Primary Palliative Care Guideline

This guideline is designed to assist healthcare practitioners treating patients with chronic, serious, or advanced illness in facilitating advance care planning and delivering primary palliative services.

What is Palliative Care?

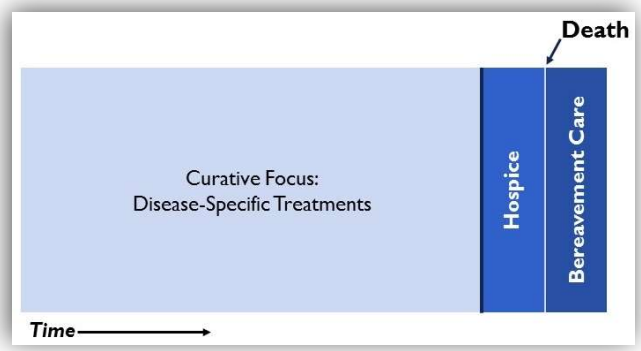
Definition: Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative Care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual suffering (referred to as "total pain"), facilitating patient autonomy, access to information, and choice.*

Palliative care focuses on defining goals of care and managing symptoms in tandem with curative techniques, for patients of any age and any stage of illness.

Why Palliative Care?

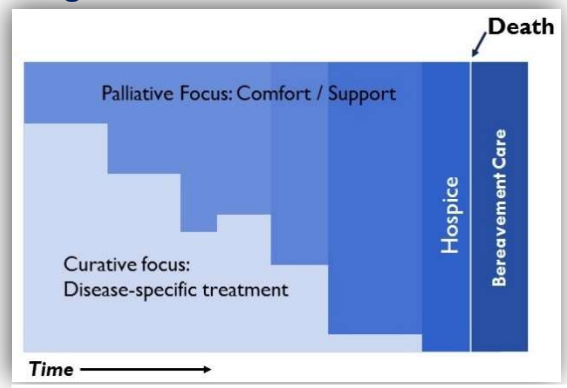
- Palliative care improves quality of life and reduces unwanted treatment and repeat hospitalizations.
- For many common end-stage diseases, patients receiving palliative or hospice care live longer.
- Early involvement of palliative care improves family coping and adjustment after death.
- Hospice care is a specialty level of palliative care for patients at the end of life.

Traditional Care Model



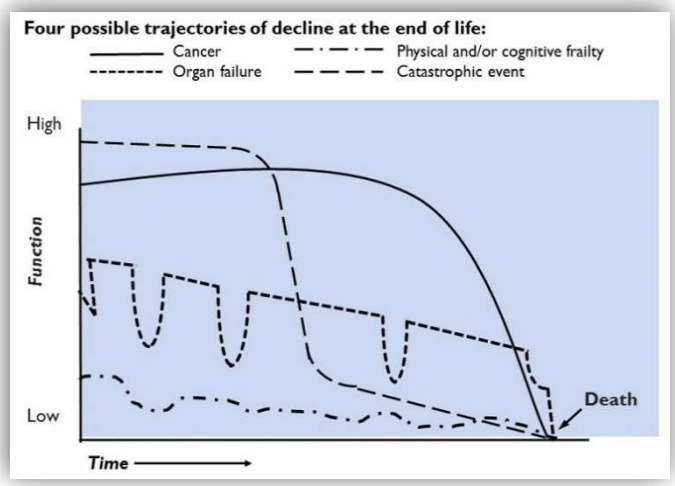
This diagram illustrates the traditional care model for serious illness: life-prolonging or cure-directed therapy is pursued right up to the terminal stage, at which point an abrupt shift is made to comfort care.

Integrated Palliative Care Model



Palliative care occurs at the same time as curative care. Palliative components should be integrated into the chronic illness care plan throughout the course of illness alongside life-extending treatment. This integration does not require specialty palliative care services. Attention to advance care planning; the patient's goals; symptom management; and the emotional, social, relational, and spiritual aspects of illness should be a routine part of care. Care plans should be discussed and adjusted as the patient's condition and goals change as suggested by the "steps" in the diagram. For patients who choose hospice, the entire focus is palliative.

Trajectories of Illness†



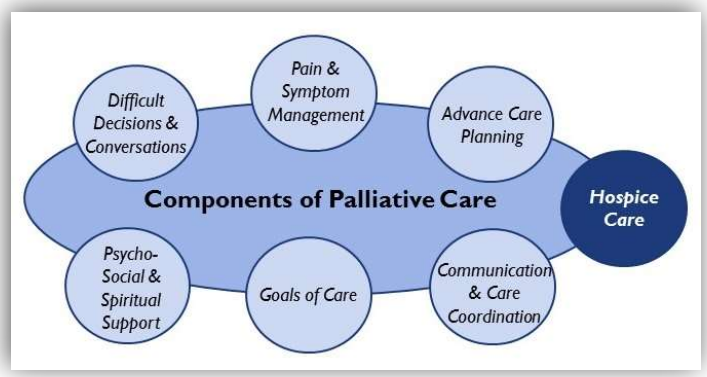
Different trajectories imply different roles for Palliative Care and care planning.

With most cancers, patients can maintain fairly high levels of function through supportive therapies. As the disease progresses or does not respond to treatment, decline can be rapid. Palliative care conversations should occur at diagnosis, disease progression, or recurrence.

Organ failure (heart, lung, kidney, etc.) involves periods of slow decline, punctuated by sudden worsening of the disease, crisis, or hospitalization. Sometimes these exacerbations are followed by a degree of "recovery," but never to baseline, and any one can result in death. Frequent review of treatment options and palliative consultation can ensure clarity of goals and comfort.

Neuromuscular disorders, frailty, and dementia pose special challenges, as decline can be slow, subtle, and prolonged. At diagnosis or at clear onset, advance care planning and palliative consultation can put in place necessary surrogate decision makers and clear instructions for future treatments.

Catastrophic events (stroke, brain injury, hip fracture, etc.) can occur at any time and at any age but are particularly devastating to function and quality of life for elders. Death may only come about after difficult decisions regarding life-sustaining treatment. Advance care planning and appointment of healthcare decision makers, well before any crisis, can clarify goals and preferences in unexpected circumstances.



What is Hospice?

- A specialty level of palliative care, wholly covered by Medicare, provided to a person and their family when life expectancy is six months or less.
- Prognosis can be challenging and many patients are referred to hospice too late to benefit or not at all.
- For patients and families to get the most benefit from hospice services, consider referral when you think the patient could die within the next year.

*World Health Organization †Trajectories of illness reproduced from Lynn J, Adamson DM. Living well at the end of life. Adapting health care to serious chronic illness in old age. Washington: Rand Health, 2003, with permission. Catastrophic event trajectory included courtesy of Jennifer Moore Ballentine, The Iris Project, 2017. This guideline originally developed by a collaborative workgroup convened by HealthTeamWorks, Colorado, 2011; adapted and updated by The Iris Project, with permission of Colorado Department of Public Health & Environment.