/
clinics, cancer centers, dialysis units, assisted and long-term care facilities, and other community settings.
Community-based palliative care services are delivered by clinicians in primary care and specialty care
practices (such as oncologists), as well as home-based medical practices, private companies, home health
agencies, hospices, and health systems.