



# Palliative Care

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## INTRODUCTION

Palliative care is both a philosophy of care and an area of specialization within several medical fields. The primary goal of palliative care is to minimize suffering and to support the best possible quality of life for patients and their families. Patients with serious and debilitating illness need and deserve excellent symptom control, assistance with difficult medical decisions, effective communication and collaboration among their providers, addressing of psychosocial problems, and an empathetic presence that fosters hope and healing relationships. Palliative care affirms life by supporting the patient's goals for the future in light of a full understanding of their medical condition, potentially including their hopes for cure, life-prolongation, relief from suffering, as well as preparation for death when time is short. This process includes exploring what would be left undone if treatment does not go as hoped, who should make medical decisions for the patient if decision-making capacity is lost, and what, if any, limits might be set on aggressive therapy.

Palliative care provides an organized, highly structured system for delivering care by an interdisciplinary team, including physicians, nurses, social workers, chaplains, counselors, as well as other health care professionals. Palliative care should be integrated within various health care settings including the hospital, emergency department, nursing home, home care, assisted living facilities, and outpatient settings. Palliative care remains very unevenly available, so many patients and families needlessly suffer having either no, limited, or delayed access to appropriate palliative care. Basic palliative care should be part of the tool kit for all physicians who care for seriously ill patients, and specialty palliative care should be available for the more challenging symptom management and complex and often conflictual medical decision making.

The integration of palliative care into the experiences of patients and families is designed to meet several objectives. First, to ensure that pain and symptom control, psychosocial distress, spiritual issues, and practical needs are addressed throughout the continuum of care. Second, to make certain that patients and families obtain the information they need in an ongoing and comprehensible manner to understand their prognosis and treatment options. This process incorporates their values and preferences and is sensitive to changes in the patient's condition over time. Third, palliative care seeks to provide seamless care coordination across settings with high-quality communication among providers. Finally, for those patients who are not going to recover, palliative care prepares patients and families, to the extent possible, for the dying process and for death, including options for

hospice care and opportunities for personal growth and bereavement support.

## COMMON ILLNESS TRAJECTORIES AND PALLIATIVE CARE

There are four distinct trajectories of functional decline before dying (E-Fig. 125-1). These trajectories have major implications for palliative care and health care delivery. Patients and families likely have different physical, psychological, social, and spiritual needs depending on the trajectory of their illness before they die. Being aware of these trajectories can help providers deliver appropriate care that integrates both disease-directed and palliative treatments.

### Trajectory 1: Short Period of Evident Decline before Death

Cancer typifies this trajectory. Function is preserved until rather late, followed by a predictable and precipitous decline over weeks to months. The onset of decline usually suggests metastatic tumor. A more predictable decline in function can assist in anticipating care needs, transitioning away from curative treatments toward a more exclusive emphasis on palliation, and eventually into hospice care. Not all malignancies follow this trajectory (e.g., prostate, breast) and some non-malignant conditions may follow this course.

### Trajectory 2: Chronic Illness with Exacerbations and Sudden Dying

Congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), end-stage liver disease, and AIDS typify this trajectory. These organ system diseases represent chronic illnesses with occasional, acute exacerbations (e.g., physiological stress that overwhelms the body's reserves), often requiring hospital admission. Patients can have a return of function after an exacerbation, but often not to the level of their baseline. They also may die suddenly during an exacerbation, but it is difficult to predict in advance. Prognosticating is very challenging in this trajectory. When patients choose to forego or stop aggressive life support, planning for aggressive symptom relief during a future exacerbation is essential.

### Trajectory 3: Prolonged Dwindling

Dementia and frailty typify this trajectory. These patients have a prolonged course of physical and cognitive decline and become increasingly frail. Additional diagnoses include other neurodegenerative conditions (e.g., Parkinson's disease, amyotrophic lateral sclerosis) and patients with multiple moderate to severe