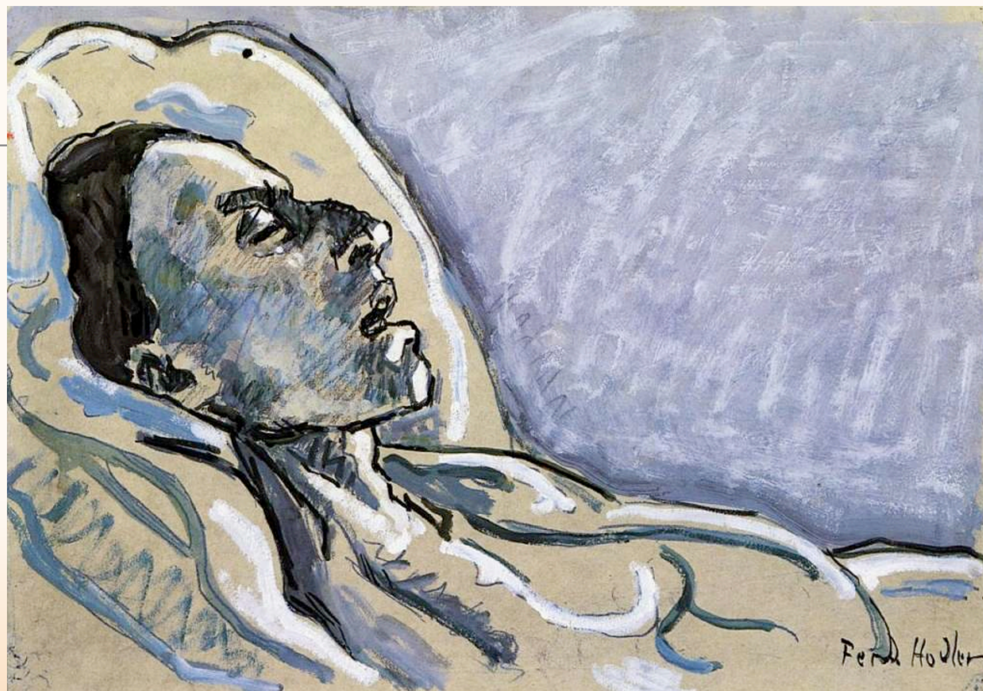


Myths about Death and Dying in America

ADITI SETHI-BROWN, MD

HOSPICE AND PALLIATIVE MEDICINE PHYSICIAN

Myth #1

Myth: Death is a Medical Event.

Fact: With or without medical intervention, death is an inevitable part of life

- Historically, death – like being born – was a family, communal and religious event
- Death moved out of homes and into medical institutions by the 20th century
- This final stage of life is distanced from the rest of living, few have a personal and direct experience with dying and death
- Death is perceived to be a failure of our medical system, not a natural part of life or natural progression of a disease.
- Natural Birth Movement // Natural, Death Positive, or Conscious Dying Movement.
- We have autonomy – we have a say in when, where and how we will die

Myth #2:

Myth: Death is always miserable and painful.

Fact: Natural death is not inherently painful.

- Depending on the disease process some people have pain, at times severe
- With good hospice and palliative care, symptoms are often well managed
- Death often occurs by dehydration. People naturally stop eating and drinking in the dying process.
- Many diseases lead to anorexia and cachexia, can be distressing to family members
- Food and water are not withheld from someone who is dying

Myth #3

Myth: Anticipated death always occurs quickly.

Fact: Death is oftentimes a process, though can occur rapidly

. Most people (>90%) die after a period of illness with gradual deterioration

Statistics on Death and Dying in America

Number of deaths: 2,712,630

Death rate: 844.0 deaths per 100,000 population

Life expectancy: 78.8 years

Infant Mortality rate: 5.90 deaths per 1,000 live births

- CDC, 2015.

