

Definitions of Palliative Care

The term “Palliative Care” is in the process of being defined and a number of groups have adopted their own definitions. As the Kansas LIFE Project learns of these developments in palliative care, we will add them to this page, noting the source of each entry.

Disclaimer

The LIFE Project does not endorse or necessarily agree with these definitions. These are being provided to you as an educational source and for you to use in the definition development for your individual organization(s). LIFE invites and welcomes additional entries and information. Please send them to donna@lifeproject.org.

The Kansas LIFE Project

The LIFE Project adopted “*Principles of Palliative Care*” in 1999. These are based on work done by Last Acts, a national coalition to improve end-of-life care. LIFE wrote a simple definition of palliative care and posted this on the “Consumer Resources” section of the LIFE Project website.

What is Palliative (comfort) Care?

Palliative Care is comfort care. Perhaps you or someone you love is facing an illness that cannot be cured. Few of us are really ready for the hard choices that may have to be made at the end of life. It can be hard for everyone involved – the dying person, their family and loved ones, and health care providers, too.

But there are ways to ease pain and make life better for people who are dying and for their loved ones. It is called palliative care.

Palliative care means taking of the whole person – body, mind, and spirit. This care is provided by a team of caregivers – physician, nurse, social worker, clergy, volunteer, patient, family and others.

Palliative care accepts dying as something natural and personal. Those who are the best providers of care at the end of life understand that this time of life – like all other times – can have important times of growth, peace and joy.

The goal of palliative care is to help you have the best quality of life possible – every day.

The LIFE Project partners believe that all health care providers should know how to give good palliative care or to help you find someone who can.

LIFE Project partners want Kansans to know about palliative care and to expect quality care from health care providers. The LIFE Project has Five Principles of Palliative Care, adapted from the Last Acts Precepts of Palliative Care that describe the kind of care we hope all Kansans receive.

Principles of Palliative Care

Respecting Patient Goals, Preferences and Choices

Palliative Care:

Is an approach to care that is foremost patient-centered and addresses patient needs within the context of family and community.

- Recognizes that the family constellation is defined by the patient and encourages family involvement in planning and providing care to the extent the patient desires.
- Identifies and honors the preferences of the patient and family through careful attention to their values, goals and priorities, as well as their cultural and spiritual perspectives.
- Assists patients in establishing goals of care by facilitating their understanding of their diagnosis and prognosis, clarifying priorities, promoting informed choices and providing an opportunity for negotiating a care plan with providers.
- Strives to meet patients' preferences about care settings, living situations and services, recognizing the uniqueness of these preferences and the barriers to accomplishing them.
- Encourages advance care planning, including advance directives, through ongoing dialogue among providers, patient and family.
- Recognizes the potential for conflicts among patient, family, providers and payors, and develops processes to work toward resolution.

Comprehensive Caring

Palliative Care:

- Appreciates that dying, while a normal process, is a critical period in the life of the patient and family, and responds aggressively to the associated human suffering while acknowledging the potential for personal growth.
- Places a high priority on physical comfort and functional capacity, including, but not limited to: expert management of pain and other symptoms, diagnosis and treatment of psychological distress and assistance in remaining as independent as possible or desired.

- Provides physical, psychological, social and spiritual support to help the patient and family adapt to the anticipated decline associated with advanced, progressive, incurable disease.
- Alleviates isolation through a commitment to non-abandonment, ongoing communication and sustaining relationships.
- Assists with issues of life review, life completion and life closure.
- Extends support beyond the lifespan of the patient to assist the family in their bereavement.

Utilizing the Strengths of Interdisciplinary Resources

Palliative Care:

- Requires an interdisciplinary approach drawing on the expertise of, among others, physicians, nurses, psychologists, pharmacists, pastoral caregivers, social workers, ancillary staff, volunteers and family members to address the multidimensional aspects of care.
- Includes a clearly identified, accessible and accountable individual or team responsible for coordinating care to assure that changing needs and goals are met and to facilitate communication and continuity of care.
- Incorporates the full array of inter-institutional and community resources (hospitals, home care, hospice, long-term care, adult day services) and promotes a seamless transition between institutions/settings and services.
- Requires knowledgeable, skilled and experienced clinicians, who are provided the opportunity for ongoing education, professional support and development.

