



به نام خدای بخشننده و مهربان
In the name of Allah, the Beneficent, the Merciful

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Palliative Care



What is Palliative Care?

- **Medical care that focuses on alleviating the intensity of symptoms of disease.**
- **Palliative care focuses on reducing the prominence and severity of symptoms.**

Definition of Palliative Care



World Health Organization

“Palliative care is an approach that **improves the quality of life of patients and their families** facing the problems 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.**”

WHO Definition of Palliative Care



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;**

WHO Definition of Palliative Care



- 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**.

What is the goal of Palliative Care?

- **The goal is to improve the quality of life for individuals who are suffering from severe diseases.**
- **Palliative care offers a diverse array of assistance and care to the patient.**

What does Palliative Care Provide to the Patient?

- Helps patients gain the strength and peace of mind to carry on with daily life**
- Aid the ability to tolerate medical treatments**
- Helps patients or families to better understand their choices for care**
- Improves everyday life of patient; reducing the concern of loved ones**
- Allows for valuable support system**

Palliative Care



The History of Palliative Care

- Started as a hospice movement in the 19th century, religious orders created hospices that provided care for the sick and dying in London and Ireland.
- In recent years, Palliative care has become a large movement, affecting much of the population.
- Began as a **volunteer-led movement** in the United states and has developed into a vital part of the health care system.

Palliative Care

50% of caregivers of Americans hospitalized with a serious illness report less than optimal care:

- ♦ 1 in 4 patients report inadequate treatment of pain and shortness of breath.**
- ♦ 1 in 3 families report inadequate emotional support.**
- ♦ 1 in 3 patients report that they receive no education on how to treat their pain and other symptoms following a hospital stay.**
- ♦ 1 in 3 patients are not provided with arrangements for follow-up care after hospital discharge.**

Who receives Palliative Care?

- **Individuals struggling with various diseases**
- **Individuals with chronic diseases such as cancer, cardiac disease, kidney failure, Alzheimer's, HIV/AIDS and Amyotrophic Lateral Sclerosis (ALS)**

Who do you think would benefit?

- High-risk patients
- Socially vulnerable
- Exhausted family caregivers
- Patients with:
 - Cognitive impairment
 - Multiple comorbidities
 - Frailty
 - Functional dependency
- Palliative care can help with illnesses other than cancer:
 - Advanced lung, heart, kidney and liver disease
 - AIDS
 - Alzheimer's disease and dementia
 - Cystic Fibrosis
 - Disabling stroke and other neurological diseases
 - Motor Neuron Disease and multiple sclerosis

Palliative Care and Cancer Care

- **Palliative care is given throughout a patient's experience with cancer.**
- **Care can begin at diagnosis and continue through treatment, follow-up care, and the end of life.**

Where to find Palliative Care?

- In most cases, palliative care is provided in the hospital.
- The process begins when doctors refer individuals to the palliative care team.
- In the hospital, palliative care is provided by a team of experts.

Palliative Care

Dame Cicely Saunders, the founder of the first modern hospice for terminally ill patients, had said that her aim was,

“to add life to their days, not days to their lives.”

“You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also **to live until you die.**”

Palliative Care and Cancer

- **"Everyone has a right to be treated, and die, with dignity.**
- The relief of pain - physical, emotional, spiritual and social - is a human right," said Dr Catherine Le Galès-Camus, WHO Assistant Director-General for Noncommunicable Diseases and Mental Health.
- **"Palliative care is an urgent need worldwide for people living with advanced stages of cancer, particularly in developing countries, where a high proportion of people with cancer are diagnosed when treatment is no longer effective."**

