

Last acts.

*A national coalition to improve
care and caring at the end of life*

Precepts of Palliative Care

DEVELOPED BY THE TASK FORCE ON PALLIATIVE CARE

DECEMBER 1997



Palliative care refers to the comprehensive management of the physical, psychological, social, spiritual and existential needs of patients. It is especially suited to the care of people with incurable, progressive illnesses.

Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms and restoration of functional capacity while remaining sensitive to personal, cultural and religious values, beliefs and practices.

Palliative care can be complementary to other therapies that are available and appropriate to the identified goals of care. The intensity and range of palliative interventions may increase as illness progresses and the complexity of care and needs of the patients and their families increase. The priority of care frequently shifts during this time to focus on the dying process with an emphasis on end-of-life decision making and care that supports physical comfort and a death that is consistent with the values and expressed desires of

the patient. Palliative care guides patients and families as they make the transition through the changing goals of care, and helps the dying patient who wishes to address issues of life completion and life closure.

Palliative care has become an area of special expertise within medicine, nursing, social work, pharmacy, chaplaincy and other disciplines. However, advances in palliative care have not yet been integrated effectively into standard clinical practice. The fundamental precepts of palliation should be a basic component of the attitudes, knowledge base and practice skills of all clinicians.

The *Last Acts* Palliative Care Task Force believes that acknowledgment and incorporation of the following core precepts into all end-of-life care can serve as a starting point for needed reform.

Precepts 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.

Palliative Care Task Force

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See attached sheet for organizations that have formally endorsed the precepts.