Number of deaths for leading causes of death:

Heart disease: 633,842

Cancer: 595,930

Chronic lower respiratory diseases: 155,041

Accidents (unintentional injuries): 146,571

Stroke (cerebrovascular diseases): 140,323

Alzheimer’s disease: 110,561

Diabetes: 79,535

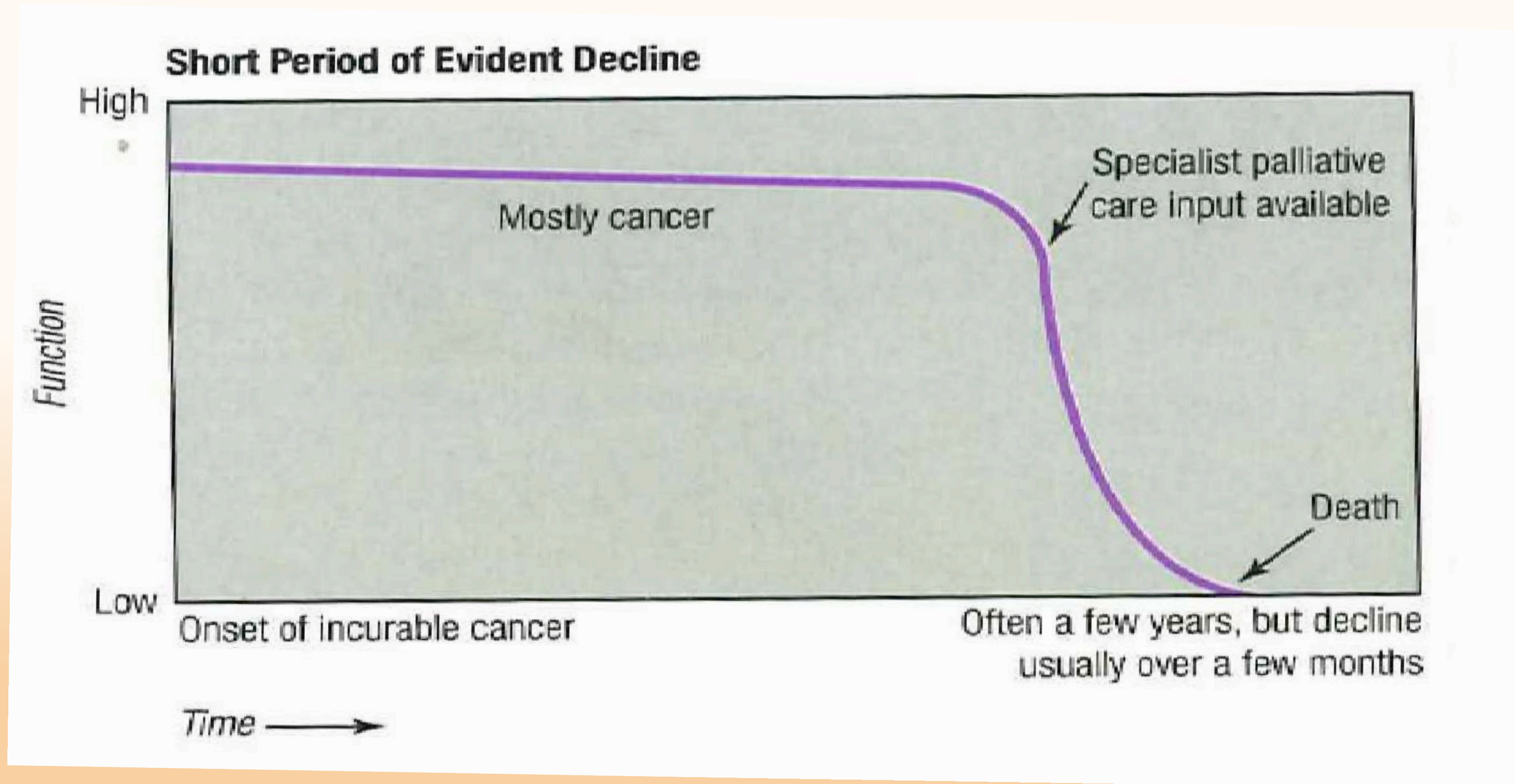
Influenza and Pneumonia: 57,062

Nephritis, nephrotic syndrome and nephrosis: 49,959

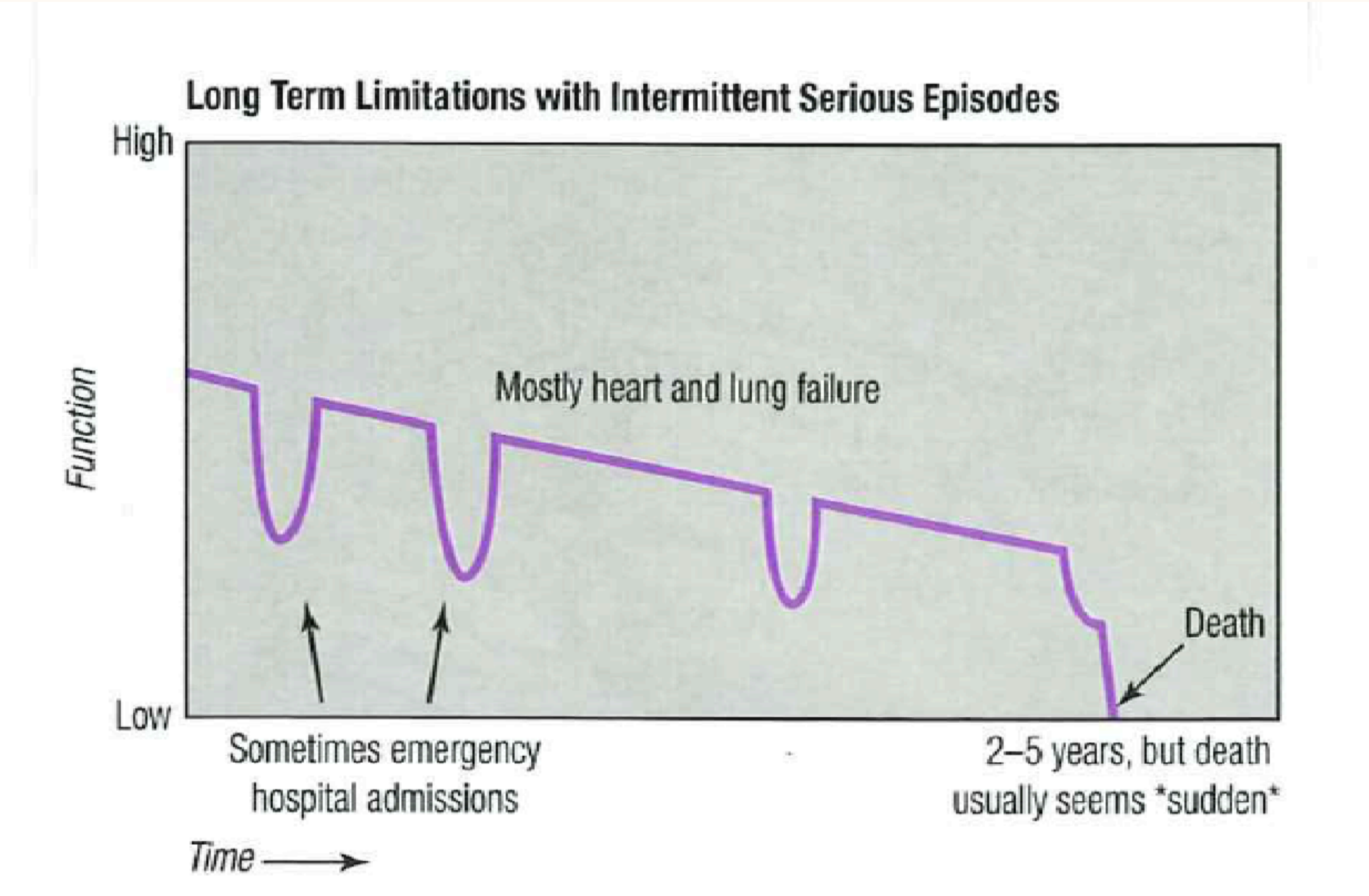
Intentional self-harm (suicide): 44,193

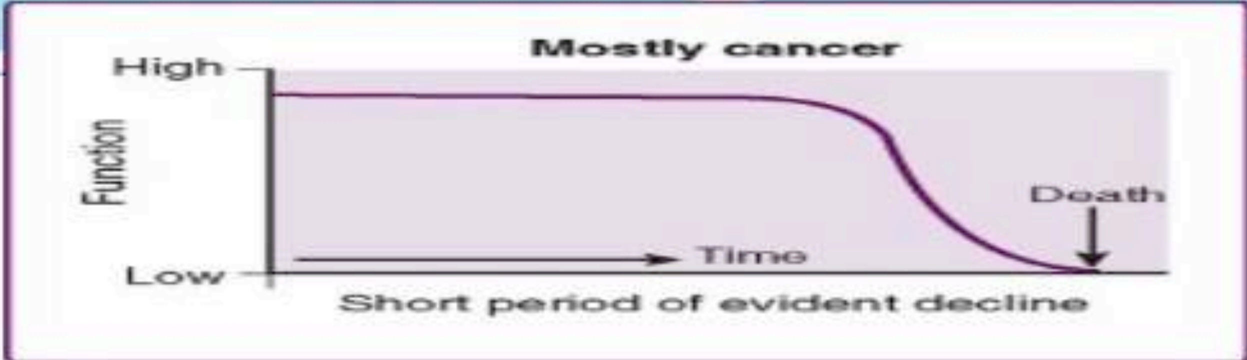
CDC, 2015.