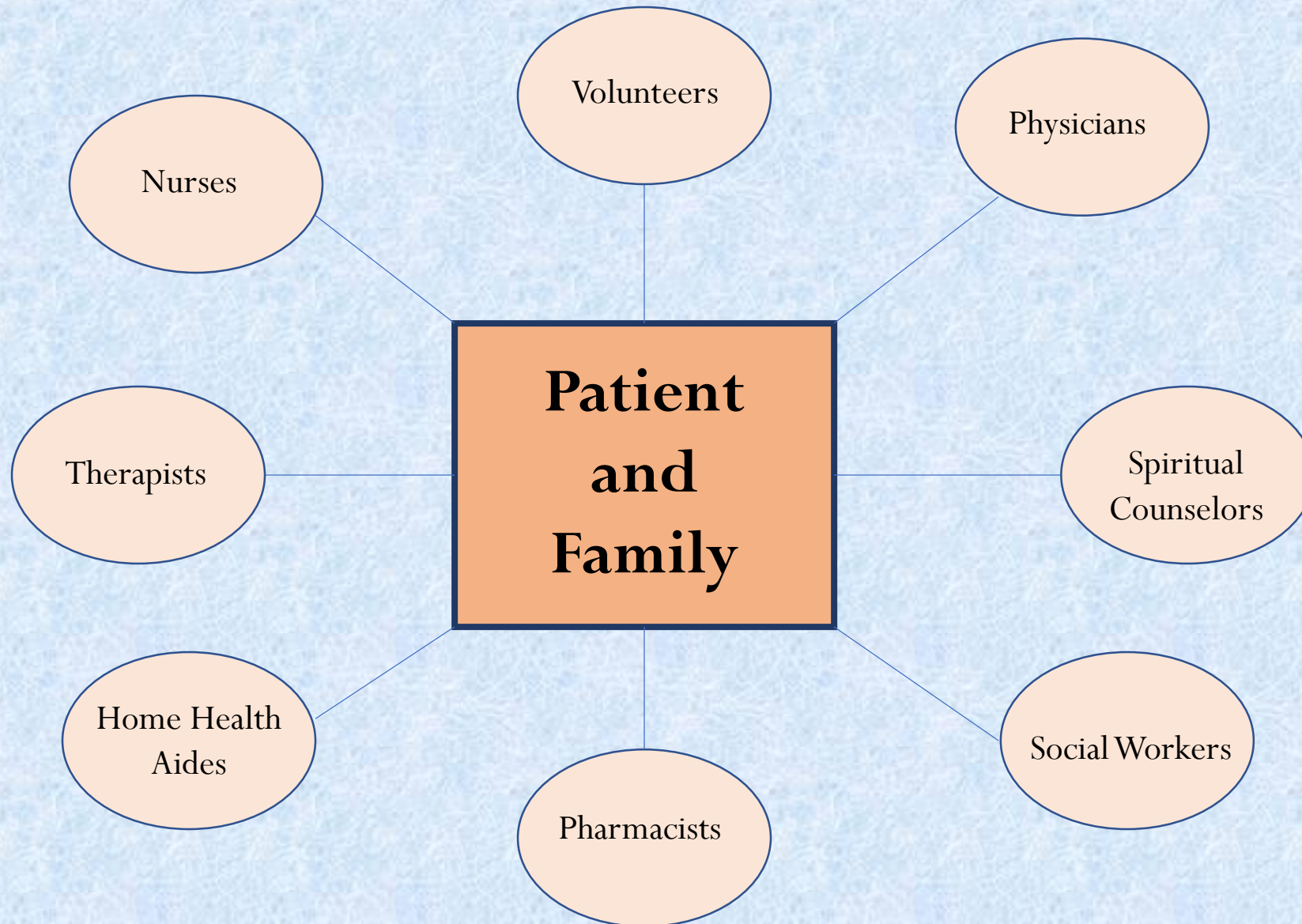
Who Provides Palliative Care?

- Usually provided by a team of individuals
- Interdisciplinary group of professionals
- Team includes experts in multiple fields:
 - Doctors
 - Nurses (Registered Nurse)
 - social workers
 - massage therapists
 - Pharmacists
 - Nutritionists



Who Provides Palliative Care?

- **Advanced Practice Provider**
- **Spiritual Advisor**
- **Community Health Worker**
- **Medical Assistant**
- **Volunteers**
- **Patient**
- **Family Member or other Loved Ones**



Approaches to Palliative Care

- **Not a “one size fits all approach”**
- **Care is tailored to help the specific needs of the patient**
- **Since palliative care is utilized to help with various diseases, the care provided must fit the symptoms.**

Palliative Care



“What is Palliative Care?”

- ♦ The goal is to relieve suffering and provide the best possible quality of life for patients and their families, at any age and any stage of serious illness.
- ♦ Focus on **intensive symptom management, communication and coordination of care.**
- ♦ Provided *along with* curative treatment.
 - ♦ **Not the same as hospice.**
 - ♦ **Not limited to end-of-life care.**
 - ♦ **Not dependent on prognosis.**





Domains of Palliative Care

- **Structure and Processes of Care** (with a comprehensive assessment and a care plan)
- **Physical Aspects of Care** (focus on relieving symptoms, improving/maintaining quality of life = patient centered)
- **Psychological Aspects of Care** (members struggling with psychological issues =Directly
 - Through Consultation
 - Specialist Referral

