



Hospice Care

It's About How You Live

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Hospice & Palliative Care Association of NYS



Mission Statement

- To promote the availability and accessibility of quality hospice and palliative care for all persons in New York State confronted with life-limiting illness.



True or False?

- Hospice is where you go when there is nothing more that a doctor can do.




About Hospice

- Hospice is a program of services, not a place
- Services are provided by an interdisciplinary team under the direction of the patient's primary care physician



The Hospice Philosophy: Hospice Affirms Life

- Hospice provides support and care for persons in the final stages of life so that they may live in *comfort and dignity*, surrounded by family, friends, and caregivers



“What you don’t want to do is put people on the shelf to endure the passage of time. Anything you can do to enrich the quality of a single day is all to the good.”

*Robert Milch, MD, FACS
Former Medical Director
Hospice Buffalo*



Comfort Care

- Hospice includes medical care with an emphasis on *pain management* and *symptom relief*
- Hospice teams of professionals and volunteers address the physical, emotional, social and spiritual needs of the *patient & family*



Services

- In order to meet the full range of needs, hospice care is delivered by an interdisciplinary team of professionals & volunteers
- An individualized “plan of care” is developed based on the needs of the patient and family



Unique to Hospice: Interdisciplinary Team

- Medical Director
- Nurse
- Social Worker
- Chaplain
- Home health aide
- Volunteer



Other Services

- Medical Equipment
- Medications
- Supplies
- Complementary Therapies
- Bereavement Counseling
- On-Call Nurse



Counseling: For the Patient

- To cope with illness
- Depression, grief, anxiety
- Spiritual issues
- Loss of meaning, fear of death



Counseling: For the Family

- Caregiver stress
- Role changes
- Depression and anxiety
- Family conflict
- Spiritual concerns
- Grief and bereavement



Caregiver Stress

- Loss of “the way things were”
- Increased responsibilities
- No advance directive
- Socially isolating
- Physical effects of illness & medication



Eligibility

- Terminal diagnosis of 6 months or less if the disease runs its “normal” course.
- Hospice services are available to all persons, regardless of race, religion, age, ancestry, citizenship, veteran status, marital status, handicap, sexual preference or ability to pay



Cultural Competency

- Cultural sensitivity
- Considerations of communication
- Interpreters
- Role of the family
- Beliefs regarding death and dying
- Specialized programs
- Access for underserved populations

Diagnosis

- 40% - 50% of hospice care is provided to cancer patients; hospice is also for patients with HIV/AIDS; advanced respiratory, cardiac, liver and kidney diseases; Alzheimer's disease; Parkinson's disease; Multiple Sclerosis; or Amyotrophic Lateral Sclerosis (ALS)



Routine Home Care

- Most medical care for patient comfort can be provided at home
- Services are provided in the home of the patient or caregiver
- The goal is to enable the patient to remain at home in the care of loved ones



Hospital Care

- *Short-term* hospital care is provided in hospitals affiliated with hospice
- Hospital care is for the control of symptoms that temporarily cannot be managed at home and for short-term periods in the final days of life



Nursing Home

- Nursing home residents may elect for hospice care in affiliated nursing homes
- Hospice works collaboratively with nursing home staff to enhance residents' quality of life



Adult Home

- Residents of adult group homes may elect for hospice care
- Hospice provides services in an adult home in the same way it provides services in private homes
- Hospice works collaboratively with the staff of the home to enhance the quality of life for the resident



Who Pays for Hospice?

- All services are covered by Medicare and Medicaid, as well as by many private insurance companies and HMO's
- No one is refused care because of inability to pay
- Hospice handles the necessary paperwork regarding your hospice insurance reimbursement



What does Hospice not cover?

- Room and board
- Drugs and therapies unrelated to the terminal illness (ex. glaucoma medication)
- Expenses incurred without IDT approval
- Curative treatment



Bereavement

- Counseling is offered to all family members during the illness & for about a year after the death
- Hospice offers bereavement support groups which are open to the community
- The hospice bereavement team also works with schools, employers & religious organizations




How to Enroll

- You or your family can begin by calling Hospice directly. Hospice will contact your doctor concerning your medical appropriateness for hospice care.
- Many times, the doctor or hospital discharge planner will contact Hospice after they have discussed it with you.
- You actually become a patient of Hospice by signing a consent form electing hospice care.



When is the “Right Time”?

- If a disease is far enough advanced that curative treatments are being stopped, then it is time to contact hospice.
- A person is considered eligible for hospice care if the physician estimates a life expectancy of six months or less, should the disease run its normal course.

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- While a patient must have an expected prognosis of six months or less, hospice care can be provided for six months or longer, depending on the course of the illness. Many people do not understand this and wait unnecessarily before seeking care.



Barriers to Hospice

- Large number of Academic Medical Centers
- NYS's rich Medicaid home care program
- “Giving up hope”
- Fee-for-service model may be an incentive for futile treatment
- Cultural perceptions
- Families unable to provide needed support at home



What Is Palliative Care?

- a. Care that provides symptom relief and other supports for people with serious illness
- b. Another term for hospice
- c. The default care choice when it is no longer possible to cure an illness
- d. Care that comes only when people are dying



Palliative Care

- Palliative Care is defined in NYS law as “health care treatment, including interdisciplinary end-of-life-care, and consultation with patients and family members, to prevent or relieve pain and suffering and enhance the patient’s quality of life, including hospice care.”
- Should be part of chronic illness management
- Should be available from time of diagnosis



Palliative Care

- Many hospitals have palliative care programs
- Greater need for community-based palliative care programs – advocacy focus for HPCANYS and the Center to Advance Palliative Care (CAPC)



Physician Aid in Dying

- HPCANYYS does not support PAD
- More work needs to be done to increase hospice utilization and promote palliative care



Palliative Sedation

- Used in rare cases where patient suffering is resistant to other forms of treatment
- Considered only for the patient whose death is imminent



VSED

- Patient must be capable of making informed decision (not just consent)
- IDT discussion to get all “on board”
- Conversations with caregivers/family: know what to expect
- Patient can change their mind



Contact Information

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