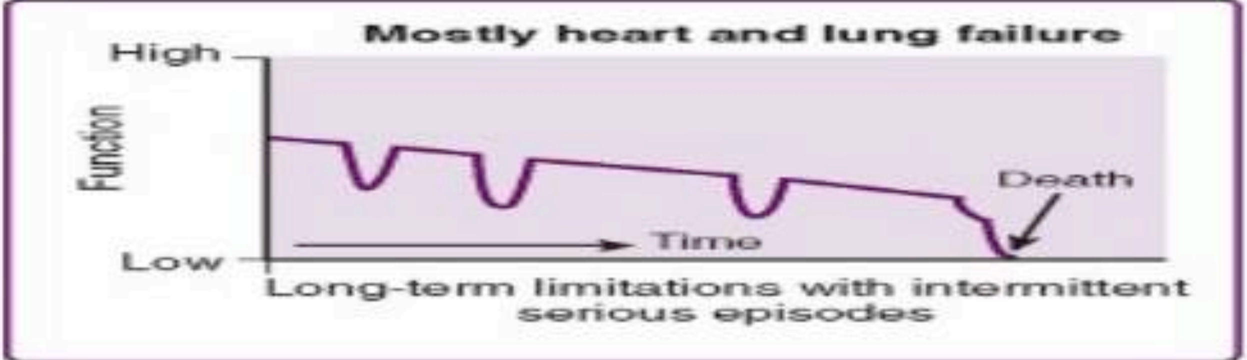
Cancer Trajectory

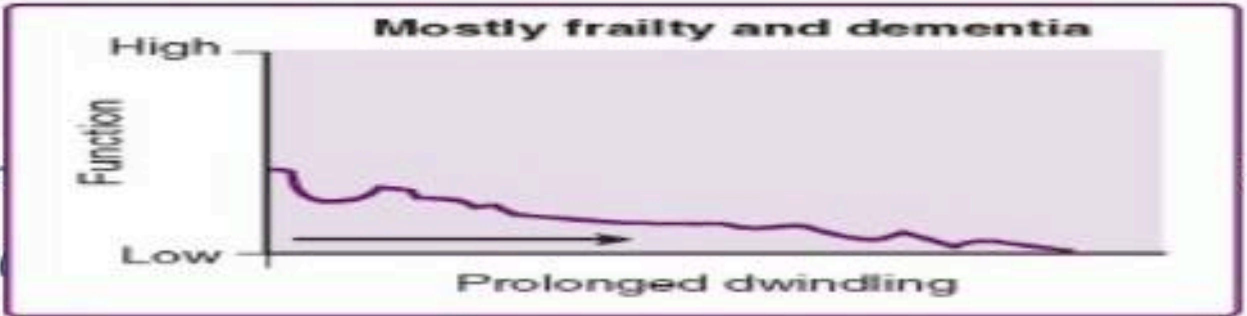


Organ Failure Trajectory



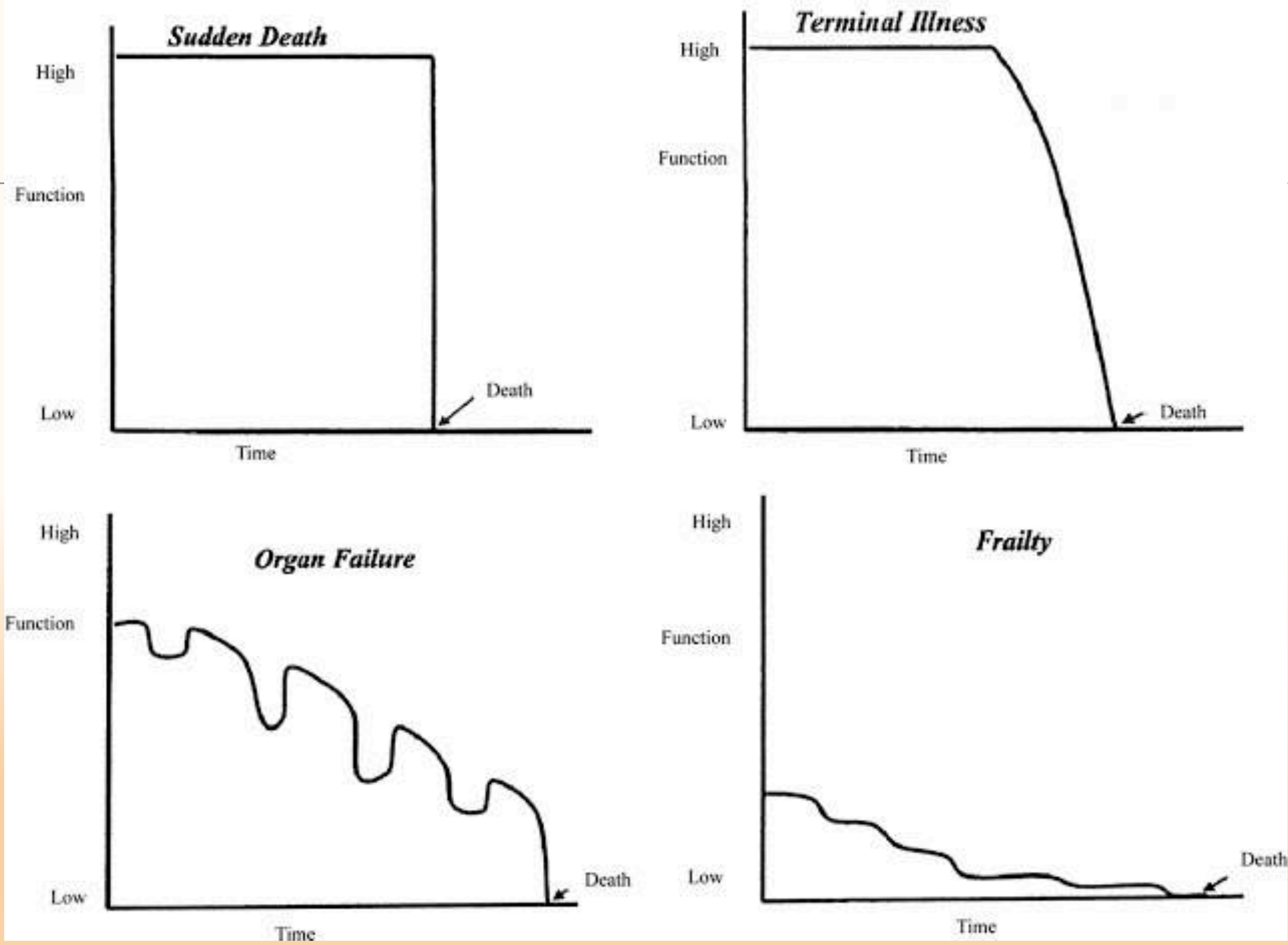






Death ... *eriatr*

Soc 2


Proposed Trajectories of Dying
Sudden Death
High
Function
Low
Death
Time
Terminal Illness
High
Function
Low
Death
Time
Organ Failure
High
Function
Low
Death
Time
Frailty
High
Function
Low
Death
Time

Myth #4

Myth: It is possible to predict the exact timing of death.

Fact: It is a mystery as to when an individual will take their last breath.

- There are some things that can guide us in making a prognosis
- We talk in terms of minutes to hours, hours to days, and days to weeks, weeks to months

Physiologic Changes of Imminent Death