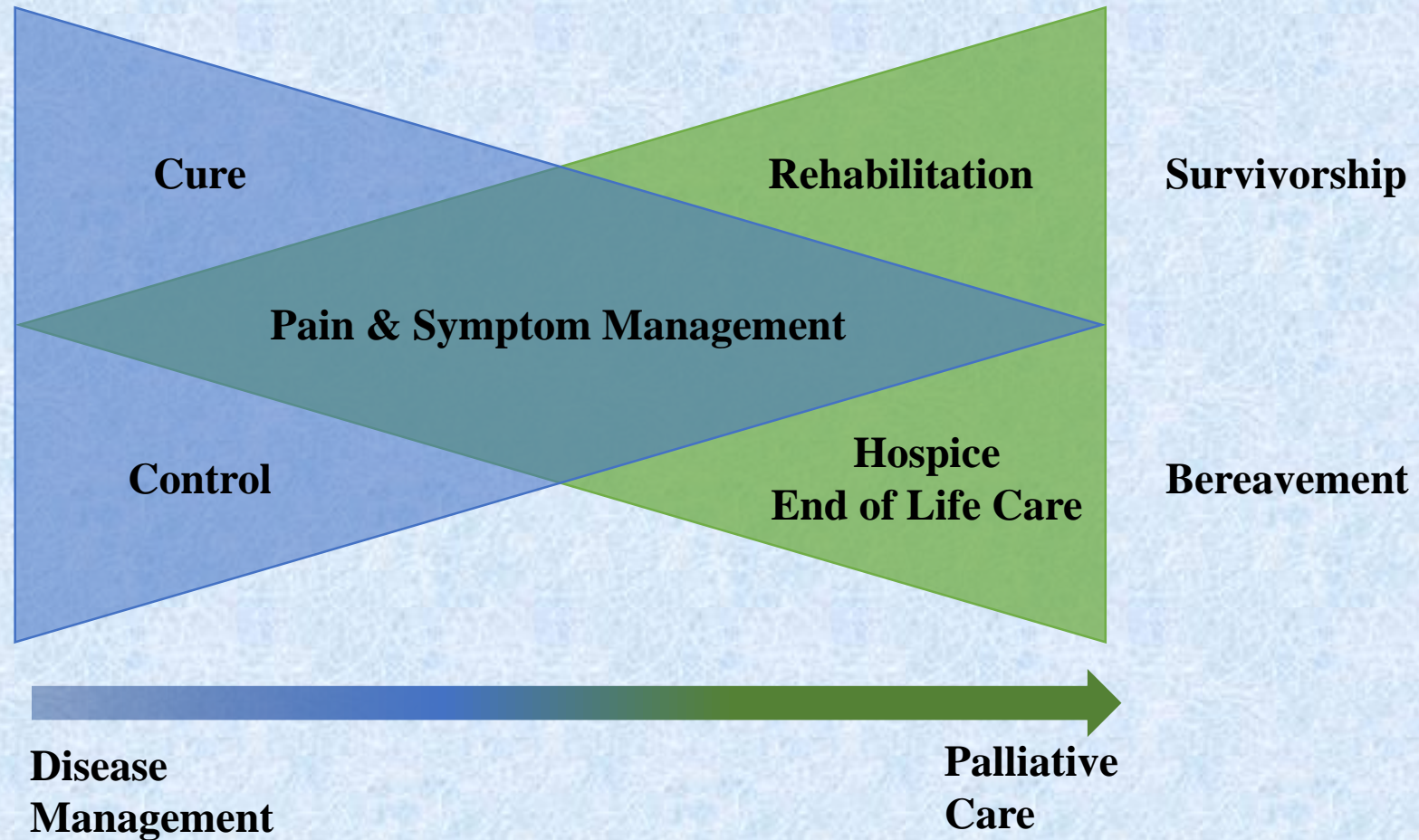
Domains of Palliative Care

- **Social Aspects of Care** (assessment environmental and social factors, including:
 - Social support network
 - Financial barriers
 - Access to care (e.g. transportation, medications)
- **Spiritual Aspects of Care** (includes religious and nonreligious factors= Offer support of spiritual counselor: priest, rabbi, imam, or other religious leader)
- **Cultural Aspects of Care** (Racial and ethnic minorities experience = Respect values, beliefs, and traditions related to health, illness, family caregiver roles and decision making)

Domains of Palliative Care

- **Care of Imminently Dying**
- **Ethical & Legal Aspects of Care** (informed decision making)

Palliative Care Enhanced Care Model



Kinds of Care

Curative Care:

- Focuses on a cure to an illness and the prolonging of life.

Palliative Care:

- Focuses on comfort and quality of life that may be provided with other treatments.