Acknowledging and Addressing Caregiver Concerns

Palliative Care:

- Appreciates the substantial physical, emotional and economic demands placed on families caring for someone at home, as they attempt to fulfill caregiving responsibilities and meet their own personal needs.
- Provides concrete supportive services to caregivers such as respite, round-the-clock availability of expert advice and support by telephone, grief counseling, personal care assistance and referral to community resources.
- Anticipates that some family caregivers may be at high risk for fatigue, physical illness and emotional distress, and considers the special needs of these caregivers in planning and delivering services.
- Recognizes and addresses the economic costs of caregiving, including loss of income and non-reimbursable expenses.

Building Systems and Mechanisms of Support

Palliative Care:

- Requires an environment that supports innovation, research, education and dissemination of best practices and models of care.
- Needs an infrastructure that promotes the philosophy and practice of palliative care.
- Relies on the formulation of responsible policies and regulations by institutions and by state and federal governments.
- Promotes equitable and timely access to the full array of interdisciplinary services necessary to meet the multidimensional needs of patients and caregivers.
- Demands ongoing evaluation, including the development of research-based standards, guidelines and outcome measures.
- Assures that mechanisms are in place at all levels (e.g., systems, direct care services) to guarantee accountability in provision of care.
- Requires appropriate financing, including the development of new methods of reimbursement within the context of a changing health care financing system.

Written by the Last Acts Palliative Care Task group, December 1997

Karen J. Lomax, MD, and Colleen Scanlon, RN,JD, Conveners

The National Consensus Project for Quality Palliative Care (NCP) which includes these organizations:

- American Academy of Hospice and Palliative Medicine
- Center to Advance Palliative Care
- Hospice and Palliative Nurses Association
- National Hospice and Palliative Care Organization
- Partnership for Caring: America's Voices for the Dying

The NCP is a groundbreaking initiative that aims to improve the delivery of palliative care in the United States.

- The NCP is a response to the need for uniformly accepted definitions of the essential elements and best practices in palliative care in order to create voluntary consensus Clinical Practice Guidelines for the establishment and development of clinical palliative care programs across the United States.

- The purpose of the NCP is to arrive at voluntary consensus Clinical Practice Guidelines describing the scope and characteristics of both specialist and primary practice setting palliative care services in the United States. Consensus Clinical Practice Guidelines are needed to stimulate and guide the development of new and existing programs across care settings and to promote formal recognition, stable reimbursement structures, and accreditation initiatives in palliative care.
- The NCP will develop two reports: voluntary consensus Clinical Practice Guidelines for specialty-level palliative care, followed by a set of palliative care Clinical Practice Guidelines for primary practice settings.

For more information about the National Consensus Project, please visit:
<http://www.nationalconsensusproject.org/>

1990 World Health Organization's Definition of Palliative Care

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment. Palliative care:

- Affirms life and regards dying as a normal process;
- Neither hastens nor postpones death;
- Provides relief from pain and other distressing symptoms;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.

Radiotherapy, chemotherapy and surgery have a place in palliative care, provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. Investigative procedures are kept to a minimum.

Taken from [Cancer Pain Relief and Palliative Care](#)

2002 World Health Organization's Definition of Palliative Care

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

- provides relief from pain and other distressing symptoms;

- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

From WHO Website, 2002

National Hospice and Palliative Care Organization's Definition from Standards

The National Hospice and Palliative Care Organization defines palliative care as treatment that enhances comfort and improves the quality of an individual's life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual's needs must continue to be assessed and all treatment options explored and evaluated in the context of the individual's values and symptoms. The individual's choices and decisions regarding care are paramount and must be followed at all times.

NHPCO Standards of Practice for Hospice Programs, 1993, 2001

National Hospice and Palliative Care Organization's Definition from Standards

Palliative Care is interdisciplinary care for persons with life-threatening illness or injury which addresses physical, emotional, social and spiritual needs and seeks to improve quality of life for the ill person and his or her family.

NHPCO Public Policy Steering Committee, August 2001

Textbook Definition

The study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is quality of life.