Early Stage
- Bedbound
- Loss of interest/ability to eat, drink
- Cognitive changes: Increased sleepiness/delirium

Middle Stage
- Further decline in mental status
- Increased Secretions

Late Stage
- Coma
- Fever
- Altered respiratory pattern
- Mottled extremities, Cyanosis

Early Stage of Imminent Death

Fatigue and weakness
- Decreased function, hygiene
- Inability to move around in bed
- Inability to lift head off pillow

Anorexia
- Poor intake
- Aspiration
- Weight loss, muscle and fat, notable in temples

Decreased fluid intake
- Dehydration, dry mucous membranes/conjunctiva

Cognitive changes
- Increasing drowsiness
- Day-Night reversal
- Delayed responses, short sentences

Middle Stage of Imminent Death

Decreased level of consciousness
- slow to arouse with stimulation
- only brief periods of wakefulness

Terminal Delirium
- Agitation, Restlessness
- Purposeless, repetitous movements

Dysphagia
- Coughing, choking

Loss of sphincter control
- Incontinence of urine or bowels

Increased Secretions
- Build up of oral and tracheal secretions
- “Death Rattle”

Late Stage of Imminent Death

Respiratory Dysfunction

- Abnormal breathing patterns

Cardiac Dysfunction

- Elevated Heart Rate
- Cooling of Extremities
- Mottling of the skin

Renal Failure

- Decreased urine output

Coma

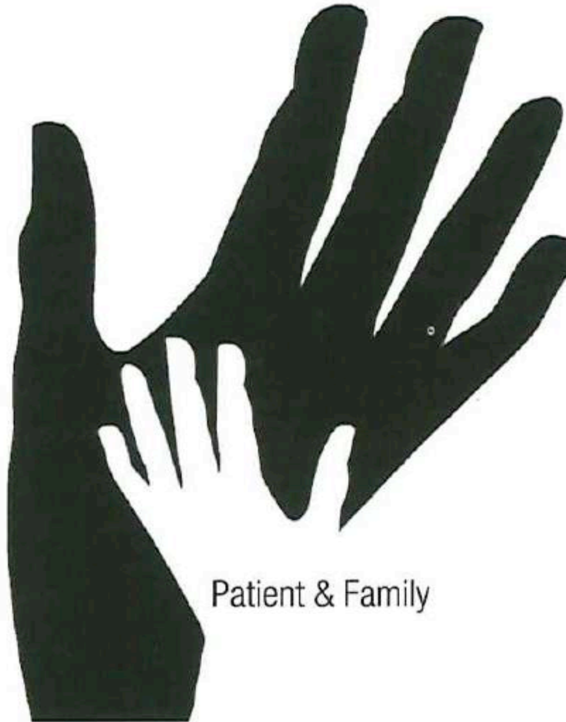
- Unresponsive to verbal or tactile stimuli

Myth #5

Myth: Hospice is a place you go when you are imminently dying.