Hospice Care:

- Focuses on comfort and quality of life when a cure is not possible with specialize care and services.

Recognize the differences in Goals of Care

- Rehabilitative Goals**
- Maintenance Goals**
- Preventive Goals**
- Palliative Goals**

Palliative Care Patient Support Services

- Three categories of support:

1. **Pain management** is vital for comfort and to reduce patients' distress.

Health care professionals and families can collaborate to identify the **sources of pain and relieve** them with drugs and other forms of therapy.

2. **Symptom management** involves treating symptoms other than pain such as nausea, weakness, bowel and bladder problems, mental confusion, fatigue, and difficulty breathing

3. **Emotional and spiritual support** is important for both the patient and family in dealing with the emotional demands of critical illness.

Settings for Palliative Care

- **Outpatient practice**
- **Hospital Inpatient**
 - **Unit based**
 - **Consultation Team**
- **Home care**
- **Nursing Home**
- **Hospice**

Cost of Palliative Care

- **Most insurance plans cover all or part of the palliative care treatment given in hospitals.**
- **Medicare and Medicaid also typically cover palliative care.**

What is the difference between Medicare and Medicaid?

- Medicare
- Medicare is an insurance program (also known as Hospital Insurance).
- It serves people over 65 primarily, whatever their income; and serves younger disabled people and dialysis patients.
- Patients pay part of costs through deductibles for hospital and other costs.
- Small monthly premiums are required for non-hospital coverage.

What is the difference between Medicare and Medicaid?

- Medicaid
- Medicaid is an assistance program.
- It serves low-income people of every age.
- Patients usually pay no part of costs for covered medical expenses.
- A small co-payment is sometimes required.

Hospice

- **Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness.**
- **Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.**

Hospice

- **A philosophy of care to assist those in the end stage of life (Hospice care is also family-centered – it includes the patient and the family in making decisions)**
- **Model of care originated in England**
- **First hospice in United States was in New Haven, 1976**
- **Fast Growth -- currently over 3500 hospice programs in United States**

Who is Eligible for Hospice?

- ♦ Advanced disease with life expectancy of “**six months or less**” given natural course of disease (may be longer if patient meets criteria)
- ♦ Poor functional/nutritional status
- ♦ High morbidity/mortality markers
- ♦ Payment sources



Common Hospice Diagnoses

- Cancer
- End-stage Heart Disease
- End-Stage Lung Disease
- End-Stage Renal Disease
- End-Stage Liver Disease
- Stroke/coma
- HIV
- Neurological Disease –Parkinsons, Alzheimers
- General Decline in Health Status

Where Hospice Care Occurs

Any place a patient is living

- In their own home
- In the home of a relative
- In a skilled nursing facility
- In a hospice home or other assisted living facility
- In shelters for the homeless
- In the penal system for incarcerated individuals

Where is Hospice?

- ♦ “Home”: primary or family residence, nursing home, group home, assisted living facility; mandated to be >80% of delivered care of any hospice’s services
- ♦ Inpatient facility: Short term, 3-5 days
- ♦ Continuous care at home: Highly regulated, typically 24 hours
- ♦ Respite care

Hospice Team

Patient and Family are considered the unit of care.

Working closely with:

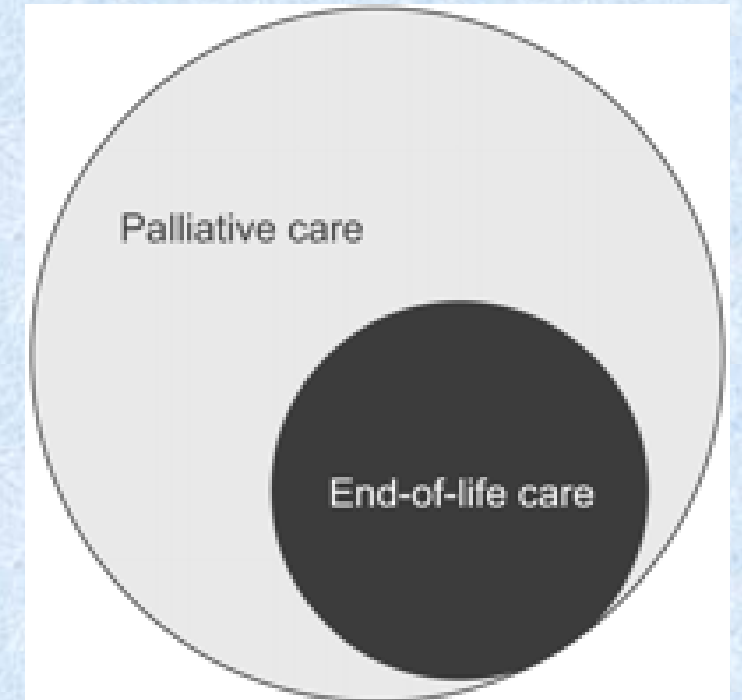
- Physician-directed team
- Nurse
- Social Worker
- Physical, Occupation, & Speech Therapist
- Dietician
- Home Health Aide
- Chaplain
- Volunteer
- Bereavement Counselor