Oxford Textbook of Palliative Medicine, 1998

Center to Advance Palliative Care Definition

Palliative care aims to reduce suffering and improve quality of life for patients with advanced illness, and their families. Palliative care is provided by an interdisciplinary team and offered in conjunction with all other appropriate forms of medical treatment.

From CAPC Website, 2003

HIV/AIDS Bureau Health Resources and Services Administration (HRSA) US Department of Health and Human Services (HHS)

Palliative care is patient- and family-centered care. It optimizes quality of life by active anticipation, prevention, and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social and spiritual needs. It facilitates patient autonomy, access to information and choice.

A Clinical Guide to Supportive and Palliative Care for HIV/AIDS, 2003

The National Cancer Policy Board

The six major skill sets that comprise complete palliative care include:

- Communication,
- Decision making,
- Management of complications of treatment and the disease,
- Symptom control,
- Psychosocial care of patient and family, and
- Care of the dying.

National Cancer Policy Board, 2001

Growth House, Inc.

Palliative care, also called comfort care, is primarily directed at providing relief to a terminally ill person through symptom management and pain management. The goal is not to cure, but to provide comfort and maintain the highest possible quality of life for as long as life remains. Well-rounded palliative care programs also address mental health and spiritual needs. The focus is not on death, but on compassionate specialized care for the living. Palliative care is well-suited to an interdisciplinary team model that provides support for the whole person and those who are sharing the person's journey in love.

Growth House website, 2003

The International Association for Hospice & Palliative Care

Palliative care is the care of patients with active, progressive, far-advanced disease and a short life expectancy, for whom the focus of care is the relief and prevention of suffering and the quality of life.

International Association for Hospice & Palliative Care website, 2003

The American Board of Hospice & Palliative Medicine

Hospice and palliative medicine is an interdisciplinary approach to the study and care of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is quality of life. This discipline recognizes the multidimensional nature of suffering, responds with care that addresses all of these dimensions, and communicates in a language that conveys mutuality, respect, and interdependence.

American Board of Hospice and Palliative Medicine website, 2003

Last Acts

Precepts of Palliative Care:

- Respecting Patient Goals, Preferences and Choices
- Comprehensive caring
- Utilizing the strengths of interdisciplinary resources
- Acknowledging and addressing caregiver concerns
- Building systems and mechanisms of support

Partnership for Caring

A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, controlling pain and symptoms, and enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values is an essential component. Palliative care is sometimes called "comfort care" or "hospice-type care."

What Is Palliative Care? From StopPain.org at Beth Israel Medical Center, NYC www.stoppain.org

"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families."

--World Health Organization. Technical Report Series 804, Cancer Pain and Palliative Care. Geneva: World Health Organization 1990:11.

Palliative care is an interdisciplinary therapeutic model that focuses on the comprehensive management of the physical, psychological, social and spiritual needs of patients with progressive incurable illnesses and their families. The model applies throughout the course of the illness, and includes an array of interventions that are intended to maintain the quality of life, or attenuate the suffering, of the patient and family. As death approaches, palliative care must intensify and ensure that comfort is a priority, practical needs are addressed, psychosocial and spiritual distress is managed, values and decisions are respected, and opportunities are available for growth and resolution.

Palliative care is both an approach to patient care that should be routinely integrated with life-prolonging therapies and a growing practice specialty for highly trained physicians, nurses, social workers, chaplains, and others. Palliative medicine is the medical specialty dedicated to excellence in palliative care. Palliative care specialists typically work in teams and usually are needed when the disease is advanced, life expectancy is short, and problems become complex and more urgent. In practice, these problems most often relate to uncontrolled symptoms, conflicted or unclear goals of care, distress related to the process of dying, and increasing family burden.

The definition of palliative care has much in common with hospice. In the United States, however, palliative care is evolving in a way that goes well beyond the American version of hospice. Palliative care aims to address the physical, psychosocial, and spiritual concerns that contribute to both the quality of life and quality of dying for patients with life-threatening illnesses at any phase of the disease. Although the focus intensifies at the end of life, the core issues -- comfort and function -- defined broadly and evaluated within the context of the family, are important throughout the course of the disease.