Fact: Hospice is a philosophy of care and a system in place for delivering that care

- Majority of Hospice care occurs in homes or nursing facilities
- Some communities have an inpatient hospice facility that have certain criteria for admission
- For individuals with a prognosis of six months or less.
- Medical care for comfort is continued but curative treatments are not
- Goal is to help individuals live well until they die
- Interdisciplinary team addresses emotional, spiritual and physical aspects of care


Interdisciplinary Team
Attending Physician
Directs medical care
Home Health Aide
Assists with personal care
Bereavement Counselor
Provides support to family
Pharmacist
Assists with symptom management
Nurse
Coordinates the care to ensure comfort
Spiritual Care
Supports patient & family spiritually
Therapists
Provide physical, occupational, speech and nutrutional services
Social Worker
Identifies community services and provides support
Patient & Family
Volunteers
Provide companionship and support
Medical Director
Consults with the team and attending physician

Myth # 6

Myth: Hospice and Palliative Care are the same thing

Fact: There are distinguishing characteristics of each.

Hospice Care

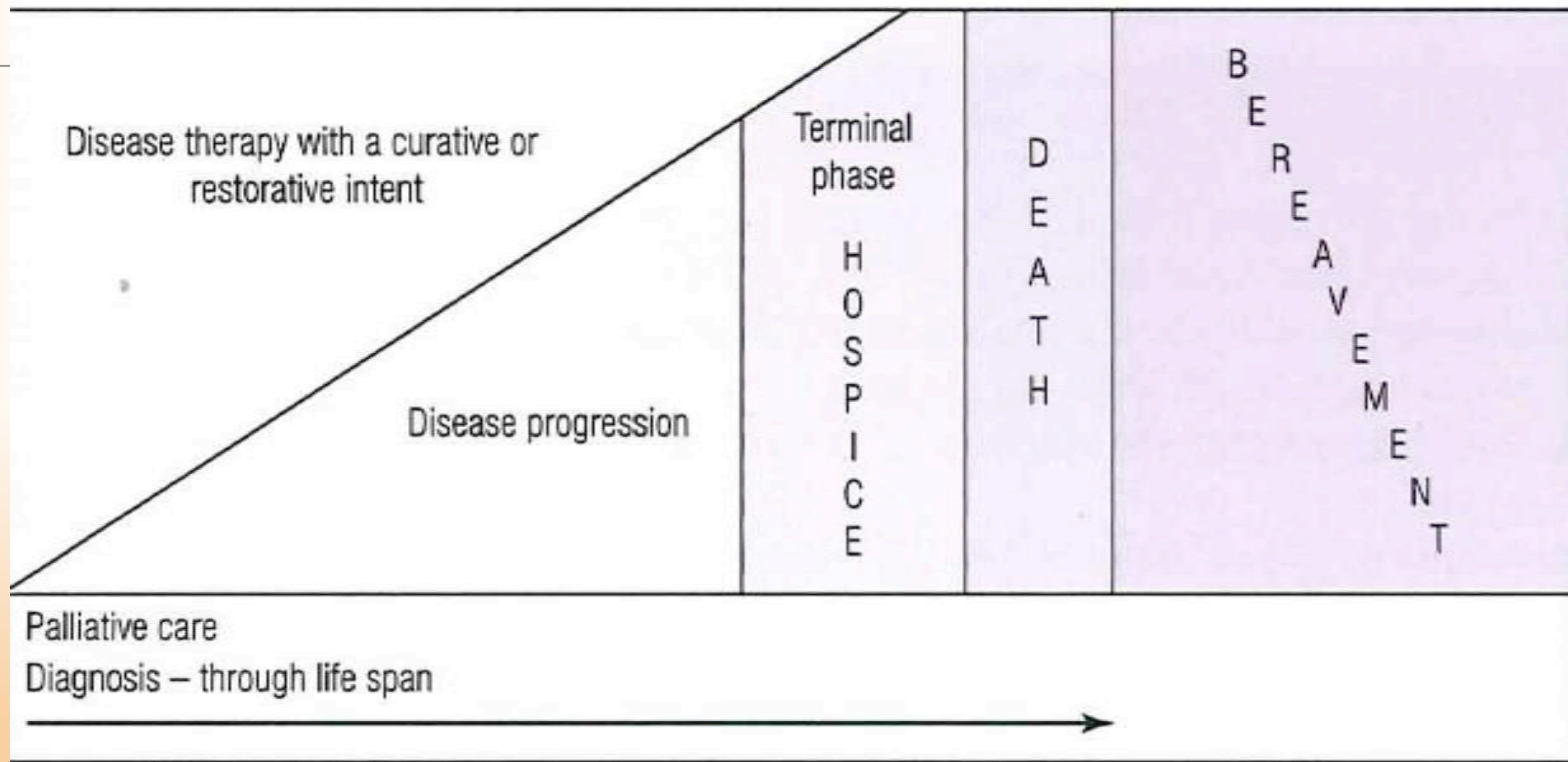
Began in 1967 as a grassroots community movement aimed at caring for cancer patients