Program Goals

- **Emphasize living**
- **Promote quality of life**
- **Encourage honesty and hope**
- **Rapid resolution of symptoms**
- **Preparation of patient and family for death**
- **Continued support for family after death of loved one**

Palliative vs. Hospice Care

- Division made between these two terms in the United States
- Hospice is a “type” of palliative care for those who are at the end of their lives.



Palliative vs. Hospice Care

- Palliative care can be provided from the **time of diagnosis**.
- Palliative care can be given **simultaneously with curative treatment**.
- **Both services have foundations** in the same philosophy of **reducing the severity of the symptoms of a sickness or old age**.
- Other countries do not make such a distinction

Comparing Palliative Care and Hospice Care

Palliative Care	VS	Hospice Care
Physical and psychosocial relief		Physical and psychosocial relief
Focus on quality of life		Focus on quality of life
Multidisciplinary Team Approach		Multidisciplinary Team Approach
<i>Any stage of disease</i>		<i>Prognosis 6 months or less</i>
<i>May be concurrent with curative treatment</i>		<i>Excludes curative treatment</i>

Hospice Access Issues

- ♦ Culture
- ♦ Race
- ♦ Religious Diversity
- ♦ Insurance issues
- ♦ Geography
- ♦ Healthcare staff
 - ♦ Median survival in Hospice care is 2-3 weeks, primarily due to late physician referrals

Benefits of Medicare Hospice

- Team approach to care
- Cost for home hospice covered by Medicare 100%
- Medications, supplies, and equipment related to the terminal disease covered 100%
- Acute care in facility setting for symptoms that are unable to be controlled in the home, collapse of support system or imminent death
- Respite benefit for caregivers
- Ongoing support to bereaved family

Private Insurance

- **Every insurance is different**
- **Some offer inpatient and respite services**
- **Some offer room and board at facilities**
- **Some cover medications**
- **Some allow hospitalization**
- **This is evaluated with every admission to hospice**

Levels of Care

- **Routine Home Care**
- **General Inpatient Care**
 - **24 Hour Nurse for Short-term Stay**
- **Respite Care for Caregiver Stress**
- **Continuous Care**
 - **Expanded Level of Skilled Nursing**

Routine Home Care

- Most common level of care
- Can be provided in home, residential setting or nursing home
- Includes care from team members on regularly scheduled visits

General Inpatient

- Higher level of care
- Provided in a facility for symptom management
- Hospice continues to manage the plan of care
- General Inpatient guidelines are very specific
- Any symptom that cannot be controlled in the home setting
- Symptoms: pain, nausea/vomiting, or caregiver breakdown
- Each case is unique and needs to be addressed and determined by the hospice team

Respite Care

- **This level of care is reserved for caregiver relief**
- **Medicare/Medicaid will pay for up to 5 consecutive days of inpatient respite care per month**
- **Short-termed inpatient care designed to give a rest from handling the care of the patient**

Continuous Care

- Expanded level of skilled care in patient's home to manage a crisis
 - For Example: Terminal Restlessness
Pain Crisis
- Nursing care must equal more than total of 50% of total hours necessary to prevent hospitalization
- Minimum of 8 hours in a 24 hour period

Patient Focused Approaches

- Decisions are driven by the patient's goals of care and wishes
- Provide support to patient to express wishes
- Provide support to family and caregivers so that patients may realize goals of care
- Navigate, coordinate a complex/confusing healthcare system, understand the plan of care

Family Related Challenges

- Family Functioning
 - May have less than optimal relationships
- Incongruent patient and family member needs
- Communication process barriers
- Impaired concentration
- Timing and amount of information
- Family members not wanting to bother the health care team
- Family members' rejection of support
- Cultural issues and provider comfort level

Family Meeting

- When possible, the patient should determine who they would like to be present
- Identify the health proxy
- Helpful to have members of the care team available to the patient to aid in decision making
- Ensure an environment where patients and families feel comfortable sharing information

Shared Decision Making

- Engages patients and families in decisions about their care
- Increases their involvement and satisfaction
- Helps patients and families clearly communicate their goals and needs
- No “one right way” to intervene