Traditional Model of Hospice Care

Palliative Care

Expands the traditional medical goals of curing illness and prolonging life to:

- emphasize the patient-centered goals
- reduce symptom burden
- enhance function
- support hopes of patients with serious illness
- assist with difficult medical decision making


Palliative Care
World Health Organization Model
Disease therapy with a curative or restorative intent
Disease progression
Terminal phase
HOSPICE
DEATH
BEREAVEMENT
Palliative care
Diagnosis – through life span

Hospice vs Nonhospice palliative care

Hospice care: aimed at supporting patients who forego curative or life-prolonging medical treatment.

Nonhospice palliative care: aimed at improving quality of life for patients with serious and complex chronic illness in whom prognosis is uncertain or may be measured in years.

Myth #7:

Myth: Hospice kills people with morphine

Fact: Using morphine to hasten death would be euthanasia which is illegal in the US.

- Morphine titrated slowly for management of pain and shortness of breath has not been shown to hasten death.
- Hospice does not kill people. It allows death to occur in its normal, natural time frame in a humane way.
- There are other medications used in Hospice for symptom management.

Myth #8

- Myth: Talking about death results in death coming sooner and causes more distress to the dying
- Fact: Talking about death openly creates opportunities for all involved and does not hasten death
  - Most people who are dying, know they are dying.
  - Many individuals dying try to protect their loved ones from pain and anguish
  - Talking about death can bring a sense of peace and comfort to individuals if they are open to discussing their experience
  - Others have no interest in talking about death and find it stressful and anxiety provoking
  - Must meet individuals where they are on their terms.
  - When is a good time to talk about death?

Myth #9

- Myth: We should shield children from death.

- Fact: Children are often open to talking about death and they learn from us how to cope with the reality of death.
  - Normalizing the fact that everything that is born dies, including us, teaches children about death
  - What matters most is: How we listen, how we feel when we speak, and then what we say.
  - Use simple, direct, concrete language
  - Caution with euphemisms
  - Reassure that the person who died loved the child and that love never dies.
  - Acknowledge grief and integrate the death of a loved one into living – keep connection alive

Myth #10

Myth: When my time comes, I will be prepared for my death

Fact: Majority of people do not have advance directives in our country

- Advance Directives include living wills and appointment of health care power of attorney
- There is more to preparing for death than medico-legal paperwork.
- Some traditions even have practices for death.

References

1) Institute of Medicine (US) Committee on Care at the End of Life; Field MJ, Cassel CK, editors. Approaching Death: Improving Care at the End of Life. Washington (DC): National Academies Press (US); 1997. 2, A Profile of Death and Dying in America. Available from: https://www.ncbi.nlm.nih.gov/books/NBK233601/

2) https://www.cdc.gov/nchs/fastats/deaths.htm

3) Grauer, P, Shuster, J, Protus, BM. Palliative Care Consultant: A reference guide for palliative care. 3rd ed. Ohio Hospice and Palliative Care Organization. 2008, pp 12-13.